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<https://escholarship.org/uc/item/4275k6r1>

Journal

Heart & lung : the journal of critical care, 33(6)

ISSN

0147-9563

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Publication Date

2004-11-01

DOI

10.1016/j.hrtlng.2004.06.003

Peer reviewed

Emotional well-being in spouses of patients with advanced heart failure

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BACKGROUND: The physical demands and psychological stressors of caregiving negatively impact the emotional well-being of spouses in many chronically ill populations such as patients with Alzheimer's disease and end-stage renal failure. Heart failure (HF) is a chronic illness with a poor prognosis that is increasing in prevalence and incidence, yet little is known about its effect on the family, particularly the spouse.

OBJECTIVE: We conducted this study to describe the emotional well-being of spouses of patients with HF, to identify factors associated with spouses' decreased emotional well-being, and to compare emotional well-being between spouses with higher and lower levels of perceived control. We proposed a model that included age, sex, employment status, perceived control, and caregiver burden to explain the emotional well-being of spouses.

METHODS: Data were collected from 69 spouses of patients with advanced HF (mean age 54 years and predominantly female) using 2 subscales of the SF-36, control attitudes scale-family version and caregiver appraisal tool. Descriptive statistics, Pearson correlations, and stepwise multiple regression were used to analyze data.

RESULTS: The model explained 40% of the variance in the emotional well-being of spouses ($P = 0.001$). Perceived control ($P = 0.001$) and age ($P = 0.046$) were associated with emotional well-being. In spouses with higher levels of control, emotional well-being was significantly higher than in spouses with lower levels of control ($P = 0.003$). Older spouses had higher levels of emotional well-being compared with younger spouses ($P = 0.01$).

CONCLUSIONS: Health care professionals must assess the level of control perceived by spouses of patients with advanced HF and provide information and counseling directed toward increasing their sense of control. Younger spouses are particularly at risk for decreased emotional well-being and may require special intervention. (Heart Lung® 2004;33:354-61.)

Patients with advanced heart failure (HF) have many reasons to feel significant emotional distress. Negative changes in health status, forced retirement, decreased functional status, so-

cial isolation, and financial instability are all unfortunate consequences of a disease process that is claiming increasing numbers of patients each year.¹ In numerous investigations, patients with advanced HF have reported significant emotional distress and poor quality of life as a result of the changes related to advanced HF.²⁻⁶ However, research examining the consequences of this disease process on the family, particularly the spouse, is limited.

The emotional well-being of spouses is important in part because the family is the ultimate unit of care. Moreover, research shows that spouses' level of emotional well-being influences the psychological adjustment of patients.⁷ Spouses of patients with chronic health problems frequently are required to be caregivers. Unfortunately, the physical demands of caregiving for a loved one with a severe

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Supported by a cardiovascular research grant from the American Heart Association Western Affiliate (NCR 133-09).

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0147-9563/\$ – see front matter
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doi:10.1016/j.hrtlng.2004.06.003

physical disability may decrease emotional well-being in a spouse and may put that spouse at increased risk for physical health problems and mortality.⁸

BACKGROUND

Several investigators have reported that after a cardiac event, emotional well-being is more impaired in spouses than in patients.^{9–11} For example, Moore¹⁰ found that spouses of patients who underwent coronary bypass surgery experienced anxiety, depression, and grief over changes related to their partner's altered health status. Moore et al.¹⁰ attributed their findings to the increased uncertainty spouses experienced after their partners' cardiac surgery and to the changing physical status of patients and the uncertainty of the recovery period. Similarly, Moser and Dracup¹² found in a sample of >400 post-acute myocardial infarction or revascularization patients and their spouses that the spouses were substantially more anxious and depressed and had lower levels of perceived control than patients. It may be that patients who experience cardiac surgery or an acute myocardial infarction benefit from being the focus of the health care system, whereas spouses and other family members are isolated from the support of the healthcare team and consequently experience poorer emotional recovery than patients.

In contrast to the work of previous researchers, we found that HF patients experienced poorer emotional well-being than spouses.^{13,14} In a study by Evangelista et al.,¹³ patients had significantly poorer emotional well-being than spouses. Similarly, Martensson et al.¹⁴ found that patients with HF and their spouses experience significantly different levels of depression with patients reporting greater depression and poorer physical quality of life. The contradictory nature of the findings in HF patients and patients with ischemic events (acute myocardial infarction and cardiac revascularization) led us to hypothesize that differences between patients and spouses in the context of HF would be influenced by the sense of control that spouses experience related to their loved one's health and that this perceived control may be particularly important in determining the level of spousal emotional distress.

