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## FACTORS ASSOCIATED WITH STRESS AND COPING AT 5 AND 10 YEARS AFTER HEART TRANSPLANTATION

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### Abstract

**Background**—Heart transplant-related stressors and coping are related to poor outcomes early after transplant. The purposes of our study were to (1) identify the most frequent and bothersome stressors and most used and effective coping strategies, and (2) compare the most frequent and

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bothersome stresses and most used and effective coping styles between patients at 5 and 10 years after heart transplantation. We also examined differences in coping styles by patient characteristics, and factors associated with frequency and intensity of stress at both 5 and 10 years after heart transplantation.

**Methods**—This report is a secondary analysis of data from a prospective, multi-site study of quality of life outcomes. Data are from 199 and 98 patients at 5 and 10 years after transplant, respectively. Patients completed the Heart Transplant Stressor Scale and Jalowiec Coping Scale. Statistical analyses included frequencies, measures of central tendency, t-tests, Chi-square and generalized linear models.

**Results**—At 5 and 10 years after heart transplantation, the most bothersome stressors were regarding work, school, and financial issues. Patients who were 10 years post transplant reported less stress, similar stress intensity, and less use and perceived effectiveness of negative coping than patients who were 5 years post transplant. Long-term after transplant, demographic characteristics, psychological problems, negative coping, and clinical factors were related to stress frequency and/or intensity.

**Conclusions**—Heart transplant-related stress occurs long-term after surgery. Types of transplant-related stress and factors related to stress confirm the importance of ongoing psychological and clinical support after heart transplantation.

Survival and quality of life benefits of heart transplantation and complications related to transplant and immunosuppression early and long term after surgery are well known.<sup>1-3</sup> Psychological sequelae (i.e., psychological distress, anxiety, depression and adjustment disorders)<sup>4-9</sup> have also been reported. Risk factors for psychological disorders early after heart transplantation include increased pretransplant illness severity, lifetime history of psychiatric disorders, younger age, lower social support, poor self-esteem, poor sense of self-mastery, use of avoidance coping strategies, and other life events.<sup>4, 10-12</sup> Furthermore, post transplant stressors have been correlated with poor outcomes up to 1 year after transplant including more functional disability, worse quality of life, and decreased satisfaction with transplant.<sup>13-16</sup> Limited evidence suggests that rates of psychological disorders decrease over the next several years.<sup>4</sup> At 5 or more years after transplant, psychological disorders (e.g., anxiety and depression) increase<sup>10, 17-19</sup>, although the reasons, which may be related to new transplant-related stressors (e.g., adverse events) or other life stressors, are unclear.

Patients use a variety of coping styles to manage stress. Coping styles used by patients after transplant include optimism, seeking social support, having faith denial/avoidance, passivity, and fatalistic coping.<sup>12, 20-22</sup> Use and perceived effectiveness of coping styles have been related to quality of life and physical functioning after transplant.<sup>1, 14, 22, 23</sup> Given that heart transplant-related stressors and coping are related to outcomes early after transplant, it is important to understand these relationships long-term after transplant, especially given the potential for ongoing and new heart-transplant related adverse events across time. Thus, we have chosen two long-term periods of time (5 and 10 years after heart transplantation) to examine stress and coping.

This report and our larger study of outcomes long term after heart transplantation are guided by the stress, appraisal, and coping model of Lazarus and Folkman.<sup>24</sup> Previous reports focused on our predefined outcomes (i.e., survival, functional ability, emotional status, work ability, satisfaction with heart transplant, and perceived quality of life) (table 1). In this report, we focus on relationships between stressors related to illness and treatment (i.e., heart transplant-related stressors), appraisal of stress, and coping, as identified in table 1. Stressors are defined as stressful occurrences related to illness and treatment (e.g., acute rejection,

cancer, and orthopedic problems). Stress is “a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being”.<sup>24</sup> Coping is defined as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person”.<sup>24</sup> Coping strategies are specific ways of coping (e.g., tried to keep busy and prayed or put your trust in God), and coping styles are conceptually related coping strategies (e.g., optimistic and emotive).<sup>25</sup> Coping occurs subsequently as a way to manage occurrences that are perceived as stressful. Stressors, appraisal of stress, and coping ultimately affect outcomes.

The purposes of our study were to (1) identify the most frequent and bothersome stressors and most used and effective coping strategies, and (2) compare the most frequent and bothersome stresses and most used and effective coping styles between patients at 5 and 10 years after heart transplantation. We also examined differences in coping styles by patient characteristics, and factors associated with frequency and intensity of stress at both 5 and 10 years after heart transplantation.

## METHODS

### Sample

This report is a secondary analysis of data collected from a prospective, multi-site study of quality of life outcomes after heart transplantation. The non-random sample of participants was transplanted between July 1, 1990 and June 30, 1999 at four U.S. medical centers and was 5 to 10 years post transplant. From a total pool of 1,437 heart transplant recipients, 884 patients were eligible to participate in our study, 597 patients enrolled at any time between 5 and 10 years after transplant, and 555 patients completed one or more booklets of self-report instruments. Our overall retention rate was 70%, and patients completed booklets, on average, for 2.5 years. Samples for this report were from two independent cohorts, n=199 and n=98 patients at 5 and 10 years after transplant, respectively. Reasons for non-enrollment and inclusion criteria have been described previously.<sup>1</sup> Patients who met study entry criteria and chose not to enroll (n=127) were significantly younger than enrolled patients (n=597); no other differences in demographic and clinical characteristics were detected between groups.<sup>1</sup>

