Title
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Journal
Journal of Cardiac Failure, 8(5)

ISSN
1071-9164

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Publication Date
2002-10-01

DOI
10.1054/jcaf.2002.128005

Journal of Cardiac Failure Vol. 8 No. 5 2002

Emotional Well-being of Heart Failure Patients and Their Caregivers

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ABSTRACT

Background: Heart failure (HF) dramatically affects the lives of both patients and their caregivers, yet limited research exists examining the relationship between emotional well-being of HF patients and their caregivers. Therefore, we conducted a study to (1) describe and compare the emotional well-being of HF patients and their caregivers, (2) determine if gender differences exist in emotional well-being of patients and caregivers, and (3) identify factors associated with emotional well-being of HF patients.
Methods: The emotional well-being of 103 patient-caregiver dyads was assessed using the mental health subscale of the SF-12.
Results: Patients were 57.6 ± 12.1 years, predominantly Caucasian (76.7%) and male (67.0%). Caregivers were 59.5 ± 17.6 years, predominantly females (70.9%) and spouses of patients with HF (82.6%). Patients had significantly lower (poorer) emotional well-being scores than caregivers. Both gender and age were associated with patients' emotional well-being; male and younger participants had higher (better) scores than female and older patients ($P < .05$). In a multivariate model, patient's age, gender, and caregivers' emotional well-being accounted for 54% of the variance in patients' emotional well-being.
Conclusion: We found that the emotional well-being of caregivers is associated with the emotional well-being of HF patients. Our findings suggest the need to focus on supporting caregivers and providing them with the strategies they need to support their loved ones with HF.
Key Words: Gender differences, SF-12, quality of life.

Heart failure (HF) poses several challenges to patients who have to deal with debilitating changes associated with the condition and consequent effects of treatment. Patients are forced to make lifestyle changes that significantly affect their emotional well-being. It is not surprising then that the emotional well-being of HF patients has generally been documented as poor.[1-3] Studies of the association between emotional well-being and clinical outcomes in patients with HF consistently demonstrate that poorer emotional well-being is related to increased risk for hospitalization and death.[4-5] These findings have led to further efforts on the part of health care researchers and providers to explore factors that predict emotional well-being in HF patients.

Interest in the roles of the family and caregiver on patient outcomes is beginning to attract the attention of researchers. However, previous research has focused on either describing caregiver burden and strain[6] or explor-

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Manuscript received April 22, 2002; revised manuscript received June 26, 2002; revised manuscript accepted July 9, 2002.

This research was partially supported by a grant from the American Heart Association Western Division (NCR, 133-09, PI, K. Dracup) and from University of California School of Nursing Intramural Research Grant.

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1071-9164/02/0805-0004$35.00/0
doi:10.1054/jcaf.2002.128005

ing predictors of caregiver burden.[7] Recently, investigators have examined caregiving in the HF population. In the first investigation,[6] researchers found that the prolonged negative effects of caregiving adversely affected the health status of caregivers. Investigators[8] also examined the role of caregiver preparation and esteem on emotional well-being of HF patients receiving community-based inotropic infusions. Findings from this study revealed that caregiver mental health is associated with patients' emotional well-being, with increased caregiver esteem related to decreased patient emotional well-being. In a third investigation,[9] researchers found that marital quality was associated with emotional well-being of HF patients and their spouses. Although all three studies provide observations that illuminate our understanding of how the patient-caregiver dyad affects patient and caregiver outcomes, additional research is needed to explicate the manner by which the emotional well-being of caregivers affects the emotional well-being of patients.

The current investigation was conducted to determine whether caregiver characteristics were related to emotional well-being of patients with HF resulting from systolic dysfunction. The study addressed the following questions: (1) Is there a difference in emotional well-being between patients and caregivers? (2) Are there differences in emotional well-being between genders in both roles? and (3) Is patients' emotional well-being associated with individual sociodemographic and clinical characteristics, caregiver characteristics, or caregiver emotional well-being?

Methods

Sample

A prospective, comparative design was used. After approval of the study by the appropriate Institutional Review Board, a convenience sample of 103 patients and 103 caregivers was recruited from a single outpatient HF clinic located within a tertiary, university-affiliated medical center between January 2000 and December 2000. Patients were included in the study if they were 18 years of age or older; able to read, write, and speak English; had a left ventricular ejection fraction (EF) of less than 40% documented by echocardiography or ventriculography; had symptoms of HF for 6 months or longer; and expressed a willingness to participate in the study. Caregivers were included if they were 18 years of age or older; able to read, write, and speak English; were living in the same household as the patient; and were the primary caregiver for the patient for more than 1 month.

