The lived experience of adults with heart failure: a phenomenological study

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Key words: Heart failure, lived experience, phenomenology, spirituality, family
Parole chiave: Insufficienza cardiaca, vissuto esperienziale, fenomenologia, spiritualità, famiglia

Abstract

Background. Although a number of studies have been conducted on patients with Heart Failure (HF), they have not given a rigorous comprehensive description of what it is like to live with HF. The objective of this study was to describe the lived experience of adults with HF.

Study design. A hermeneutic phenomenological design was used.

Methods. Cohen’s method was used to conduct the study. Thirty HF patients were enrolled between February and July 2014 from an outpatient cardiovascular clinic in Tuscany, Italy. Phenomenological interviews took place at patients’ homes, and the investigators analyzed verbatim transcripts. Once data saturation was achieved, to ensure data trustworthiness, participants were asked to confirm all the extracted themes. Atals. ti vers.7 was used for data analysis.

Results. The patients were mostly male (67%) with a mean age of 71 (SD 9.15) and an age range of 48–86. Seven themes emerged from the phenomenological analysis: 1) important life changes; 2) social isolation caused by the illness; 3) anger and resignation associated with the disease; 4) relief from spirituality; 5) will to live; 6) uncertainty about the future and 7) the inescapability of disease and death.

Conclusion. The meaning that patients attribute to their lived experience helps to create their needs, which are important to direct care. Family support and religious beliefs are an important source for HF patients to better manage their fears and cope with the future. Findings of this study provide nurses with a comprehensive description of what it is like to live with HF, which can be useful in helping to meet patients’ needs more effectively and in tailoring interventions.

Introduction

Heart failure (HF) is a major public health problem that affects over 15 million people in Europe and 5.7 million people in the United States (1, 2). The prevalence of HF increases with age, and consequently it affects more than 25% of the population aged 75-84 years (3, 4). Patients with HF are also affected by multiple comorbid conditions that increase mortality and hospitalization (5). The overall economic cost of HF in

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2012 was estimated to be $108 billion per year worldwide, and with further aging of the population, the economic burden of HF will continue to rise (6).

Studies that have explored with phenomenology the lived experiences of HF patients can be divided into three groups: studies that have focused on specific experiences; studies that have involved specific patient populations; and studies that have described the whole experiences of those living with HF.

Studies that have focused on specific experiences have analysed the experience of support and the experience of living with cognitive impairment. Nordgren, Asp, & Fagerberg (7) studied a sample of nine patients between the ages of 49 and 64, and four themes emerged in relation to support: 1) support - tenuous security and a frail situation; 2) medications - support for life; 3) conditional support within the context of formal care; and 4) information and knowledge. In the study by Sundin, Bruce, & Barremo (8) that involved five patients with HF, two themes were reported in relation to support: 1) feeling confident about support; and 2) feeling abandoned. This study was informative but was limited by the lack of trustworthiness and data saturation and by including only female participants. Another study focusing on support was conducted by Nordgren, Asp, & Fagerberg (9) where support was experienced as 1) dependency from care; 2) surrender to care; and 3) unclear participation. Pressler et al. (10) also studied the specific experiences of patients with HF living with cognitive impairments. The investigators found that living with HF and cognitive deficits was a complex situation and that it was difficult for patients to separate cognitive, physical and social challenges. These challenges were also related to medication adherence and the self-management of symptoms that patients experienced as vulnerabilities.

One study described the experiences of a specific HF population, women (11). In this study, four major themes emerged from the analysis: 1) acknowledging losses; 2) accepting the losses; 3) changing lifestyle; and 4) deepening relationships.

The last group of studies focused on the whole experience of living with HF, but two had methodological problems. Thornhill et al. (12) studied 25 patients with HF aged between 35 and 83 years and found the themes of 1) diagnostic process; 2) change in life activities; and 3) the role of others in resilience and emotional reactions. Although informative, this study had methodological problems related to a lack of trustworthiness. Ekman et al. (13) conducted another study and found the themes of 1) feeling imprisoned in illness; and 2) feeling free despite illness. Chiaranai (14) studied Thai patients with HF and extracted three themes from the analysis: 1) identifying losses or changes in their lives; 2) accepting the losses; and 3) regaining some control.

