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# Compassion as the cornerstone of palliative nursing care for patients with heart failure: a phenomenological study

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## Abstract

**Objective** This study explored the lived experiences of nurses providing such end-of-life care to patients with heart failure using the lens of hermeneutic phenomenology.

**Results** Three overarching themes were identified: (1) creation of psychological comfort, (2) offering magnanimity in humanity and (3) the paradox of end-of-life care. The first theme included subthemes related to empathy and psychological support for the family. The second theme included subthemes related to respecting the patient's dignity and altruism, and the third theme included subthemes related to both positive and negative reactions to providing care in this context. A constitutive pattern emerged in the form of "compassion as the cornerstone of end-of-life nursing care for patients with heart failure". Findings reveal the hidden aspects involved in the provision of compassionate care and shine a light on the meaning of this from the perspective of nurses.

**Keywords** Heart failure, End-of-life care, Nursing care, Phenomenology, Palliative care

## Introduction

As a chronic and debilitating disease, heart failure is a major global public health issue and the most common reason for the hospitalization of people over 65 years of age [1, 2]. Heart failure patients, particularly when in their end-of-life phase, experience frequent rehospitalizations associated with significant economic and social burden [3]. Heart disease itself is associated with a 10% survival rate (10 + years). In Norway, heart failure accounts for 3.6% of all deaths [4], whilst in Korea, 10.4 people per 100,000 die due to heart failure [5] and the mortality rate of heart failure in Oman is reported to be 25% [6]. In Iran, there is a particularly high mortality rate of approximately 18.2% for heart failure patients [7]. When these patients have an ejection fraction below 10% and become dependent on dopamine, they are often considered to be at the end of their life [8], and this is when nurses engage in end-of-life discussions with them. This has placed great demand on the need for high quality and palliative nursing care in this context [9]. Patients with heart failure, especially in their end-of-life phase need to know more about their disease, symptoms and provision for their end-of-life care [10]. Indeed, information regarding end of life and its associated care is considered crucial for these patients [11, 12]. Nurses play an important role in this, and in the provision of palliative care [13]. However, according to international evidence, the

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accessibility to palliative and end-of- life care for patients with heart failure is lacking [14–17].

Previous research has demonstrated how nurses play an essential role in caring for patients who are at the end of their lives as they consider both the personal, and educational needs of patients who are dying in learning about both the life and death. For example, nurses can focus on managing symptoms without increasing the risk of death whilst also observing the patient's values and preferences [18]. They also create a trust-based relationship with patients and their families during the end phase of heart failure [19]. Nevertheless, there can be a sense of futility alongside other challenges in providing such nursing care, some of which are related to a severe shortage of palliative care specialists for heart failure patients, particularly in Iran [8]. In Iran, one of the major ethical challenges facing the health system is euthanasia. Many Iranian nurses for example, have a negative attitude toward euthanasia for patients in the later stages of the disease [20]. Moreover, according to the laws of Iran, no one can end another person's life. Thus, nurses must continue to perform resuscitation, even in the face of its futility [21].

Considering the above, the use of hermeneutic phenomenology was employed to examine the lived experiences of nurses delivering end-of-life care to patients with heart failure in the context of Iran. Hermeneutic phenomenology as an approach was considered most appropriate for this study as it is concerned with reaching a new understanding of the meaning behind the phenomenon of end-of-life care to heart failure patients as experienced by nurses. The implementation of this approach also enables nurses to explain their lived experiences of caring for heart failure patients. Our research question was: "What is the meaning of nurses providing end-of-life care to heart failure patients according to their lived experiences?

## Methods

### Study design

A qualitative study was conducted using the lens of Heideggerian hermeneutic phenomenology. This is a philosophical approach used to uncover the concealed significance to be found in human experiences, captured within the world they inhabit. This approach facilitates the exploration of individuals' lived experiences and offers a pathway to gain insights through the revelation of meanings. This approach also requires us to conduct a thorough in-depth conversations with individuals to acquire an accurate comprehension and interpretation of the phenomena which arises from their lived experiences [22]. The Standards for Reporting Qualitative Research have been used to guide the reporting of this research [23].

