

Dark or Bright Half of the Moon: A Qualitative Study Exploring the Experience of Iranian Heart Failure Patients Regarding their Quality of Life

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Abstract

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BACKGROUND: Heart failure (HF) is a major public health problem in different societies and has numerous impacts on quality of life (QOL).

AIM: The present study was carried out with the aim to explore the experience of HF patients regarding the negative effects of the disease on their QOL.

METHODS: In this qualitative exploratory study data collection was performed through face-to-face, semi-structured, in-depth interviews with 19 patients with HF, who were selected through purposive sampling method from April to September 2017. Data analysis was carried out based on the framework analysis method.

RESULTS: The negative consequences of HF on QOL emerged in the form of 6 main themes including symptoms, disease complications, cognitive impairment, psychological distress, functional limitations and economic problems. Most of the participants (14 out of 19) assessed their QOL as well or very well.

CONCLUSION: The majority of the patients in this study, despite the many negative impacts of HF, had a high QOL that could indicate their satisfaction and effective coping with HF by creating a positive outlook and the perceived positive effects of the disease.

Introduction

Heart failure (HF) is a major and growing public health problem worldwide. Twenty-six million people in the world suffer from HF [1]. In Iran, patients with HF account for 3.3% of the population [2]. This condition is caused by myocardial injuries, ischemic heart diseases, hypertension and diabetes. It can also be caused by cardiomyopathies, valvular heart diseases, myocarditis, infections, systemic toxicity and cardiotoxic drugs. HF is a chronic progressive condition in which the heart cannot meet the metabolic demands of the body [3]. The 1-year mortality has been reported in 20% of HF patients,

and 5-year mortality has been reported in 59% of men and 45% of women [4]. Patients experience physical and emotional symptoms such as dyspnea, fatigue, oedema, sleep disorders, depression and chest pain, which can disrupt their quality of life (QOL) [5]. Maintaining a good QOL is as important as survival to patients with HF. QOL in patients with HF is lower than the general population and those with other chronic diseases [6], [7]. The prognosis of this condition is worse than that of many malignant diseases, and its unpredictable future is considered as one of its main features [8]. Health status deteriorates progressively due to the heart's deficiency in pumping out blood, which is characterised by acute episodes of the decompensated symptom.

Therefore, patients require frequent, long-term and costly hospitalisations [9].

Moreover, the available evidence suggests that changes in patients' health status may not necessarily affect QOL [10]. According to the World Health Organization (WHO), QOL means one's perception of his or her position in life in the cultural context and value systems in which one lives and is related to one's goals, expectations, standards and concerns [11]. As a dynamic, subjective and multidimensional concept, the QOL does not reflect the physiological status of patients; therefore, in similar clinical situations, patients have different perceptions of QOL [5], [12]. Our search for the perceived negative effects of HF on QOL in Iran showed that no research had been conducted in this area. However, Understanding the negative effects of HF on QOL will lead to the provision of effective supportive interventions, increased health promotion and reduced burden of disease in patients and their families. Since qualitative studies enable the researcher to perceive the experiences of the participants to the highest possible extent [13], the current study has been conducted using this method. The present qualitative study aimed to explore the perceived negative effects of HF on QOL from the perspective of patients with HF and their self-assessment of QOL.

Methods

Study Design and Participants

This study had a qualitative exploratory design. Purposive criterion sampling was initiated and continued until data saturation. The inclusion criteria consisted of informed consent, the confirmation of HF diagnosis and the ability to speak Farsi. The exclusion criterion was severe psychiatric or cognitive problems. Out of the 19 participants in this study, 14 patients were admitted to Imam Reza Hospital, consisting of those who had referred to the HF subspecialty clinic. The other 5 participants had referred to a specialised HF outpatient private clinic in Mashhad, Iran.

Data collection

The data was collected through face-to-face, individual, semi-structured, in-depth interviews. All of the interviews were conducted by one of the researchers (H.H) in the Cardiovascular Research Center in a quiet room, far from any noise. The interview questions (topic guide) consisted of: Would you please explain about your life after being affected by HF? Has HF affected your QOL? What are the negative effects of HF on your QOL that have led to your disappointment? What is the greatest negative

effect of HF on your life? What is the most important limitation caused by HF in your life? What would you rate your QOL from zero to ten? Please explain why you rated your QOL this way? After obtaining the participants' permission, the interviews were recorded using a voice recorder. After conducting each interview, the researcher responsible for conducting the interviews would write down all the field notes and the recorded voices at the first possible chance. They were written word-by-word; first, handwritten, and then, typed. All the interviews were conducted from April to September 2017, and each one lasted 35-90 minutes, with an average of 60 minutes. The individual and clinical features of the participants were extracted from their medical records.