### Instruments and Procedures

The Heart Transplant Stressor Scale<sup>26</sup> and Jalowiec Coping Scale<sup>25</sup> were selected for this report based on their relevance. The Heart Transplant Stressor Scale measures stress related to having had a heart transplant and has 81 items (i.e., stressors) and six stress subscales (physical, psychological, self-care, family, work/school/financial, and hospital/clinic).<sup>26</sup> Patients document whether or not they have a stressor and if they have a stressor, the level of stressfulness (i.e., intensity) (0=no stress, and 1=have stressor and not stressful at all to 4=have stressor and very stressful). The Jalowiec Coping Scale measures coping related to the stress of having had a heart transplant and has 60 items (i.e., coping strategies) and eight subscales (i.e., coping styles, determined via confirmatory factor analysis).<sup>25</sup> The eight subscales cluster into two summary scales as follows: positive coping styles = confrontive, optimistic, supportant, self-reliant, and 4 items from the palliative subscale and negative coping styles = evasive, fatalistic, emotive, and 3 items from the palliative subscale).<sup>25</sup> Patients indicate the frequency (0=never used to 3=often used) and perceived effectiveness (0=not helpful to 3=very helpful) of coping strategies. The two instruments have adequate psychometric support (i.e., reliability and validity) in this population of patients.<sup>25, 26</sup> Demographic data (age, gender, race, marital status, and education) and clinical data (comorbidities and complications of transplantation [diabetes, orthopedic problems, gout,

cardiovascular problems, oncologic problems, gastrointestinal problems, renal problems, psychological problems, acute rejection, infection, and cardiac allograft vasculopathy]) were also collected.

Institutional Review Board approval was obtained at each of the four medical centers prior to subject enrollment. Patients who were between 4.5 and 10 years post heart transplantation were informed of our study and invited to participate. Patients who consented to join our study completed instruments every six months (between 5 and 10 years post transplant), based on their date of transplant. Instruments with return envelopes were provided to patients by research assistants. Non-response to surveys was followed-up with telephone calls. Returned surveys were screened for missing or unclear data, and participants were contacted. Surveys were subsequently mailed to the data coordinating center at the University of Alabama, Birmingham for data entry. Clinical data were collected every six months by research assistants from participating medical centers and were also collected external to this study and made available to us by the Cardiac Transplant Research Database, a voluntary heart transplant registry at the University of Alabama, Birmingham.

### Statistical analyses

Data were analyzed using SAS version 9.2 (SAS, Cary, NC). Statistical analyses included frequencies, measures of central tendency, chi-square, *t*-tests, and generalized linear models. Subscale and total scale scores were calculated for both the stress and coping instruments and converted to a standardized scale of 0.00 to 1.00. The standardized stress and coping scores were compared between the two cohorts of patients at 5 and 10 years post heart transplantation using independent *t*-tests. Differences in use of coping styles by dichotomous characteristics including age (<60, ≥60), gender, marital status (married, not married), education (high school, >high school), and presence of clinical problems (yes, no) were examined using 2-sample *t*-tests at both 5 and 10 years after transplant. Generalized linear models were used to identify factors associated with overall stress regarding frequency and intensity at 5 and 10 years after heart transplantation. Independent variables were identified based on our theoretical model of Lazarus and Folkman shown in table 1. Only variables with  $p < 0.2$  in the univariate analysis were included in the multivariable models. The variables entered in the final models included five demographic variables (age, gender, race, marital status and education), three clinical variables, (NYHA class, orthopedic problems, psychological problems, and infection), and two coping scales (i.e., use of positive and negative coping styles). Multicollinearity was checked using variance inflation factor (VIF), and no evidence of collinearity was found in the final GLM models. Significance was established at  $p = 0.05$ .

## RESULTS

### Descriptive Analyses

**Demographic and clinical characteristics**—A description of the cohorts of patients at 5 and 10 years after heart transplantation is provided in Table 2. On average, patients were  $55 \pm 10$  years at transplant, 80% male, and 92% Caucasian at 5 years after transplant ( $n=199$ ) and  $53 \pm 10$  years at transplant, 78% male, and 87% Caucasian at 10 years after transplant ( $n=98$ ). The majority of patients at both time periods had multiple co-morbidities. At 10 years post transplant, patients were significantly younger when transplanted and had a higher frequency of some co-morbidities and complications of transplantation than patients at 5 years post transplant.

**Stressors and coping strategies**—Frequency and intensity of stressors are listed in Table 3. At 5 years after transplant, six stressors, three from the physical subscale, were

reported by 40% of patients (side effects from medications, paying for medications, fatigue, weight management, sexual activity, and having endomyocardial biopsies), with frequencies that ranged from 41%–58%. Fatigue and weight management were also reported by 40% of patients at 10 years after transplant, followed by side effects from medications, sexual activity, death/illness of another transplant patient, and having cancer (frequencies ranged from 37%–29%). Regarding the most bothersome stressors (mean item score 2.0, 0=not stressful at all to 3=very stressful), items were primarily from the work/school/financial subscale (e.g., being away from work, being unemployed due to illness, trying to find employment, decreased income after heart transplantation, and paying medical bills) at both 5 years and 10 years after transplant. Mean item scores for most bothersome stressors ranged from 2.2 to 2.0 at 5 years and 2.4 to 2.1 at 10 years. At 10 years post transplant, physical, psychological, and family-related stressors were also among the most bothersome stresses.

Coping strategies, by use and perceived effectiveness, are listed in Table 4. At 5 years after transplant, five of the six most commonly used coping strategies (mean item score 2.0, (0=never used to 3=often used) were from the optimistic subscale (e.g., tried to think positively and tried to keep a sense of humor) (mean item scores=2.0–2.3). At 10 years after transplant, three of six strategies used which had scores 2.0 were also from the optimistic subscale. The most effective coping strategies (mean item score 2.0, 0=not helpful to 3=very helpful) at both time periods were from the following subscales: optimistic, confrontive, palliative, and supportant, with mean item scores ranging from 2.3 to 2.5 at 5 years and 2.3 to 2.6 at 10 years. Importantly, all of the most frequently used and most effective coping strategies were from the positive coping summary scale.