Table 1. Demographic Characteristics of Patients and Caregivers (n = 206)

Characteristic	Patients (n = 103)	Caregivers (n = 103)
Age, yr (mean ± SD)	57.61 ± 12.05	59.47 ± 17.64
Gender		
Male	69 (67.0%)	30 (29.1%)
Race, N(%)		
White	79 (76.7%)	83 (80.6%)
Black	6 (5.8%)	8 (7.8%)
Other	18 (17.5%)	12 (11.7%)
Employment status, N(%)		
Employed	22 (21.4%)	58 (56.3%)
Unemployed/retired	81 (78.6%)	45 (43.7%)
Marital status, N(%)		
Married	83 (80.6%)	89 (86.4%)
Not married	20 (19.4%)	14 (13.6%)
Education, N(%)		
≤High school	39 (37.9%)	44 (42.8%)
Vocational or junior college	35 (34.0%)	30 (29.1%)
≥College	29 (28.5%)	29 (28.5)

Patient and caregiver characteristics are summarized in Table 1. The 103 patients were predominantly male, white, married, and retired. The patients in the sample had an average EF of 25.5 ± 5.8 percent (range, 10-40); and had an average peak oxygen consumption (VO_2) of 14.0 ± 5.0 (range, 6.2-28.4). Etiology of HF was ischemic (34.1%), dilated (31.3%), or other causes (45.6%)—including idiopathic, valvular, congenital, and postpartum. Sixteen percent had New York Heart Association (NYHA) class I, whereas 23%, 40%, and 21% had NYHA class II, III, and IV, respectively. The 103 caregivers were primarily female and white; 83% were spouses and the remaining 17% were a child, a parent, or a close friend of the patient.

Data Collection Procedures

After informed consent was obtained, the participants were asked to complete a battery of study instruments, which usually occurred before or after a regularly scheduled visit with their cardiologist. Questionnaire completion took between 10 and 15 minutes. The patient-caregiver dyads were given the option to complete the questionnaire at the clinic before leaving or taking it home and mailing it back to the researchers in a prestamped envelope, which was the choice preferred by 88% of participants. Sociodemographic and clinical data were obtained from the patient's medical record and from the patient. Of the 128 patient-caregiver dyads that originally consented to participate in the study, 103 complete sets of questionnaires for the patient and caregiver dyad were returned, for an overall response rate of 80%. When sociodemographic and clinical characteristics of patient and caregiver dyads who completed the study questionnaires were compared to those dyads who did not return their study questionnaires, no significant differences were noted ($P > .05$).

Study Instruments

Demographic information was collected through a simple form administered to each patient-caregiver dyad and through a form collected by a research assistant during chart review to establish patient eligibility. The following information was obtained from the patient and caregiver dyads: age, race, gender, educational attainment, current employment status, and relationship to each other. A research assistant obtained the following information through chart review: age, length of cardiac illness, etiology of HF, EF, and NYHA functional class.

One of the instruments that all patients and caregivers were asked to complete was the 12-item short form (SF-12) health survey, a general survey for monitoring outcomes in patients with chronic conditions. The SF-12 is able to produce two summary scales—a physical component summary (PCS) and a mental component summary (MCS)—originally developed for the SF-36.[10,11] We used the MCS scores, which includes five items that measure vitality, social functioning, role limitations, and mental health to reflect the emotional well-being of patients and caregivers for the current study. The MCS-12 and MCS-36 have been shown to be highly correlated ($r > .90$) in several studies of patients with chronic illness.[12,13] A higher score on the MCS indicates greater overall mental health and emotional well-being.

Data Analysis

Data were analyzed using SPSS for Windows (version 8.0, SPSS, Inc., Chicago, IL).[14] Descriptive statistics including means, ranges, and standard deviations were used to describe the emotional well-being of patients and caregivers. Paired *t* tests were used to measure differences between emotional well-being of patients and caregivers. To explore a possible confounding effect of gender and role on both patients' and caregivers' emotional well-being, an analysis of variance was computed. Pearson product moment correlation coefficients were computed to explore relationships between patient and caregiver characteristics and emotional well-being measures. Stepwise linear multiple regressions were conducted to identify factors associated with emotional well-being of patients. Patient characteristics (age and gender) and the caregiver demographic information (age, gender, and caregiver relationship, which was dummy-coded for spouse [1] or nonspouse [2]) were included as covariates. To reflect the context variables, the patient covariates were entered first. Next, to depict the impact of caregiver characteristics on patient outcomes, age, gender, and relationship of caregiver to the patient were added as a second step. Caregivers' emotional well-being scores were then added as a third step. The significance level for both the univariate and multivariate analyses was set at $P < .05$.