In conclusion, although a number of studies have been conducted on patients with HF, they have not given a rigorous comprehensive description of what it is like to live with HF. In fact, as said earlier, some studies have been focused on specific experiences or populations and other studies, even though focused on the whole experiences, lacked a methodological rigor. Therefore, the aim of the present study was to describe the lived experience of patients with HF. Understanding the lived experience of patients with HF could provide an important foundation for future research aimed at detecting the multiple psychosocial problems experienced by those with HF and could allow more tailored interventions to be developed to improve patients’ outcomes.

Methods

Design

A hermeneutic phenomenological design was used to conduct this study (13).
Participants
Thirty participants were enrolled from an outpatient cardiovascular clinic in Tuscany, Italy. Participants were enrolled if they met the following criteria: 1) a diagnosis of HF for at least three months according to diagnostic criteria specified in the guidelines of the European Society of Cardiology (15); and 2) willingness to participate in the study and to sign the informed consent form. Patients were enrolled for a period of five months, and enrollment continued until data saturation was achieved with 30 participants. All patients approached for the study agreed to participate.

Data collection procedures
Data were collected between February 2014 and July 2014. The second author approached patients during a routine follow-up visit at the cardiovascular clinics. During this first meeting, the interviewer informed the patients about the aim of the study and obtained their signed informed consent. With the informed consent, patients also gave the interviewer permission to abstract from their clinical record some clinical information, such as their New York Heart Association (NYHA) functional class and the duration of their illness. During this meeting, an appointment was made in order to conduct the interview at the patient’s home.

Using phenomenological methods (16), an unstructured interview was conducted. All participants were asked to describe their experience of having HF and to describe the meaning of this experience. The interviewer did not ask any further questions but encouraged participants’ storytelling with a welcoming attitude and empathy. When participants stopped and seemed to have nothing more to say in response to the initial question, the interviewer asked if they had anything more to add. The interviews ended when participants had nothing more to add. The interviews lasted from one to two hours.

Each interview was audio recorded and transcribed verbatim. During and after each interview, the interviewer recorded field notes (e.g. non-verbal behaviors, tone of voice and facial expressions) to enrich comprehension of the phenomenon. After interviewing 30 participants, data saturation was achieved.

Data Analysis
All interviews and field notes were transcribed in the Italian language and were then translated into English to allow collaborative analysis with foreign investigators. All interviews were transcribed verbatim, and the transcripts then were read and re-read several times by two investigators in order to check the accuracy between the text and the audio recordings. Next, themes were extracted from each individual interview. The team of investigators conducted data analysis according to the hermeneutic phenomenological methodology of Cohen et al. (2000). The investigators bracketed their presuppositions before data collection by describing their ideas of living with HF. Afterward, each investigator independently immersed himself in reading and re-reading the transcripts in order to analyze the data. All the researchers then discussed the extracted themes in order to reach agreement.

Methodological rigor
Cohen’s method allows a deeper knowledge of the meaning that people give to their lived experience, and rigorous analysis is enhanced by bracketing. Bracketing is the critical reflection technique that requires suspending one’s own thoughts and prejudices to avoid having researchers’ views alter the understanding of participants’ experiences. Bracketing strengthens the credibility of findings and reduces the influence that the point of views and thoughts of investigators could alter the meaning of participants’ interviews (16). Reading and re-reading the transcripts several times allows
researchers to understand the meaning of an experience. Investigators use reflective awareness to provide a better knowledge of data and a better understanding of the holistic experience. When the holistic sense is understood, all data can be analyzed on a deeper level. To enhance trustworthiness, patients confirmed all extracted themes after the interview in a second meeting.

Results

The patients were mostly male (67%) with a mean age of 71 (SD 9.15) and an age range of 48–86 years. Most participants (80%) were married, educated less than high school level (86%) and were retired (83.4%). While 70% of the patients were in NYHA functional class I or II, 30% were in NYHA functional class III or IV (Table 1).

