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Living with a heart transplant: long-term adjustment

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Abstract. The number of heart transplants performed worldwide has increased greatly in the past 10 years, and survival rates will continue to improve with the introduction of new immunosuppressive therapies. With this improved lifespan outlook, the experience of living with a heart transplant needs to be understood as a chronic condition. Twenty-nine recipients who were a minimum of 5 months post-transplantation (mean 22 months) and 23 significant others were interviewed twice 6 months apart using close-ended and open-ended questions developed from the Common Sense Model of health beliefs. Results suggest that although life improved for the majority post-transplantation, recipients continue to experience work problems, financial burdens, family role changes, lifestyle changes, and side effects associated with long-term drug treatment.

Key words: Heart transplants, quality of life – Quality of life, heart transplants

Heart transplantation has become an accepted treatment for end-stage heart disease. The number of heart transplants performed worldwide as of July 1990 was 15000, and in the United States the number of heart transplants performed annually has increased from 49 in 1980 to 1676 in 1989 (US Heart Transplant Registry, personal communication, August 1990). Refined organ procurement methods and immunosuppressive regimens, especially since the introduction of cyclosporin in 1983, have improved 1-year survival rates to slightly over 80% and estimated 5-year survival rates to 72% [13]. Long-term survival for heart transplant recipients is largely dependent on adopting certain lifestyle behaviors: adherence to a lifelong regimen of immunosuppressive medications, dietary restrictions, exercise regulation, and special precautions to prevent infection.

Infection and rejection are the most common overall causes of mortality (US Heart Transplant Registry, personal communication, August 1990). Chronic rejection most often occurs 6 months or more post-transplantation and is the most common cause of organ loss after the 1st year. It is a progressive, low-grade rejection, thought to be immunologically based, producing diffuse coronary artery disease [29]. Approximately 30%–40% of patients undergoing heart transplantation will have advanced coronary artery disease within 5 years [7, 24].

The purpose of this study was to better understand the experience of living with a heart transplant, using a paradigm of chronic illness, from the perspective of both the recipient and significant other (SO). There is substantial documentation of the relationship of social support to mental and physical health [6]. Social context, especially the interaction with a SO, has the potential to reinforce or undermine coping behaviors [10, 28]. The specificity of support and the distinction between perceptions of support received and support given have also been found to be independent predictors of health behaviors [1].

The Common Sense Model (CSM) of illness [16] was used as a theoretical framework for measuring perceptions and beliefs about the transplant experience. This self-regulative model of behavior suggests that information about health threats consists of three sets of component processes: (1) representation, (2) coping or action plans, and (3) appraisal (Fig. 1). Leventhal [14] notes that "these sets of variables have typically been treated as distinct stages in a linear sequence for processing information" (p. 5). However, it may be more valid to treat them as components with the assumption that they operate in a state of constant interaction rather than in only one sequence [14].

The first set of variables, the mental representation of a health threat, contains five major attributes: (1) identity or symptoms and labels associated with a condition; (2) cause; (3) timeline, chronic or acute; (4) consequences of the health threat; and (5) control of adverse side effects associated with the health threat.

Next, coping entails selecting and executing responses to specific information contained in the representation. For example, someone who believes that hypertension is caused by stress may skip a dose of medication on days

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he/she feels relaxed. This coping action may be viewed as noncompliant by health care providers, but it makes sense and is consistent with the person's representation about what causes his/her blood pressure to go up.

Finally, in appraisal, the effectiveness of coping actions is evaluated by monitoring emotional and physical outcomes. Effective coping minimizes emotional distress and yields positive concrete body signs and symptoms that are used to assess one's health status.

Leventhal and colleagues [17] argued that symptoms play an important role in the patient's effort to cope with chronic conditions because they provide efficient mechanisms for determining health status since they provide continuous and readily available information for monitoring disease status and assessing the effectiveness of treatment. Studies using the CSM have shown that symptoms guide beliefs and health-related behavior in hypertension [2, 22, 26], type II diabetes [11, 25], cancer treatment [19], perceptions about aging [27], and even in subjects given a fictitious disease [9].