### Data collection

This research was conducted in two separate educational centers, both of which receive cardiac patients from all over the country in the capital of Iran, Tehran. Nurses were selected as participants via purposive sampling. Participants were eligible for inclusion if they were employed in the cardiology departments and had at least one year of experience in providing end-of-life care for heart failure patients. In our sampling, we aimed for maximum variation, (e.g., age, gender, educational attainment, and length of experience in providing care). Maximum variation sampling was used in our recruitment strategy as it enabled comparability where nurses varied in demographic data. Selecting nurses with different characteristics also enabled us to highlight the similarities and/or diversity in their lived experiences. Overall, participants ($n = 14$) were aged between 25 and 49 years, and identified as either women ($n = 8$) or men ($n = 6$). The majority of participants held a bachelor's degree ($n = 9$), while the remainder possessed a master's degree. Their experience in caring for patients with heart failure varied from between 4 and 15 years.

Potential participants were given comprehensive information about the purpose of the study and invited to participate in an interview after giving their informed consent to the research team. Semi-structured interviews were conducted face-to-face and lasted between 40 and 65 min. These interviews were conducted over a period of 4 months toward the end of 2023. All nurses were interviewed once. Interviews took place in a private conference room located within the inpatient departments. The interview guide was developed by the research team and aligned to the aim of this study (Table 1).

**Table 1** The interview guide

| | |
|---|---|
| Main questions | What experience do you have with end-of-life care? |
| | How have you experienced end-of-life care for a heart failure patient? |
| | How does this care make you feel? |
| | What does this care mean to you? |
| | Based on your experiences, what significance does this type of care have? |
| Probing questions | Is your intention with… to convey this? |
| | Could you provide an example to clarify your point? |
| | Please elaborate further |

**Table 2** The 7-step of data analysis

| | |
|---|---|
| 1 | Reading all the interviews to gain a general understanding |
| 2 | Writing interpretive summaries for each of the interviews |
| 3 | Group analysis of selected versions of the interview texts and identification of sub-themes and themes |
| 4 | Returning to the interview texts and/or participants for clarification of areas of disagreement and contradictions in the presented interpretations, and writing an overall and comprehensive analysis of each interview text |
| 5 | Comparing interview texts to identify, determine, and describe common meanings |
| 6 | Identifying and extracting constitutive patterns that establish connections between themes |
| 7 | Presenting the final findings in the form of main themes |

### Data analysis

Interviews were audio recorded. After each interview, audio text was initially transcribed onto paper and underwent multiple reviews to obtain clarity in what was said. Transcripts were subsequently translated into English. Data collection and analysis occurred concurrently. In order to make sense of the data collected, a 7-step method proposed by Diekelmann et al. (1989) was utilized [24]. This method of analysis is common in hermeneutic phenomenological research [25–27], and it is used in hermeneutic phenomenology due to its ability to enable researchers to make sense of the data and unearth new meanings in a structured way (Table 2).

Firstly, for each interview transcript, an interpretive synopsis was generated by the lead researcher. Both semantic and latent meanings were extracted early on for further interpretation. The research team engaged in several iterative discussions to refine both sub-themes and overarching themes. With the ongoing progression of additional interviews, previous themes became more evident and were thus developed further, and occasionally new topics arose. The team consulted outside nursing experts and texts to provide any further clarity required, and any conflicts were resolved through respectful academic discussions. Lastly, interpretive summaries were generated throughout as a more comprehensive analysis was established to identify optimal associations between the resulting themes.

### Rigor

To assess rigor, criteria such as credibility, dependability, confirmability, and transferability were employed [28]. To establish credibility, the research team maintained ongoing involvement with the subject matter and data. To assess dependability, the viewpoints of an external observer were also incorporated. To ascertain confirmability, all conducted activities were documented, and a report detailing the research process was kept up to date and prepared for reporting. To establish transferability, the findings were shared to enable feedback from two further nurses outside our participant group with expertise in providing end-of-life care for patients with heart failure.