Results

The means and standard deviations for emotional well-being scores of patients and caregivers are presented in Table 2. Caregivers reported a higher (better) emotional well-being then patients ($P < .001$). Gender differences in emotional well-being of both patients and caregivers were documented. Female patients and caregivers had lower emotional well-being compared to their male counterparts; however, the difference was only statistically significant for patients ($P = .018$).

Table 3 displays the associations among patients' sociodemographic and clinical characteristics and patients' emotional well-being. As expected, we found that the clinical parameters (HF etiology, EF, NYHA class, and VO_2) were associated with each other but not with patients' emotional well-being. Only patients' age and gender were associated with patients' emotional well-being; younger patients and male patients had higher (better) emotional well-being scores. Table 4 provides the associations between patients' and caregivers' age, gender, and emotional well-being scores. Moderately high levels of association were found between patients' and caregivers' emotional well-being. A significant asso-

Table 2. Differences in Emotional Well-being of Patients and Caregivers by Role and Gender

	Patients Mean ± SD	Caregivers Mean ± SD	Paired-*t*	*P*
Mental Health Score[a]	46.8 ± 12.0 (n = 103)	50.9 ± 8.0 (n = 103)	−1.6	.000**

	Male Mean ± SD	Females Mean ± SD	F	*P*
Patients	48.7 ± 11.8 (n = 69)	42.8 ± 11.3 (n = 34)	5.813	.018*
Caregivers	53.0 ± 7.1 (n = 30)	50.1 ± 9.3 (n = 73)	2.491	.118

[a] The mental health score on the SF-12 was used as a measure of emotional well-being; higher scores indicate higher emotional well-being.
*$P = <.05$; **$P = <.001$.

Table 3. Correlations Between Patient Characteristics and Emotional Well-being (n = 103)

Variable	1	2	3	4	5	6	7
1. Mental Health Score[a]							
2. Age	−.201*						
3. Gender	−.233*	−.136					
4. Heart failure etiology	.012	−.015	.098				
5. Ejection fraction	.094	.226*	.027	.218*			
6. New York Heart Association class	−.089	−.106	−.101	−.318*	−.281**		
7. VO_2 max	.010	.024	.197*	.237*	−.349**	−.577**	

[a]The mental health score on the SF-12 was used as a measure of emotional well-being; higher scores indicate higher emotional well-being.
*P = <.05; **P = <.001

ciation was also found between caregivers' age and the patients' emotional well-being; a higher (better) score was associated with younger caregivers, but when the age of the patient was controlled for, the relationship between caregivers' age and patients' emotional well-being were not observed in the model. Last, we found that the caregivers' gender was not associated with patients' emotional well-being scores.

As hypothesized, the emotional well-being of HF patients and their caregivers were related, even while controlling for patient and caregiver characteristics (Table 5). Patients' age and gender and caregivers' emotional well-being accounted for 54% of the variance in patients' emotional well-being.

Discussion

Various aspects associated with caregiver characteristics have recently been examined as potential risk factors for poor emotional well-being experienced by patients with HF.[6,8,9] Observations from the present study advance this field of inquiry. First, we found a difference in patients' and caregivers' emotional well-being; caregivers had a significantly higher emotional well-being than patients. This is consistent with findings from a similar study examining caregivers of HF patients.[8]

In contrast, Moore and colleagues[15] found that although there was a difference between spouses' and patients' psychologic distress after coronary artery bypass surgery, the psychologic distress of spouses was higher than that of patients 6 weeks after surgery. It should be noted that the majority of caregivers in the study by Moore and colleagues was female and middle-age, similar to the current study, so the major difference between the two study populations was indeed the patients' surgical *vs* medical status. Moore et al attributed their findings to the increased uncertainty that spouses experienced after their partners' cardiac surgery to the changing physical status of patients and the dynamic changes of the recovery period. Similarly, Moser and colleagues[16] found in a sample of 417 post–acute myocardial infarction or revascularization patients and their spouses that spouses were substantially more anxious and depressed and had lower levels of perceived control than patients. They also demonstrated that spouses' level of emotional distress was a strong predictor of patients' psychosocial adjustment. These investigators speculated that spouses were more distressed than patients because support and resources traditionally focus on patient problem, often at the expense of spouses who end up assuming caregiver duties without adequate preparation.