Since heart transplant recipients can be viewed as individuals who have a highly symptomatic lifelong condition, it is important to better understand how the perception and interpretation of the symptoms experienced guide coping behaviors [18]. These symptoms are primarily side effects related to treatment with the immunosuppressive drugs prednisone, cyclosporin, and azathioprine.

In contrast to the highly symptomatic nature of side effects associated with this condition, rejection is asymptomatic and is a histological diagnosis derived from a myocardial biopsy. The cardiovascular effects of rejection, inflammation, and cardiac failure, are associated with rather general symptoms, such as fatigue, elevated temperature, and changes in blood pressure. Furthermore, classic cardiac symptoms, such as angina or palpitations, are absent after transplantation because of the denervation of the transplanted heart. Without the ability to monitor familiar cardiac symptoms after the transplant, recipients face some degree of uncertainty about how to interpret bodily information to assess their health status.

The major goals of this paper will be to describe and compare the components of representation, coping, and appraisal of living with a heart transplant over a 6-month period in both heart transplant recipients and significant others.

Materials and methods

Overview of design

This descriptive study consisted of two 1-hour semistructured interviews or questionnaires administered 6 months apart on heart transplant recipients who were at least 5 months post-transplantation and their SOs. Potential subjects were recruited from the population of heart transplant recipients from one medical center located in the midwestern United States. Eligible recipients had to be able to tolerate a 1-hour interview. Of 41 eligible recipients, 33 agreed to participate in the initial interview (T1) and 29 were interviewed 6 months later (T2); 2 recipients died and 2 refused to participate. Data on cardiovascular status was obtained from the medical record once during the 6-month interval between interviews. Twenty-seven SOs were interviewed ($n = 11$) or answered a mailed questionnaire ($n = 16$) at T1 and all SOs ($n = 23$) answered mailed questionnaires at T2.

Procedure

Permission to approach heart transplant recipients was obtained from the heart transplant surgeon through a letter of introduction. Recipients were asked permission to obtain information from their medical record and to contact a designated SO in order to request their participation to either be interviewed or to answer a mailed questionnaire. With the exception of one recipient, who was interviewed by telephone at both T1 and T2, all recipient interviews were conducted during a hospital admission that included routine myocardial biopsy.

Subjects

This paper reports data from the 29 recipients and 23 SOs who participated at both T1 and T2. Recipients ranged from 5 months to 5 years post-transplantation (mean 22 months). The majority (69%) were male, the mean age was 49.8 years, and 79% were married. Of the SOs, 78% were female, the mean age was 44.9 years, 78% of SOs were spouses, 13% were siblings, and 9% were children (Table 1).

Recipient interview. Upon arrival at the interview, recipients were asked to read and sign the consent form and were given an opportunity to ask any questions they had about the study. The interview included questions about health beliefs; health status; social support received with managing diet, medications, exercise, and mood swings; moods; symptom experience; health habits; and demographic data. After the initial interview was completed, subjects were given an opportunity to ask questions, thanked for their participation, and reminded that they would be contacted in 6 months. The same procedure was followed 6 months later, and at the conclusion of each interview, recipients were given a small honorarium for their time.

Significant other. Only 11 participants were interviewed at T1 and the remaining SO data was obtained through a mailed questionnaire. SOs were instructed that responses to the questionnaire would not be shared with the recipient. Data obtained from SOs included: (1) demographic items; (2) their representation of the transplant experience (e.g., cause, timeline, consequences, and control over and

Table 1. Description of recipients and significant others (SO)

	Recipient ($n = 29$)	SO ($n = 23$)
Mean age (SD)	49.8 (8.73)	44.9 (9.99)
Age range (years)	33–61	22–59
Mean months post-transplantation	22.2 (range 5–60 months)	
Gender – males	69%	22%
Marital status		
married	79%	85%
divorced/widowed	15%	7%
never married	4%	7%
Education		
less than high school	10%	17%
high school	38%	30%
beyond high school	52%	52%
Pretransplant employment		
full-time	66%	65%
part-time	4%	22%
homemaker	10%	9%
retired/disabled	21%	4%

susceptibility of the recipient to rejection); (3) how much support they provided to the recipient with respect to diet, medications, exercise, and managing mood swings; and (4) a satisfaction with life score. Upon receipt of the questionnaire or completion of the interview, the SO was given a small honorarium for his/her participation.

