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Predictors and Outcomes of Health Related Quality of Life in Caregivers of Cardiothoracic Transplant Recipients

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Abstract

Cardiothoracic transplant programs generally require that transplant recipients have family caregivers to assist them post-transplant. The burden of caregiving on the family members remains poorly understood. If caregivers' well-being is compromised by caregiving, it may bode poorly for transplant recipients' own health in the long-term post-transplant. We examined caregiver HRQOL during the first year after their family member's transplant, its predictors, and its relationship to subsequent patient survival. Adult (aged 18+) caregivers of 242 cardiothoracic transplant recipients (lung=134; heart=108) completed assessments of demographics, psychosocial characteristics, and caregiver burden at 2 months post-transplant, and HRQOL at 2, 7 and 12 months post-transplant. Recipients' survival time was obtained from medical records. Caregiver HRQOL was generally high across the first year post-transplant in emotional and social functioning; caregiver physical functioning significantly worsened. There were no differences by type of recipient transplant. Greater caregiver burden predicted poorer caregiver HRQOL in several physical domains at 12 months post-transplant. Transplant recipients whose caregivers had lower perceived general health at 12 months post-transplant showed poorer survival rates during the subsequent 7 years of follow-up. Transplant teams should identify those caregivers at risk for poorer general health post-transplant in order to maximize positive outcomes for the entire family.

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Keywords

caregivers; quality of life; cardiothoracic transplant; psychosocial resources

Introduction

Current trends in medical treatment and healthcare economics have resulted in shortened hospital stays, and extended life expectancies for chronically ill adults, thus placing increased responsibility for their care on the family.(1) Caregivers provide over $257 billion worth of unpaid services each year, which is more than double the cost of home health and nursing home care combined.(2, 3) As hospitals rely more heavily on family caregivers to assist with patient recovery, it is imperative to determine the effects that such burden may have on caregivers. Previous research on caregivers has focused primarily on the impact of caregiving to adults whose health deteriorates over time.(2–14) This research has demonstrated that providing care to a chronically-ill family member increases the risk of compromised health and well-being in caregivers.(10, 15–18)

Caregiving in the context of organ transplantation presents a different scenario from that studied in most caregiving research: transplant recipients' medical course is usually dramatically improved with receipt of the new organ and caregivers to transplant recipients are more likely to be spouses than adult children. Furthermore, as the field of transplantation has advanced, the benefits of transplantation to the organ recipient have increased, both in the short-term (e.g., fewer post-surgical complications, shorter hospital stays related to the initial surgery) and long-term (greater post-transplant life expectancy, longer periods of good physical functional status and quality of life[22–38]). These benefits for the recipient might be expected to positively affect the caregiver's health related quality of life (HRQOL) as well. Thus, one might hypothesize that caregivers would show high levels of HRQOL following their family member's transplant, with those levels becoming even better as the transplant recipient regains health across the first months and years post-transplant. Alternatively, the advantages of rapid hospital discharge post-surgery and a longer post-transplant lifespan may pose additional challenges to caregivers, including increased levels and durations of caregiving responsibility.(19–21) Indeed, the first year post-transplant is critical, but fraught with change and readjustment for recipients and their caregivers, with issues including medical instability and complications for the recipient and high task loads for the caregiver. This might lead to declines rather than improvements in caregiver HRQOL during this period. Thus, it is not clear whether caregiver HRQOL improves or deteriorates as a result of transplantation.

To date, most studies of caregivers' HRQOL after transplantation are either cross-sectional or focus on caregivers of kidney or liver patients.(17, 22–26) Less is known about cardiothoracic recipients, and whether their HRQOL improves or deteriorates over time. In particular, despite the growth in rates of lung transplantation, few data exist on lung recipients' caregivers; the focus has been solely on caregivers to lung transplant candidates.(18, 21, 27–30) Further, because lung transplant recipients have higher rates of medical complications after transplant and tend to show a slower pattern of HRQOL improvement post-transplant than other types of solid organ transplant recipients,(4, 22, 25, 31–41) we speculate that lung transplant caregivers' well-being might be poorer than that of other types of transplant caregivers.

The issue of caregiver well-being is important to address because the well-being of transplant recipients depends, in large part, on the help they receive from their family caregiver, and transplant programs generally require that cardiothoracic transplant recipients have family caregivers. Caregiver burden and impaired HRQOL may lead to negative downstream consequences for the transplant recipient including problems with adherence and increased risks of morbidities and mortality,(25, 29, 30, 42–44) as well as recipient mental health and HRQOL.(39, 40, 45) These issues have received little attention in cardiothoracic recipients and their family caregivers. Therefore, examining caregivers' HRQOL and identifying predictors of caregiver HRQOL post-transplant are important in determining how caregiver HRQOL may influence recipient outcomes. Based on both conceptual models and empirical evidence regarding factors associated with caregiver HRQOL, we included potential predictors representing the following domains: caregiver demographics, patient characteristics, caregiver psychosocial resources, and caregivers' perceptions of caregiving burden.(10, 15–18, 20, 21, 23, 24, 26, 27, 29, 46) We hypothesized that, controlling for caregiver demographics and patient characteristics, caregivers with fewer psychosocial resources (e.g., lower optimism, poorer social supports) and greater caregiving burden would have poorer HRQOL at 1-year post-transplant.

