Original Article

Burden Of Treatment And Psychological Distress In Heart Failure In Jordan From Patients' Perspectives

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Abstract

Background: Psychological distress has become an alarming phenomenon in patients with heart failure worldwide. The burden of treatment is associated with psychological distress in patients with heart failure. There is a crucial need for conducting qualitative research addressing the unique contextual factors associated with the burden of treatment and psychological distress in patients with heart failure in Jordan.
Objective: This study aims to gain a deeper understanding of patients' burden of treatment and psychological distress among Jordanian patients with heart failure.
Design and method: A qualitative descriptive design was used. Data were collected through in-depth, semi-structured interviews with 28 patients with heart failure.
Findings: The main theme of our findings can be expressed as "Facing Healthcare Challenges" which includes five subthemes from analyses of interviews: Looking for the humanistic touch, long waiting time, insufficient health care resources, insufficient health information, and a call for specialist psychological health support to understand their suffering.
Conclusion: This study highlighted that healthcare challenges as a burden of treatment might trigger psychological distress in patients with heart failure. This study has provided insight into the need for interventions to improve the structural organization of hospitals and healthcare system provision to mitigate psychological distress in these patients.

Keywords: psychological distress, Heart failure, Burden of treatment, health care challenges, Jordan.

Introduction

Globally, heart failure (HF) has been considered an epidemic, clinical, and public health problem, associated with crucial mortality, morbidity, and healthcare expenditures, particularly among those aged above 65 years (Roger, 2021; Tsao et al., 2022). There are about 64 million persons worldwide who have HF (Savarese et al., 2022). The burden of treatment is the term that refers to the "workload" assigned to long-term ill patients by the healthcare system and healthcare professionals and its effect on the patient's well-being and functioning. Patients with HF are highly susceptible to experiencing the burden of treatment and these burdens remain indistinct to healthcare providers (Abu Sumaqa et al., 2022; Hassen et al., 2022; Eton et al., 2015). The Burden of treatment for heart failure seems to decrease patients' capacity to adhere to their treatment plans and causes poor adherence (Gallacher et al., 2013; Nordfonn et al., 2019; Mair et al., 2011). Additionally, Burden of treatment might lead to the worsening of the disease and more recurrent episodes of decompensation (May et al., 2016). Psychological distress such as anxiety and depression were higher among patients with HF than among healthy older individuals and

other cardiovascular conditions (Celano et al., 2018; Easton et al., 2016; Heidenreich et al., 2022). Additionally, psychological distress is associated with negative outcomes such as decreased adherence to treatment, poor quality of life, increased hospitalization, and mortality (Celano et al., 2018). In Jordan, the prevalence rates of psychological distress including depression and anxiety among patients with HF reached 47.3% and 56.7%%, respectively (Alemoush et al., 2021). Therefore, in Jordan, psychological distress among patients with HF is considered a health problem and an alarming phenomenon. The link between Burden of treatment and psychological distress is less examined. Some studies showed an association between greater burden of treatment and psychological distress (Eton et al., 2017, Nordfonn et al., 2021; Cardona et al., 2023). Yet, few studies have addressed the association of Burden of treatment, with psychological distress in patients with HF. The burden of treatment has many generic features, on the other hand, it is also highly likely to differ between countries and specific diseases (Dobler et al., 2021; Tran et al., 2017). This is mainly because it is a contextual construct that depends on variable factors (Tran et al., 2017). Many of the findings from previous studies may or may not apply to the Jordanian healthcare context because the majority of them have been conducted in different developed countries. Therefore, in this study, we aimed to explore Burden of treatment and psychological distress from Jordanian HF patients' perspectives.

Method

A phenomenological design was used to explore the experiences of patients with HF related to the burden of treatment and psychological distress. The study was conducted in the cardiac outpatient clinics at three public hospitals in Jordan. Ethical approval was gained from the Research Ethics Committee at the nursing faculty at the University of Jordan and all hospitals where data collection was performed. Purposive sampling of twenty-eight patients with HF was used. The sample included all adult Jordanian patients diagnosed with HF. Before the interviews, participants signed a consent form after an explanation of the purposes and the procedure of the study. Semi-structured interviews were held in the cardiac outpatient clinics. During the interviews, we used interview guides that were developed by the researchers and began with the broad research question – "Can you tell me about healthcare challenges and psychological distress?", and participants were asked permission to tape record the interviews. Interviews with patients lasted between 60 and 80 minutes, during the period from August 2022 to November 2022. In this study, data collection continued until data saturation was achieved. Interviews were recorded and transcribed. Data analysis was done using the field notes that were obtained during the discussion. Interviews were transcribed, translated into English, and analyzed by using the NVivo 7 program. After transcription of all interviews, the first author carried out a qualitative data analysis by data coding, defining categories, clustering, and extracting the themes, which was then reviewed for validity by an independent rater.