Instruments

The interview items included open-ended and scaled items to measure each of the five attributes of representation. Identity, or symptom experience, was measured using a Symptom Frequency and Symptom Distress Scale that has been previously validated with heart transplant recipients [20]. Using a 5-point scale, recipients rated the frequency (0 = never, 4 = always) and distress (0 = not at all, 4 = extremely) of 29 symptoms associated with immunosuppressive therapy. Second, an open-ended item asked recipients to identify what symptoms they believed were associated with rejection. At T2 recipients were also asked to attribute a reason for the symptoms they experienced.

Recipients were asked to identify a reason for their transplant and timeline was measured by asking recipients to rate whether they viewed their transplant as a cure, as a chronic condition, or whether they viewed themselves as always ill. Consequence was measured by asking recipients to rate whether the transplant improved their life, did not change it, or made their life worse; they were also asked to rate the seriousness of rejection, using a 5-point scale. The perception of control over side effects associated with treatment was measured by having recipients rate, on a 5-point scale, how controllable and susceptible they felt a number of treatment side effects were, including rejection.

Coping was measured by asking recipients to rate their adherence to dietary, medication, and exercise regimens. Recipients were also asked to rate their perceptions of social support received from their SO in managing mood swings, diet, medication, and exercise regimens, using a 4-point scale (1 = rarely supportive, 4 = always supportive).

Positive affect was assessed using two scales: the 5-item Satisfaction with Life Scale (SWLS) [8] and the 8-item Life Orientation Test (LOT) [5], which measures dispositional optimism. Optimism is a stable personality trait that has been found to be a significant predictor of more favorable expectations and less symptom reporting [5]. The SWLS has good concurrent validity, a test-retest reliability of 0.82, and an internal consistency of 0.82 [8]. The LOT has been used on both healthy and chronically ill adults and has good internal consistency (0.76) and test-retest reliability (0.79) [5]. Negative moods (tension, depression, and fatigue) were measured using the short version of the Profile of Moods States (POMS) [30]. The POMS has internal consistency of greater than 0.80 for all subscales [30]. One item was used for a self-rating of health status from 1 (poor) to 4 (excellent).

Functional health status was assessed using eight subscales from the Sickness Impact Profile (SIP) to measure the degree of sickness-related dysfunction in areas of sleep-rest, home management, mobility, social interaction, ambulation, work, alertness behavior, and recreation-pastime. The psychometric properties of the SIP have been extensively reported on chronically ill adults [4]. Subscales are scored so that the higher score indicates more dysfunction. Questions were also asked about pre- and post-transplant employment status.

Results

Representation of a heart transplant

Symptoms. Frequency and distress scores for symptoms associated with immunosuppressive therapy were computed using an average rating for the symptom items for each recipient. The most frequent symptoms were not necessarily the most upsetting, although these dimensions were highly correlated ($P < 0.001$) at T1 ($r = 0.64$) and T2 ($r = 0.76$). Over the 6-month period, the mean frequency of symptoms reported did not change from T1 (mean 1.05, SD = 0.60) to T2 (mean 1.09, SD = 0.52), while the mean distress rating increased slightly from 1.57 (SD = 0.59) at T1 to 1.73 (SD = 0.86) at T2; however, this increase was not statistically significant. Individual mean symptom frequency ratings are not presented since they did not change. The mean distress ratings of 29 symptoms at T1 and T2 are shown in Fig. 2.