## Results

Sentiments captured from the nurse participants in this study were collated into three overarching themes (A) creation of psychological comfort, (B) offering magnanimity in humanity and (C) the paradox of end-of-life care. The first theme included sub-themes related to empathy and providing psychological support for the family. Sub-themes captured within the second overarching theme included respecting the patient's dignity and altruism. Finally the third overarching theme included sub-themes related to positive and negative feedback. These themes and sub-themes revealed the meaning of end-of-life care of heart failure patients for nurses according to their lived experiences. The constitutive pattern which emerged was "compassion as the cornerstone of end-of-life nursing care for patients with heart failure".

### A- creation of psychological comfort

Nurses in this study used strategies such as empathy to provide psychological support to the patient's family. This strengthened the psychological health of heart failure patients.

### A-1- empathy

Nurses empathized with patients by showing them that they understood them, could put themselves in their place and could see them as a member of their own family.

*"Many patients come here with the fear of death. We talk to them, calm them down and reduce their fear of death. I personally told a patient to have patience, it is a difficult time, very difficult, but we will do our best to make you feel better"* (Participant (P) 4).

*"Put ourselves in the place of a patient whose blood pressure is dependent on medicine, and if we stop the medicine, he will die. I have always said that these patients who are at the end of their life are like my family members."* (P2).

Nurses also talked about the importance of listening to patients at the end of their life and empathizing with them. This in turn enabled them to display the essence of care in this context. *"Sometimes it takes me a long time to give medicine to a patient who is in the last days of his life.*

*My colleagues ask me why it takes me so long, but I cannot just give medicine to patient without listening to him with all my heart. I even cry with him because I think this calms him down."* (P5).

#### A-2- providing psychological support for the patient's family

Participants were aware of the importance of providing psychological support for the family of heart failure patients. The essence of care was demonstrated through providing such support to the patient's wider family, who were also experiencing psychological distress at this time.

*"When a patient is at the end of his life, his family feels that they have committed a sin in the past and now the punishment for their actions is to witness the death of their loved one. But we know that this is not true, and we try to support the family and free them from such feelings".* (P8)

*"I said to the brother of an ill patient who already had a very low ejection fraction; 'maybe you are tired, it is better to change your place with someone else, because you have been sitting with the patient for a long time and lost a lot of energy, you need to rest".* (P12)

Participants expressed their belief that family support is a necessity, especially in the context of their loved one dying unexpectedly. The patient's family may not always be prepared, and in this case, they can quickly become the focus of nurses' attention.

*"Sometimes families do not expect the imminent death of their patients, and the patients suddenly die. Therefore, when the family faces the tragedy of unexpected death, we help the family and offer our condolences".* (P9)

#### B- offering magnanimity in humanity

Participants recognised the need to offer magnanimity in humanity, even in the face of aggression and disrespect from patients, which may arise from their contextual discomfort and mental anguish. This humanizing approach was captured within the following sub-themes in relation to respecting the patient's dignity and embracing altruism.

#### B-1- respecting the patient's dignity

During the provision of heart failure patients' end-of-life care, nurse participants considered it important to respect the patient's dignity, even in case where they were being aggressive and until the very end.

*"Some patients are very angry, aggressive and may curse us, but we ignore them. We accept the end-of-life heart failure patients in any way, even if they have just a day left. The important thing is that we will not miss any compassionate care for them".* (P14)

*"I try to ensure that the patient receives the best care possible until the last moment of his life, even if there is no hope for his recovery, or his pulse is no longer detectable."* (P10).

Participants also expressed how nurses should convey feelings of respect to a patient at the end of their life.

*"End-of-life care for heart failure patients means that nurses, in dealing with patients, show them respect through their behavior, and are able to convey a feeling of respect in patients by doing their best for patients and valuing them."* (P3).

Being honest with patients was one way that nurses demonstrated this respect.