Seven themes emerged from the phenomenological analysis of the interviews and field notes: 1) important life changes; 2) social isolation caused by the illness; 3) anger and resignation associated with the disease; 4) relief from spirituality; 5) will to live; 6) uncertainty about the future; and 7) the inescapability of death.

Important life changes

This theme was in all descriptions. All participants reported that HF caused important changes in their lives. These changes were related to employment, their social role within the family, lifestyles (e.g. decreasing physical functioning, diet changes) and sexual life. For example, a 68-year-old male patient in NYHA class II reported ‘I had to stop my job and I feel this has impacted negatively on me and my family life because I feel useless and now we have to live with only one salary.’ Another patient reported ‘Before HF I was dynamic, I used to run, to cook, but all of a sudden I had to stop.’ A 71-year-old woman in NYHA class III said: ‘I can’t do things like to clean. My husband, for example, helps me to clean the floor and I can only dust. I don’t try to do the most strenuous and heavy activities’.

The decrease of physical performance created frustration in our participants and a sense of dependence on family members. For example, a 65-year-old man reported ‘Before HF, I used to help my wife with housework, I bred animals on my farm, I felt as an “iron man”, but now I can’t do anything. When I go to the ambulatory [HF clinic] I have to stop 10 times before I get in. It is really a bad situation. If you have not experienced it, you can’t believe it. Now they [family members] have to help me; they have to cook for me.'
When I go to the toilet they have to help me, even to pull up my pants because I don’t have the strength.’ Several participants related life changes to changes in their diet and habits. Another patient reported ‘My personal life style has changed. I have to be careful about what to eat. I take medicines and I must be careful not to eat a lot of salt. I cannot drink a glass of wine anymore and every morning I have to weigh myself.’ Participants also reported changes related to their sexual life because of fatigue. A 56-year-old man in NYHA class II reported: ‘My sexual life has finished. The ABC [basic] of life has finished. I can’t have moments of deep intimacy with my wife anymore’.

Social isolation caused by the illness

Although all participants were living with their family members, the theme of social isolation emerged. Social isolation caused by HF symptoms (e.g. breathlessness) was related to relationships and leisure activities outside the family. A 62-year-old woman in NYHA class II reported ‘I have friends but I can’t go on holiday with them anymore. They recently went on holiday for 8–10 days and invited me, but I couldn’t go because I feel tired and walking is more and more difficult for me.’ Another 72-year-old woman reported ‘I never leave home because when I come back I have stairs to climb and I can’t cope with them anymore’. One man noted ‘My friends do not call me and I feel so isolated from the world because I stay home and I cannot move and talk to anyone.’ A 66-year-old man reported ‘If I make some little effort I feel breathlessness and I have to rest at home’.

Some participants felt so isolated that they preferred to stay in the hospital. For example, a 77-year-old male in NYHA class III reported ‘I was sad when I had to leave the hospital because in the hospital there were many people; I had another person [patient] in my room and so I wasn’t alone. Instead at home I feel alone.’

Anger and resignation associated with the disease

Many participants talked about anger and resignation. Most often, participants experienced anger soon after their diagnosis, while resignation was felt after an individual inner process related to the acceptance of their chronic clinical condition. A 55-year-old man in NYHA class II told us: ‘It was a hell at the beginning; I got angry. Now I feel resigned.’ Another man of the same age and NYHA class reported ‘You have to put your soul to rest! If you get angry or if you cry, it’s the same. Your blood pressure goes up. Instead, I have to be calm. Life is this: if you blame or cry all day you don’t gain anything.’ A 72-year-old female in NYHA class III talked about the process of resignation: ‘Before the illness I used to do everything, but at the end I accepted the illness and I accepted that other people have to help me.’ A 68-year old woman in NYHA class III noted: ‘I cannot do anything to change this situation. You must resign and you must move on. You need a lot of patience.’