Perceived control is the self-generated belief that one has at one's disposal a response that can influence the adversiveness of an event.¹⁵ Belief is an important part of the construct of control. The perception of control has been associated with positive

outcomes; control need not be exercised or real to be effective. Because perceived control is not an intrinsic personality characteristic and is amenable to change, it has potential for use in clinical interventions.¹⁶ Many researchers have manipulated control experimentally and found that control, even when not exercised, can decrease the stress response and adverse emotional impact of stressful events.^{17,18} Other researchers working among clinical populations (e.g., cancer and rheumatoid arthritis patients) have shown that feelings of control are associated with better psychosocial adjustment including less anxiety and depression and improved self-esteem.^{19,20}

Given the important role that spouses play as caregivers and sources of social support, additional research is needed to explicate the factors that influence emotional well-being and perceived control of spouses of advanced HF patients. Spouses may find it difficult to provide physical and emotional care to patients if they themselves are experiencing an emotional crisis. Accordingly, we conducted this study (1) to describe the level of emotional well-being in spouses of advanced HF patients; (2) to determine whether sociodemographic characteristics, perceived control, and caregiver burden were associated with impaired spousal emotional well-being; and (3) to compare emotional well-being between spouses with higher versus lower levels of perceived control.

METHODS

Study design

A cross-sectional correlational design was employed. After approval for the study by the appropriate Institutional Review Board was received, a nonprobability sample of 69 spouses was solicited from a university-based HF clinic. To be included in this study, participants had to be a spouse of a person with HF, to be the primary caregiver for the patient, and to be living in the same household as the patient. Patients were identified as having advanced HF if they had an ejection fraction <40%, had New York Heart Association class III or IV disease, and had experienced symptoms >6 months.

Procedures

Spouses had to express a desire to participate in the study to a research assistant or one of the study investigators in response to a printed announcement in the clinic. A sample size of 60 was set based on hypothesized differences in perceived control (objective no. 3). Based on a previous study con-

ducted in the spouses of patients with coronary artery disease,²¹ we determined that a minimum of 60 patients would be required to identify a moderate difference between groups with power set at 0.80 and significance at 0.05. Related to the second purpose, a multiple regression analysis requires 5 to 20 participants for each variable in the equation (including the dependent variable).²² A sample size of 60 would allow the entry of 5 independent variables using the value of 10 participants/variable.

Once informed consent was obtained, spouses were asked to complete the study instruments. They either completed them in the clinic waiting room or took them home and mailed the completed instruments to the investigators using the addressed, stamped envelopes provided.

Emotional well-being was measured using 2 relevant subscales of the Medical Outcomes Study 36-item Short Form Health Survey (SF-36).^{23,24} The SF-36 has been used extensively to measure quality of life in a variety of populations.²³ The instrument also has been administered to general populations to see how a particular condition causes health to depart from a "healthy standard."²⁴ The SF-36 uses a 36-item, forced-choice questionnaire consisting of 8 subscales designed to measure quality of life in the domains of physical, mental, and social functioning. We used the mental health (5 items) and health perceptions (5 items) subscales to assess emotional well-being. Raw scores were standardized to range from 0 to 100 with higher scores indicating better functioning. Factor scores based on a principal components analysis of these 2 subscales formed a summary measure of emotional well-being. The validity and reliability of each of the scales of the SF-36 in patient populations has been confirmed in multiple studies.²³ Cronbach's alpha for the combined scale was .75.

Perceived control was measured using the Control Attitudes Scale–Family Version (Table I), a 4-item scale designed to measure the degree of control a spouse feels related to the health status of the patient with advanced HF.²⁵ Response statements are scored on a Likert scale from 1 (none) to 5 (very much), and a total score is obtained by summing the items. The total score range is 4 to 20 with higher scores reflecting higher levels of perceived control. Instrument reliability and validity were established in an intervention study among spouses of high-risk cardiac patients.²⁵ Cronbach's alpha for the current study was 0.90.

Caregiver burden was measured using two subscales of the Caregiver Appraisal Tool,²⁶ a 47-item instrument that measures 5 dimensions of caregiver

Table I

The Control Attitudes Scale–Family Version

1. Regarding your family member's heart problems, how much control do you feel?
2. Do you feel you could take the right steps if your family member were to have a heart attack or other emergency related to his or her heart?
3. Regarding your family member's heart problems, how helpless do you feel?
4. Regarding your family member's heart problems, how helpless do you think he or she feels?

appraisal: burden, satisfaction, mastery, impact, and cognitive reappraisal. To minimize respondent burden, we selected for use the 2 subscales that assess caregivers' perceived burden and impact of the caregiving role on their lives. Our selection was based on our desire to identify predictors of negative aspects of caregiving. We therefore did not ask about satisfaction, mastery, or cognitive reappraisal—aspects of caregiving that reflect the positive side of caregiving. An increasing body of literature^{27,28} suggests that caregiving may lead to positive emotions when the caregiver finds new meaning in the experience (cognitive reappraisal) and/or experiences satisfaction in mastering the complex tasks of caregiving. Respondents answered each of the items using a 5-point scale that asked either the extent to which the statement was true (never to nearly always) or the extent to which the caregiver agreed (strongly agree to strongly disagree). Higher scores reflect higher perceived burden and impact. The psychometric properties of both subscales have been previously documented.²⁶ Internal consistencies (Cronbach's alpha) for the current study were .81 and .70, respectively, for the subjective burden and caregiving impact indices.

