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Patient perspectives about depressive symptoms in heart failure: A review of the qualitative literature

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Abstract

Background—Scientists have systematically established the prevalence and consequences of depressive symptoms in patients with heart failure (HF). However, a comprehensive understanding of patient perspectives about depressive symptoms, in combination with HF, has not been published. A patient-centered approach may support the design of interventions that are effective and acceptable to patients with HF and depressive symptoms.

Objective—To review qualitative findings about patient perspectives of the contributing factors, associated symptoms, consequences, and self-care strategies used for depressive symptoms in HF.

Methods—Qualitative studies were included when they were published between 2000 to 2012, in English, and described emotional components about living with HF. Three electronic databases were searched using key words “heart failure,” “qualitative,” and “depression or psychosocial or stress or emotional.”

Results—Thirteen studies met inclusion criteria. Patients with HF reported that financial stressors, overall poor health, past traumatic life experiences, and negative thinking contributed to depressive symptoms. Patients described cognitive-affective symptoms of depression and anxiety, but not somatic symptoms of depression. Perceived consequences of depressive symptoms included hopelessness, despair, impaired social relationships, and a decreased ability to engage in HF self-care. Recommended management strategies consisted of enhanced social support and cognitive strategies.

Conclusions—Depressive symptoms in patients with HF were associated with a number of contributing factors, including those not specifically related to their disease, and serious consequences that reduced their self-care ability. Non-pharmacological management approaches to depressive symptoms that include improved social support or cognitive interventions may be effective and acceptable strategies.

Keywords

Anti-depressive agents; cognitive therapy; cardiovascular diseases; patient-centered care

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Introduction

Major depressive disorder occurs in 25% of patients with HF¹ and consists of five or more symptoms present for most of the day, almost daily, or for at least two weeks. One of these symptoms must be either depressed mood or loss of interest or pleasure in usual activities, and the symptoms significantly interfere with, or cause distress in social, occupational, or other areas of functioning.² Depressive symptoms are also common in patients with HF, with a prevalence ranging from 30–50%.^{1,3} Depressive symptoms can occur with or without major depressive disorder and consist of depressed mood, guilt, hopelessness, low self-esteem, fatigue, sleep disturbances, appetite change, and inability to concentrate.⁴ As these are subjective symptoms, they are measured by self-report instruments.

Patients with HF and concomitant depressive symptoms have a significantly increased risk of death, rehospitalization, and worse health-related quality of life.^{1,3} Quantitative studies have previously provided evidence about the epidemiology, contributing factors, and consequences of depressive symptoms in patients with HF.^{1,4–7} However, our understanding about the patient perspective of living with depressive symptoms and comorbid HF is incomplete.

An Institute of Medicine report about the state of healthcare in the U.S. defined patient-centered care as an approach that takes into consideration patient personal preferences, cultural traditions, values, families, and lifestyles. Patient-centered care empowers patients to be responsible for self-care and reduces the use of healthcare interventions that are unwanted, inappropriate, or not needed.⁸ A patient-centered approach to research about depressive symptoms in patients with HF would provide a better understanding about the experience of living with concomitant depressive symptoms and HF from the patient perspective. Use of a patient-centered research approach could then contribute to the development of interventions that are appropriate and sensitive to the needs of this population.

A synthesis of qualitative findings about living with depressive symptoms and HF will support a clear understanding about this experience. Thus the purpose of this paper is to review qualitative research findings about HF patient perspectives on living with depressive symptoms, including perceived factors that contributed to depressive symptoms, associated symptoms, consequences of depressive symptoms, and self-care practices used to manage depressive symptoms.

Methods

I performed a thorough review of the literature using PubMed (OVID), PsychInfo (OVID), and CINAHL (EBSCOHost) using the search terms “heart failure AND qualitative AND depression (or stress, or emotion, or psychosocial).” All abstracts were reviewed and studies were included when they were published in between 2000 and April 2012, reported a qualitative study that included patients with HF, and reported on psychosocial or emotional aspects of living with HF. Reference lists of included papers were also hand searched to identify relevant studies. Twenty-two papers met inclusion criteria and were evaluated further. Seven of these did not include psychosocial or emotional aspects of living with HF, and 2 papers were systematic reviews of previous qualitative studies. Thus, 13 articles were included in this review.