Thus, the objectives of our study were to: (1) determine how the HRQOL of caregivers to cardiothoracic transplant recipients changes over the first year post-transplant; (2) compare the trajectory of change in HRQOL in caregivers of lung versus heart transplant recipients; (3) determine whether we can predict caregiver HRQOL at one year post-transplant with caregiver demographic and psychosocial factors assessed early after transplant; and (4) determine whether caregiver HRQOL at one year post-transplant would predict subsequent cardiothoracic recipient survival.

Materials and Methods

Study Sample

In collaboration with the Cardiothoracic Transplantation Program at the University of Pittsburgh Medical Center, all family caregivers of all lung or heart transplant recipients (aged 18+), who underwent transplantation between November 1999 and August 2004 and survived beyond the first two months post-transplant, were recruited to participate in a prospective investigation of their well-being. Eligible caregivers were identified by asking recipients to name their primary caregiver, i.e., the person who provided them the greatest amount of daily care and assistance. We attempted to recruit the caregiver of every recipient who enrolled in our parallel study of cardiothoracic transplant recipients.(41) Of the 304 recipients in our study, 289 had a primary caregiver, and 269 of those caregivers enrolled in our study (response rate, 95.4%). Because our focus was on caregivers who maintained the caregiving role, the present study focuses on those caregivers whose recipient remained alive during the study period (up to 12 months post-transplant) and who did not exit the caregiver role during this time. Thus, our study sample included 242 caregivers (134 lung recipient caregivers, 108 heart recipient caregivers).

Procedure

Following protocol approval by the University of Pittsburgh Institutional Review Board, all respondents gave informed consent and received individual interviews. Face-to-face interviews were conducted if caregivers accompanied patients to post-transplant evaluations at 2, 7, and 12 months post-transplant. Otherwise, home or telephone interviews were conducted to accommodate the schedules and/or preferences of caregivers to maintain their participation. Participants were paid $40 for each completed interview, which took an average of 60 minutes. There were no significant differences for mode of interview on the variables examined in our study. All interviewers had master's degrees in mental health or behavioral disciplines. Following interview training, inter-rater reliability was evaluated and exceeded an intraclass correlation of 0.90 on each instrument. Transplant-related information about the patients was obtained from medical record reviews.

Instruments

Caregiver HRQOL—Caregivers' HRQOL was measured with the Medical Outcomes Study Short Form (SF-36).(47) It assesses 8 components of HRQOL (general health, physical functioning, vitality, bodily pain, role limitations due to physical health, role limitations due to emotional health, social functioning, mental health). The psychometric properties of the SF-36 are well documented.(47, 48) Each scale is scored from 0 to 100 with a higher score being more positive (i.e., less pain, less limitation). Cronbach's alphas for the present sample ranged from 0.74 to 0.90 for the 8 HRQOL areas.

Transplant Recipient Survival—Patients' medical records maintained by the transplant team were reviewed through a maximum of 7.5 years post-transplant (since the last patient in our cohort was enrolled in 2004). Years of survival were calculated.

Predictors of Caregiver HRQOL and Transplant Recipient Survival—Four predictor domains were assessed at the initial interview and through medical record review. These included caregiver demographics, care recipient's health-related background information, psychosocial resources and coping strategies, and caregiver burden.

Caregiver Demographics: Caregivers reported standard demographic characteristics (e.g., gender, age, race, income, education, occupation) during their initial interview.

Transplant Recipient Health Characteristics: Care recipients' health-related history data were obtained from medical records, and their physical functional status was obtained via the SF-36 physical functioning subscale, as rated by transplant recipients at 12 months post-transplant in our parallel study of transplant recipients(41) (Cronbach's α=0.89).

Psychosocial Resources: Caregiver *optimism* was measured with the Life Orientation Test (LOT),(49) a measure for assessing expectations about the future. Items were averaged to yield an overall score (1=low optimism, 5=high optimism; Cronbach's α=0.81 for the present sample). *Mastery*, or the degree to which respondents felt they had personal control over the things that happen to them, was measured with the Sense of Mastery Scale.(50) The items were averaged to yield an overall score (1=low mastery, 4=high mastery; α=0.80).

Social support was examined with two measures. First, the quality of the caregiver's relationship with the patient was assessed with a 20-item measure modeled on the work of Spanier(51) and Pearlin and Schooler(50) and used in transplant-related caregiver samples.(19–21) This instrument yields an overall support score (1=poor relationship, 5=excellent relationship; α=0.94). Second, *friend support* was assessed with 12 items concerning the degree to which caregivers felt they could rely on friends for emotional or practical support.(52) The measure yields a summary index (0=low support; 3=high support; alpha=0.91). These two measures had skewed distributions; scores were dichotomized to identify respondents with the poorest support (lower third of the distribution) relative to remaining respondents.