Data analysis

To describe the level of emotional well-being in spouses, we used means $\pm$ SDs and other descriptive statistics as appropriate. To determine whether sociodemographic characteristics, perceived control, and caregiver burden were associated with impaired spousal emotional well-being, a correlation matrix was constructed to test the relationships among variables. Emotional well-being was then

Fig 1 Mental health and health perception of men and women in the sample compared with age-adjusted norms in the population.

used as the dependent variable in a stepwise regression, in which variables correlated with emotional well-being at a significance level $\leq .10$ were included in the model. Variables were entered into the model in a hierarchical fashion with sociodemographic variables entered as a block first followed perceived control and caregiver burden. Customary criteria for entry into and removal from the model were used, and significance was set at .05. To compare emotional well-being between spouses with higher versus lower levels of perceived control, we divided spouses into 2 groups, ie, high perceived control and low perceived control, using a median split of the mean perceived control score. There is no standard norm for perceived control, but in a previous investigation,²⁵ investigators successfully used the median split to construct groups for comparison of a number of dependent variables. Independent Student *t* tests were used to compare the two spouse groups with regard to emotional well-being. For this analysis, significance was set at .05.

RESULTS

Sample characteristics

Of the 75 spouses who agreed to participate, 69 (92%) completed all study instruments. Three fourths of the participants were female. Spouses in this study were generally younger than many spouses of advanced HF patients in the community (average 54 years old, SD 12.2, range 30 to 77). This average age undoubtedly reflected the young age of patients usually referred for HF evaluation at this center. Spouses had been married an average of 24 years (SD 15.2, range 1 to 53). Half of the spouses

had high school or lower educational levels, and only 15% had completed a bachelor's or a graduate degree. Sixty-two percent were employed outside the home. The majority did not have dependent children. Demographic and clinical characteristics were similar for spouses who did and did not complete the study instruments ($P > .05$).

Level of emotional well-being

Lower scores on the SF-36 subscales reflect worse quality of life. Spouses reported significantly lower total mental-health and health-perception scores than the age-adjusted norms for men and women in the general population (Figure 1).

Factors associated with spousal emotional well-being

To answer the second research question, we considered a multivariate model of possible factors associated with of spousal well-being. The model included demographic variables (age, sex, employment status), perceived control, and indicators of caregiver burden (perceived burden and impact on the caregiver). Of the sociodemographic variables, only age contributed to the variance in emotional well-being; younger age was associated with greater distress. Of the psychosocial variables, higher perceived caregiver burden and lower perceived control were associated with increased distress (Table II).

Comparison of emotional well-being based on perceived control

Finally, to assess the role of perceived control, we compared the levels of emotional well-being be-

Table II

Multiple regression table for emotional well-being of spouses

Model	SS	df	F	R	Adjusted R ²	Significance
	10606	3,65	22.74	.716	.490	.000
Variables	Beta	T	Significance			
Age	0.5	3.1	.001			
Sex	−0.05	−0.5	.636			
Employed	−0.02	−0.2	.807			
Burden	−0.4	−4.5	.001			
Control	4.6	4.2	.001			

tween spouses with higher ($n = 35$) versus lower ($n = 34$) perceived control (Figure 2). Spouses with higher perceived control reported significantly higher emotional well-being than did spouses with lower perceived control (77.6 and 65.3, respectively, $P = 0.003$).

DISCUSSION

We found that spouses in our sample had low levels of emotional well-being. Our findings are consistent with research in other chronic-illness populations^{29–31} and among frail older adults^{32,33} demonstrating that caregivers³⁴ are psychologically vulnerable. Consistent with Scott,³⁵ our findings indicate that the emotional well-being scores of care-

givers in our sample were below the normative values established for age-matched samples in the general population.