Results

Contributing factors

Patients with HF identified a number of factors they perceived contributed to their depressive symptoms. Financial difficulties contributed to their depressive symptoms. Inability to work, living in poverty, and difficulty accessing disability allowances caused considerable emotional distress for some patients.^{9–11} As one patient said:¹⁰:

“I think the main thing well that, that upsets me is finances. If my finances get to the point where I get to a week before payday and I don’t have any money, then I get very stressed and I think that stresses everybody. But I think it especially stresses me (p. 313).”

Patients with HF and depressive symptoms also described living in a general state of poor health and experiencing multiple symptoms. Heart failure-related breathlessness and fatigue, as well as symptoms associated with multiple comorbidities, contributed to symptoms of depression.^{10,11} Some patients perceived that living with comorbidities was actually more difficult than living with symptoms of HF.⁹

Previous traumatic life events, some of which occurred many years ago, were also described as a contributing factor to long-term emotional distress. Traumatic experiences described by patients included the death of a child in a tragic accident, the death of multiple children, the suicide of a child, and rape.¹⁰ Several patients also described experiencing emotional trauma related to surviving sudden cardiac death.^{10,12,13} One patient described his near-death experience:¹²

“I was blacking out, had breathlessness, so 911, here they come and the boys came in. They immediately had their big black battery with them and they gave me a jolt ... to have a cardioversion while you’re conscious...It’s like being electrocuted (p. 36).”

Finally, patients with HF described negative thinking as an important factor contributing to their depressive symptoms. Negative thoughts were automatic, persistent depressing thoughts about the self, world, future, or relationships with others.^{14,15} Multiple researchers^{10,16–19} found that patients with HF experienced the negative thought, “I’m a burden to others,” in response to the physical limitations of HF. Patients described feeling depressed, guilty, dependent, resentful, irritable, anxious, and frustrated in response to this negative thought. For example, one patient stated⁹:

“Sometimes you get very, very low. I just sit back and watch the old girl do it. That hits me here, thinking I should be doing that. I know up here that I can’t and you get very depressed (p. 276).”

Associated symptoms

Patients with HF and depressive symptoms expressed associated feelings of guilt, low self-worth, irritability, emptiness, anger, frustration, tearfulness, powerlessness, loss of interest in hobbies, and loss of interest in sex.^{9–11,13,16,18,20–22} However, somatic symptoms often associated with depression (lack of energy, changes in appetite, and changes in sleeping patterns) were rarely mentioned by patients.

Anxiety and fear were frequently described as occurring simultaneously with depressive symptoms. Patients disclosed that they were anxious about their future, the trajectory of comorbidities, the unpredictable nature of HF, actual and potential pain, the likelihood of hospital readmissions, impending or potential medical procedures, the likelihood of a

shortened life span, and the possibility of dying in the middle of the night.^{9,11,16,18–20,23} One patient described his fears about an uncertain future:⁹

“I just feel, you know, next week I might not be here...that’s my initial sort of fear, you know, oh my God how much longer have I got (p. 276).”

Consequences

Patients described a number of negative consequences of their depressive symptoms. The consequences of depressive symptoms included feeling hopeless, helpless, and full of despair,¹⁶ which resulted in withdrawal from interpersonal relationships and acting out these feelings on their family members. As one patient said:²¹

“When I feel bad I can’t stand either myself or my wife, or any other people. Then I become a loner, I want to be by myself (p. 230).”

Caregivers for patients with HF and depressive symptoms indicated that this frequently resulted in irritability, and that patients often verbally lashed out at spouses and children. One caregiver described what it was like to live with a patient with HF who was depressed:¹⁷

“His attitude toward me and his youngest daughter has changed. He takes it out on us. I explained to her that it is his illness. He has no energy. He is very depressed and very down (p. 320).”

Patients reported that depressive symptoms decreased their ability to manage their prescribed treatments and provide self-care.^{11,24} Some described feeling hopeless and lacking motivation to engage in self-care. For example, one patient stated²⁴:

"Sometimes you just get fed up and I think that was just a day that I had a real down spiraling. I just ate what I wanted. I put salt on everything and just didn't care (p. 239)."