#### **Comparisons of stress and coping styles at 5 and 10 years after transplant—**

Stress and coping styles were determined for summary scales and subscales at 5 and 10 years after heart transplantation. The frequency of patients who reported at least one stressor within each subscale ranged from 40%–88% (table 5), and the frequency of patients who reported using at least one coping strategy within each coping style subscale ranged from 67%–93% (table 5) for both time periods. The frequency of stress, overall and by subscale, was low (0.3, scale=0–1) and was significantly lower at 10 versus 5 years after transplant for all subscales and overall (Table 5). The intensity of stress overall and for the subscales was moderate (range=0.5–0.7, scale=0–1) (Table 5) and was not significantly different at 5 and 10 years after transplant. Notably, stress intensity related to the job/school/financial subscale was highest among all subscales, while stress related to self-care was lowest at both time periods.

The frequency of use of coping styles was low (0.3, scale=0–1) for negative coping styles and moderate for positive coping styles at 5 and 10 years after transplant. There was significantly less use of evasive, fatalistic, and emotive coping styles, which are from the negative coping summary scale, at 10 years as compared to 5 years after transplant (Table 5). Both positive and negative coping styles were moderately effective, as perceived by the patient, except for the emotive subscale, which was less effective (0.3, scale=0–1). Furthermore, patients at 10 years after transplant reported significantly less effectiveness of fatalistic and emotive coping styles and negative coping as compared to patients who were 5 years post transplant. (Table 5).

#### **Differences in coping use and effectiveness by patient characteristics—**

Use (0=never used and 1.0=often used) and effectiveness (0=not helpful to 1=very helpful) of negative and positive coping summary scales was examined by demographic and clinical characteristics at 5 and 10 years after heart transplantation. At 5 years post transplant, patients who were younger, female, and had psychological problems and episodes of acute

rejection more frequently used negative coping styles (table 6). At 10 years post transplant, patients who had psychological problems more frequently used negative coping styles (table 6). Perceived effectiveness of negative coping differed by presence of diabetes in the 5 year cohort and marital status, education level, and presence of diabetes in the 10 year cohort.

#### **Factors associated with stress at 5 and 10 years after heart transplantation—**

Factors associated with overall stress at 5 and 10 years after heart transplantation were identified. At 5 years after transplant, use of negative coping and having psychological problems were significantly related to a higher frequency of stress, and along with all variables in the model accounted for 28% of variance in frequency, while at 10 years after transplant, use of negative coping, NYHA class II or III and having orthopedic problems, psychological problems, and infection were significantly related to a higher frequency of stress, and along with all variables in the model, explained 42% of variance in frequency (table 7). Factors significantly related to higher intensity of stress at 5 years after transplant were being younger, female, being married, infection, and use of negative coping. At 10 years after transplant, having orthopedic problems was significantly related to a higher intensity of stress. These models explained 21% of variances at 5 years and 17% of variance at 10 years, respectively.

## **DISCUSSION**

Among long-term survivors of heart transplantation, while frequency of reporting stress was low, patients had moderate levels of stress, and the most bothersome stressors were regarding work, school, and financial issues. Patients who were 10 years post transplant reported less stress, similar stress intensity, and less use and perceived effectiveness of negative coping than patients who were 5 years post transplant. At 5 and 10 years after transplant, demographic characteristics, negative coping, and clinical factors were significantly related to stress frequency and / or intensity.

Notably, the most intense stressors early after heart transplantation versus later are different. At 1 year after transplant, we previously reported that among the five most intense stressors, only one stressor was related to work/school/financial issues (i.e., paying medical bills), and others were related to physical (e.g., side effects from medications) and self-care (e.g., weight management) stress.<sup>3</sup> In contrast, at 5 and 10 years after transplant, the majority of the most bothersome stressors were related to work, school, and financial issues. Hetzer et al.<sup>19</sup>, also reported work-related disability in patients long-term after heart transplantation. Furthermore, < 50% of patients return to work after heart and other solid organ transplants.<sup>27, 28</sup> Heart transplant-related factors associated with return to work early and later after surgery include having fewer episodes of acute rejection, fewer endocrine-related problems, no cardiac allograft vasculopathy, less physical disability, and more satisfaction with health.<sup>27, 29</sup> These findings suggest an opportunity for referral to social workers who could assist patients with job retraining, return to work, insurance, and medical bills.

We also found that patients used more positive coping styles to deal with the stress of having had a heart transplant, particularly optimism, and that patients perceived these coping styles to be fairly effective. As a positive coping style, optimism encompasses acceptance of one's medical condition, hope, and getting on with life. Kaba et al.<sup>21</sup> also reported the frequent use of optimism as a coping strategy up to two years after heart transplantation.

While less common, negative coping styles (i.e., evasive, emotive, and fatalistic coping styles) were used by some patients in our study. Use of passive coping was also reported more frequently in heart transplant patients as compared to a reference group of normative patients up to two years after surgery.<sup>20</sup> Furthermore, passive coping was reported more

frequently in depressed patients versus patients who were not depressed long term after transplant.<sup>17</sup> The literature from other populations of patients, including patients with diabetes and cancer, is equivocal regarding the relationships between negative coping styles (i.e., evasive and emotive coping), stress, and depression.<sup>30–32</sup> The relationship between negative coping styles and stress and depression, long-term after transplant, suggest that long term heart transplant patients may benefit from on-going psychological support. However, more empirical evidence is needed on whether coping styles can be changed, perhaps using cognitive-behavioral therapy, and which coping styles are most amenable to change.<sup>33</sup>

Although the cohorts are independent, it is interesting to note that patients who were 10 years post transplant reported less stress, less frequent use of negative coping, and less perceived effectiveness of negative coping than patients who were 5 years post transplant. It is not possible to discern whether cross-sectional comparisons between time periods for these independent cohorts emerged due to time post transplant or differences in cohorts. Thus, additional research is warranted.

We also demonstrated a relationship between demographic characteristics (i.e., age and gender) and stress with these analyses and for age in a previous report.<sup>34</sup> However, the literature is equivocal regarding the relationship of stress with age and gender after heart transplantation.<sup>4, 8, 9, 35</sup> Our findings suggest possible target groups of patients who could benefit from psychological surveillance and follow-up. Additional study of these relationships is warranted. Stress was also related to co-morbidities and long-term complications of transplantation, including orthopedic problems and infection, which to our knowledge, has not been reported previously.