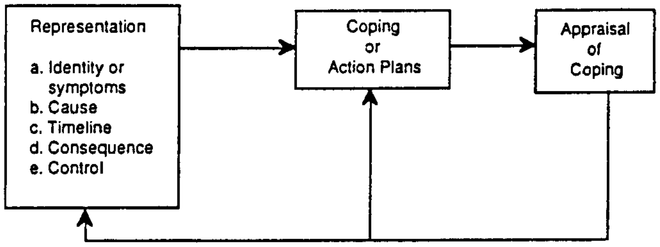

Fig. 1. The Common Sense Model of illness

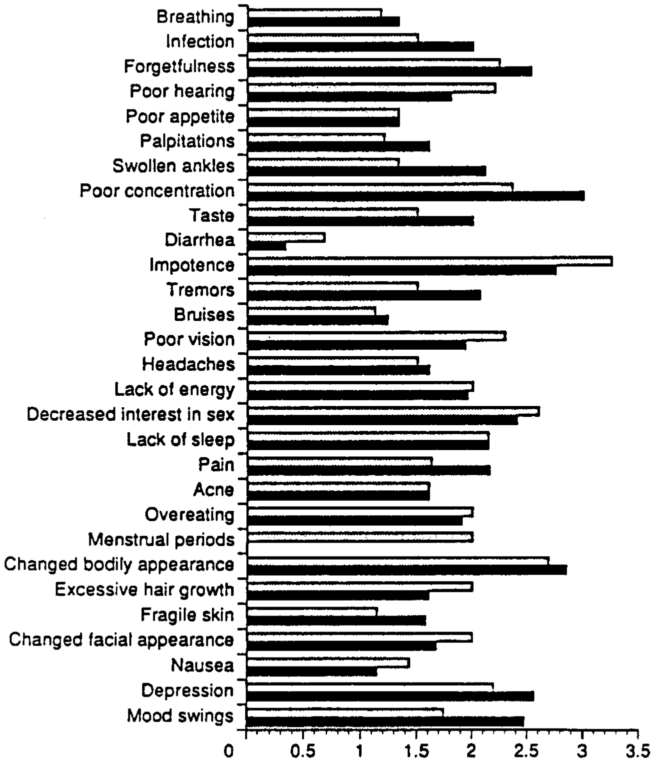

Fig. 2. Mean symptom distress ratings at initial interview (T1) and 6 months later (T2). □ Distress at T1; ■ distress at T2

To assess the stability of the recipient's beliefs about symptoms associated with rejection, responses to the question "How would you know if you were having a rejection episode?" were compared at T1 and T2. At T1 and T2, respectively, 31% and 41% of recipients said they would not know because they had never experienced rejection, and 17% and 14%, respectively, stated that rejection had no symptoms and could only be detected by

Table 2. Correlations of symptom frequency and distress with psychosocial adjustment measures at initial interview (T1) and 6 months later (T2). SWLS, Satisfaction with life scale. $P < 0.05$

	T1		T2	
	Symptom frequency	Symptom distress	Symptom frequency	Symptom distress
Optimism	−0.38	−0.45	−0.46	−0.46
SWLS	−0.47	−0.59	−0.60	−0.54
Tension	0.41	0.54	0.64	0.62
Depression	0.38	0.52	0.49	0.41
Fatigue	0.55	0.41	0.66	0.67

myocardial biopsy. Percentage responses of recipients who identified a symptom were nearly identical at T1 and T2 and included: fatigue (31% and 41%), shortness of breath (24% and 20%), flu symptoms (21% and 14%), gastric distress (17% and 14%), or an elevated temperature (17% and 14%).

Comments to open-ended questions at T2 suggest that rejection remained a major concern. "Rejection – just the word scares me that I'll die before I do all the things I want to do yet. Having to go through an annual admission every year, I hate those 3 days and wondering what the results will be. I feel more anxious and worried about rejection and serious side effects of the medications as I get farther from the transplant... sort of wondering how long can my luck hold?"

The CSM suggests that it is the interpretation of symptoms that guides subsequent behavior. At T2 recipients were asked to describe what each symptom meant. They attributed symptoms to three major causes: (1) symptoms of anxiety: headaches, sleep problems, menstrual irregularity, poor appetite, and depression; (2) symptoms of aging: forgetfulness, pain, poor concentration, and hearing problems; and (3) symptoms primarily due to side effects associated with treatment, which included the remaining symptoms. Although fatigue is one of the most frequent symptoms associated with possible rejection, it was attributed to being a drug side effect by 31% and 41% of recipients at T1 and T2, respectively.