Will to live

While some participants reported resignation and discouragement due to their illness, others had the will to react to this new situation in order to get at least a bit of physical autonomy to satisfy their own personal interests or because they were motivated by affection and family bonds. Family was a source of the will to live and to go on; family was very stimulating and motivating. A 66-year-old man in NYHA class III said: ‘Now I got this thing [HF] that threw me down, but I’m reacting well; I want to live!’ A 71-year-old man in NYHA class II reported: ‘I have only one nephew and he gives me the desire to live day by day.’ A woman in NYHA class III reported: ‘I found the will to live thanks to my sons and my husband. They are the central point of my life.’ A 57-year-old man who loved
hunting said: ‘If God helps me, I want to pay the hunting fee and I want to come back for hunting and fishing.’ Another female participant said: ‘I have to do a lot of things because I have a family, a daughter and a nephew, so I have to go on for them. Now I’m living the illness with patience and with the will to go on, and to go on with courage and strength.’

Relief provided by spirituality

For many patients, believing in God created an important sense of relief and peace because they felt that someone was caring for them. Patients experienced that getting close to God helped them to accept their illness and to gain more inner strength. For example, an 83-year-old woman in NYHA class III reported ‘The relief that I feel every day comes from there [she pointed the sky].’ Another woman in NYHA class II reported: ‘I don’t refuse the illness but I accept it thanks to my faith. I accept the will of God. I feel that faith gives me life. Faith gives me strength. God, do what you want, I am in your hands.’ A 70-year-old man said: ‘Faith in God gives me the strength to accept this situation and move forward.’ A 78-year-old man said: ‘God is a relief for me and praying to God helps me so much. He gives me strength and will.’

Uncertainty about the future

The effects of the disease affected patients’ perspectives because they saw that their expectations were deeply changed by their new psychophysical status. Some participants thought about nothing but their illness. One participant said ‘Who knows how many days I have to live?’ and ‘You live with this big question mark.’ Another patient stated ‘I know what happened yesterday or today but I don’t know what could happen tomorrow. I try to live my life without thinking about my future, but sometimes there grows up inside of me a deep sense of uncertainty.’

Inescapability of death

Some participants, mainly those in NYHA classes III and IV, were aware of the precariousness of their situation because their conditions could suddenly worsen. Consequently, they realized that death was inevitable and that they had no weapons to defend themselves from death. A sense of the inescapability of death was in their descriptions. For example, a 78-year-old man in NYHA class III reported ‘You have to put the soul to rest because you don’t know when death arrives, if today or tomorrow. I know that I will never get healed.’ An 82-year-old man in NYHA class IV said: ‘I think it’s time. If the vein bursts, we bid farewell to all. I can’t say “no”, “I don’t want”. When the moment arrives, there is nothing to say, unfortunately.’

Discussion

The purpose of this study was to gain a deeper understanding of HF patients’ lived experience. Our findings show that HF patients had complex experiences related to the disease and the living context. Our participants experienced changes in their life, social isolation due to the illness, a sense of anger and resignation associated with the disease and a deep uncertainty about the future. In addition, our participants experienced a will to live thanks to family affection and bonds and relief from spirituality. These findings are important because a deep understanding of HF patient experiences was limited in the literature, and understanding patients’ experiences allows their needs to be better met (16). In fact, prior research studied the lived experiences of HF patients but was limited by considering specific experiences, by studying specific HF patient populations or by methodological weaknesses, such as a lack of trustworthiness and data saturation. All these limitations have been addressed in our study.
All our participants experienced important life changes, and other investigators have also reported this theme (11, 12). Changes in our participants were related to employment, their social role within the family, lifestyle, sexual life and decreased physical performance. The impact of HF on social roles and lifestyle were also described by Thornhill et al. (12), who reported that the diagnosis of HF caused changes in patients and that these changes in turn influenced patients’ lifestyles, social lives, jobs and family relationships. However, our participants reported that life changes were also associated with physical limitations, a change in diet and sexual life. Participants experienced frustration due to physical limitations and diet changes and a sense of dependency on family members. In the literature, only Rhodes and Bowles (11) described changes related to physical and social limitations that were caused in their participants by shortness of breath and a perceived loss of control. Several quantitative studies (Hoekstra et al. 2012a, Hoekstra et al. 2012b, Hoekstra et al. 2012c) have addressed the issue of sexuality in HF patients, but no previous qualitative studies have reported sexual issues in the experiences of patients with HF or have linked this issue to life changes. Quantitative studies have found that sexuality in patients with HF was affected by physical symptoms of HF and was a concern mainly in younger male patients with a history of cardiac ischemic illness (17-21).