Our findings reinforce the need for clinicians to identify impairment in spousal emotional well-being and to initiate appropriate treatment or referral. Given the critical role that spouses play in recovery, we must focus on spouses' feelings as they care for patients with advanced HF. Spouses are an important part of the health care team, so it must be remembered that the spouse lives the experience of being diagnosed with a chronic life-threatening illness. Often these spouses have been married ≥ 30 years. Roles may be reversed, or new roles such as caregiver may be assumed during the chronic-ill-

Fig 2 Emotional well-being in spouses with high and low levels of perceived control.

ness phase. Men may feel unable to deal with the business of running a household, whereas women who have been in traditional roles may struggle with tasks that have always been performed by their husbands. For the healthy spouse, there is always more work than time as he or she tries to assume the roles filled by the other person as well as provide care for the spouse with HF. Given the life-threatening nature of advanced HF, frequent hospitalizations may generate concerns about finances in patients and their spouses. Patients may not be able to return to the same kind of work again, may want to take an early retirement, or may become depressed and unable to return to work. Financial concerns add to the already long list of worries. Finally, chronic illness may cause a disruption in the daily routine of the family. Familiar routines must be abandoned as spouses attend to the needs of the individual with heart failure and take on many of the tasks once performed by that person.

Our findings that younger spouses are at greater risk for decreased emotional well-being have not been reported previously. Spouses in our sample were generally younger than many spouses of advanced HF patients in the community and may not reflect the general population of spouses of advanced HF patients. However, our findings do advance this field of inquiry. We have postulated 2 possible explanations for our data. First, for younger spouses, chronic illness may add to an already heavy burden of maintaining a job while simultaneously caring for school-age children and elderly parents. Second, it may be that older spouses, who have achieved a sense of overall life satisfaction in general, may also derive greater satisfaction in their roles as caregivers. Finding new purpose in life as a result of the caregiving experience may make that experience for older spouses more meaningful than burdensome. To support our second interpretation, we reflect on Scott's findings³⁵ that high mental health among caregivers may be related to commitment and satisfaction derived from the fulfillment of family obligations in concert with the caregivers' gratification derived from helping others. The relationship between age and emotional distress, although intuitive, has not been previously described and requires further study. However, in the interim, clinicians must be alert to the needs of younger spouses who may be at higher risk for impaired emotional well-being.

We found that spouses who feel greater burden in the caregiving role and spouses who feel they have less control over the health outcomes of their loved one were at greater risk for decreased emo-

tional well-being. This finding is consistent with other researchers who have examined spouses of advanced HF patients. Investigators have found that although all caregivers indicated a desire to provide care and perform the caregiver role, many of them experienced negative aspects of providing care, particularly those affecting their daily schedule, health, and finances.³⁵ In examining the role of caregiver preparation on emotional distress, Scott³⁵ found that when caregivers perceived that they were unprepared for the caregiving role, they experienced more adverse effects. Given that prolonged caregiving affects the health status of caregivers adversely,³⁶ our study reinforces the need to identify spouses at risk for decreased emotional well-being and to provide special support to spouses experiencing issues related to their roles as caregiver. Effective interventions can be developed to address those factors that contribute to problems in psychosocial recovery.

Finally, consistent with other studies conducted among patients and spouses after myocardial infarction and coronary artery bypass surgery,²¹ we found that spouses of HF patients who had high levels of perceived control had enhanced emotional well-being. Our findings support the hypothesis that the sense of control that spouses experience related to their loved one's health may be particularly important in determining the level of spousal emotional well-being. Our study implies that strategies that enhance feelings of perceived control may be key to maximizing the emotional well-being of spouses of advanced HF patients. Like the patient, the spouse must come to terms with the chronic nature of HF by resolving concerns about the future and determining how to cope with needed lifestyle changes. Advanced HF and associated changes in patients' functional status signify the reality of aging and mortality for the spouse just as it does for the patient. Interventions that support effective coping and enhance feelings of control must be developed and tested in this vulnerable population.

Several limitations must be considered when interpreting the results from our study. The nonrandom sample, the small sample size, and the homogeneous nature of the study participants (from a single outpatient HF clinic) limit the ability to generalize findings to all spouses of HF patients. Generalizability would be facilitated with a larger random sample drawn from multiple centers. Furthermore, in most cases the participants had to initiate contact with the researcher to participate in the study. Too few men responded as subjects, which limited our ability to compare the impact of

caregiving on men versus women. Because sex seems to have an effect on caregiver stress and burden,³⁶ it would be important to include a more equal number of men and women in future studies. We also did not consider the length of participants' marriages in our analyses, nor did we examine other factors that may influence emotional well-being in spouses, including their level of preparedness and motivation to assume the caregiving role. These areas should be of interest for future researchers.

CONCLUSION

In conclusion, spouses of advanced HF patients report substantially impaired emotional well-being. Younger spouses, spouses who feel more burdened in the caregiving role, and spouses who feel they have less control over the health outcomes of their loved one are at greater risk for impaired emotional well-being. Spouses have been identified as a critical link influencing patient outcome. These findings highlight the emotional costs spouses may pay in providing care and support to patients. Clinicians should pay particular attention to younger spouses and should ask all spouses how they feel about the burdens imposed on them by their caregiving role. Special focus should be placed on any interventions that may enhance spousal perception of control.

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