Our study was limited by the assessment of stress and coping in long-term survivors of heart transplantation, which may have contributed to bias in our findings. However, our overall retention rate and inclusion of four sites in geographically distinct regions of the U.S. strengthens our findings and generalizability. Another limitation is that samples at 5 and 10 years after transplant were independent and differed on some demographic and clinical characteristics. Additionally, we did not collect data on treatment for stress-related problems, and we do not know if psychosocial surveillance and treatment changed during the time period when we collected data. Furthermore, psychosocial problems may have been under-represented in medical records long-term after transplant, which may have influenced our findings.

In conclusion, patients have moderate levels of stress and use positive and negative coping styles that are moderately effective at 5 and 10 years after heart transplantation. The types of transplant-related stress and factors related to stress suggest that psychological monitoring and support from a social work, psychological, and clinical perspective may be helpful for patients long-term after heart transplantation.

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## References

1. Grady KL, Naftel DC, Kobashigawa J, et al. Patterns and predictors of quality of life at 5 to 10 years after heart transplantation. *J Heart Lung Transplant*. 2007 May; 26(5):535–543. [PubMed: 17449426]
2. Stehlik J, Edwards LB, Kucheryavaya AY, et al. The Registry of the International Society for Heart and Lung Transplantation: twenty-eighth official adult heart transplant report-2011. *J Heart Lung Transplant*. Oct; 30(10):1078–1094. [PubMed: 21962016]
3. Grady KL, Jalowiec A, White-Williams C. Improvement in quality of life in patients with heart failure who undergo transplantation. *J Heart Lung Transplant*. 1996 Aug; 15(8):749–757. [PubMed: 8878757]
4. Dew MA, Kormos RL, DiMartini AF, et al. Prevalence and risk of depression and anxiety-related disorders during the first three years after heart transplantation. *Psychosomatics*. 2001 Jul-Aug; 42(4):300–313. [PubMed: 11496019]
5. Mai FM, McKenzie FN, Kostuk WJ. Psychosocial adjustment and quality of life following heart transplantation. *Canadian journal of psychiatry*. 1990 Apr; 35(3):223–227.
6. Jones BM, Taylor F, Downs K, Spratt P. Longitudinal study of quality of life and psychological adjustment after cardiac transplantation. *The Medical journal of Australia*. 1992 Jul 6; 157(1):24–26. [PubMed: 1640885]
7. Kugler J, Tenderich G, Stahlhut P, et al. Emotional adjustment and perceived locus of control in heart transplant patients. *Journal of psychosomatic research*. 1994 Jul; 38(5):403–408. [PubMed: 7965929]
8. Dew MA, Simmons RG, Roth LH, et al. Psychosocial predictors of vulnerability to distress in the year following heart transplantation. *Psychol Med*. 1994 Nov; 24(4):929–945. [PubMed: 7892361]
9. Triffaux JM, Wauthy J, Albert A, et al. Psychological distress of surgical patients after orthotopic heart transplantation. *Transpl Int*. 2001 Dec; 14(6):391–395. [PubMed: 11793036]
10. Dew MA, DiMartini AF. Psychological disorders and distress after adult cardiothoracic transplantation. *J Cardiovasc Nurs*. 2005 Sep-Oct;20(5 Suppl):S51–S66. [PubMed: 16160585]
11. Dew MA, Roth LH, Schulberg HC, et al. Prevalence and predictors of depression and anxiety-related disorders during the year after heart transplantation. *Gen Hosp Psychiatry*. 1996 Nov; 18(6 Suppl):48S–61S. [PubMed: 8937923]
12. Grady KL, Jalowiec A, White-Williams C. Quality of life 6 months after heart transplantation compared with indicators of illness severity before transplantation. *Am J Crit Care*. 1998 Mar; 7(2):106–116. [PubMed: 9509224]
13. Perez-San-Gregorio MA, Martin-Rodriguez A, Diaz-Dominguez R, Perez-Bernal J. The influence of posttransplant anxiety on the long-term health of patients. *Transplant Proc*. 2006 Oct; 38(8):2406–2408. [PubMed: 17097950]
14. Grady KL, Jalowiec A, White-Williams C. Predictors of quality of life in patients at one year after heart transplantation. *J Heart Lung Transplant*. 1999 Mar; 18(3):202–210. [PubMed: 10328145]
15. Jalowiec A, Grady KL, White-Williams C. Satisfaction with heart transplantation. *Progress in cardiovascular nursing*. 2006 Summer;21(3):134–139. [PubMed: 16957459]
16. Jalowiec A, Grady KL, White-Williams C. Functional status one year after heart transplant. *Journal of cardiopulmonary rehabilitation and prevention*. 2007 Jan-Feb;27(1):24–32. discussion 33–24. [PubMed: 17474641]
17. Dobbels F, De Geest S, Martin S, Van Cleemput J, Droogne W, Vanhaecke J. Prevalence and correlates of depression symptoms at 10 years after heart transplantation: continuous attention required. *Transpl Int*. 2004 Sep; 17(8):424–431. [PubMed: 15338116]
18. Bunzel B, Laederach-Hofmann K. Long-term effects of heart transplantation: the gap between physical performance and emotional well-being. *Scandinavian journal of rehabilitation medicine*. 1999 Dec; 31(4):214–222. [PubMed: 10599898]
19. Hetzer R, Albert W, Hummel M, et al. Status of patients presently living 9 to 13 years after orthotopic heart transplantation. *Ann Thorac Surg*. 1997 Dec; 64(6):1661–1668. [PubMed: 9436552]