Social isolation was another theme in our analysis. Social isolation was due to HF symptoms (such as fatigue and breathlessness) that limited relationships and leisure activities outside the family context. Social isolation has been described in other quantitative studies (22, 23), but only one qualitative study described social isolation in HF patients (24). In this study, social isolation was compounded by many factors, such as self-imagine, drug treatment, mobility, confidence and psychological distress. In contrast to what has been reported by Leeming et al. (24) in the UK, Italians with HF felt socially isolated more because of ‘physical’ than ‘psychological’ problems.

Anger and resignation were other themes in our analysis. In general, our participants described anger at the beginning of their experiences and resignation later in the course of their illness. In fact, our participants related anger to their loss of autonomy and physical limitations and related resignation to their acceptance of the illness. In the literature, anger and resignation are reported as two contrasting feelings, but both feelings are experienced during the trajectory of HF (11, 14). Interestingly, Thornhill et al. (12) reported that resignation was related to the acceptance of the diagnosis, while in our study anger was related to the acceptance of diagnosis. These differences might be due to different cultural orientations. In another study (25) conducted among Italians with breast cancer, the diagnosis was associated with anger. Perhaps it is typical of the Italian population that a diagnosis generates anger. This might be related to the fact that patients with HF and those with breast cancer experience their illness as a process of taking on a new identity, a new ‘self’ that generates anger.

Not all participants experienced resignation in regard to HF; some experienced a will to live. They related their will to live to family support because they consider family as a central point of care that stimulates them to live. Previous studies have reported similar findings. For example, Stamp et al. (26) reported that HF patients receiving family support performed better self-care and were more motivated ‘to live’ despite their HF. Saudin et al. (8) reported that HF patients who received family support were more stimulated to better manage their illness and ‘move on’ with their lives.

Another interesting theme reported in our analysis was ‘relief provided by spirituality’. Only one other study in the literature reports
It was reported that believing in ‘someone’ or ‘something’ creates a sense of peace in patients with HF, which helps them to feel stronger in terms of managing their HF and to improve their QOL (24). As described by Naghi et al. (27), spirituality has a beneficial effect on multiple measures, including global QOL, depression and medical compliance in the treatment of patients with HF (28).

Uncertainty about the future was the sixth theme of our analysis. Our participants experienced uncertainty related to not knowing how the illness would develop and to the profound change in their life expectancies. Uncertainty was also related to the new psychophysiological status determined by HF. In contrast to Nordgren et al. (7), uncertainty in our participants was not related to practicalities, such as the management of HF and side effects of medications.

The inescapability of the death was our last theme, and, to our knowledge, no previous studies have mentioned this. Ekman et al. (13) reported something similar that they called ‘feeling despite illness’, meaning that patients felt free despite the illness and had a sense of transcendence or because they felt ready for death. Our patients felt the inescapability of death in particular when the clinical conditions of HF suddenly worsened. In these cases, our participants realized that death was inevitable for them. This physiological condition was experienced more often by patients with advanced NYHA classes III and IV and by patients who found it difficult to discuss end-of-life issues with health providers or informal caregivers.

Limitations

Our study has several limitations. First, as with all qualitative studies, our findings cannot be generalized to the general HF population. However, our study has provided a comprehensive overview that might allow a deeper understanding of the experiences of people with HF. Second, all interviews were conducted only in one Italian region (Tuscany), and some cultural differences exist between the various Italian regions. Tuscany has a good regional health care system, and this might have influenced the experiences of our participants. Third, our participants were not homogeneous in terms of their clinical conditions, such as NYHA classes, but all classes were represented in our sample. However, this is also a strength of our study, because it allows a comprehensive description of what it is like to live with HF of whatever stage.