Data analysis

In this study, the analytic process based on the framework method presented by Ritchie and Spence has been implemented [14], [15]. The data analysis consisted of 5 major stages; familiarisation with the interviews, developing a thematic framework, indexing, charting and interpretation and mapping [14]. In this study, the process of analysis consisted of a series of separate phases, based on the independent cooperation of at least two researchers by whom a consensus was reached. The research team reviewed the transcribed interviews and field notes over and over, and in some cases listened to the participants' voices to become familiarised with data, obtain a general perspective and immerse in the data, and therefore, became aware of the main ideas recurring in the data. In this way, the preliminary thematic framework was designed based on the interviews, prior thoughts and literature, and was discussed among researchers in a series of iterative meetings. Then, the corresponding author read the transcribed interviews line-by-line to mention the themes introduced through the topic guide. The text of the interview was individually coded by two researchers [(H.H) and (S.M)]. The coding was appropriately adjusted after a consensus was reached by the two above-mentioned researchers. The reliability of the final coding scheme was monitored and verified by a clinician (F.V), a health science researcher (M.M) and a sociologist (SS.M) through recording an accidental sample. Then, the transcribed interviews were entered through the codes' links into the index thematic framework. Thus, a chart was created for each theme, in which the interviews were placed in rows and the related sub-themes were placed in columns [16]. In the phase of interpretation and mapping, the researchers discussed the significance of the nature of the themes and how themes can be described and interpreted in regard with the research objectives, theories and the related models. The data were analysed manually without using the software. To increase data credibility, the researchers read the transcripts over and over and immersed in the data for a long time. Inserting the

interview quotations in the findings reflect the credibility and dependability of the study. All research processes, from developing the study to the discussion of findings, have been carried out through the collaboration of at least 2 researchers. The researchers' triangulation led to a decrease in the preconception risks or dominant prejudices in collecting data and results; thus, resulting in the study's trustworthiness.

Moreover, analytical triangulation or peer debriefing was used in the data analysis process. One of the researchers who was an expert in the field evaluated and verified the data analysis process. Data transferability was increased by providing the specification of the participants' profiles and research environment, as well as considering the heterogeneity of the samples. To verify the validity of the data analysis results, 6 of the participants were contacted to ensure that the results were consistent with their experiences (member check).

Ethical Consideration

The Ethics Committee of Gonabad University of Medical Sciences, Iran, provided the necessary ethical approval for the study (Reg. No: IR.GMU.1395.18). All participants signed an informed consent form, were made aware of the study's objectives, and were assured that their data would remain anonymous. They were also informed of their right to withdraw from the study at any time.

Results

The mean age (SD) of the participants was 59.5 (12.4) years, and the mean duration of the disease was 5.2 years. The mean (SD) of ejection fraction was 23.1% (8.3). Most participants were men (68.4%) and retired (42.1%). The mean (SD) of education degree was 11.4 (5.7) years of study.

Table 1: Themes and subthemes of the negative effects of heart failure on the quality of life

Main themes	Subthemes			
Symptoms	Fatigue	Shortness of breath	Sleep deprivation	
Disease complication	side effects of medications	Comorbidities		
Cognitive impairment	Memory loss and concentration impairment	Decision-making problems		
Psychological distress	Depression	Anxiety		
Functional Limitations	Loss of independence	Loss of sex	Loss of jobs	Loss of social activities
Economic problems	Inability to pay medical expenses	Inability to pay living expenses		

From the transcripts, 98 initial codes were obtained. These codes were then summed up into 6 themes as well as 15 subthemes. The 6 themes emerged which addressed the negative effects of HF

on QOL were symptoms, disease complications, cognitive impairment, psychological distress, functional limitations and economic problems (Table 1).

Symptoms

This theme includes the subthemes of fatigue, shortness of breath and sleep disorders. Most patients stated that HF has caused fatigue and reduced their energy levels. A 63-year-old man said: "*The most important negative effect of HF is fatigue. Sometimes, I feel I do not even have the power to raise a cup of tea*" (p9, retired). Most of the participants also complained of shortness of breath. A 62-year-old woman said: "*While doing activities, I get out of breath*" (p11, housewife). A participant in Functional Class IV said: "*I suffer from shortness of breath even while talking*" (p18, 37-year-old, higher education). Also, many patients were having difficulty falling asleep and remaining asleep. A 69-year-old man commented: "*As I am retired, I sleep during the day, so I cannot sleep a wink at night and stay up till morning*" (p6). They blamed their sleep deprivation on anxiety, orthopnea, sleeping during the day and overnight insomnia, as well as frequent overnight urination and the need to go to the washroom repeatedly. Therefore, some of them took hypnotics.