Findings

Our sample ultimately comprised 28 participants with HF from the north, middle, and south of Jordan. The age of the participants ranged from 58 to 80 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" Facing Healthcare system Challenges".

Looking for the humanistic touch

One issue discussed during the interviews was the need for humanistic and supportive communication with healthcare providers. The participants in the study highlighted that the communication provided by healthcare providers must show dignity, respect, and responsiveness. Many participants described that listening, caring, and empathetic communication was important for patients suffering from psychological distress to receive suitable care:

"The smile and use of calm communication, comforting words is the most significant thing which the nurse and doctors provide to alleviate our stress". (Ali)

Other participants said that healthcare providers should pay more emphasis on the psychological status of the patient because it considers half of the treatment.

Some participants stated that they receive disrespectful words from some nurses:

"The nurse said in a high voice ……you are the only patient in the hospital! what do you want this makes me frustrated and sad. (Ahlam)"

Some participants stated that their psychological status is considered a crucial thing in their treatment and recovery and the health care provider particularly the nurse should give hope to the patients and their families to alleviate the pressure of health-related psychological distress:

"I have a bad mood and tired psychological status when I decide to go to the hospital so I need supportive and humanistic communication, not nervousness to decrease my stress".

(Thuraya)

Furthermore, other participants stated that they need to be heard because they know their health conditions, and they wish if they be involved more in the decision-making about health care and treatment options all the possible information are explained such as signs of deterioration and when to seek health care and this makes them feel secure and calm:

"When I visit the cardiac clinic, the doctor and nurse don't give me enough time to discuss our needs and we hope to give us the care that is compatible with our health condition and this makes us more comfortable and secure". (Mohammad)

Additionally, they mentioned their right to have enough time in the cardiac clinic to get answers to their questions clearly and justifiably without interruptions as well as there still needs to be more effective communication to alleviate their psychological distress:

"When I go to the clinic, there are many patients and crowdedness. the doctor and the nurse when we enter the clinic, want us to go out quickly and we are not allowed to ask, just the doctor writes the medications quickly then the nurse shouts to see another patient and this makes me nervous and frustrated". (Ibteha)

Long waiting time

Participants emphasized the challenge of long waiting times throughout their healthcare experiences. Many participants stated the long waiting time they spent for healthcare services in clinics and hospitals; sometimes they waited up to three hours in the waiting room and this was associated with psychological distress among participants:

"Sometimes, I wait for two hours; just to renew the monthly medication prescription, there are many patients in front of the pharmacy to take their medications; it takes a long time which makes me anxious and exhausted". (Ahmad)

Participants mentioned another issue, was long travel times and inconvenient access to health care facilities, and health care was divided between primary health care, and tertiary level care, in addition to cardiac care and which consumes a long time: " I am annoyed because I live in the village, the distance was far and the waiting time is long to see the specialist and this makes me bored, exhausted and anxious". (Munera)

Furthermore, the participants mentioned that with the long waiting times, the waiting rooms were not suitable for older age, and there were no suitable chairs:

"I feel anxiety because I sit on bad chairs in the waiting area for a long time, this chair causes back pain ". (Ebtekar)

Therefore, participants suggested decreasing waiting times for older age because they are not able to wait:

"We need to be the first persons to renew the monthly medication prescription because we feel tired and they can't wait." (Adham)

Insufficient healthcare resources

Participants highlighted the challenge of the resources and services provided to them. Participants stated that there were extremely limited health services provided, or that they were not available in public clinics and this was considered psychological distress for them: "Last week the doctor asked me to do catheterization; I need to go to Amman… it needs long travel time and it is very difficult to book a near appointment for catheterization ...... I'm very tired, these things make me stressed". (Mahmood)

Another participant had comments that include uncomfortable beds, crowded rooms, and there is no specific area to walk that was appropriate for older age:

"Sometimes we were admitted to hospital and due to hospitalization we feel anxiety and there is no waiting room with such as comfortable chairs and TV ". (Hamda)

Some participants mentioned there was a shortage of healthcare providers at the hospital so they need a long wait time, in addition to late medical appointments and this makes them anxious and angry:

"There is one nurse at the cardiac clinic for many patients, it is not enough so we need long waiting time at the clinic, the appointments are too late and therefore, I go to private clinic sometimes". (Ibtesam)

Insufficient healthcare facilities and the poor patients' referral system from peripheral hospitals to central hospitals cause a delay in seeking health and a barrier to service utilization; which causes them to feel anxious and stressed:

"One cardiac clinic is not enough… we get stress from long waiting time".