We assessed *coping strategies with* the 28-item Brief COPE scale.(53) Caregivers were asked to focus on their strategies for coping with what they considered to be their care recipient's most serious recent health problem and rated the frequency of their use of each strategy on a four-point scale (1=not at all, 4=a lot). We created four composite scores from this measure, based on results of a principal components analysis. (We conducted this analysis because the

Brief COPE is a short form of a longer measure. Although the Brief COPE is widely used, whether or not the items in the Brief COPE conform to the validated subscales in the full COPE has not been established.) They were consistent with the higher-order coping factors identified by Carver et al.(54) Active coping reflected plans or behavior to actively deal with the stressor (α=0.81). The support-seeking/expression of emotions factor reflected attempts to turn to others for support and express one's feelings about the problem (α=0.71). Acceptance coping indicated that the person accepted the reality of the health problem (α=0.62). Avoidant coping reflected attempts to shun or deny the problem. Because caregivers rarely endorsed avoidant items (i.e., little variability across respondents), the internal consistency reliability of this measure was low (α=0.31) and we could not use it further. Thus, we used three coping measures in our analyses. (Although the Brief COPE also includes two items that tap self-blame coping, these items were not originally identified in Carver et al.'s(54) previous work, nor did they load on a separate factor in our analysis).

Caregiver Burden: We assessed burden with four measures to capture different aspects of caregiver burden. To assess *caregivers' daily responsibilities*, caregivers indicated which of 10 household management tasks they performed for the care recipient (e.g., housework, running errands). The sum of endorsed items was calculated. Caregivers also indicated which of 10 *personal care and nursing tasks* they performed for the care recipient (e.g., assisting with medications, helping with bathing). The sum of endorsed items was calculated. Next, caregivers rated nine items concerning how much the caregiver role *limited the time they had for other non-caregiving domains* of their lives (e.g., personal affairs, recreational or vacation activities; adapted from Montgomery et al.(55)). The items were averaged (1=little time restriction; 5=high time restriction for other activities; α=0.88). Finally, to assess *perceived psychological burden*, we used the 18-item version of the Zarit Burden Interview,(56) which focuses on caregiver feelings of role strain and personal strain. The items were averaged (1=low personal burden; 5=high personal burden; α=0.81).

Analysis

The study groups' background and clinical characteristics were compared with χ^2 tests for categorical variables and t tests for continuous variables. Descriptive data on caregivers' HRQOL at each time point, as well as temporal patterns of HRQOL change were compared between caregivers to lung and heart recipients using mixed-model, hierarchical analysis of variance (ANOVA) for continuous variables.(57, 58) Each model included an effect for group (lung vs. heart), time (2, 7, and 12-month interviews) and the group x time interaction, which determined whether the rate of change over time differed across the two study groups. The mixed-model approach allowed us to use data from all time points for all caregivers included in our sample, under the assumption that missing data are missing at random. We included all caregivers who had missing HRQOL data at any of the three interviews (n=23 at Time 1, n=28 at Time 2, n=27 at Time 3) in the analyses because we found no large or significant relationship between data missingness at any follow-up assessment and the other variables examined in this report.

We examined potential predictors' associations with caregiver HRQOL at 12 months post-transplant via Pearson correlation coefficients. We then entered variables showing at least a modest association with any of the HRQOL outcomes (r>0.20) into a multivariable analysis to identify each variable's independent effect, controlling for all others. These effects were estimated via multiple regression analysis for each HRQOL variable, with predictors entered in two blocks. Block 1 included demographic and recipient health-related variables. In Block 2, we added psychosocial resources and caregiver burden (as well as early posttransplant caregiver HRQOL), in order to identify their predictive value over and above the Block 1 variables. The predictors were examined and found to meet all analytic assumptions adequately.(59) These regression analyses focused on the 216 caregivers who provided data at 12 months posttransplant. Cases with missing data on any of the variables were excluded from the regression analysis.

Finally, in order to evaluate the impact of caregiver HRQOL at 1 year post-transplant on subsequent patient survival time, we fit a Cox proportional hazards model, controlling for patient characteristics likely to be linked to mortality (type of transplant received, patient age, length of initial hospitalization after transplant and patients' physical functional status at 1 year post-transplant, the latter two characteristics serving as proxies to reflect patient morbidity during the first year). In addition, we controlled for type of caregiver relationship to the patient (spouse vs. other family member) since this might affect mortality risk as well. The proportionality assumption was evaluated before fitting the models.(59)

Results

Caregiver Demographics, Psychosocial Resources, and Perceived Burden

Table 1 presents descriptive information on assessed variables for the entire sample, as well as separately for lung and heart transplant caregivers. Like other caregiver populations, there were more women than men in our sample. The majority of caregivers were over 50 [M(SD) = 52.1(11.2)], and European American. About half had at least some education beyond high school and had annual incomes of less than $40,000. There were very few differences between lung and heart subgroups. A larger proportion of the heart caregivers was female, most likely because heart recipients are more likely to be men (and hence have their spouses as caregivers), while the gender distribution among lung recipients is equal. Caregivers of lung recipients indicated more transplant-related health worries than did caregivers of heart recipients. Although there appeared to be a trend for lung recipients to have longer post-transplant hospital stays, this difference was not significant (p=.095).

Enrolled caregivers showed no large or statistically significant differences from caregivers who refused to enroll on demographic characteristics or their family member's health status or history. Typical reasons for refusal to enroll included lack of time and lack of interest in participating. Within our sample, no caregivers were unable to be relocated for follow-up. Twenty-four caregivers withdrew consent after either the first interview (n=14) or the second interview (n=10). Typical reasons for withdrawal included not enough time, or not interested in further participation. However, we observed no differences on variables collected at the initial interview among caregivers who continued in the study vs. those lost to attrition.