*"When patients are at the end of their life, I become more sensitive towards them and provide the necessary explanations about this stage of disease to them and their families with honesty".* (P11)

#### B-2- altruism

The altruism offered to patients through the delivery of care was associated with a sense of selflessness from nurses. In some cases, this resulted in nurses going above and beyond in their duty. *"The nurses may want to take a break because they are tired, but seeing physically disabled patients makes them skip the rest time, especially when patients need help. I have the sense of altruism towards the end-of-life patients, but I didn't have the same feeling when I was working in other wards. This feeling of altruism enables us to do our work."* (P1).

#### C- the paradox of end-of-life care

Nurses recognised how they could experience the differing effects of providing end-of-life care to heart failure patients. This was interpreted as a paradox between both the positive and negative reactions to providing care in this context.

#### C-1- positive reactions

One of the positive reactions to providing end-of-life care to heart failure patients was the strengthening of nurses' beliefs and self-confidence.

*"Working with these patients has strengthen my belief and this has impacted my personal life, making me feel less afraid of death. It is like a mountain whose reflection returns to me and increases my self-confidence. This has made me more grateful to God for the things he has given me and I have become more grateful of life".* (P6)

*"I always feel that a nurse, who provides end-of-life care to patients, is like a gardener of paradise, a happy gardener".* (P13)

*"I always think that working in this department brings blessing in my life, because my problems have been resolved in a way that I believe it was due to end-of-life care that I provide to these patients."* (P5).

#### C-2- negative reactions

Nurses in this study highlighted the negative aspects caused by providing end-of-life care to heart failure patients. These are largely related to hopelessness, stress, depression and pain.

*"It's really hard to work with a patient who you know is going to die, maybe because nurses know that in the end there is nothing they can do for these patients."* (P10).

*"Caring for end-of-life patients natively affects the nurses' spirit and mood, in a way that they can't tolerate anything anymore in the work environment. Sometimes we lose our tolerance as if we are working in a burning desert".* (P3)

Some nurses encounter patients who problematically think about death constantly. Such rumination can have a negative impact upon the wellbeing of nurses.

*"The most important thing that can easily be experienced is patient who sees his life is over and is getting closer to death. When we talk to them, they all say that our life is over and we don't have time anymore. You know, this is stressful for nurses".* (P1)

Providing end-of-life care for heart failure patients and not seeing them recover or discharged has also led to depression in some nurses.

*"We may develop depression, because we do not see patients being discharged, we always see their death. We do not see the result of our work in a positive way, and this is painful to us".* (P14)

**The constitutive pattern** 'Compassion as the cornerstone of end-of-life nursing care for patients with heart failure'.

Providing end-of-life care to heart failure patients means providing care with psychological support and an ethical approach. While this type of care has positive effects for nurses, it also brings negative effects upon them. Nevertheless, the meaning of end-of-life care, according to the nurses' lived experiences, lies within the constitutive pattern of "compassion as the cornerstone of end-of-life nursing care for patients with heart failure".

## Discussion

In this study, the meaning of providing end-of-life care to heart failure patients was analyzed through the lived experiences of nurses. The concepts revealed in this study are aligned with the guiding philosophy of the study, because according to Heidegger, the world in which a person lives is a world shared with others, and being with others is an experience that comes from being in the world [22]. Compassion was revealed as the cornerstone of end-of-life nursing care for patients with heart failure. Our study referred to the creation of psychological comfort, offering magnanimity in humanity and the paradox of providing end-of-life care. A similar study conducted in Japan similarly highlighted how from the healthcare providers' viewpoint, psychological distress is the most important concern of heart failure patients at the end of their life [29]. Evidently nurses in other contexts similarly try to reduce the fear and worries of patients who are at the end of their lives [30]. This confirms somewhat of a universal experience for nurses in this context and indicates that these findings may also be replicated elsewhere.