Disease complications

This theme includes the subthemes of the side effects of medications and comorbidities. One-third of the participants complained about the side effects of the medications: "*I resent my medicine box. This much medicine hurts you*" (p1, 63-year-old, retired). Generally, the participants felt depressed about a large number of tablets and the combination of drugs they were prescribed because they did not realise the purpose of pharmacotherapy. HF is usually accompanied by comorbidities such as diabetes, hypertension and kidney disease. "*Every moment, I think blood is clotting in my vessels; my blood pressure is fluctuating ...*" (p11, 62-year-old, housewife).

Cognitive impairment

This theme includes the subthemes of memory loss, concentration impairment and decision-making problems. About a quarter of the participants were experiencing cognitive impairments such as memory loss and concentration impairment. "*Since the time I was affected by HF, I have forgotten where my things are*" (p17, 48-year-old, housewife). A 41-year-old woman said: "*I need to read something several times to comprehend the material*" (p13, higher education). These patients are unable to concentrate for a long time, and they do not enjoy simple activities such as reading. Patients also need

to optimise shared decision-making interventions, and they are unable to make appropriate decisions on their own: *"I am not as strong as I used to be in decision-making, and I usually regret my decisions later on"* (p17, 48-year-old, housewife). Decision-making problems lead to impairment in self-care, failure in the timely reporting of the symptoms of disease severity, disability, frequent hospitalisation, decreased QOL and increased mortality rate, which indicates the importance of evaluating cognitive impairment in patients with HF.

Psychological distress

This theme includes the subthemes of depression and anxiety. Fatigue, shortness of breath and unpredictable life-threatening acute crises in HF lead to psychological distress. The unpredictable nature of HF in some participants, especially in women, had caused depression. A 62-year-old woman said: *"I easily burst into tears. I am hopeless..."* (p11). Another participant said: *"When I have chest pain, not only do I feel depressed, but I also have to convince others that it is nothing important"* (p7, 69-year-old, higher education, retired). Patients without an implantable cardioverter-defibrillator (ICD) were afraid they would have a heart attack again. An anxious patient said: *"I am afraid of loneliness. I am constantly stressed"* (p1, 63-year-old, retired). The bad mood had negative effects on QOL. Depression and anxiety in patients with HF are associated with a greater number of symptoms. Treatment of depression and anxiety in patients with HF might significantly improve QOL.

Functional limitations

This theme includes the subthemes of loss of independence, sex, job and social activities. About one-third of the participants had experienced the negative effect of HF on their independence; *"I lack the freedom to act that I am supposed to have in my daily life, and I need help to do my daily tasks"* (p4, 69-year-old, housewife). Two male participants complained of sexual dysfunctions such as erectile dysfunction and libido reduction. A 57-year-old diabetic man stated: *"The most important limitation of HF is sexual issues"* (p3, retired); in contrast, a 41-year-old woman said: *"Our sex frequency has decreased to a great extent, but I have no problem because my husband and I are not much excited about it"* (p13, higher education). Loss of job and reduction in income had negative effects on QOL. Most male participants complained that they were not able to do professional work. A 68-year-old man said: *"If you do not work, you will be like a dead person, and time will not pass"* (P2, retired). Compulsory job resignation was a bitter experience for younger men. A 37-year-old man said: *"I used to be a teacher. I felt like I was an emperor in the classroom. At present, I*

am not satisfied, because I lost my empire" (p18, higher education, unemployed). Being deprived of social activities, such as entertainment, hobbies, traveling, sports and participating in parties had a negative impact on the QOL of some of the participants; *"That I cannot walk and exercise much, has made me feel that I lack something"* (p4, 69-year-old, housewife) and *"It makes me upset that I am always at home"* (p15, 63-year-old, housewife). A 69-year-old man said: *"I wish I could travel and do sightseeing more frequently, but I cannot"* (p6). Medications (*diuretics*) for controlling HF-related symptoms do not allow patients to be socially active.