HRQOL in caregivers of lung and heart transplant recipients

Figure 1 plots caregivers' mean scores for each HRQOL scale at 2, 7, and 12 months post-transplant. The first three columns in Table 2 present the means (and their standard errors) separately by lung and heart transplant caregiver subgroups on each of the HRQOL outcomes. The mixed effects analysis indicated no differences between these subgroups, as shown in the Table. However, there were several significant changes across time. Thus, as indicated in Table 2 and shown in Figure 1, although caregivers' energy level (vitality) improved during the course of the year, their average level of physical functional impairment significantly worsened, as did their level of pain. No other domain of HRQOL showed reliable change over time, and there was no differential change by caregiver subgroups over time.

Figure 1 also shows normative scores on the HRQOL subscales. At 12 months post-transplant, caregivers significantly exceeded normative levels on role-emotional ($t = 5.08$, $p < .001$), social functioning ($t = 4.54$, $p < .001$), and mental health subscales ($t = 4.67$, $p <$.

001). However, because caregiver physical functioning and pain levels worsened, they were similar to or below normative levels on these measures as well as general health, vitality, and role-physical at 12 months post-transplant. Pain level was significantly worse than the normative level ($t = 2.05$, $p = .041$; all other *p*s > .05).

Predictors of Caregiver HRQOL at 12 months post-transplantation

Table 3 shows the results of regression analyses examining whether caregivers' background, psychosocial characteristics, and their HRQOL early post-transplant predicted their HRQOL at 12 months post-transplant. As would be expected, HRQOL at 2 months post-transplant was a strong predictor of 12-month caregiver HRQOL. However, even beyond this variable, there were other significant predictors. These predictors were generally more related to physical than mental or social components of HRQOL. Among the demographic variables, younger caregivers reporting better general health, physical functioning, and fewer role performance limitations due to physical problems. Among the psychosocial resources, greater optimism predicted greater vitality, and a stronger sense of mastery shortly after transplant predicted greater general health and mental health. Among caregiver burden variables, less activities impairment predicted better physical functioning, and less perceived personal burden was associated with greater vitality and less bodily pain.

Caregiver HRQOL as a predictor of transplant recipients' survival time

These analyses examined whether poorer caregiver HRQOL at 12 months post-transplant predicted reduced patient survival time through 7.5 years post-transplantation, controlling for other patient-related characteristics (see Methods). The parameters of caregivers' HRQOL that we included were the SF-36 physical health scales, encompassing general health, physical functioning, vitality, bodily pain, and role-physical. We excluded other caregiver HRQOL scales for two reasons. First, on average, caregivers did not show poor HRQOL in these areas (they significantly exceeded normative levels, as noted earlier). Second, we had to limit the number of predictors included because we did not have a sufficient ratio of events to predictor variables to examine all possible predictors.(60, 61)

Results indicated that the set of predictors contributed significantly to explaining time to mortality (improvement in fit over null model, χ^2 (10) = 32.13, $p <.001$) (see Table 4). Type of transplant and patients' own physical functional status at 12 months post-transplant were both significant predictors of mortality: lung recipients were over twice as likely to die during the follow-up period as heart recipients, and for every 1 point decline in patients' SF-36 physical functioning scores, patients' risk of death was increased by 2% during the follow-up period. Beyond these effects, caregiver general health was also a significant, independent predictor of patients' mortality risk. Thus, for every 1 point decline on the caregiver general health subscale, patients' mortality risk increased by 2%. Analogously, for each 5-point decline on the caregiver general health subscale (the size of the change on the SF-36 scales that has been suggested to indicate a clinically important change),(62) patient mortality rates worsened by 10%.

The impact of caregiver general health on patient mortality is shown graphically in Figure 2 in which we arbitrarily divided caregivers' scores into 5 levels (scores of 0–20, 21–40, 41–60, 61–80, and 81–100) for illustrative purposes (since we considered the measure as a continuous variable in the analyses). The poorer the caregivers' general health score, the poorer the patients' survival time. Because 24 caregivers had withdrawn consent by 1 year post-transplant, these survival analyses are based only on caregivers remaining in the cohort. However, we examined whether patient survival time among these 24 caregivers differed from those who remained in the study and we found no differences in patient survival time between these groups.

Discussion

To our knowledge, ours is the first study to examine HRQOL in lung transplant recipients' family caregivers over the first year post-transplant and to identify predictors of their HRQOL. In our sample, which included heart transplant caregivers as well, we found no differences by transplant type but instead observed that our total caregiver sample had HRQOL levels that remained high during the first year post-transplant across most domains, with two important exceptions. Caregivers' physical functioning and bodily pain worsened over time and was no longer higher than normative levels by the end of the first year. Further, even after controlling for earlier HRQOL, we found that several demographic factors, psychosocial resources, and caregiver burden variables significantly predicted caregivers' HRQOL by the end of the first year post-transplant, which attests to their robust effect on the outcome. Namely, we found that younger age, greater optimism, a stronger sense of mastery, lower activities impairment, and less perceived personal burden were each independently associated with different aspects of caregivers' HRQOL.

