

Exploring the triggers of psychological distress among Jordanian patients with heart failure: a phenomenological study

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Abstract

Purpose – This study aims to gain a deeper understanding of triggers of psychological distress among Jordanian patients with heart failure (HF).

Design/methodology/approach – A phenomenological study was adopted. In-depth, semi-structured, audio-taped interviews were conducted for 25 patients with HF. The analysis was done using interpretative phenomenological analysis.

Findings – The main theme of the findings can be expressed as “faced with stressors that are unable to cope with”, which encompasses circumstances and contexts associated with the psychological distress they faced. The following four sub-themes emerged from the data: being endorsed in significant life changes, feeling guilty about being a burden, financial burden aggravating stress and feeling overwhelmed by the fear of death.

Originality/value – The findings revealed that psychological distress is affected directly by many triggers. The findings indicate the need for informing health-care providers to support these patients and address the challenges and develop clinical guidelines to assess psychological distress among these patients.

Keywords Psychological distress, Heart failure, Triggers, Phenomenology, Jordan

Paper type Research paper

(Information about the authors can be found at the end of this article.)

Introduction

Globally, heart failure (HF) is considered as a major clinical and public health problem as an emerging epidemic (Roger, 2021). As noted through the reviewed literature, the prevalence rate of HF reached approximately 64 million people worldwide (Savarese *et al.*, 2022). Furthermore, in the USA, the prevalence of HF is approximately 6.9 million in 2020 and it is predicted that by 2030, the prevalence rate of HF will increase to nearly 8.5 million people (Urbich *et al.*, 2020). In developing countries, the number of HF patients is rising. For instance, in Saudi Arabia, Egypt and the United Arab Emirates, there are an estimated 320,933; 931,135 and 93,865 cases, respectively (Reyes *et al.*, 2016; AlHabeeb *et al.*, 2018). In Jordan, a developing Arabic country with an estimated population of 10.6 million, the prevalence of HF is around 100,000; the estimated incidence is approximately 8,251 annually [Jordanian Ministry of Health (JMH), 2017]. Psychological distress including depression and anxiety are common among patients with HF and associated with adverse outcomes such as reduced adherence to treatment, poor function, increased hospitalizations and elevated mortality (Celano *et al.*, 2018). Rates of anxiety and depression among patients suffering from HF is four to five times more than that in the general population (Isaksen *et al.*, 2016; Uchmanowicz and Gobbens, 2015). As noted from

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the reviewed literature, at the global level, the prevalence rate of depression and anxiety among patients suffering from HF ranged between 9% to 96.1% and 11% to 70%, respectively (AbuRuz, 2018; Aggelopoulou *et al.*, 2017; Isaksen *et al.*, 2016; Shen *et al.*, 2011; Uchmanowicz and Gobbens, 2015).

Despite the advancement in the medical care of patients with HF in Jordan, the prevalence rates of psychological distress including depression and anxiety among patients with HF reached 65% and 62%, respectively (AbuRuz, 2018). Therefore, psychological distress including depression and anxiety among HF patients is considered an alarming phenomenon in Jordan. The predominantly Western context of most existing studies means that many of their findings might or might not apply to the Jordanian context; therefore, this study addresses an important research gap by exploring in-depth psychological distress among patients with HF in Jordan. After an extensive search, no qualitative studies were found on psychological distress among patients with HF in Jordan. Therefore, in this study, we aimed to explore the experiences of patients with HF in Jordan regarding the triggers of psychological distress.

Method

Design

An interpretive phenomenological design guided by the philosophical tenets of Heidegger (Creswell, 2014) was used to examine the experiences of patients suffering from psychological distress related to HF. Through interpretive phenomenology, the researcher focus on identifying the essences as they emerged from the participant interviews, and the researcher gain an enhanced understanding and meaning of a phenomenon when contextualizing it in his own life experiences (Smith *et al.*, 2009; Smith, 1996).

Sample and setting

The population targeted for this study was all adult Jordanian patients with HF. Inclusion criteria were 18 years and older, a primary diagnosis of HF verified by medical signs and symptoms, X-ray studies of HF, agree to participate and out-patient at the clinic. In this study, data saturation was achieved when no new relevant information started to emerge.

Semi-structured interviews were held in three hospitals in Jordan. A purposive sample with a total of 25 patients with HF was recruited from the cardiac outpatient clinics.