Our study referred to providing psychological support to the end-of-life patients and their families. Since the provision of informal care by family members is a part of end-of-life care [31], the psychological support of a patient's family is crucial, especially during the end-of-life phases. Thus, in addition to managing the symptoms of the disease, end-of-life care requires supporting patients and their families psychologically as well as physically [32]. One study in UK revealed how heart failure patients and their families require increasing input from specialist palliative care services to both manage symptoms and access support in the end-of-life care [33]. This type of care is also provided elsewhere such as in Greece, where nurses similarly provide psychological support to patients' families during end-of-life care, by being empathetic towards them [34]. As the impact on mental health is high in the context of caregiving, interventions provided by the health systems are required to protect the mental health of families [35], as well as nurses in this context.

Our study illuminated how magnanimity in humanity was provided. Respecting patients' dignity and altruism were considered key in the delivery of this type of care. Our interpretations illuminate how respecting a patient's dignity at this time is essential in the context of this type of nursing care. Moreover, a person who empathizes with others, can also respect them more completely. Indeed, our study revealed how nurses in particular empathize with patients and remain by their side, respecting them wholly. Likewise, Heidegger states that, the truth is revealed when people come out of hiding [22]. This connects to the honesty with which nurses in our study communicated with patients as they also considered honesty to be a value essential in the provision of respectful end-of-life care. Indeed, patients with heart failure need to know everything about their disease from the start [10]. This position is supported by cardiologists in both Sweden and the Netherlands [36].

Altruism is considered to be one of the most important elements of nursing care [37]. Providing end-of-life care for heart failure patients is associated with differing effects for nurses, both positive and negative. For some it increased their self-confidence, resolve of their personal problems, and gratitude where the metaphor "the gardener of paradise" was used. Yet for others, providing end-of-life care in this context was stressful where the

metaphor of "working in the burning desert" was used to describe their experience. Similarly, the results of a study conducted in Japan indicated that nurses, in providing end-of-life care to patients not only faced burnout and fatigue, but also experienced positive reflections such as work satisfaction [38]. Nurses in Israel also described the provision of end-of-life care has having complex effects on the healthcare professionals, from secondary traumatic stress to post-traumatic growth [39]. Thus, these formal carers must be protected from burnout by supporting them to consider their work as a challenge and find greater meaning in their actions [40, 41].

### Limitations

Since there is limited research on end-of-life care for patients with heart failure in Iran, researchers can utilize the findings of our study to design and conduct further studies using the end-of-life care scale, which is specifically tailored toward these patients. Whilst this was the first much needed study of its kind to be conducted in Iran, the results of qualitative studies are context- dependent and so cannot be wholly generalized to other contexts. However, a key strength of this study is that the findings of hermeneutic phenomenological research are co-constructions developed through interpretation of both researchers and participants. Thus, this study makes important contributions to meaning making within the world of nursing.

## Conclusion

Participants experienced differing effects upon themselves, and these insights may enable future nurses to reflect on their own wellbeing and protection when providing similar care in this context. Findings also provide us with what it means to provide care in this context along with what is most valuable to people in receipt of palliative nursing care at the end of their lives. Such meanings are important as we reveal nursing phenomena more widely in the literature for the humanizing of death and dying in our society.

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**Author contributions**
Study design: MAR, MMH. Data collection: MAR, MMH. Data analysis: MA, MMH. Study supervision: MAR, MA, MMH, SP. Manuscript writing: MAR, MMH, SP. All authors have read and approved the final manuscript.

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**Data availability**
The data underlying this article cannot be shared publicly because they contain information that could compromise participants' privacy and consent. The data will be shared on reasonable request with the corresponding author.

## Declarations

**Ethics approval and consent to participate**
Recruitment commenced after ethical permission for the study was granted by the ethics committee of Iran University of Medical Sciences (IR.IUMS.REC.1402.482). Written informed consent was obtained from all participants, and the right to withdraw at any stage of the research was respected. All procedures were carried out in compliance with the ethical rules and regulations of the Helsinki Declaration.

**Consent for publication**
Not applicable.

**Competing interests**
The authors declare no competing interests.

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