Our results indicate that transplant teams should identify caregivers who may be at risk for poorer HRQOL (namely, those with high perceived burden or low levels of psychosocial resources) in order to maximize positive outcomes for the entire family after transplant. Caregivers who are identified with these risk factors may be targeted for increased psychosocial support from the transplant team in order to strengthen their psychosocial resources. For example, support from a therapist or social worker may help caregivers better cope with the burdens they perceive, or they may be provided with resources to get instrumental support with caregiving tasks to help lighten the load. Similarly, psychological or group support may be provided to help boost caregivers' optimism and mastery levels, such as in-person or online support groups. The costs associated with such care may be justified to avoid future problems for family caregivers, especially given the important role they appear to play in the well-being of transplant recipients based on our own and other's findings.(25, 29, 30, 39, 40, 42, 43, 45)

Of particular importance, greater impairments in caregiver health perceptions by the end of the first year predicted poorer patient survival, independent of patients' own health status. We speculate that this may occur because caregivers with poorer health perceptions may be unable to provide needed assistance to their family member so that this individual's health can be maximized. This finding complements and augments previous work with caregivers of lung transplant candidates and other organ recipients that showed the critical role that caregivers play in the health and well-being of transplant recipients and the potential toll that caregiving responsibilities may have on the caregiver.(18, 21, 25, 27, 29, 30, 39, 40, 42, 43, 45) Future research should examine caregiver health and HRQOL changes beyond the first year post-transplant so that we can further explore potential mechanisms accounting for caregiver HRQOL and patient mortality linkages.

Our findings also indicate that it is important to address the potential impacts of transplant on family caregivers in initial education and counseling efforts by the transplant team (if they don't already do so), and that the team should encourage development of family strategies to protect caregivers' well-being in order to maximize patients' health and longevity. Although transplant teams may already provide this education pre-transplant, it may be difficult for families to retain the information or process it completely at the same time that they face the stresses of maintaining the patient's health while they are awaiting a transplant. Even if teams provide this information at discharge, there may not be enough time for families to understand all the information they are receiving, given brief post-transplant hospital stays. We suggest that a new approach may be to develop ongoing educational sessions post-transplant for recipients and their family caregivers to ensure that information is processed and families' questions and concerns are addressed.

Some study limitations deserve mention. First, because this study was conducted in one transplant center, our findings may lack generalizability. However, our sample of cardiothoracic recipients was similar to national and international data on basic demographics and indications for transplant,(63, 64) and our caregivers are demographically similar to other transplant caregiver samples.(18, 19, 21, 23, 24, 26, 29, 30) Another study limitation was that our sample was predominantly European-American, and generalizing to other ethnic groups may not be possible. However, at least for the lung recipient cohort, our sample's ethnicity is similar to that of the US recipient population.(63) Yet another limitation may be that we did not include a non-caregiver control group with whom to compare changes in HRQOL over time. However, published results of non-caregiving community-dwelling older adults(65, 66) indicate that HRQOL remains stable over time, and shows little variability, particularly over a one year period. Thus, we believe that our findings regarding the decline in physical health and pain over the first year post-transplant are more likely due to caregiving demands rather than a function of normative changes over time. Finally, while our study examined the predictive effects of caregiver HRQOL on patient mortality, we could not examine the factors explaining this relationship. It would be important to examine these outcomes in future work. Future work might also consider impact on HRQOL of exiting the caregiver role. Because we chose to focus specifically on individuals who remained as caregivers during the course of the study, we have no information on whether the HRQOL of caregivers who exited the role due to recipient death or by their own choice experienced better or worse HRQOL levels compared to their levels while caregiving.

In sum, among a sample of individuals who served as caregivers during the first year after their family member's transplant, we found that their HRQOL is high and generally remains so during this time. Decrements in caregivers' physical well-being indicate an important aspect of HRQOL that should be addressed while they are busy caring for their transplant recipient. Finally, our results showed that caregiver HRQOL should be an important concern for transplant teams because of its potential as a risk factor for transplant recipients' mortality. Directions for future work include replicating our study in other samples in order to ensure generalizability of findings, tracking the influence of the identified significant factors on caregivers' HRQOL outcomes, and exploring the mechanisms by which the HRQOL of caregivers may come to predict patient health outcomes in the long-term after transplant.