Economic problems

Treatment costs and loss of a job can have negative effects on the participants' QOL. A 65-year-old man said: *"Treating HF, the provision of medications, pacemaker implantation and frequent hospitalisation, especially for those who are retired with low retirement incomes and are not able to work, is very costly and affects the QOL negatively"* (p10). Some patients seemed to need financial support but did not receive any special aid. Also, the results showed that patients with low socioeconomic status found it difficult to cope with HF. It seemed that the participants who were satisfied with their economic situation gave a higher score to their QOL. The uncertainty about the ability to cover treatment costs had made more than one-third of the participants worry about providing money to cover the costs of renting a house, transportation, urban services, clothing and their children's education, and it had even influenced their nutritional costs. A 41-year-old woman said: *"I do not shop the way I used to any more. I am scared I may be hospitalised and be short of money"* (p13, employee).

The patients' self-assessment of their QOL

The patients' self-assessment of their QOL showed that most participants (14 out of 19 people) rated their QOL as well or very well. A large proportion of these patients believed that their high QOL was the result of economic security. A 69-year-old man said: *"Thank God ... I am satisfied with my life, and I do not think I have a problem. I rated my QOL 9 at the moment and rated it 10 before being affected by the disease ... If I did not have a good economic condition, I would rate it 2"* (p7, higher education, retired). A 71-year-old anesthesiologist rated his QOL 8 before and 7 after the disease; *"if I had economic problems in my life, I would rate my QOL 4"* (p14, 71-year-old, higher education, employee). In addition to economic security, many participants attributed their high levels of QOL to their satisfaction with the social support they received from their family especially their spouse. A 67-year-old man said: *"My wife babies me, we have got a lot closer to each other ... If she were*

not there for me, the score of my QOL would drop from 9 to 3 or 4" (p8, retired). Also, half of the participants believed a healthier lifestyle and religious-spiritual growth to be effective in their high QOL. A 63-year-old man said: "My score of QOL was 5 before my HF, and is 7 after it. The reason behind it is that I quit smoking and drug addiction, and this improved my life in many ways" (p1, 63-year-old, retired). A 57-year-old man associated his QOL score after his illness to being close to God (p3, retired). In this regard, a 47-year-old man said: "The score of my QOL was 5 before my illness and is 8 after it. The reason behind it is paying attention to religious issues, healthy eating and reduced stress" (p19, employee).

Discussion

The results of this study present many perceived negative effects of HF on patients' QOL, but having a good QOL in most of them show that they had found ways to endure, adapt, and accept the negative effects of HF. The majority of the patients reported they had symptoms, so limitations in daily life due to symptoms were affecting their QOL negatively. The most frequently reported symptoms were fatigue and breathlessness. The symptoms of HF such as dyspnea and fatigue are reported in 80% of the patients. Worsening symptoms are the main cause of hospitalisation [5]. Symptoms were a major influence on QOL [17]. Sleep deprivation can contribute to the exacerbation of symptoms. Patients with HF sleep more in the daytime compared with healthy people. Symptoms such as orthopnea and depression associated with HF may contribute to shortened sleep time and impaired sleep efficiency [18]. The side effects of polypharmacy had negatively affected the QOL of these patients.

Moreover, they had problems due to their lack of ability to distinguish between the side effects of the drugs and HF symptoms — side effects such as frequent urination and drug-related impotence affected QOL [19].

Many patients expressed fear of medication as it made them feel iller and caused hypotension and gastrointestinal dysfunction. Comorbidities such as diabetes and arthritis were common. Most of the time, their presence alongside HF was assumed as a double burden. HF affects older individuals, who have extensive comorbidity. Non-cardiac comorbidities are highly prevalent in older patients with HF and strongly associated with adverse clinical outcomes [20]. In this study, most participants evaluated their QOL as satisfactory in spite of experiencing the negative effects of symptoms and multiple complications of the disease. It seems most of them had accepted the symptoms and complications, and did not consider such disorders to be important because they had

changed their lifestyles and organised their daily lives using their resources and abilities. Bosworth showed that the patients had been coping with the disease and lived well despite the unpredictable nature of HF [21]. Ekman arrived at similar results, stating that it seemed that the medical diagnosis of HF was not important for some patients [6].

Nevertheless, the results of this study do not confirm the results of some previous studies with a quantitative approach reporting a low QOL in patients with HF [7]. The reason behind this difference may be that many of these studies have measured and reported the pre-determined dimensions associated with the assessment of the general health status rather than the QOL. The 36-item Medical Outcomes Study Short Form (SF-36), which is the most commonly used generic QOL instrument, mainly assesses health status rather than QOL; therefore, it cannot reflect QOL.