Participants mentioned the unavailability of some drugs and this causes feelings of stress due to the financial strains. Another participant stated a lack of full insurance coverage for all treatments and this causes stress for him:

"I take the foreign Plavix (medication), but I have not found it for several months; sometimes my doctor prescribed alternative medications for some medications and it was not suitable for me, that is difficult for me to buy my original medications, I need to buy it …… and this causes annoyed for me". (Nezar)

Insufficient health information

Participants mentioned that the health information that they had received from their healthcare providers was insufficient and not comprehensive to get the whole picture of the patient's situation. Accordingly, there was uncertainty was often associated with fear and anxiety of making mistakes in the care related to insufficient information that might cause harm to them:

" No information was provided regarding the side effects of medications, how to self-care related to my disease, future therapeutic plan and this causes fear and stress for me". (Hamdan)

Other participants mentioned that they didn't receive enough information regarding their medications including side effects, drug interactions with other medications, and proper time to take particularly diuretics if they go outside the home:

" I hate going outside of my home because the diuretic increased urination and I don't know how to use it when I go outside… I feel frustrated and stressed ". (Najah)

Some participants stated that no explanation and getting answers might be provided if they didn't ask the physician:

"The doctor and nurse explained my status of me, they were giving me the information that I need if I asked them and this makes me anxious". (Fathya)

For some participants, uncertainty was associated with feelings of burden and reduced certainty and confidence:

"When I have a problem, I can't understand if this problem is caused by HF or something else. This makes me feel so apprehensive and uncertain because I don't have an answer, and this makes me feel very insecure. No one taught me how to evaluate clinical changes, and I live with this lack of knowledge and a deep uncertainty and fear of making mistakes". (Nemat)

A call for specialist psychological health support to understand their suffering.

Another challenge was the absence of specialized care for patients suffering from psychological distress. Participants highlighted that healthcare providers did not always recognize that examining patients suffering from HF who might suffer from psychological distress would not ensue in the same manner that it would be for a simple common disease.

Participants stated they would have liked to have spoken to their nurse about their psychological status but they had not been allowed to do:

"When I tried to talk with the nurse about my mood that led me to discontinue my medications for two days… she told me I'm busy, she ignored me and don't talk with me, just she gives me the medication and this makes me sad and stressed". (Hasherm)

Participants stated the desire for healthcare providers with specialized psychological care training who are competent in caring for patients suffering from psychological distress related to HF: "the nurses should be well trained and specialized in dealing with the tired psychological status of patients". (Haleema)

It was apparent in participants 'accounts that healthcare providers should be aware of patients' perspectives and needs; the provided care is not holistic and mainly focused on their cardiac condition, neglecting their psychological needs which are crucial to the patient's health and care: "Healthcare is not comprehensive, the focus only on the physical side, and there is ignoring for the psychological side when performing nursing care". (Alaa)

It was apparent through interview texts that the participants welcomed the notion of specialist psychological health support in hospitals and this allow them to talk about their emotions, and psychological distress and expressing express how they felt, to better understand why they felt, and to encourage them to talk to others and they wish the focus of their care and treatment encompassing psychological and physical health:

"When the nurse says bismillah tawakal aala Allah, at that precise moment I will come back to Allah to reach the tranquil soul ". (Fares)

It was apparent in the interviews, that the participants need spiritual care which builds on effective relationships with health providers to encourage them to change their negative views such as despairing about their disease, and engage with it more positively:

" We need a spiritual dose from nurses and doctors and this spiritual care motivates us and gives us a sense of hope eventually we will feel tranquility in our soul, which will give us power, and we feel peacefulness ". (Zaina)

Discussion

Most participants in the study looked for the humanistic touch and emphasized that the communication delivered by the health care providers particularly nurses was not in a humanistic and supportive manner and they need this humanistic communication to decrease their psychological distress. This finding is consistent with many previous studies which found that humanistic communication was associated with lower levels of psychological distress (Cardona et al., 2023; Kunneman et al., 2019; Hauser, 2017; Wiechula et al., 2016). This might be attributed to humanistic communication with patients which must include a commitment to dignity, respecting humanity, actively listening with responsiveness, acting with care, and empathy, and building trusting relationships with healthcare providers to decrease their anxiety and meet their needs (Kunneman et al., 2019). However, several studies mentioned that the communication needs of patients suffering from HF are not always met by healthcare providers (Checa et al., 2020; Cardona et al., 2023; Fabbri et al., 2020; Fitzsimons et al., 2019; Harding et al., 2008; Rogers et al., 2000). Some participants stated that the need for supportive humanistic communication to deliver information regarding signs of deterioration and when to seek health care, treatment options and makes them feel calm and less anxious. This might be explained by participants' desire to be involved more in the decision-making and treatment options by using good communication from the healthcare provider to feel more comfortable and less stressed. This is congruent with the results of many previous studies (Ahmad et al., 2016; Bergeson & Dean, 2006; Doorenbos et al., 2016; Modig et al., 2012; Płotka et al., 2017; Hauser, 2017; Riegel et al., 2012). This might be also explained as patient-centered communication which aims to understand the patient's needs, feelings, and unique psychosocial, and cultural contexts, and patients share in decision-making about healthcare (Naughton, 2018).