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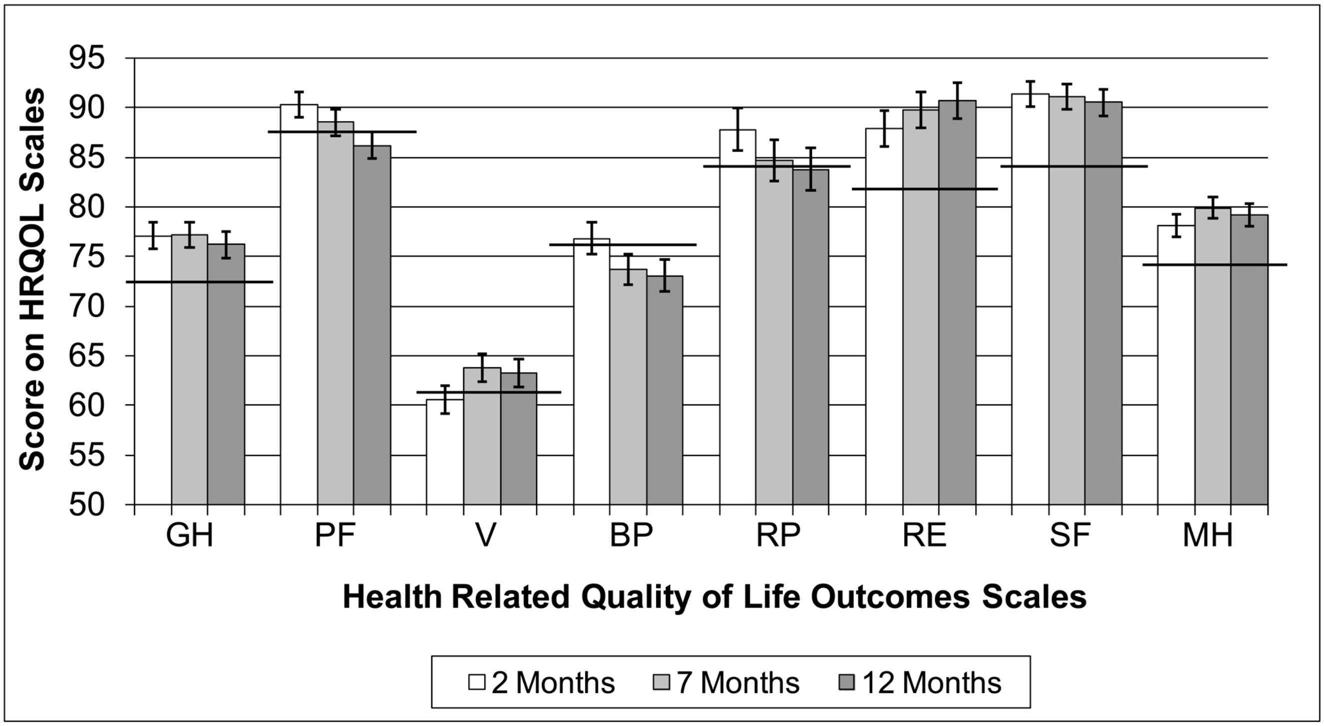

Figure 1.

Quality of life in 242 caregivers of cardiothoracic transplant patients at 2, 7, and 12 months post-transplant.

Note: The line across the time points on each QOL component represents the normative value on that component for adults aged 18–64. GH = general health, PF = physical functioning, VT = Vitality, BP = bodily pain, RP = role physical, RE = role emotional, SF = social functioning, and MH = mental health.

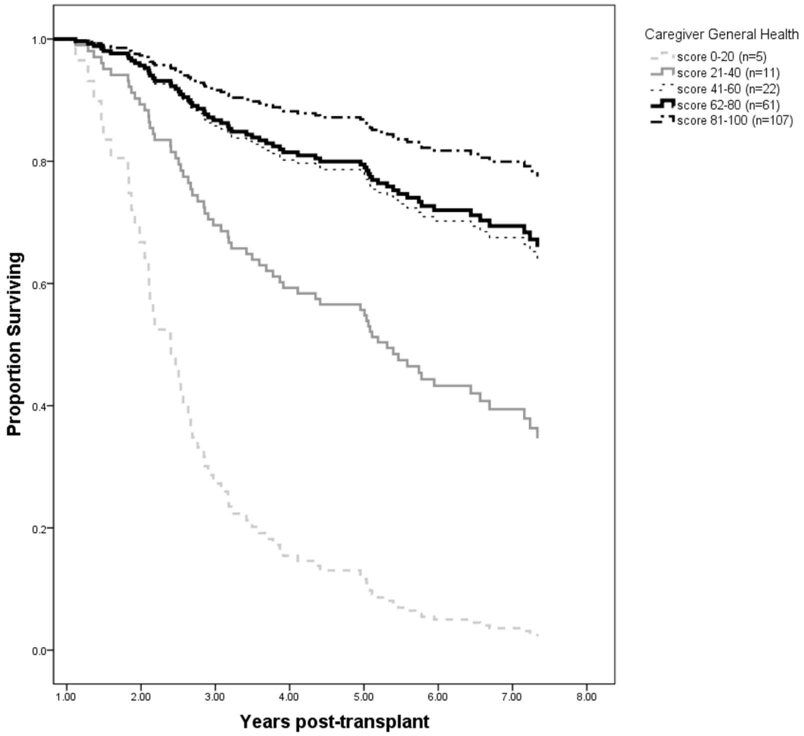

Figure 2.

Proportion of patients surviving as a function of caregivers' general health scores

Table 1

Background characteristics, psychosocial resources, coping strategies, and caregiver burden in 242 lung and heart transplant caregivers.