An infrequent, but crucial consequence of depressive symptoms in patients with HF was suicidal ideation or action. Several patients expressed prior suicidal thoughts; however, some stated that they did not intend to act upon these thoughts.^{9,10} In one case study, authors described how a patient whose HF was managed with a ventricular assist device committed suicide by intentionally disconnecting the power supply to his device.²⁵

Self-care practices for depression

Patients rarely reported the use of prescription antidepressants as a strategy for depressive symptoms.^{9,10,17} Patients from only one study¹⁰ described engaging in exercise and physical activities as a component of depression self-care. However, a key component of self-care for depressive symptoms was obtaining physical and emotional support from family and friends.^{9,17,19,20} Patients asserted that having good social support was important because it made them feel loved and served as an important outlet for expression of their thoughts and feelings.²⁰ Some patients described poor social support systems, or confided that they did not take advantage of their existing social support system. Several patients had not told their spouses about their depressive symptoms.⁹ However, patients who did perceive positive social support described the importance of this asset as a buffer against the stress associated with HF:¹⁹

“Not only [do my children] help me do things, but they also help take away some of the stress that is because of my disease (p. 88).”

In a number of studies, patientes recounted the regular use of cognitive strategies to manage their depressive symptoms. Positive self-talk, thinking about thankfulness, and positive

affirmations were used to manage symptoms of depression.^{10,19,21} Europe and Tyne-Lenne²¹ found that men with HF predominantly tried to think positive thoughts such as “I’m alive.” Other patients focused on a multitude of positive thoughts and affirmations to help them cope with their depressive symptoms.^{10,19,21}

Discussion

Prior quantitative data have identified factors that independently predicted depression in patients with HF; these included poorer functional status (as measured by New York Heart Association functional class),²⁶ previous episodes of clinical depression,^{26,27} and smoking.²⁶ However, this review of qualitative studies found several important contributors to depressive symptoms that have been previously overlooked by researchers and clinicians. For example, patients perceived that past traumatic life events were a strong influence on their symptoms of depression.^{10,12,13} Although there is a large body of research which supports the role of traumatic life events as strong independent predictors for the development of depressive symptoms, the contribution of these experiences have not been studied in patients with HF.^{28–31} Thus, this gap in our understanding could influence the effectiveness of treatment strategies should these experiences remain hidden.

The contribution of negative thinking to the development and continuation of depressive symptoms was emphasized by many patients. In particular, negative thoughts about being a burden to family and friends worsened depressive symptoms. This finding was supported by earlier qualitative reviews of studies focused on the experience of living with chronic HF.^{18,22} Patients in those earlier investigations frequently reported “feeling like a burden.” However, negative thinking, as a contributor to depressive symptoms, has not been examined by researchers who study predictors of depressive symptoms in patients with HF, even though this construct can be measured using several psychometrically robust instruments.³²

Patients disclosed a variety of feelings and symptoms that occurred in conjunction with depressive symptoms; these included guilt, irritability, emptiness, anger, frustration, tearfulness, and loss of interest in hobbies. These cognitive-affective symptoms are similar to those reported by depressed people without HF or other chronic illnesses.³³ However, these patients with HF rarely described somatic symptoms that may be associated with depression, such as fatigue, changes in appetite, or difficulty sleeping. Patients in these qualitative studies may have excluded somatic symptoms from their discussions because they were not asked about them. However, it is possible that these patients either did not experience somatic symptoms, or more likely, they assumed that somatic symptoms were because of their HF, rather than their depression.

Researchers and clinicians may treat depression in patients with HF as if it exists in a silo. However, this review suggested that anxiety was a distressing symptom that often occurred in conjunction with depressive symptoms. Anxiety is a common comorbid condition among patients with HF who are depressed.³⁴ Therefore, a patient-centered approach to research and treatment for depressive symptoms in this population should include consideration of anxiety.