The relationship between symptom experience and psychological and functional health appraisal measures was also examined. Scores on the symptom frequency and distress scales correlated significantly ($P < 0.05$) in the expected direction with measures of optimism, SWLS, tension, depression, and fatigue (Table 2). Optimism and satisfaction with life were associated with less frequent symptoms and less distress from these symptoms. Tension, depression, and fatigue were associated with more symptoms and more distress related to these symptoms.

Cause, timeline, and consequences. Responses to questions about what recipients and SOs believed to be the reason(s) a heart transplant was needed, perception of timeline of living with a transplant, and the consequences of having the transplant are summarized in Table 3.

At T1 62% of recipients viewed the transplant as a cure, compared to 31% at T2. Instead, 38% of recipients at T2 described their transplant as something that improved their overall health or cured their heart condition but that created new health problems. Recipients thought of their heart problem as the "disease-free" part of their health and the new problems created by treatment as the "disease" or "illness". One recipient commented that the transplant "improved the physical side of things – I can do more – but emotionally there's more anxiety, wondering if I will stay healthy, fear of rejection, future very uncertain." Another stated that the transplant "improved my heart and health, but caused lots of financial problems and problems in my sex life." This representation of a chronic health problem has been referred to as "encapsulated" and has been related to successful coping in cancer patients [13]. A part of oneself is viewed as diseased but large parts of the self are disease-free.

Perception of control over a number of complications associated with treatment, including rejection, was assessed by having recipients rate each item on a 5-point scale. The mean rating for control over rejection did not change from T1 (mean 3.65, SD = 1.37) to T2 (mean 3.57, SD = 1.12). The highest perception of control was over rejection, with recipients stating that rejection was highly

Table 3. Summary of responses of recipients ($n = 29$) and of significant others ($n = 23$) to cause, timeline, and consequences of a heart transplant at initial interview (T1) and 6 months later (T2)

Cause: "The reason I needed a heart transplant was because of.."	Recipient % of responses		Significant other % of responses	
	T1	T2	T1	T2
Viral infection	22.9	17.7	13.9	3.6
Prior heart problems	12.5	14.5	27.8	14.3
"Worn out" heart	12.5	29.0	22.2	71.4
Family history	16.7	11.3	2.8	3.6
Stress	12.5	4.8	13.9	.0
Alcohol	6.3	4.8	2.8	.0
Smoking	6.3	3.2	2.8	.0
Other	10.5	12.8	13.9	7.2
Timeline: "Which statement do you agree with most?"				
Transplant cured my health problem	62.1	31.0	55.2	39.1
Transplant is like a chronic illness	27.6	13.8	43.5	21.7
Remain ill after transplant	3.4		4.3	8.7
Not cured, not chronic illness		17.2		30.4
Transplant cured heart problem but created new problems	3.4	37.9		
Consequences: "How has the transplant changed your life?"				
Improved it	79.3	65.5	52.2	52.2
Did not change it	6.9	13.8	26.1	13.0
Made it worse	13.8	6.9	21.7	21.7
Improved health, but new problems	13.8		13.0	

Table 4. Comparison of recipient ($n = 29$) and significant other ($n = 23$) susceptibility, seriousness, and controllability ratings about rejection at initial interview (T1) and 6 months later (T2)

	T1		
	Recipient Mean (SD)	Significant other Mean (SD)	
Susceptibility	1.70 (0.82)	2.70 (1.40)	$t(22) = 3.18, P = 0.004$
Seriousness	4.09 (1.38)	4.70 (0.77)	$t(22) = 1.75, P = 0.095$
Controllability	3.65 (1.37)	3.39 (0.94)	$t(22) = 0.73, P = 0.472$
	T2		
	Recipient Mean (SD)	Significant other Mean (SD)	
Susceptibility	1.86 (0.26)	2.73 (1.35)	$t(21) = 2.31, P = 0.031$
Seriousness	4.26 (1.05)	4.74 (0.54)	$t(22) = 1.85, P = 0.077$
Controllability	3.57 (1.12)	3.22 (0.90)	$t(22) = 1.22, P = 0.236$

controllable with medications. "I can only think of this big fight going on in my body. The medications are trying to keep my heart from rejecting and keep me free of cholesterol blocks, my body wants to do its own thing, and it's a battleground, but so far the medications seem to be doing their job." The lowest perceptions of control were over complications of forgetfulness and arthritis, symptoms attributed more to aging.