Some participants claimed a short time in the cardiac clinic prevented them from getting answers to questions clearly, and justifiably with humanistic communication to alleviate their psychological distress. This might be attributed to healthcare providers who might feel they don't have enough time to listen and explain, to the patient and patients might be interrupted by healthcare providers (Andriyanto, 2019; Howick &Rees, 2017; Marvel et al., 1999; Nelson, 1997; Sulistyowati et al., 2020). Some participants reported that they receive disrespectful words from some nurses which makes them feel frustrated and anxious. These words might convey an important meaning to patients who looked for reassurance, understanding, and support from healthcare providers and these are crucial aspects of good communication (Hill et al, 2020; Moen et al., 2016; Shaheen et al. 2020).

The current study findings emphasized the need to exemplify the nursing philosophy of humanistic care and help the nurses to achieve the satisfaction of patients by using effective and humanistic communication skills based on patients' needs (Geng et al., 2022). This study finding is consistent with the results of many previous studies which found that long waiting time is one of the main contributing factors to psychological distress (Bleustein et al., 2014; Gowani et al., 2017; Lewis et al., 2018; Sumner et al., 2018; Thu et al., 2015). Some participants indicated that inadequate healthcare facilities and the unavailability of some procedures for cardiac follow-up in their region challenges that might cause psychological distress. Congruent with the current study findings, several studies found that insufficient healthcare resources were associated with psychological distress (Burström et al., 2012; Checa et al., 2020; Gallacher et al., 2011; Kessing et al., 2016; Nordfonn et al., 2019; Nordfonn et al., 2021; White-Williams; 2020). Additionally, the physical environment such as large windows indoor plants, and good light might promote perceptions of control, and positive distractions might alleviate psychological distress (Andrade et al., 2017; Jamshidi et al., 2020). Participants reported psychological distress related to insufficient health information about their health status, treatment plan, and medications. This was congruent with the results of many previous studies which found that insufficient health knowledge was associated with psychological distress (Ahmad et al., 2016; Boyer et al., 2020; Hwang et al., 2014; Mohammadi et al., 2021; Malak et al., 2021; Modig et al., 2012; Polikandrioti et al, 2010; Torabizadeh et al., 2021; Yazew et al, 2017). Similarly, other studies' findings showed that health information helped decrease uncertainty which reduces anxiety related to an unclear disease trajectory (El-Hneiti et al., 2019; Browne et al., 2014; Harding et al., 2008; Liljeroos et al., 2014; Rodriguez et al., 2008). Upon reviewing the literature related to patients suffering from HF, contradictory findings were

detected (Van Der Wal et al., 2006). It was apparent through interview texts that some participants reported a call for specialist psychological health support to understand their suffering. Some participants claimed that in the absence of specialized care for patients suffering from psychological distress related to HF, they received routine care, which did not meet their healthcare needs. The current study findings emphasized that nurses should use routine depression and anxiety screening protocols for patients suffering from HF to improve recognition of it (Subih et al., 2020; Tully et al., 2014). Besides, several studies documented the importance of the inclusion of routine assessment of psychological distress in HF treatment protocols which might alleviate psychological distress (Alemoush et al., 2021; AbuRuz, 2018; Dou, 2018; Fischer et al, 2014; Guerra et al., 2018; Johansson et al., 2006; King et al., 2022; Lichtman et al., 2014; Li, 2019; Lin et al., 2020; Piepoli et al., 2016; Tully et al., 2014; Wang & Zhang, 2018; Yang, 2017; Yang et al, 2022; Zhang, 2019). Our study suggests that future clinical practice should highlight HF patients' experience of burden of treatment as an important aspect of treatment plans.

Conclusion

It is hoped the findings of this study will guide and inform healthcare providers and policymakers regarding Burden of treatment that HF patients encountered to assist in providing better care and psychological support for these patients. Future studies assessing Burden of treatment might offer insights that would enable the healthcare system to take practical steps to improve HF care which might alleviate the psychological distress of these patients. Our study suggests that future clinical practice should highlight HF patients' experience of Burden of treatment as a significant aspect of treatment plans.

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