Characteristic	Total Sample (N = 242)	Lung Caregivers (n = 134)	Heart Caregivers (n = 108)	Group Comparison, Test Statistic[a]	p-value
Background Characteristics					
Caregiver Demographic Characteristics[b,c] - %					
Gender (female)	71.5	65.7	78.7	4.98*	.026
Age (≤ 50)	37.2	39.6	34.3	0.72	.397
Race (European-American)	90.9	94.0	87.0	3.54	.856
Educational level (≤ High School)	43.8	43.3	44.4	0.03	.090
Occupation (≤ Clerical/sales workers)	50.4	45.5	56.5	2.87	.128
Family Income (≤ $39, 999)	52.9	48.5	58.3	2.31	.128
Relationship to recipient (spouse/partner)	78.5	79.1	76.9	0.32	.572
Recipient Transplant-Related Characteristics					
Indication for transplant – % lung recipients				--	
(COPD/Emphysema)		37.3	--		
(Idiopathic pulmonary fibrosis)		24.6			
(Cystic Fibrosis)		14.9			
(Other)		23.2			
Indication for transplant – % heart recipients				--	
(Idiopathic myopathy)		--	37.0		
(Ischemic myopathy)			38.0		
(Other)			25.0		
Days in hospital post-transplant - %				6.37	.095
≤ 14 days	41.4	37.3	46.3		
15 – 21 days	22.3	19.4	25.9		
22–28 days	13.6	15.7	11.1		
> 29 days	22.7	27.6	16.7		
Physical functional status at 2 mos. post-transplant, Mean (SD)	55.6 (25.2)	54.0 (25.2)	57.7 (25.1)	1.11	.267
Acute rejection early posttransplant (% yes)	39.3	40.3	38.0	0.14	.711
Caregiver Psychosocial Resources[d,e]					
Psychosocial Resources					

Characteristic	Total Sample (N = 242)	Lung Caregivers (n = 134)	Heart Caregivers (n = 108)	Group Comparison, Test Statistic[a]	p-value
Optimism – Mean (SD) (1=low, 5=high)	3.9 (0.7)	3.9 (0.6)	3.8 (0.7)	1.12	.263
Mastery – Mean (SD) (1=low, 4=high)	3.0 (0.5)	3.1 (0.5)	3.0 (0.5)	1.06	.288
Relationship with recipient, % poor	35.5	33.6	38.0	0.50	.479
Family support, % poor	35.5	35.2	35.9	0.02	.904
Friend Support, % poor	30.6	31.3	29.6	0.08	.774
Coping Strategies - Mean (SD), (1=low use, 5=high use)					
Active	2.8 (0.9)	2.9 (0.9)	2.8 (0.9)	0.31	.755
Seeking Support	2.1 (0.6)	2.1 (0.6)	2.1 (0.6)	0.36	.719
Acceptance	2.2 (0.5)	2.2 (0.5)	2.2 (0.5)	1.01	.272
Caregiving Burden - Mean (SD)					
No. of daily household tasks	6.0 (2.3)	5.9 (2.2)	6.1 (2.5)	0.56	.577
No. of nursing tasks (0=none, 1=one, 2=two or more)	0.8 (.8)	0.8 (0.8)	0.8 (0.8)	0.44	.659
Activities impairment (1=low, 5=high)	2.3 (0.7)	2.4 (0.7)	2.3 (0.7)	0.37	.709
Personal burden (1=low, 5=high)	1.9 (0.5)	1.9 (0.5)	1.9 (0.6)	0.02	.981

[a] t-tests for continuous variables and Chi-square tests for categorical variables.

[b] Lung caregivers had missing data on: income (n=2), recipient physical functioning (n=1).

[c] Heart caregivers had missing data on: recipient physical functioning (n=2).

[d] Lung caregivers had missing data on: optimism (n=5), mastery (n=5), family support (n=6), coping measures (n=5), caregiver household tasks (n=3), nursing tasks (n=3), activities impairment (n=4), personal burden (n=4).

[e] Heart caregivers had missing data on: optimism (n=1), mastery (n=3), family support (n=5), coping measures (n=4), caregiver household tasks (n=1), nursing tasks (n=2), activities impairment (n=1), personal burden (n=1).

Table 2

Quality of life outcomes, Mean (SE), among 242 caregivers of cardiothoracic transplant recipients across three post-transplant interviews (using Mixed-Model Analysis)[a]

	Months Post Transplant								
SF-36 HRQOL Measure	**2 months**	**7 months**	**12 months**	**Group Effect[a]**	**p-value**	**Change over Time Effect[a]**	**p-value**	**Group by Time Interaction Effect[a]**	**p-value**
General Health[b]				0.75	.388	0.24	.790	0.29	.745
Lung Recipients	78.2 (1.8)	77.6 (1.7)	76.6 (1.8)						
Heart Recipients	76.0 (2.0)	76.8 (1.9)	75.7 (2.0)						
Physical Functioning[b]				0.02	.888	5.74	.003	0.32	.724
Lung Recipients	90.1 (1.7)	88.4 (1.8)	85.7 (1.7)						
Heart Recipients	90.4 (1.9)	88.6 (1.9)	86.7 (1.9)						
Vitality				0.71	.401	3.32	.037	0.12	.889
Lung Recipients	61.7 (1.9)	65.0 (1.9)	63.9 (1.9)						
Heart Recipients	59.5 (2.0)	62.6 (2.1)	62.7 (2.1)						
Bodily Pain				1.15	.284	3.37	.035	1.34	.262
Lung Recipients	78.9 (2.2)	73.7 (2.2)	75.4 (2.2)						
Heart Recipients	74.8 (2.4)	73.7 (2.4)	70.7 (2.5)						
Role Physical[b]				0.19	.890	1.98	.140	0.14	.871
Lung Recipients	87.1 (2.8)	85.7 (2.8)	84.8 (2.8)						
Heart Recipients	88.6 (3.1)	83.8 (3.1)	82.8 (3.1)						
Role Emotional[b]				0.21	.646	1.96	.143	0.58	.562
Lung Recipients	87.1 (2.4)	90.9 (2.4)	92.8 (2.4)						
Heart Recipients	88.7 (2.6)	88.8 (2.6)	88.7 (2.7)						
Social Functioning[b]				0.09	.760	0.20	.814	1.7	.189
Lung Recipients	90.4 (1.7)	91.8 (1.7)	91.4 (1.7)						
Heart Recipients	92.4 (1.9)	90.4 (1.9)	89.7 (1.9)						
Mental Health[b]				0.54	.465	0.95	.387	0.38	.682
Lung Recipients	77.4 (1.5)	80.3 (1.5)	78.5 (1.5)						
Heart Recipients	78.8 (1.6)	79.6 (1.7)	79.8 (1.7)						

