



Living with heart failure: Psychosocial resources, meaning, gratitude and well-being



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ABSTRACT

Objectives: The present study explored the experiences of people living with advanced heart failure (HF) to determine the extent to which (1) psychosocial resources relevant to HF patients were qualitatively reported, and (2) to determine the extent to which psychosocial resources were correlates of subsequent well-being as assessed by validated quantitative measures.

Background: HF is a serious life-limiting illness that involves impaired heart functionality. Patients commonly face severe physical fatigue and frequently endure disabling depression. Individuals with HF often report the use of social support and religion/spirituality (R/S) as helpful, but little work has systematically linked their reliance on these resources and well-being.

Methods: 111 participants completed four open-ended questions to assess aspects of living with HF. Open-ended questions were coded to identify psychosocial resources: positive meaning, gratitude, R/S, social support, and medical resources. Data were collected once and then again 3 months later. Participants also completed measures of well-being, including religious meaning, life meaning, satisfaction with life, depressive symptoms, death anxiety, and health-related quality of life. Bivariate correlations were used to relate psychosocial resources and well-being.

Results: Patients reported many psychosocial resources, particularly positive meaning, R/S, social support, and medical resources. Positive meaning and R/S were inversely linked with depressive symptoms. R/S was also related to less death anxiety, while social support was related to higher anxiety about death three months later.

Conclusions: Findings advance our understanding of the struggles HF patients experience and the roles of psychosocial resources such as meaning and gratitude in alleviating these struggles. Results may help explain how resources like R/S and social support may influence well-being.

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Introduction

Heart failure (HF) is a chronic, life-limiting illness resulting from the heart's inability to maintain normal blood circulation.¹ It is increasingly prevalent in the US, with 5.7 million adults currently diagnosed,² the vast majority over age 65.³ Common symptoms include difficult and painful breathing even during rest, fluid retention and swelling of the lower extremities, and general weakness and fatigue.² Current treatments for HF can slow the progression of the disease, but do not cure it.⁴ Multiple medication regimens and major lifestyle changes are necessary to manage the disease and minimize negative symptoms.^{4,5} Along with physical constraints, HF patients must deal with hospitalizations, increasing

threats of mortality as their disease inevitably progresses, and increasing dependence on others for care.⁶

These stressors make living with HF extremely difficult, and not surprisingly, HF patients are particularly vulnerable to depressive symptomatology⁷ and lower quality of life, enjoyment and satisfaction.⁸ Levels of depression and impaired quality of life are higher in HF patients even relative to patients with other types of cardiac-related diseases such as myocardial infarction.⁹

The present study aimed to more directly ascertain reports of HF patients in their own words regarding the extent to which they experienced the presence of psychosocial resources shown in previous research to be particularly important for well-being in HF patients. Further, the influence of these psychosocial resources on current well-being and subsequent well-being were examined. In the interest of better understanding coping and well-being in individuals with progressed HF, we focused on patients who had severe HF (categories III and IV) on the NYHA classification system

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of heart functioning and who were not eligible for transplant. Data were collected from HF patients twice over three months to capture changes in well-being. A qualitative question format similar to those used in past studies was deployed¹⁰ examining psychosocial resources including: positive meaning, gratitude, religion/spirituality (R/S), social support, and medical resources. Answers were coded and correlated with quantitative measures of well-being. Given that patients frequently experience sadness and emotional struggle,^{7,9} depressive symptoms, satisfaction with life, and life meaning were assessed. Patients in the later stages of HF, like those in this study, increasingly face mortality as a stressor⁶; subsequently, measures of death anxiety and religious meaning were obtained. As physical limitations in functioning pose as one of the most difficult barriers HF patients face,^{4,5} physical functioning and health-related quality of life were assessed. Bivariate correlational analysis was used to examine the link between psychosocial resources at time 1 and well-being at times 1 and 2. It was hoped to encompass not only concurrent interactions between psychosocial resources and well-being, but also to demonstrate how use of psychosocial resources may be associated with subsequent well-being three months later.