Patients depicted the consequences of depression as hopelessness, impaired interpersonal relationships, and decreased ability to engage in self-care. These patients did not include survival or increased hospitalizations in their discussion of the consequences of depressive symptoms. Based on the findings of these investigations, it is likely that many patients are not aware of the link between depression and worse survival outcomes with HF. Patients may also view emotional, social, and physical aspects of quality of life as more important

than quantity of life. Future studies should include measures of quality of life as a primary outcome when testing interventions for depressive symptoms in patients with HF.

We believe it is highly significant that patients did not describe antidepressant prescriptions for treatment of depression. An apparent lack of antidepressant therapy in these studies may be attributed to several explanations. Although antidepressants are often considered first-line therapy for depression, they are rarely used in the HF population; only 1 out of 4 depressed patients with HF are treated with antidepressants,³⁵ and those patients who are prescribed antidepressants are often under-treated or may not receive appropriate follow-up care to titrate dosages.^{1,36} Finally, there is evidence that antidepressants may not be effective in this population. The SADHART-HF investigators⁹ suggested that the efficacy of antidepressants was equivalent to placebo when used to manage symptoms of depression among patients with HF and depression.

Patients in these qualitative studies described using non-pharmacological treatments, such as social support and cognitive strategies to manage their depressive symptoms. Jeon and colleagues¹⁸ also found that patients coped with distressing emotional symptoms by using positive self-talk and social support. It is likely that these strategies were developed by individuals without professional clinical guidance. Thus, patient-centered researchers should focus on the development and testing of non-pharmacological interventions for depressive symptoms in patients with HF. Interventions that enhance social support or focus on cognitive strategies may also be more acceptable and more effective than antidepressant therapy among patients with HF. Because negative thinking was frequently reported as a pivotal contributing factor, future investigators should determine the efficacy of cognitive therapy, a psychological therapy focused on reducing negative thinking,³⁶ as an management strategy for depression in patients with HF.

Conclusion

Financial stressors, poor health, past traumatic life experiences, and negative thinking contributed to depressive symptoms in patients with HF. Patients reported cognitive-affective symptoms of depression and anxiety, but did not describe somatic symptoms of depression. Perceived consequences associated with depression were severe, and included hopelessness, despair, impaired social relationships, and a decreased ability to engage in HF self-care. Patients developed enhanced social support and used cognitive techniques for managing depression. Clinicians should understand that depressive symptoms in patients with HF are associated with a number of factors other than their illness, and that patients with HF may not recognize or report somatic symptoms related to depression. Patient-centered research is imperative to develop and test non-pharmacological strategies for the management of depressive symptoms in this population, with a special focus on the improvement of health-related quality of life.

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Table 1

Summary of qualitative studies that described depressive symptoms in patients living with HF

First Author (year)	Purpose	Sample	Findings related to depressive symptoms
Zambroski (2003) ¹¹	Describe the experience of living with HF	N = 11 (6 women, NYHA Class not recorded)	<ul style="list-style-type: none"> Depressive symptoms included feelings of depression, guilt, and fear Traumatic events (such as near-death experiences) and an inability to do daily activities worsened depressive symptoms
Riegel (2002) ¹⁰	Describe how HF influences patients' lives and determine facilitators and barriers to HF self-care	N = 26 patients with HF (65% male, 58% NYHA functional class III/IV)	<ul style="list-style-type: none"> Patients reported experiencing depressive symptoms and anxiety Patients were upset by the fact that they were unable to do the things they used to do HF is only one struggle among many other stressors that they experience Emotional support was obtained from family, friends, healthcare providers, and neighbors
Dekker (2009) ⁹	Describe the experience of living with depressive symptoms in patients with HF	N = 10 (5 women, 70% NYHA Class III/IV)	<ul style="list-style-type: none"> Negative thinking and multiple stressors worsened depressive symptoms Patients used cognitive strategies, activities, and social support to manage depressive symptoms Antidepressant therapy was rarely mentioned as a strategy for managing depressive symptoms
Pattenden (2007) ⁸	Describe how patients with HF and family care givers cope with daily life	N = 36 patients (64% male, 58% NYHA Class III/IV) N = 20 family caregivers	<ul style="list-style-type: none"> Patients found comorbidities more difficult to live with than HF Patients described feeling guilty and experienced negative thoughts about not being able to do household chores Patients described experiencing traumatic events, financial stressors, and anxiety Few patients were taking antidepressants or receiving any treatments for depression Supportive family helped alleviate depressive symptoms
Bennett (2000) ¹²	Describe symptoms and self-care strategies of patients with HF using focus groups	N = 23 patients (16 men, NYHA Class not reported) and 18 family members (17 women)	<ul style="list-style-type: none"> Depressive symptoms included feeling depressed, fear, worry, thoughts of death, sadness, and tearfulness Patients used distraction, social support, and positive self-talk to manage depressive symptoms
Ryan (2009) ¹⁵	Describe the lived experience of patients with advanced HF	N = 9 (6 male, all NYHA Class III/IV)	<ul style="list-style-type: none"> Patients described experiencing feelings of hopelessness, emptiness, panic, anxiety, terror, and defeat. Patients' depressive symptoms were worsened by their inability to do basic tasks of everyday living
Fitzsimons (2007) ¹⁶	Describe the palliative care needs of patients with end-stage heart	N = 18 6 of these were patients with HF (4	<ul style="list-style-type: none"> Patients attributed depressive symptoms to their decline in health and inability to participate in daily activities