The mechanism for higher emotional well-being scores of caregivers compared to patients in the current study is not clear. The difference did not appear to be mediated by patients' clinical factors, including HF etiology, functional status (as measured by NYHA class and VO_2), and disease severity (as measured by EF). Scott[8] has suggested that caregiver esteem is increased by the activities and responsibilities of caregiving,

Table 4. Correlation Between Patient and Caregiver Age, Gender, and Emotional Well-being

	Caregiver		
Patient	Age	Gender	Mental Health Score[a]
Age	.476**	−.136	−.013
Gender	−.041	−.777**	−.061
Mental Health	−.201*	.191	.649**

[a]The mental health score on the SF-12 was used as a measure of emotional well-being; higher scores indicate higher emotional well-being.
1-tailed significance: *P < .01; ** < .001

Table 5. Factors Associated With Patients' Emotional Well-being

Variable	Adjusted R^2	F	*P*
Patients' gender	.045	5.813	.018*
Patients' age	.092	6.166	.014*
Caregivers' mental health score	.536	40.299	.000**

*P < .05 **P < .001.

which, in turn, positively influence mental health. She found that spouses in her study indicated a desire to provide care and perform the caregiver role and concluded that "the higher emotional well-being of caregivers compared to patients may be related to the commitment and satisfaction derived from the fulfillment of family obligations, in concert with the gratification derived from helping others."[8]

Our findings that female patients and caregivers have lower emotional well-being scores were similar to findings of Rohrbaugh and colleagues.[9] Gender differences were independent of disease severity. However, contrary to these investigators' findings,[9] we found that gender differences in emotional well-being scores were less pronounced in caregivers and that gender differences were statistically significant for patients but not for caregivers. Karmilovich[6] also found that female patients with HF had more psychologic distress than did their male counterparts. Additional studies that contain a larger number of female patients are needed to provide more evidence about gender differences in emotional well-being among HF patients.

Our findings that the age of patients was significantly associated with their emotional well-being has also been previously documented in the HF literature.[1] Elderly patients are more likely to be distressed with their HF symptoms. Distress among elderly patients has been attributed to the complex clinical management associated with multidrug regimens and other significant modifications of lifestyle.[9]

Finally, our findings support the strong positive association between patients' emotional well-being and caregivers' emotional well-being. Our findings that caregivers' emotional well-being is an important predictor of patients' emotional well-being complements and extends findings from a previous investigation by Langeluddecke and colleagues that established a strong positive association between spouses' anxiety and patients' depression 12 months after an acute cardiac event.[17] Likewise, Brecht and colleagues found that positive psychologic adjustment after myocardial infarction was influenced by the quality of patient-caregiver relationship.[18] Scott[8] also found that caregiver esteem and mental health had a significant effect on patients' emotional well-being; that higher self-esteem in caregivers was associated with poorer emotional well-being in patients—care recipients felt more helpless as their caregivers become more competent in their roles. Obviously the patient-caregiver relationship is complex and requires further examination of caregiver characteristics and perceptions related to the caregiving role and their effect on patient emotional well-being. However, in the interim, it appears that interventions that improve emotional well-being of caregivers may have a positive impact on emotional well-being of patients. Additional studies aimed at developing and testing strategies to achieve these goals are needed to provide more relevant information that may improve patient outcomes.

Several important limitations must be considered when interpreting our findings. First, as with many descriptive studies, some potentially confounding variables were not included in the analyses (e.g., comorbidities of patients or caregivers, patients' perceived social support) that could have influenced the association between patients' and caregivers' emotional well-being. Additional information about caregivers' situations needs to be examined in future research. The ability to provide care may be impaired if the caregiver has medical limitations or other concerns to consider in addition to patient's daily needs. Likewise, patients perceived social support may mediate the association between patients' and caregivers' emotional well-being and therefore should also be assessed in future studies examining these variables. Moreover, in a cross-sectional design, causality cannot be inferred. The relationships tested in the multivariate model require further testing in a prospective, longitudinal study to determine the true influence of caregivers on patient emotional well-being.

A second limitation relates to the use of a convenience sample. Patients in the sample volunteered to participate in the study and may not reflect the characteristics of the general HF population. The sample was obtained from a population referred to and being managed in a university-based, multidisciplinary HF management program; therefore, our findings may not generalize to other HF populations who are being managed using a different medical approach.