Conclusion

The findings of this study provide an overview of the lived experiences of patients with HF, give new insights and reinforce the findings of previous research (7, 12, 14). Thoroughly understanding the lived experiences of patients with HF could play an important role in designing nursing care. The meaning that patients attribute to their lived experience helps to create their needs, which are important to direct care (16). Our findings indicate that family and religious beliefs were an important source of support for our patients because they helped them to better manage their fears and to cope with their future. Our findings also suggest that life changes have an impact on patients’ social and family lives as well as their sexual lives, which alters intimate relationships between patients and their partners. Healthcare professionals could help patients to manage this issue by providing support and education. The current literature shows that sexuality is an important topic for nursing practice. For example, Hoekstra et al. (18) examined the current practice of HF nurses discussing sexual health and found that most nurses do not assess sexual health in HF patients or feel responsible for it.

The inescapability of the death was not previously mentioned in the HF literature.
Mortality rates in HF patients are comparable to mortality rates in cancer patients (29). The majority of HF patients do not know that cancer does not necessarily have a worse prognosis than HF, and HF patients are less informed about life expectancy. Life expectancy in HF patients is also reduced by comorbid conditions (30). Our findings could alert nurses to the need to give more support and more palliative care to patients with HF, especially during the last stages of the disease. The role of palliative care in dealing people with HF is still unclear in the literature. Because HF is a dynamic syndrome characterized by phases of symptom exacerbation and relief, it is very difficult for health professionals to predict the exact time to start palliative care services (31). In this regard, the World Health Organization has recommended starting palliative care at the time of diagnosis (32). Recent studies conducted in Europe (UK, Ireland and Germany), the USA and Canada have shown that patients with HF and their caregivers need palliative care (32-34). However, palliative care service is not considered in Italy as a support healthcare resource for patients with HF. Consequently, Italian patients and their caregivers might lack this important support during the last stages of the illness.

Acknowledgments
The Centre of Excellence for Nursing Scholarship Rome (Italy) funded this study

Ethical considerations
The Institutional Review Board of the hospital where participants were enrolled approved this study before data collection began.

Riassunto
Il vissuto esperienziale di pazienti con scompenso cardiaco: uno studio fenomenologico

Premessa. In letteratura, diversi studi qualitativi sono stati condotti su pazienti affetti da scompenso cardiaco (SC), ma la maggior parte di essi non ha definito una rigorosa e metodologica descrizione di com’è vivere con lo SC. Pertanto, l’obiettivo di questo studio è stato quello di descrivere l’esperienza vissuta di pazienti con scompenso cardiaco (SC).

Disegno dello studio. Ermeteneutico fenomenologico.


Risultati. I pazienti erano per lo più di sesso maschile (67%), con un’età media di 71 (SD 9,15) e un intervallo di età di 48-86 anni. Sette temi sono emersi dall’analisi fenomenologica: 1) Importanti cambiamenti di vita; 2) Isolamento sociale causato dalla malattia; 3) Rabbia e rassegnazione associata con la malattia; 4) Sollievo dalla spiritualità; 5) Voglia di vivere; 6) L’incertezza sul futuro e 7) L’ineluttabilità della malattia e della morte.

Conclusioni. Il significato che i pazienti attribuiscono al loro vissuto esperienziale aiuta a capire in profondità le loro esigenze di cura. Il supporto familiare e le credenze religiose sono percepite dai pazienti con SC come una fonte importante che li aiuta a gestire meglio le loro paure e affrontare l’incertezza del futuro. I risultati di questo studio forniscono ai professionisti sanitari che operano sui pazienti una descrizione completa di com’è vivere con lo SC e una profonda visione del fenomeno al fine di poter soddisfare al meglio le molteplici esigenze dei pazienti in modo più efficace pianificando interventi sanitari mirati.

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