[a] F tests, mixed-model analysis.

[b] log transformed prior to analyses to reduce skewness in its distribution. Raw means are presented in order to facilitate interpretation.

Table 3

Standardized regression coefficients indicating effects of demographic, psychosocial resources, and perceived caregiver burden factors on HRQOL at 12 months post-transplant (controlling for HRQOL at 2 months post-transplant).

	Quality of Life Measures							
Potential Predictors[a, b]	**General Health**	**Physical Functioning**	**Vitality**	**Bodily Pain**	**Role Physical**	**Role Emotional**	**Social Functioning**	**Mental Health**
Caregiver Demographics								
Age, younger	.21[**]	.22[**]	−.05	.10	.14[*]	.03	.00	−.02
Gender, female	.08	.06	−.02	−.10	.01	.17[**]	.00	−.02
Education, > high school	.16[**]	.13	.08	.10	.12	.11	.03	−.01
Income, > $39,999	.03	.17[*]	.03	.11	.03	.06	.16[*]	.00
R^2	.09	.13	.01	.07	.04	.05	.04	.00
F(5,201)	4.04[**]	6.23[***]	0.43	2.93[*]	1.84	2.20	1.50	0.12
Caregiver Psychosocial Resources[c]								
Optimism, higher	.09	.11	.18[*]	.08	.10	.06	.14	.07
Mastery, higher	.15[*]	.02	−.11	.01	−.03	.03	.00	.21[**]
Relationship with recipient, better	−.01	−.08	.07	−.08	−.05	.02	−.06	.03
Family support, better	.08	−.03	−.09	.01	.06	.10	.12	.09
Caregiver Burden Variables								
Nursing tasks, more	.02	−.04	−.11	.03	.00	−.09	−.08	−.05
Activities impairment, greater	−.01	−.17[*]	−.02	−.03	−.10	.00	.05	−.08
Personal burden, greater	−.07	−.03	−.18[*]	−.16[*]	−.08	−.13	−.11	−.02
Caregiver HRQOL at 2 mos. post	.45[***]	.44[***]	.29[***]	.43[***]	.19[*]	.18[*]	.19[**]	.26[**]
Increment to R^2	.27	.24	.33	.25	.08	.12	.12	.23
F(df = 8,193)	10.06[***]	9.30[***]	11.92[***]	8.00[***]	2.29[*]	3.63[**]	3.31[**]	7.27[***]

[*] p < .05;

[**] p < .01;

[***] p < .001 (Note: specific p-values for each coefficient are available from the first author upon request.)

[a] All models examining potential risk factors controlled for transplant group (lung vs. heart recipients; no significant effects). Additional demographic characteristics (race/ethnicity, occupation, type of relationship with recipient), patient health characteristics (physical functional status, length of hospital stay posttransplant, occurrence of acute graft rejection) and posttransplant caregiver psychosocial

characteristics (active coping, support/emotional expression coping, acceptance coping, friend support, caregiving tasks related to household management) showed small bivariate associations with all HRQOL outcomes variables (r or phi < .20). Thus, they were not included in the multivariate models.

[b] Caregivers had missing data on: family support (n=8), nursing tasks (n=4).

Table 4

Hazard ratios of patient and caregiver factors as a predictor of transplant recipient's survival time up to 8 years post-transplant.

	Survival Time		
Potential Predictors	**HR**	**Confidence Interval**	**p-value**
Patient age, older	0.99	.97, 1.02	.549
Type of transplant, lung	2.28	1.32, 2.27	.003
Length of hospital stay post-transplant[a]	1.11	0.89, 1.37	.361
Patient physical functioning, 1 yr post-transplant[b]	0.98	0.97, 0.99	.001
Relationship to caregiver, spouse	0.78	0.40, 1.48	.439
Caregiver's general health (SF-36) [b]	0.98	0.96, 0.99	.025
Caregiver's physical functioning (SF-36) [b]	1.01	.99, 1.03	.322
Caregiver's vitality (SF-36) [b]	1.00	.99, 1.02	.754
Caregiver's bodily pain (SF-36) [b]	1.01	1.00, 1.03	.131
Caregiver's role physical (SF-36) [b]	1.00	.99, 1.01	.876

[a] ordinal variable defined as in Table 1

[b] higher score = better functioning/HRQOL