Finally, our study was limited by choice of instruments used to assess patients' and caregivers' emotional well-being and the manner in which data were collected. A number of other emotional well-being measures and clinical assessments is available and the use of subjective indicators of emotional well-being (perceptions) or the inclusion of a qualitative component to assess patient and caregiver emotional well-being in more depth may improve our understanding of patient and caregiver emotional well-being. Related to data collection, patients and caregivers were instructed to complete the questionnaires independently. However, that the questionnaires were taken home and mailed back to the researchers by a majority of patient-care dyads poses a threat to patient and caregiver confidentiality. Interviewing patients and caregivers separately may be an option to consider in future investigations.

Summary

The current study supports the important role that caregivers play in the care of patients with HF. The emotional well-being of caregivers was an independent predictor of patient emotional well-being. Our findings indicate that health care providers should focus more on gaining information on caregiver emotional well-being through ongoing assessments and communication with the caregiver, with the ultimate goal of identifying and meeting caregivers' needs. Listening to and observing these caregivers can offer providers and researchers knowledge about what emotional well-being means for caregivers, what contributes to and detracts from their emotional well-being, and how emotional well-being might be taken into consideration in the delivery of care.

Health care professionals should explore, develop, and test interventions to address caregivers' ability to perform the tasks necessary to provide care for patients with HF. Caregivers may need education about the disease process itself, the daily treatment regimen, expectations for the future, and caregiver responsibilities as a means to reducing feelings of uncertainty associated with caring for patients with HF. That the caregiver contributes to patient outcomes underscores the need to develop strategies to support this individual. Such efforts may include counseling sessions to discuss the caregivers' source of burden and stress and to provide referral to available sources of support. Including caregivers in health education sessions and providing them with support may be beneficial to improving caregivers' emotional well-being and ultimately lead to improved patient outcomes in the setting of HF.

References

1. Dracup K, Walden J, Stevenson LW, Brecht L: Quality of life in patients with advanced heart failure. J Heart Lung Transplant 1992;11:273–279
2. Walden J, Stevenson LW, Dracup K: Extended comparison of quality of life between stable heart failure patients and heart transplant recipients. J Heart Lung Transplant 1994;13:1109–1118
3. Hawthorne M, Hixon E: Functional class, mood disturbance, and quality of life in patients with heart failure. Prog Cardio Nurs 1994;9:22–32
4. Bennett SJ, Pressler ML, Hays L, Firestine L, Huster GA: Psychosocial variables and hospitalizations in persons with chronic heart failure. Prog Cardio Nurs 1997;12: 4–11
5. Konstam V, Salem D, Pouler H, Kostis J, Gorkin L, Shumaker S, Mottard I, Woods P, Konstam MA, Yusuf S: Baseline quality of life as a predictor of mortality and hospitalization in 5,025 patients with congestive heart failure. Am J Cardiol 1996;78:890–895
6. Karmilovich S: Burden and stress associated with spousal caregiving for individuals with heart failure. Prog Cardio Nurs 1994;9:33–38
7. Canam C, Acorn S: Quality of life for family caregivers of people with chronic health problems. Rehab Nurs 1999; 24:192–200
8. Scott L: Caregiving and care receiving among a technologically dependent heart failure program. Adv Nurs Sci 2000;23:82–97
9. Rohrbaugh MJ, Shoham V, Cranford JA, Nicklas JM, Sonnega JS, Coyne JC: Couples coping with congestive heart failure: role and gender differences in psychological distress. J Fam Psychology 2002;16:3–13
10. Stewart AL, Sherbourne D: The role of social supports and life stress events in use of mental health services. Med Care 1988;27:1393–1400
11. Ware JE, Sherbourne D: The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. Med Care 1992;30:473–483
12. Ware JE, Kosinski M, Keller SD: A 12-item short-form health survey. Med Care 1996;34:220–233
13. Gandhi S, Salmon J, Zhao S, Lambert B, Gore P, Conrad K: Psychometric evaluation of the 12-item short-from health survey (SF-12) in osteoarthritis and rheumatoid arthritis clinical trials. Clin Ther 2001;7:1080–1098
14. SPSS User's Guide, 3rd ed. Chicago, IL: SPSS Inc., 1998
15. Moore S: Psychological distress of patients and their spouses after coronary artery bypass surgery. AACN Clin Issues Crit Care Nurs 1994;5:59–65
16. Moser DK, Dracup K, Doering LV: Emotional distress after cardiac events is worse among spouses than patients. Circulation 1998;98:323
17. Langeluddecke P, Tennant C, Fulcher G, Baird D, Hughes C: Coronary artery bypass surgery: impact upon the patient's spouse. J Psychiatr Res 1989;33:155–159
18. Brecht L, Dracup K, Moser D, Riegel B: The relationship of marital quality and psychosocial adjustment to heart disease. J Cardio Nurs 1994;9:74–85