Literature review

Qualitative studies have furthered our knowledge of living with HF by providing phenomenological evidence of the suffering and limitations wrought by HF.¹¹ For example, people living with HF have voiced feelings of decreased sexual intimacy, worthlessness because of their inability to work, boredom, and guilt.¹² Feelings of abandonment from health care providers also trouble patients diagnosed with HF.¹³ Not only have patients commonly reported abandonment and fear, but many also struggled with the fact that they were becoming more dependent on other people, and the thought that they would soon need help carrying out everyday activities.¹⁴ Patients also discussed a lack of understanding about their illness, including why they developed it, and how it would progress for them.⁴

Thus, the literature paints a fairly dismal picture of living with this serious, life-limiting illness. However, research regarding living with other illnesses has presented evidence that individuals can maintain positive attitudes despite dealing with their disease. In their groundbreaking work on people living with HIV/AIDS, Folkman and her colleagues documented that even in the midst of terrible suffering and sickness, people often reported concurrent positive emotions and experiences.^{15,16} They proposed that such positive experiences are important phenomena in and of themselves. Studies have documented that seriously ill individuals report positive states such as gratitude and appreciation for life and a sense of meaning in life.¹⁷

Further, studies have suggested that such positive experiences may buffer the impact of disease on well-being. For example, in a study examining women's experiences with chemotherapy treatments, some women stated that it brought their family closer together and they developed a more positive outlook on life.¹⁷ To date, positive aspects of living with HF have not been explicitly examined, although some research with HF patients suggests that this may be an important part of the experience of living with this illness. For example, although numerous studies have demonstrated higher levels of distress and poorer quality of life,¹⁸ one study that compared HF patients to a matched sample without HF found that those with HF had higher levels of spiritual well-being.¹⁹

In addition, several studies of HF patients have documented the importance of individual resources in coping with this illness. For example, several studies have highlighted the crucial role that social support plays.²⁰ In addition, medical support, specifically maintaining relationships with doctors and nurses,¹⁴ and spiritual issues, have also been suggested as playing an important role in adjustment to HF.¹⁰

A better understanding of these resources and positive states may lead to interventions to help HF patients to better access them and, ultimately, improve their quality of life. The present empirical investigation sought to better clarify the positive experiences of living with HF. Heretofore, the positivity shown by HF patients has not been explored specifically, and it was hoped the current study will begin to fill this gap in literature. Goals were also set to identify the potentially beneficial or detrimental links existing between psychosocial resources and well-being in HF patients.

Methods

Participants and procedures

The sample consisted of 111 HF patients recruited from a large regional cardiology practice in Cincinnati, OH; demographic information can be found in Table 1. Patients were 67 men and 44 women; 55% were Caucasian, 38% were African-American, 11% were Latino, and 5% were Native American. 60% of participants were married, 18% widowed, 14% divorced, and 5% single. Income and education ranged widely: annual household income ranged from under \$10,000 (14%) to over \$50,000 (11%), and education level ranged from "some high school" (19%) and "high school diploma" (32%) to "some college" (30%), "college degree" (10%), and "graduate degree" (6%). Eligibility included having fairly severe HF (NYHA Classification Level III and IV) and being ineligible for transplant due to the progressed severity of their illness. Mean length of HF diagnosis was 6.5 years (SD = 5.6 years). The study was approved by an Institutional Review Board. Participants completed a series of quantitative questionnaires assessing well-being and then wrote responses to four open-ended questions. Most surveys

Table 1
Demographic information of study participants (n = 111).

Gender	Race	Marital status	Family income	Education
Male 60.3% n = 67	Caucasian 55.0% n = 61	Married 60.4% n = 67	Less than \$10,000 13.5% n = 15	Some high school 18.9% n = 21
Female 39.6% n = 44	African American 37.8% n = 42	Widowed 18% n = 20	\$10,000–\$25,000 28.8% n = 32	High school degree 31.5% n = 35
	Latino/Hispanic 10.8% n = 12	Divorced 13.5% n = 15	\$25,000–\$50,000 34.2% n = 38	Some college 29.7% n = 33
	Native American 5.4% n = 6	Single 5.4% n = 6	\$50,000–\$100,000 10.8% n = 12	College degree 9.9% n = 11
	No response 1.8% n = 2	No response 2.7% n = 3	Above \$100,000 3.6% n = 4	Graduate degree 6.3% n = 7
			No response 9.0% n = 10	No response 3.6% n = 4

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