SOs rated the controllability of rejection much as recipients did; however, SOs tended to rate rejection as more serious than recipients did. SOs also rated the recipient as more susceptible to complications than the recipients' self-ratings of susceptibility at both T1 (mean 2.70 vs. mean 1.70, $t(22) = 3.18$, $P = 0.004$) and T2 (mean 2.73 vs. mean 1.86, $t(22) = 2.31$, $P = 0.031$; Table 4).

Coping behaviors

Self-reports of adherence to diet, exercise, and taking medication showed that 76% of recipients reported following a special diet at T1 and 86% at T2, mainly for the purpose of weight and cholesterol control. At T1 only 59% of recipients reported following a prescribed exercise plan, compared to 76% at T2, although at T2 more recipients reported bone and joint complications that limited their ability to exercise. "Laziness and lack of motivation are my problem. I know I should be exercising but I just can't get myself going. Also it's hard to exercise alone. It would be easier if I had someone to do it with or a class, but that's too expensive. I just can't afford it." At T2, 85% of the recipients reported having never attended a cardiac rehabilitation program. All recipients at T1 and T2 reported taking three immunosuppressive drugs – cyclosporin, azathioprine, and prednisone – with 100% reporting never missing a dose.

There was a striking similarity between the perceptions of recipients in receiving support and of SOs in providing support with respect to taking medications, exercising, sticking to a diet, and managing mood swings (Table 5). Both recipients and SOs reported the most support with taking medications and the least support with managing mood swings, suggesting that managing the psychological side effects is perceived as the most difficult task for both groups of subjects. Ratings of both support given by SOs and support received by recipients with respect to taking medications were significantly lower from T1 to T2.

Appraisal

Analysis of recipient SWLS scores revealed a significant decrease from T1 (mean 25.93, SD = 7.3) to T2 (mean 23.72, SD = 7.3). Results from the POMS showed that recipients reported more tension (mean 2.49 and mean 2.40) and fatigue (mean 2.16 and mean 2.19) than depression (mean 1.62 and mean 1.65), but these ratings did not significantly change from T1 to T2 (Table 6). Self-rating of health status also did not change from T1 (mean 3.10, SD = 0.72) to T2 (mean 3.00, SD = 0.71), with recipients rating themselves in good health. Self-ratings of health status did significantly correlate ($P < 0.05$) in the expected

Table 5. Mean ratings at initial interview (T1) and 6 months later (T2) of support received by recipients ($n = 29$) and support given by significant others ($n = 23$)

	Support received by recipient		Support given by significant other	
	T1 Mean (SD)	T2 Mean (SD)	T1 Mean (SD)	T2 Mean (SD)
Taking medications	3.81 (0.66)	3.36 (1.09)[a]	4.00 (0.00)	3.58 (0.84)[b]
Following diet	3.54 (0.71)	3.39 (1.06)	3.41 (0.85)	3.45 (0.67)
Exercising regularly	3.36 (1.10)	3.14 (1.18)	3.50 (0.86)	3.27 (0.94)
Managing mood swings	2.91 (1.00)	2.74 (1.18)	3.05 (0.74)	3.00 (0.84)

[a] $t(21) = 2.11, P = 0.047$

[b] $t(18) = 2.19, P = 0.042$

Table 6. Comparison of recipient ($n = 29$) and significant other ($n = 23$), psychosocial appraisal measures at initial interview (T1) and 6 months later (T2)