Data collection tool

The data collection tool used for this study was in-depth interviews because it is consistent with the hermeneutic phenomenological approach. The principal investigator (PI) conducted the face-to-face interview. This format allowed participants to express their personal experiences deeply and honestly in a comfortable atmosphere (DiCicco-Bloom and Crabtree, 2006). Interviews ranged from 55 to 80 min and included only the interviewer. Each interview started with general questions about the patient's background. Then, each interview began with the broad research question – "Tell me about what circumstances contributed to the psychological distress you faced?" The probes were "Can you explain to me more about...?" and "What do you mean by?" These questions aimed to encourage the participants to talk openly about their experience of triggers of psychological distress. Supplementary questions were asked to explore all the relevant issues omitted by the participants. The interview questions covered their experiences and concerns during their psychological distress, in the light of Arab cultural beliefs and practices.

Transcription and data analysis

The data were analyzed by the PI by interpretative phenomenological analysis (Smith and Shinebourne, 2012). The analysis started when the PI listened many times to an

audio-taped interview, and then transcription for the audiotapes was started by her within three days. All interviews were transcribed into Arabic and then translated into English using a word processing package. Each transcript was then transferred to the NVivo 2 program.

Ethical issues

The study was approved by the IRB committee at the University of Jordan and all hospitals where data collection was performed. After a thorough explanation of the aims and the procedure of the study and before the interviews, participants signed a consent form. All participants were free to participate and they can withdraw from the study at any time. The participants were informed that they were given a pseudonym and an ID number from the point of data collection. The audio recordings were kept in password-protected computers accessible only to the PI.

Credibility and trustworthiness

To ensure the credibility of the study results, the transcripts of all interviews were given to other researchers for looking for other possible meanings in the data. The PI discussed the emerging themes and interpretations with other researchers and considered their suggestions throughout the writing process. To enhance trustworthiness, a final list of themes was returned to some participants who had shown interest in reviewing them, and they confirmed that the analysis truly reflected the real meaning of their experiences. Moreover, every theme in the findings was also supported by quotes from the participant's interviews.

Findings

Our sample ultimately comprised eight participants with HF from north, middle and south of Jordan. The age of the participants ranged from 52 to 75 years. The educational level ranged from those who had elementary school level to baccalaureate level. Analysis revealed the main theme from the interviews to be "Faced with stressors that are unable to cope with."

This theme refers to circumstances and contexts that predisposed patients with HF to psychological distress. Further analysis led us to conclude that the main theme consists of four sub-themes: "Being endorsed in significant life changes", "Feeling guilty of being a burden", "Financial burden aggravates stress feeling" and "Overwhelmed by the fear of death".

Being endorsed in significant life changes

One issue discussed during the interviews was the influence of life changes including work, social role within the family and lifestyles on the psychological status of the participants.

All of the participants expressed negative feelings such as sadness, anxiety, anger, stress and frustration related to their physical limitations, as one patient affirmed:

I'm sad, I'm used to running, playing football, and having fun, but now I don't have the power to do any of that which makes me frustrated. (Ali)

Another participant added: I feel anxious and sad because I feel tired when I'm climbing stairs in my home, that every child is supposed to do it normally [...] also it takes me about 20 minutes because I have to keep sitting down and trying to catch my breath, so I need aid to climb it and this makes me angry when I remember my self before this disease. (Fatima)

Most of the participants stated that the influence of role loss on their psychological status was because they often found themselves unable to work and contribute to the family as they had before dealing with HF:

Sometimes I become sad because I want to do more for my family to secure their future, solve their problems, and see my grandchildren around me but now due to HF I think that I can't do anything, almost nothing and this makes me anxious. (Ahmad)

Many participants spoke with frustration about the loss of their ability to participate in usual social roles and its negative influence on their psychological status:

Before the disease, I visit my friends and relatives [. . .]. Attend weddings, I was happy [. . .] and now I can't, just stay at home and this leads me to feel anxious, sad [. . .]. now I feel I became new another person. (Ateya)

There is psychological distress among most women participants related to their limitations in carrying out housework, their responsibilities at home and their husbands:

I feel sad and annoyed because there are a lot of things that I would like to do but I can't, for example cleaning the kitchen, and mirrors and cooking my favorite food such as *Dawalee* [. . .] *also caring for my family*. (Ahlam)

Some participants stated there is medical advice from their doctors such as lower salt intake, eating a healthy diet, quitting smoking, resting at home and daily medication intake.