20. Kaba E, Shanley E. Identification of coping strategies used by heart transplant recipients. *British journal of nursing* (Mark Allen Publishing). Aug 14–Sep 10. 1997; 6(15):858–862.
21. Kaba E, Thompson DR, Burnard P. Coping after heart transplantation: a descriptive study of heart transplant recipients' methods of coping. *Journal of advanced nursing*. 2000 Oct; 32(4):930–936. [PubMed: 11095232]
22. Myaskovsky L, Dew MA, McNulty ML, et al. Trajectories of change in quality of life in 12-month survivors of lung or heart transplant. *Am J Transplant*. 2006 Aug; 6(8):1939–1947. [PubMed: 16889548]
23. Grady KL, Naftel DC, Young JB, et al. Patterns and predictors of physical functional disability at 5 to 10 years after heart transplantation. *J Heart Lung Transplant*. 2007 Nov; 26(11):1182–1191. [PubMed: 18022086]
24. Lazarus, RS.; Folkman, S. *Stress, appraisal and coping*. New York: Springer; 1984.
25. Jalowiec, A. The Jalowiec Coping Scale. In: Strickland, O.; Dilorio, C., editors. *Measurement of nursing outcomes*. 2nd ed. Vol. Vol 3. New York: Springer; 2003.
26. Jalowiec A, Grady KL, White-Williams C. Stressors in patients awaiting a heart transplant. *Behavioral Medicine*. Washington, D.C. Winter. 1994; 19(4):145–154.
27. White-Williams C, Jalowiec A, Grady K. Who returns to work after heart transplantation? *J Heart Lung Transplant*. 2005 Dec; 24(12):2255–2261. [PubMed: 16364879]
28. De Baere C, Delva D, Kloeck A, et al. Return to work and social participation: does type of organ transplantation matter? *Transplantation*. Apr 27; 89(8):1009–1015. [PubMed: 20147883]
29. White-Williams, et al. Factors associated with work status at 5 and 10 years after heart transplantation. *Clinical Transplantation*. 2011 Nov-Dec; 25(6):E599–E605. [PubMed: 21981768]
30. Roy R, Symonds RP, Kumar K, Ibrahim K, Mitchell A, Fallowfield L. The use of denial in an ethnically diverse British cancer population: a cross-sectional study. *Br J Cancer*. 2005; 92(8): 1393–1397. [PubMed: 15812548]
31. Samuel-Hodge CD, Watkins DC, Rowell KL, Hooten EG. Coping styles, well-being, and self-care behaviors among African Americans with type 2 diabetes. *Diabetes Educ*. 2008; 34(3):501–510. [PubMed: 18535323]
32. Vos MS, Puter H, van Houwelingen JC, de Haes HC. Denial and social and emotional outcomes in lung cancer patients: the protective effect of denial. *Lung Cancer*. 2011; 72(1):119–124. [PubMed: 20705356]
33. De Ridder D, Schreurs K. *Clinical Psychology Review*. Developing Interventions for Chronically Ill Patients: Is Coping a helpful Concept?. 2001; 21(2):205–240.
34. Shamaskin A, Rybarczyk B, Wang E, White-Williams C, Cotts W, McGee E, Grady K. Older patients have better quality of life, adjustment and adherence than younger patients 5 years post heart transplantation. *J Heart Lung Transplant*. 2012 May; 31(5):478–484. [PubMed: 22266379]
35. Duitsman D, Cychosz CM. Gender differences in psychosocial characteristics of heart transplant recipients. *J Transplant Coord*. 1995; 5:137–143.

**Table 1**

Model for study on long-term quality of life in heart transplant patients using the Lazarus and Folkman stress and coping conceptual framework

<b>Antecedent Variables</b>	<b>Mediating Variables</b>	<b>Variables</b>	<b>Outcome Variables</b>
<b>Stressors</b>	<b>Appraisal</b>	<b>Coping</b>	<b>Quality of Life and Others</b>
<i>Physical Factors</i>		<i>Psychosocial and Demographic Factors</i>	
<u>Stressors related to Illness and Treatment</u>		<u>Coping</u>	
Pre HT factors		Coping strategies	
Cause of native heart disease <sup>a</sup>		Perceived coping ability <sup>f</sup>	
Length of pre HT illness <sup>b</sup>		Use and effectiveness of coping strategies <sup>h</sup>	
Duration of wait for a HT <sup>a</sup>		Compliance with HT regimen <sup>g</sup>	
UNOS status at time of HT <sup>a</sup>		Use / abuse of alcohol, drugs, and smoking <sup>b</sup>	
Medical and surgical history <sup>a</sup>		Coping resources	
Medications <sup>a,b</sup>		Marital status <sup>i</sup>	
Complications <sup>b</sup>		Education <sup>i</sup>	
Treatments <sup>a,b</sup>		Occupation <sup>d</sup>	
Symptoms <sup>c</sup>		Income <sup>d</sup>	
Acute rejection episodes <sup>a</sup>		# of financial aid resources <sup>d</sup>	
Infection episodes <sup>a</sup>		Social support network (size) <sup>j</sup>	
Co-existing illnesses <sup>b</sup>		Social support effectiveness indicators	
Surgeries <sup>b</sup>		Quality of spouse/family relationships <sup>j</sup>	
Type of immunosuppressive regimen <sup>a</sup>		Helpfulness of HT team interventions <sup>k</sup>	
Severity of illness indicators		Satisfaction with social support resources <sup>j</sup>	
NYHA class <sup>b</sup>		Social interaction indicators	
# hospitalizations and # of days hospitalized <sup>b</sup>		Attendance at HT support group meetings <sup>j</sup>	
Cardiac status indicators		Attendance at church <sup>j</sup>	
Coronary angiography <sup>a</sup>		Participation in social activities <sup>j</sup>	
LVEF <sup>a</sup>			
Cardiac index <sup>b</sup>		<u>Outcomes</u>	
Pulmonary capillary wedge pressure <sup>b</sup>		Survival <sup>a</sup>	
Systolic blood pressure <sup>b</sup>		Functional ability <sup>l</sup>	
Peak VO <sub>2</sub> on TMT <sup>b</sup>		Emotional status <sup>m,n</sup>	
Retransplantation <sup>a</sup>		Work ability <sup>d</sup>	
Lipid profile		Satisfaction with HT <sup>f</sup>	
Cholesterol, triglycerides, HDL, LDL <sup>a</sup>		Perceived QOL <sup>o,f</sup>	
Physiologic status indicators		(life satisfaction + overall rating of QOL)	
Other serum lab tests <sup>a</sup> and body weight <sup>a</sup>			