	Recipient			
	T1		T2	
Scales	Range	Mean (SD)	Range	Mean (SD)
Satisfaction with life	10–34	25.93 (7.3)	5–34	23.72 (7.3)[a]
Optimism	15–40	30.55 (6.8)	14–40	29.30 (6.2)
Tension	1–4.17	2.49 (0.9)	1–4.67	2.40 (0.9)
Depression	1–2.75	1.62 (0.5)	1–5.0	1.65 (0.8)
Fatigue	1–3.6	2.16 (0.6)	1–4.4	2.19 (0.8)
	Significant other			
	T1		T2	
Scale	Range	Mean (SD)	Range	Mean (SD)
Satisfaction with life	11–35	23.57 (7.4)	6–35	20.96 (8.1)

[a] $t(28) = 2.61, P = 0.014$

Table 7. Recipient ($n = 29$) mean scores on eight subscales of the Sickness Impact Profile (SIP) at initial interview (T1) and 6 months later (T2)

	T1		T2	
Functional area	Range	Mean (SD)	Range	Mean (SD)
Work	0–124.5	47.06 (34)	0–70.1	23.20 (30.2)[a]
Sleep-rest	0– 71.7	16.63 (17.9)	0–69.3	13.41 (16.7)
Recreation-pastimes	0– 47.9	15.54 (14.4)	0–51.7	13.96 (15.0)
Alertness behavior	0– 69.2	14.41 (18.1)	0–66.5	16.12 (23.1)
Social interaction	0– 72.9	14.04 (17.2)	0–47.1	10.39 (15.1)[b]
Home management	0– 63.5	10.49 (14.0)	0–35.5	7.74 (10.5)
Ambulation	0– 29.5	6.40 (8.7)	0–37.4	5.51 (9.4)
Mobility	0– 35.7	3.82 (8.5)	0–21.1	2.47 (5.8)

[a] $t(28) = 3.23, P = 0.003$
[b] $t(28) = 2.15, P = 0.040$

direction at T1 and T2 with: measures of well-being that included SWLS ($r = 0.60$ and $r = 0.56$), optimism ($r = 0.63$ and $r = 0.77$), two of the negative moods, depression ($r = -0.38$ and $r = -0.33$) and fatigue ($r = -0.52$ and $r = -0.36$), and symptom frequency ($r = -0.41$ and $r = -0.40$) and distress ($r = -0.40$ and $r =$ NS).

All SIP subscale means decreased from T1 to T2, indicating improved function, except for alertness behavior. Although this increase was not statistically significant, forgetfulness and inability to concentrate became more of a problem over the 6-month period. Work was the area of greatest reported dysfunction at T1 (mean 47.06, SD = 34.0) and T2 (mean 23.2, SD = 30.2), although the degree of dysfunction significantly decreased ($t(28) = 3.23$, $P = 0.003$) as did dysfunction in social interactions ($t(28) = 2.15$, $P = 0.04$; Table 7).

Before receiving their transplant, 66% of the recipients worked full-time, while 17% reported working full-time at T1 and 28% at T2. Open-ended responses from the SO suggest that role reversal occurred when the spouse, usually the wife, assumed the major wage earner role postsurgery. At T2 five SOs mentioned that they were now the breadwinner and, in addition, were more responsible for doing household chores that their male spouse had done in the past.

Although full-time employment increased from 17.2% at T1 to 27.6% at T2, over 40% of recipients were retired or disabled at both interviews. Many recipients did not work because of decreased stamina or because they would earn a salary that made them ineligible to receive publically financed services.

The relationship between the functional area of work and negative mood was further examined. Mean scores for tension were compared for recipients who were employed ($n = 16$) and for those who were unemployed ($n = 13$). Tension was significantly higher (mean 2.88, SD = 0.81) $t(1,27) = 2.94$, $P = 0.007$) in the unemployed group than in those employed (mean 2.00, SD = 0.81) at T1. There was a tendency for higher tension (mean 2.71, SD = 0.26) in those not employed ($n = 14$) at T2 than in those employed (mean 2.14, SD = 0.22), but this difference was not significant. These data suggest that the distress is related to being unable to work rather than working in a job that created excessive demands on the individual.