This medical advice is considered lifestyle changes that make negative feelings for some participants:

I'm smoking for 20 years [. . .]. and after my disease(HF), my doctor tells me I must stop smoking but I can't because when I leave it I feel pressure on my chest and I become anxious [. . .] [. . .]. I like a lot of salt with food but now my wife put a little salt in food so I hate the taste of food and this makes me sad and angry. (Mufleh)

Feeling guilty about being a burden

Another challenge the participants noted during their interviews was that they perceived themselves as a burden to others as they required help from their family members with daily activities and this contributes to psychological distress among them:

Very early in the morning, my wife comes to clean me up and give me medication, I feel frustrated because I became weak and I felt guilty since I must care for her [. . .]. my wife is sad to see me like this [. . .]. it's a pity for her. (Zayd)

I used to do house chores, but now my daughters do most of the work [. . .]. I can't sit in the toilet without the help of others this makes me anxious and frustrated. (Nora)

Many participants suffer from common symptoms related to HF that include breathlessness, peripheral edema and fatigue, all of which interfere with daily life that lead to psychological distress. Participants expressed a sense of helplessness that was based on debilitating anxiety that prevented them from interacting with other people, ultimately leaving them reliant on their family for daily activities and financial support:

I feel anxious and sad [. . .]. I couldn't meet people. I couldn't even look after myself. I'm tired and I depended on my son and my wife for many things [. . .]. I feel helpless. (Abd alazeez)

Feeling overwhelmed by the fear of death

The participants expressed fear of the unknown in the future because of the unpredictable nature of the illness, and there was uncertainty that originated from the deterioration of their

physical abilities and the occurrence of symptoms including breathlessness, peripheral edema and fatigue. They felt they were closer to death than ever before and they think about death more than before their HF:

There are several aspects of my life that I'm afraid of [...] as this disease can lead to so many complications, now I tired due to shortness of breath, particularly during the night, my ankle sometimes swollen and hurt me [...] [...]. My health is deteriorating now [...] I have a lot of thoughts about everything I feel and at night, all these fears that I feel come make me stressed and fear. (Mahmoad)

Other participants reported that they have fear of hospitalization, pain and suffering because of their deterioration of health. Accordingly, when the disease progressed, they became more stressed and irritable, particularly during episodes of shortness of breath. One of the participants claimed that he worried and was fearful about the future of his daughters after his death, which kept him sometimes awake at night with bad psychological status:

I love and care for my family and I fear leaving it, especially my daughters and this makes me sad and depressed. Sometimes I do have sleepless nights because sometimes I think about my condition, if will I get a heart attack that I am scared of, and if I die, who would look after my family? (Nora)

Some participants expressed fear of hospitalization and worsening symptoms because of deterioration of their health, and they stated feelings of uncertainty because of insufficient information provided to them about their condition and future treatment plans. Accordingly, the participants expressed uncertainty and unknown fear toward the future:

I feel frustrated and fear because I don't know a lot about my disease and If I will cure"; "I fear from admitted to the hospital because I fear the needle puncture, it is painful and I'm thinking a lot of bad things at hospital and this makes me in a bad mood and anxiety. (Muntaha)

Financial burden aggravates stress

Finance is considered a significant challenge for participants and they had a great concern about economic status because of losing jobs and health-care expenses, especially with recurrent admissions that cause psychological distress for them. Accordingly, the participants reported negative feelings because of bad financial situations as they were the primary economic supporter of their families. Some participants were not covered by insurance and this was a crucial challenge that causes stress for them. They pay the treatment expenses with their own money. The absence of health insurance prevents them from doing the required investigations and sometimes discontinuing some of their treatment leading to bad psychological status for them:

I do not have health insurance [...] I take Plavix (anticoagulant). I'm anxious because my financial status doesn't allow me so I do not always have the price of medications so I feel suffocated. (Raya)

Other participants claimed that the costs of transportation and the need to assume the costs of treatment led them to feel stressed and anxious and assumed this was a difficult situation to overcome:

When I was feeling severe shortness of breath and felt suffocated and my ankle was full of fluid, I went to the hospital, and then the doctor ordered admitted me to the medical ward, which increased my expenses including transportation, my food, my medications every time I entered as this considered like a pressure makes me depressed. (Jaber)

Some participants' statements allowed for an understanding of the economic impact of the disease, such as having to leave work or being retired because of their physical limitations resulting in decreased income and psychological distress for them:

I am retired, on a fixed income of 250Jordanian Dinar (JD), I have 4 daughters at home, 2 of them still study at universities and others haven't finished school yet. I don't know who will fund them!!! and the gas bill and light bill are consuming me. I was really upset last week, and my brother helped me a little bit to buy my medication [. . .]. I know my bills are part of my stress. (Hassan)