Antecedent Variables	Mediating Variables	Variables	Outcome Variables
Stressors	Appraisal	Coping	Quality of Life and Others
Exercise capacity (# mets achieved on TMT) <sup>b</sup>			
<i>Psychosocial Factors</i>		HT = heart transplant	
<u>Appraisal of Stress</u>		UNOS = United Network for Organ Sharing	
Symptom distress <sup>c</sup>		NYHA = New York Heart Association	
Work stress (for patients working) <sup>d</sup>		LVEF = left ventricular ejection fraction	
Stress index <sup>e,f</sup>		VO <sub>2</sub> = oxygen consumption	
(transplant-related stressors + overall stress level)		TMT = treadmill test	
Perceived health status <sup>f</sup>		HDL = high density lipoproteins	
Difficulty complying with HT regimen <sup>g</sup>		LDL = low density lipoproteins	
		QOL = quality of life	
		CTRD = Cardiac Transplant Research Database	

Measurement tools:

<sup>a</sup>=CTRD,

<sup>b</sup>=HT Chart Review Form,

<sup>c</sup>=HT Symptom Checklist,

<sup>d</sup>=Work History,

<sup>e</sup>=HT Stressor Scale,

<sup>f</sup>=Rating Question Form,

<sup>g</sup>=Assessment of Problems with the HT Regimen,

<sup>h</sup>=Jalowiec Coping Scale,

<sup>i</sup>=Demographic Questionnaire,

<sup>j</sup>=Social Support Index,

<sup>k</sup>=HT Intervention Scale,

<sup>l</sup>=Sickness Impact Profile,

<sup>m</sup>=Positive and Negative Affect Schedule,

<sup>n</sup>=Cardiac Depression Scale,

<sup>o</sup>=Quality of Life Index

**Table 2**

Characteristics of Enrolled Patients at 5 and 10 Years Post HT

Characteristics	Percentage or mean + SD		p value <sup>†</sup>
	5 Years Post HT (n=199)	10 Years Post HT (n=98)	
Demographics			
Age at transplant, years	55.2±10.0	52.7±9.9	0.0441
Gender			0.5674
Male	80	78	
Female	20	22	
Race/ethnicity			0.2717
White	92	87	
Black	7	8	
Hispanic	0	4	
Other	1	1	
Marital status			0.5031
Married	77	79	
Divorced/separated	13	10	
Single	6	9	
Widowed	5	2	
Education			0.3062
< High school	39	45	
High school or above	61	55	
Years of education	14.2±2.7	13.9±2.6	0.2982
Clinical characteristics			
UNOS 1A or 1B at transplant	62	41	0.0034
NYHA class <sup>a</sup>	1.32±0.48	1.40±0.55	0.2138
Comorbidities (%)			
Hypertension	85	91	0.1616
Hyperlipidemia	74	85	0.0340
Renal dysfunction	39	41	0.7612
Cancer (including skin cancer)	24	49	<.0001
Diabetes	32	23	0.1222
Orthopedic problems	22	31	0.0843
Psychological problems	26	18	0.1364
Gastrointestinal problems	23	17	0.1818
Gout	19	17	0.6452
Genitourinary problems	17	11	0.2275
Rejection	75	86	0.0405
Infection	46	45	0.8283
CAD	38	58	0.0008

UNOS, United Network for Organ Sharing; CAD, coronary artery disease

<sup>a</sup>New York Heart Association functional class between 5 and 10 years after transplant.

<sup>†</sup>Two-sample t-test for continuous variables and Chi-square test for categorical variables. Patients at 5 and 10 years post HT were two independent cohorts.

**Table 3****Most Frequent and Bothersome Stressors at 5 and 10 Years After Heart Transplant**

Stressor	5 Years Post HT			10 Years Post HT		
	n	%	Stressor	n	%	Stressor
Trying to control your weight	115	58.1	Feeling worn out	48	49.0	
Feeling worn out	102	51.5	Trying to control your weight	40	40.8	
Having side effects from meds	100	49.5	Having side effects from meds	36	36.7	
Paying for your meds	89	45.0	Participating in sexual activity	35	35.7	
Participating in sexual activity	82	41.4	Hearing a transplant pt died/sick	32	32.7	
Having heart biopsies	82	41.4	Having cancer	28	28.6	

  

Stressor	5 Years Post HT		10 Years Post HT	
	Mean*	SD	Mean*	SD
Being away from your job	2.24	0.56	2.35	0.71
Participating in sexual activity	2.23	0.79	2.27	0.78
Having back/spine	2.10	0.82	2.11	0.90
Being unemployed due to illness	2.10	0.87	2.11	0.79
Tring to find employment	2.09	0.73	2.08	0.79
Paying your hospital and MD bills	2.01	0.85	2.08	0.76

\* Mean score of 4-likert scale with 0=not stressful at all and 3=very stressful

Table 4

## Most Used and Effective Coping Strategies at 5 and 10 Years After Heart Transplantation

<u>Most Used Coping Strategies at 5 and 10 Years After Heart Transplantation</u>		5 Years Post HT		10 Years Post HT	
Coping	Mean*	SD	Coping	Mean*	SD
Tried to think positively	2.34	1.05	Tried to think positively	2.18	1.12
Tried to keep a sense of humor	2.22	1.06	Prayed or put your trust in GOD	2.02	1.24
Tried to keep life as normal as possible	2.15	1.12	Tried to keep life as normal as possible	2.02	1.11
Thought about the good things in your life	2.15	1.08	Tried to keep a sense of humor	2.01	1.13
Tried to see the good side of the situation	2.07	1.08	Thought about the good things in your life	1.94	1.16
Tried to handle things one step at a time	2.04	1.11	Tried to handle things one step at a time	1.92	1.16