Discussion

The purpose of the present study was to examine the experience of living with a heart transplant, using the Common Sense Model over a 6-month period. Data show that although the majority (62%) of recipients, when initially interviewed, viewed the transplant as a cure to their heart problem yet 6 months later more recipients saw the transplant as a trade-off, curing the heart problem but creating new health problems to cope with. This finding suggests that even over a relatively short time period of 6 months, the perceptions of this condition changed from one of an acute illness model of heart transplantation to an encapsulated model. An acute model of illness generally serves us well in prompting us to seek treatment and cope with most illness. Yet, it may not lead us to optimal coping strategies when a chronic condition exists.

Literature on compliance [12] suggests that when drug regimens are complex, noncompliance becomes more likely. Yet, 100% of recipients reported taking three immunosuppressive medications all of the time. In fact, both recipients and SOs perceived more difficulty in managing mood swings than in following a low-fat diet, exercising regularly, or taking medications. The high level of compliance with medications may be related to the perceived consequences of failing to take these drugs. Recipients frequently said they thought about skipping doses but never did so because the consequence would be rejection, soon followed by death. These findings are consistent with the Common Sense Model, which would predict that when the consequence of not engaging in a behavior is too threatening, it may override barriers associated with adherence to a complex treatment regimen. In contrast, even though recipients thought a low-fat diet and regular exercise were good for their health, they did not perceive serious negative consequences from not engaging in these behaviors.

Few differences emerged when comparing responses of the recipients and SOs in perceptions of cause, timeline, or ratings of health status. SOs' beliefs about recipients' susceptibility to rejection were significantly greater than those of recipients. SOs also tended to view rejection as more serious and less controllable than recipients did. This is consistent with findings that chronically ill patients rated their quality of life higher than did family members and health professionals [31] and Magaziner et al. [21], who found that hip fracture patients rated a variety of health status measures more favorably than did a significant other. Recipients have a more optimistic bias about postoperative adjustment that may serve as an important coping mechanism for maintaining a more positive psychological outlook on recovery [32]. The significant negative association of optimism with symptom frequency and distress suggests that optimism alters perception or interpretation of certain body sensations.

Because this study is descriptive, it does not identify predictors of positive health outcomes that might be used for planning the long-term management of heart transplant recipients and their family members. More work is needed to examine the development of a mental representation of a health threat by following heart transplant candidates from the time they are awaiting transplantation to at least 2 years post-transplantation. Data here show good agreement beween recipients and SOs on what specific support is difficult to provide. A finding consistent with others [23] is role reversal, identified as a stressor by female spouses of recipients even after the recipient returned to work. And despite the recipient returning to work, finances continued to be a major stressor. A limitation of the SIP is that it does not capture concerns about functioning that were found in responses to open-ended questions, such as sexual functioning and managing moodiness and depression.

The data suggest a need to provide an educational intervention to guide a representation that is more compatible with chronic self-regulation. The Common Sense Model is particularly suited to such interventions [3, 34] because it focuses on impacting aspects of the representation that influence behavior and emphasizes the need to present both abstract information about a health threat and more concrete coping skills to be able to carry out the behaviors. For example, recipients frequently knew they were to follow a low-fat diet but often said they did not know how to do this, especially when certain medications created unusual hunger. Many recipients knew they were to exercise regularly but found it difficult to do alone or did not know how to incorporate exercise into their life when they were beginning to experience problems with side effects from drugs, especially bone and joint problems associated with prednisone therapy. Without attention to these levels of information, inconsistencies persist that may reduce the likelihood of recipients engaging in risk-reducing coping behaviors.

This education could be delivered at annual admissions. Although annual admissions are a high-anxiety time for recipients, research suggests [15] that optimal behavior change occurs under conditions of some anxiety to serve as a motivator, in combination with concrete action plans to guide coping. Support groups that include family members and other heart transplant recipients can facilitate coping with the behavioral, affective, and financial problems that are encountered in long-term management.

In conclusion, this research has both theoretical and practical value by contributing to an understanding of how a representation proposed by the Common Sense Model can be used to describe the experience of living with a heart transplant. Because the Common Sense Model places emphasis on the subjective nature of perception about health threats and the dynamic relationship between perception and coping as individuals have more experience with an illness, it is a model well suited to studying the experience of living with a transplanted heart.

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