Discussion

Being endorsed in significant life changes was an important stressor that was mentioned by participants which might cause psychological distress for them. The change from being a healthy person to being an ill person was emotionally challenging. This is in line with the results of many previous studies (Leeming *et al.*, 2014; Seah *et al.*, 2016; Shamali *et al.*, 2020; Walsh *et al.*, 2018; Yu *et al.*, 2008). Most women participants had difficulty performing household activities and this was the strongest trigger of psychological distress for them. This might be attributed that women need to fulfill their role in caring for the family to feel satisfied and secure, cooking, cleaning the home and attending social events, and this role might not be fulfilled because of HF symptoms and physical limitations; therefore, they feel as helpless that caused negative feelings (Al-Zaru *et al.*, 2020; Checa *et al.*, 2020; Strachan *et al.*, 2014). Many participants stated that they feel anxious, stressed and frustrated about the loss of their role to participate in usual work or social roles and its negative influence on their psychological status. Consistent with the findings of this study, Sedlar *et al.* (2020) indicated that negative emotional response was associated with physical limitations of HF, particularly inability to work, change their family role and social isolation.

Furthermore, participants reported the complexity of treatment and adhered to a healthy lifestyle such as adhering to a low-sodium diet and quitting smoking, and these were associated with psychological distress. This is consistent with the results of many previous studies (Al-Matubsi *et al.*, 2011; Harkness *et al.*, 2015; Jaarsma *et al.*, 2017; Kessing *et al.*, 2016; Nordfonn *et al.*, 2021; Riegel *et al.*, 2019). The findings in the current study illustrate the effect that HF has on patients' social roles and relationships resulting in patients' feelings of sadness, frustration uncertainty and increased depressive symptoms (Choi, 2020; Olano-Lizarraga *et al.*, 2021). The participants expressed grief and feelings related to decreased physical capability which requires reliance on family or friends. This was congruent with previous studies (Andersson *et al.*, 2012; Gowani *et al.*, 2017; Hopp *et al.*, 2012; Heo *et al.*, 2019; Holden *et al.*, 2015; Kimani *et al.*, 2018; Nordfonn *et al.*, 2019; Walthall *et al.*, 2019). These negative feelings among most participants because of the Jordanian culture, in which the parents' responsibilities include ensuring that their children receive an education, facilitating long-term work and participating in marriage preparations. Thus HF threatened their participation in collective family life, and thinking about these responsibilities might cause negative feelings. Results from the current qualitative study indicated that most of the study participants reported financial burden aggravates stress and they claimed that they discontinued some of their medications because they are very expensive or not available at the hospital. Consistent with the current study findings, many studies documented the higher health-care expenditures for treating patients suffering from HF, and these studies also highlight the claim that HF disease was associated with a significant financial health-care burden on the families (Alghamdi *et al.*, 2021; Escobar *et al.*, 2020; Cook *et al.*, 2014; Delgado *et al.*, 2014; Kwok *et al.*, 2021; Lesyuk *et al.*, 2018). The findings are also consistent with several studies that indicated that low economic status was associated with psychological distress among patients suffering from HF (Aggelopoulou *et al.*, 2017; AbuRuz, 2018; Chu *et al.*, 2014; Dastgeer and Saleem, 2021; Husain *et al.*, 2019; Lefteriotis, 2013; Nordfonn *et al.*, 2021; Nordfonn *et al.*, 2019). In the current study, participants experienced feeling overwhelmed by the fear of death because their health condition is exposed to sudden changes. These feelings are also reported in other studies (Horne and Payne, 2004; Reeman and Noble, 2011). This might be attributed by many fears originating from the deterioration of their physical abilities, the worsening of

their cardiac symptoms and the fear of a prolonged and painful death. The findings are also congruent with the findings of several studies that indicated that the uncertainty was associated with a higher level of psychological distress among patients suffering from HF (An *et al.*, 2021; Bosworth *et al.*, 2004; Burström *et al.*, 2012; Chen *et al.*, 2018; Hopp *et al.*, 2012; Jiang and He, 2012; Olano-Lizarraga *et al.*, 2022; McHorney *et al.*, 2021; Seah *et al.*, 2016).

Conclusion

It is hoped that the findings of this study will help in raising the awareness of society, people and health-care providers about the triggers of psychological distress of patients with HF. Furthermore, it improves the understanding of nurses on how patients with HF perceive their psychological distress and how the psychological distress affects their lives to provide care and support to alleviate this psychological distress.

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