  

<u>Most Effective Coping Strategies at 5 and 10 Years After Heart Transplantation</u>		5 Years Post HT		10 Years Post HT	
Coping	Mean*	SD	Coping	Mean*	SD
Prayed or put your trust in GOD	2.54	0.78	Prayed or put your trust in GOD	2.59	0.74
Tried to think positively	2.50	0.71	Tried to think positively	2.44	0.65
Tried to keep a sense of humor	2.45	0.70	Thought about the good things in your life	2.39	0.78
Thought about the good things in your life	2.44	0.73	Tried to keep a sense of humor	2.37	0.72
Tried to handle things one step at a time	2.36	0.73	Tried to handle things one step at a time	2.31	0.66
Tried to keep life as normal as possible	2.25	0.80	Exercised or did some physical activity	2.28	0.74

\*Mean score of 4-likert scale with 0=never used and 3=often used.

\*Mean score of 4-likert scale with 0=not helpful and 3=very helpful

**Table 5**

Frequency and Intensity Scores of Stress & Frequency and Effectiveness Scores of Coping 5 and 10 Years After Heart Transplantation

Frequency and Intensity Scores of Stress at 5 and 10 Years After Heart Transplantation															
Stress subscale	Stress Reported*			Frequency Score <sup>†</sup>			Intensity Score <sup>†</sup>			p	b				
	5 Yr		10 Yr	5 Yr		10 Yr	5 Yr		10 Yr						
	n	%	n	%	Mean	SD	Mean	SD	Mean			SD			
Physical stress	176	88.4	80	81.6	0.0857	0.28	0.20	0.21	0.17	0.0013	0.54	0.22	0.58	0.20	0.1166
Hospital/Clinical stress	95	47.7	31	31.6	0.0074	0.25	0.31	0.15	0.25	0.0031	0.54	0.25	0.51	0.23	0.6069
Self care stress	159	79.9	68	69.4	0.0366	0.22	0.20	0.15	0.16	0.0009	0.49	0.21	0.47	0.24	0.4374
Family stress	141	70.9	55	56.1	0.0098	0.19	0.20	0.13	0.18	0.0157	0.57	0.25	0.54	0.26	0.3669
Job/School/Financial stress	145	72.9	39	39.8	<.0001	0.18	0.19	0.09	0.14	<.0001	0.61	0.25	0.68	0.24	0.1434
Psych/Emotional stress	164	82.4	76	77.6	0.2753	0.19	0.19	0.13	0.15	0.0052	0.52	0.22	0.54	0.21	0.6339
<i>Total Stress</i>	188	94.5	88	89.8	0.0964	0.21	0.16	0.14	0.12	<.0001	0.53	0.19	0.53	0.20	0.8379

  

Frequency and Effectiveness of Specific Coping Styles at 5 and 10 Years After Heart Transplantation															
Coping Style (subscale)	Coping Used*			Frequency Score <sup>†</sup>			Effectiveness Score <sup>†</sup>			p	b				
	5 Yr		10 Yr	5 Yr		10 Yr	5 Yr		10 Yr						
	n	%	n	%	Mean	SD	Mean	SD	Mean			SD			
Confrontation	177	88.9	85	86.7	0.4995	0.54	0.29	0.49	0.30	0.1624	0.67	0.19	0.68	0.18	0.7294
Evasive	177	88.9	80	81.6	0.0632	0.32	0.21	0.26	0.21	0.0117	0.44	0.19	0.43	0.19	0.5339
Optimistic	180	90.5	91	92.9	0.5706	0.62	0.27	0.56	0.28	0.1055	0.69	0.19	0.69	0.18	0.8657
Fatalistic	164	82.4	66	67.3	0.0026	0.29	0.22	0.21	0.22	0.0030	0.49	0.31	0.39	0.20	0.0030
Emotive	162	81.4	80	81.6	0.9690	0.29	0.22	0.23	0.20	0.0274	0.26	0.23	0.20	0.19	0.0157
Palliative	177	88.9	83	84.7	0.2443	0.36	0.20	0.32	0.22	0.1265	0.64	0.21	0.64	0.20	0.9404
Supportant	169	84.9	88	89.8	0.2876	0.43	0.27	0.40	0.25	0.3366	0.54	0.29	0.52	0.25	0.5303
Self-Reliant	177	88.9	86	87.8	0.6733	0.54	0.27	0.47	0.29	0.0319	0.62	0.19	0.61	0.20	0.5560
<i>Positive Coping</i>	181	91.0	92	93.9	0.4562	0.54	0.25	0.49	0.26	0.0910	0.68	0.16	0.68	0.16	0.9829
<i>Negative Coping</i>	181	91.0	87	88.8	0.4654	0.29	0.18	0.22	0.18	0.0049	0.43	0.19	0.38	0.18	0.0424

\* Patients who reported at least one of the stress items within each subscale

<sup>†</sup> standardized scale of 0.00 to 1.00



<sup>a</sup>Two-sample independent t-test

<sup>b</sup>Chi-square test

\*Patients who used at least one of the coping strategies within each coping style subscale