First Author (year)	Purpose	Sample	Findings related to depressive symptoms
	failure, renal failure, and respiratory disease	female, all NYHA Class III/IV) N = 17 family caregivers N = 18 clinicians	<ul style="list-style-type: none"> Patients take out their depressive symptoms on their family caregivers Patients' main source of emotional support are family and friends Despite the high reported levels of depressive symptoms, very few patients were taking antidepressant therapy
Bosworth (2004) ¹⁸	Use focus groups to describe quality of life as understood by patients with HF	N = 15 men with HF (5 men in each focus group; 50% NYHA Class III/IV)	<ul style="list-style-type: none"> Patients experienced depressive symptoms including depression, low self-worth, frustration, fear, anxiety, loss of interest in activities, and guilt Physical limitations led to feeling like a burden, which increased depressive symptoms Patients coped with negative emotions by substituting old activities (that they couldn't do anymore) with new ones, positive thinking, engaging in spirituality, and finding social support.
Allen (2009) ¹⁹	Describe the lived experience of women with HF	N = 4 women with NYHA class III HF	<ul style="list-style-type: none"> Patients reported experiencing depressive symptoms in response to physical limitations Patients felt anxious about the future and their risk of death Social support helped patients cope with depressive symptoms
Europe (2004) ²⁰	Describe the patient's experience of living with chronic HF	N = 20 men with NYHA Class II and III HF	<ul style="list-style-type: none"> Depressive symptoms included feelings of bitterness, emptiness, irritation, and shame—and these feelings were intensified by physical limitations. Patients were anxious and fearful about dying. Patients used cognitive strategies such as thinking positively to cope with depressive symptoms.
Horne (2004) ²²	Describe the experiences of patients with advanced HF and their needs for palliative care	N = 20 patients with HF (14 men, 52% NYHA Class IV)	<ul style="list-style-type: none"> Patients felt like a burden, which worsened their depressive symptoms Patients described experiencing depressive symptoms such as thoughts of death, fear, anxiety, and hopelessness
Riegel (2007) ²³	Use a mixed-methods design to describe factors that lead to expertise in HF self-care	N = 29 patients with HF (11 women, 59% NYHA Class III/IV)	<ul style="list-style-type: none"> Depressive symptoms resulted in hopelessness, decreased motivation for self-care, and feeling like a failure These depressive symptoms interfered with patients' ability to engage in HF self-care
Tigges-Limmer (2010) ²⁴	Present a case report of a man with HF and a left-ventricular assist device (LVAD) who committed suicide	N = 1 depressed patient with HF	<ul style="list-style-type: none"> A patient with HF and an LVAD developed severe depression 3 years after implantation; symptoms included hopelessness, thoughts of death, insomnia, loss of appetite, and despair Despite taking antidepressants and engaging in intensive therapy, the patient committed suicide by disconnecting himself from the driveline of his device—a type of "soft" suicide.