About a quarter of the participants had been negatively affected by cognitive impairments, which is consistent with the results of numerous qualitative studies that have reported concentration and memory impairment in patients with HF [21], [22]. Since self-care depends on having the ability to learn, perceive, interpret, respond and make decisions, it is difficult for patients with cognitive impairment to take care of themselves [23]. The importance of this issue has also been reflected in the literature that has suggested the urgency of further research on cognitive impairment in HF [24]. The most common psychological distress that had negatively affected the QOL of some of the participants in this study was depression and anxiety; this finding was in agreement with that of other related studies [25], [26]. Such feelings lead to lack of coping with the illness [27] and have negative effects on QOL in HF [28]. The results of other studies indicate that 30 to 40% of the patients with HF experience emotional distress such as depression. However, the meaning of QOL in HF is more about being able to be happy and enjoying spending time with the significant other, rather than not having emotional distress [5], which indicates why most participants enjoyed a high QOL despite the negative effects of HF. Depression in HF is associated with the fear of developing physical symptoms such as shortness of breath and functional limitations. Fear and anxiety can also lead to the denial of the symptoms of the illness and, as a result, lack of timely referral to the doctor. It seems essential that the periodic assessment of the psychological distresses of patients with HF be considered and its results are taken into consideration in therapeutic interventions.

The severity of symptoms could compromise functional capacity. HF is a progressive chronic disease, and the patients experience worsening health status following the exacerbation of fatigue and shortness of breath in the process of the disease. This poses an ever-increasing constraint in daily activities, leading to the patients' lack of independence. A small

number of participants believed sexual issues to be the most important negative effect of HF. In a correlational study, three-quarters of the patients with HF reported that both their inclination and their sex frequency had decreased, and in the remaining one-quarter of the subjects, sexual activity had stopped, but these changes had not affected their marital relationship [29].

Regarding functional limitations, some participants, especially men who had gone through the acute phase of the disease, were willing to resume their professional work and social activities, but despite their good physical and mental state, they relaxed at home and did not work. Evidence suggests that after having gone through the acute phase of the disease, people with HF can resume their normal life and career, but this is often neglected [30]. The results of a review of some qualitative essays show that one of the most prominent effects of HF on daily life is social isolation and loss of social activities of the affected following physical limitations due to experiencing shortness of breath and fatigue, diet, taking medications and diuretics (the increased amount and frequency of urination), fear and the lack of communication with family and friends [31]. Therefore, the affected people participate in recreation and leisure and travel less frequently, so they experience the feeling of being imprisoned at home [32]. Economic problems were found to be one of the most important negative factors affecting QOL. The majority of the participants in the study stated that despite the negative effects of HF on their economic situation, they had received no systematic support from any organisations. Considering the increasing burden of cardiovascular diseases and the effects of social and financial support on the treatment of HF, financial support programs such as the full coverage of drug and hospitalisation costs by contributors can be considered as a part of the plan for improving QOL in these patients [5].

Ferrans believes that QOL means having a good feeling about the important parts of life from the perspective of individuals, and what is important for some people at a stage of life may be unimportant to others [33]. This can explain the good feelings of most patients about the significant parts of life and why HF has not been able to blemish their satisfaction with life. Calman notes that the QOL consists of reviewing the current situation and determining the distance between the individual's existing situations (the individual's present experience) and his or her expectations [34]. On this basis, it can be concluded that the people who believed their QOL was good had adjusted their expectations based on their abilities. Consistent with the results of this study, the results of two other qualitative studies have shown QOL to be good and very good in more than half of the patients with HF, and good and excellent in patients with serious disabilities [5], [35]. According to the participants in the study, HF has led to spiritual

growth, religious growth, appreciation, a healthier lifestyle, a positive outlook, self-strengthening, getting closer to one's family and receiving more support from them. This way, they reduced the negative effects of HF and tried to maintain their QOL through appreciating the positive effects of the illness and creating a positive outlook. One of the limitations of this study was related to the geographic constraints of this exploratory study. Another limitation was that all the participants were Muslims.

The fact that the majority of the patients had a good QOL despite the many negative effects of HF may reflect their satisfaction with life and their effective coping with HF through creating a positive outlook and perceiving the positive effects of the disease. Therefore, healthcare providers can significantly help patients in coping with HF and increasing their QOL by focusing on the possibilities and the positive effects of HF as well as handling the limitations and negative effects. Moreover, some of the participants had also experienced post-traumatic growth; some of them claimed that their QOL had even improved after being affected by HF. Accordingly, an investigation into the positive effects of the disease and post-traumatic growth in HF by enthusiastic researchers can help lighten the "bright half of the Moon".

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