Table 6

Difference in Coping Use and Effectiveness by Patient Characteristics

Characteristics	5 Years Post HT						10 Years Post HT									
	Frequency Score <sup>†</sup>		Effectiveness Score <sup>†</sup>		p value		Frequency Score <sup>†</sup>		Effectiveness Score <sup>†</sup>		p value					
	Positive coping	Negative coping	Positive coping	Negative coping	Positive coping	Negative coping	Positive coping	Negative coping	Positive coping	Negative coping	Positive coping	Negative coping				
Age																
< 60	0.56	0.31	0.67	0.42	0.48	0.22	0.68	0.39	0.50	0.25	0.70	0.45	0.46	0.19	0.65	0.38
60																
<i>p value</i> *	<i>0.0819</i>	<i>0.0240</i>	<i>0.3173</i>	<i>0.2342</i>	<i>0.7156</i>	<i>0.4050</i>	<i>0.4200</i>	<i>0.7512</i>								
Gender																
Female	0.60	0.35	0.68	0.41	0.52	0.26	0.70	0.41	0.52	0.27	0.68	0.43	0.47	0.20	0.67	0.38
Male																
<i>p value</i>	<i>0.0637</i>	<i>0.0047</i>	<i>0.9967</i>	<i>0.6057</i>	<i>0.3870</i>	<i>0.1633</i>	<i>0.3923</i>	<i>0.6318</i>								
Marital status																
Married	0.53	0.27	0.68	0.43	0.47	0.20	0.69	0.41	0.50	0.25	0.69	0.44	0.50	0.25	0.64	0.31
Not married																
<i>p value</i>	<i>0.4290</i>	<i>0.1849</i>	<i>0.7329</i>	<i>0.6976</i>	<i>0.7251</i>	<i>0.2586</i>	<i>0.2449</i>	<i>0.0318</i>								
Education																
high school	0.54	0.28	0.69	0.45	0.49	0.24	0.68	0.44	0.54	0.29	0.67	0.42	0.47	0.20	0.67	0.35
> high school																
<i>p value</i>	<i>0.9726</i>	<i>0.6552</i>	<i>0.4772</i>	<i>0.3395</i>	<i>0.5829</i>	<i>0.2594</i>	<i>0.7824</i>	<i>0.0186</i>								
Diabetes																
Yes	0.52	0.29	0.65	0.38	0.49	0.20	0.68	0.45	0.54	0.28	0.69	0.45	0.47	0.22	0.68	0.36
No																
<i>p value</i>	<i>0.6004</i>	<i>0.8432</i>	<i>0.1356</i>	<i>0.0080</i>	<i>0.7951</i>	<i>0.7127</i>	<i>0.8673</i>	<i>0.0376</i>								
Psychological problems																
Yes	0.57	0.36	0.62	0.40	0.59	0.34	0.62	0.33	0.53	0.26	0.70	0.44	0.45	0.18	0.69	0.40
No																
<i>p value</i>	<i>0.3224</i>	<i>0.0002</i>	<i>0.0009</i>	<i>0.1826</i>	<i>0.0427</i>	<i>0.0004</i>	<i>0.1026</i>	<i>0.1313</i>								
Rejection																

Characteristics	5 Years Post HT					10 Years Post HT				
	Frequency Score <sup>†</sup>		Effectiveness Score <sup>‡</sup>		p value	Frequency Score <sup>†</sup>		Effectiveness Score <sup>‡</sup>		p value
	Positive coping	Negative coping	Positive coping	Negative coping		Positive coping	Negative coping	Positive coping	Negative coping	
Yes	0.57	0.31	0.68	0.42	0.48	0.21	0.68	0.21	0.68	0.38
No	0.46	0.22	0.68	0.45	0.47	0.22	0.68	0.22	0.68	0.42
<i>p value</i>	<b>0.0049</b>	<b>0.0018</b>	<i>0.9796</i>	<i>0.2919</i>	<i>0.8940</i>	<i>0.8557</i>	<i>0.9537</i>	<i>0.8557</i>	<i>0.9537</i>	<i>0.4013</i>
Infection										
Yes	0.52	0.27	0.70	0.45	0.48	0.21	0.68	0.21	0.68	0.37
No	0.55	0.30	0.66	0.42	0.48	0.21	0.68	0.21	0.68	0.40
<i>p value</i>	<i>0.2915</i>	<i>0.2472</i>	<i>0.0891</i>	<i>0.3022</i>	<i>0.9879</i>	<i>0.9465</i>	<i>0.9799</i>	<i>0.9465</i>	<i>0.9799</i>	<i>0.3336</i>
CAD										
Yes	0.52	0.29	0.69	0.45	0.51	0.22	0.68	0.22	0.68	0.41
No	0.55	0.28	0.68	0.42	0.43	0.20	0.67	0.20	0.67	0.36
<i>p value</i>	<i>0.4999</i>	<i>0.7812</i>	<i>0.6944</i>	<i>0.2797</i>	<i>0.1167</i>	<i>0.5854</i>	<i>0.6542</i>	<i>0.5854</i>	<i>0.6542</i>	<i>0.1748</i>

\* Two-sample t-test

<sup>†</sup> standardized scale of 0.00 to 1.00

Table 7

## Generalized Linear Model of Overall Stress

Variables	Stress Frequency Score			Stress Intensity Score				
	5 Years		10 Years	5 Years		10 Years		
	b	p	b	p	b	p		
<u>Coping</u>								
Positive coping	-0.075	0.1892	0.003	0.9701	0.011	0.8844	0.152	0.2557
Negative coping	0.410	<.0001	0.205	0.0439	0.243	0.0185	0.073	0.7210
<u>Demographics</u>								
Age (>60 years)	-0.016	0.4599	0.004	0.8766	-0.063	0.0261	-0.005	0.9229
Gender (Male)	-0.010	0.7109	-0.029	0.2921	-0.081	0.0208	-0.003	0.9584
Race (Non-white)	0.015	0.7048	0.055	0.0865	0.054	0.2838	0.079	0.1977
Marital status (Not married)	0.002	0.9521	-0.017	0.5662	-0.065	0.0454	-0.003	0.9571
Education ( High school)	0.008	0.6946	-0.039	0.0728	0.044	0.1009	-0.008	0.8563
<u>Clinical Characteristics</u>								
NYHA class (II or III)	-0.031	0.1797	0.064	0.0113	-0.018	0.5453	-0.047	0.3338
Orthopedic problems	-0.030	0.2250	0.070	0.0042	0.010	0.7503	0.102	0.0372
Psychological problems	0.068	0.0059	0.061	0.0491	0.045	0.1497	0.052	0.3860
Infection	-0.002	0.9316	0.045	0.0442	0.060	0.0227	0.011	0.7961
$R^2$	0.28		0.42		0.21		0.17	