

Tailored Personas for Palliative Care Decision-Making Among Caregivers of Patients with End-Stage Heart Failure: A Qualitative Study

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Abstract

Background: Palliative care can effectively improve the quality of life for patients with end-stage heart failure, and caregivers play a critical role in palliative care decision-making. However, there are significant differences among caregivers in terms of their decision-making characteristics, and research on caregivers' decision-making characteristics and corresponding support needs remains limited.

Objective: The aim of this study was to apply a user persona methodology to establish a profile of palliative care decision-making characteristics among caregivers of patients with end-stage heart failure, thereby providing a basis for the development of personalised decision-support interventions.

Methods: A descriptive qualitative research design was adopted. Between April and May 2026, purposeful sampling was used to select primary caregivers of patients with end-stage heart failure from two tertiary hospitals in Shanghai for semi-structured interviews. The interview data were organised and coded using NVivo 14.0 software. Content analysis was employed to identify characteristic labels of palliative care decision-making among caregivers, and caregiver personas were constructed through feature clustering. These caregiver personas were presented in the form of character portraits accompanied by characteristic labels.

Results: A total of 22 eligible caregivers of patients with end-stage heart failure participated in this study. Four caregiver personas were identified: the proactive type, the anxious-conflicted type, the resistant-avoidant type, and the isolated-helpless type. Significant differences were observed across the four caregiver personas in five dimensions: cognitive level, psychological state, value preferences, social support, and resource needs.

Conclusion: There is significant heterogeneity in the palliative care decision-making patterns of caregivers of patients with end-stage heart failure. The four caregiver personas developed can effectively identify the characteristics and needs of different caregiver groups, providing a theoretical basis for the clinical implementation of precise and personalised palliative care decision support.

1. Background

Heart failure represents a substantial and increasing global public health burden, affecting approximately 64 million individuals worldwide[1]. End-stage heart failure represents the final stage of disease progression, severely impacting patients' physical function and quality of life; its high rates of readmission and mortality place a heavy burden on patients, their families and the healthcare system[2]. With an ageing population, the cohort of patients with end-stage heart failure continues to grow, and their needs for symptom management, psychological and social support are becoming increasingly prominent. Traditional treatments aimed primarily at prolonging survival are no longer sufficient to meet the needs of patients and their families[3].

Palliative care is a patient- and family-centred, integrated model of care that focuses on symptom management, psychological support, social support and the preservation of dignity. It can effectively alleviate patients' physical symptoms, strengthen psychological support, improve quality of life, reduce hospital admission rates, and save on healthcare costs and resources[4, 5]. The American Heart Association explicitly states that palliative care should be provided to all patients with heart failure[6].

As the disease progresses, patients with end-stage heart failure often experience impaired consciousness and cognitive decline, leading to a diminished ability to make decisions regarding palliative care[7]. At this stage, caregivers often play a key role in decisions regarding the initiation of palliative care.[8]. Research has shown that caregivers often play a key role in conveying patients' wishes, and their involvement in decision-making helps healthcare teams better understand patients' end-of-life preferences[9]. Conversely, if caregivers are excluded from the decision-making process, they may feel marginalised, lose trust in the healthcare team, experience conflicts over treatment, and even see the patient's quality of life compromised[10]. However, due to factors such as traditional beliefs, value systems, and differences in perceptions of illness, there is significant heterogeneity in caregivers' decision-making regarding palliative care, which directly affects the timing of palliative care initiation and its effectiveness. Research shows that when caregivers lack knowledge about the disease, experience emotional distress, or face decision-making conflicts regarding palliative care, this can lead to delays in initiating palliative care, thereby increasing patient suffering[9]. Therefore, exploring the decision-making characteristics of different types of caregivers regarding palliative care is particularly important for improving patients' quality of life.

In previous studies, Choi et al. [11]conducted a systematic analysis of the factors influencing caregivers' palliative care decision-making; however, this study did not reveal the heterogeneity of these influencing factors among caregivers with different characteristics, making it difficult to implement targeted interventions. The Ottawa Decision Support Frameworkproposes that decision-making characteristics is influenced by individuals' knowledge, values, emotional responses, social support, and decision support needs[12]. User profiling originates from the fields of human-computer interaction and marketing. By collecting and analysing multi-dimensional data on target users, it extracts common attributes to create virtual avatars of real users, which can serve as models of the target user base[13]. Compared with other qualitative research findings, user profiling offers significant advantages, as it presents users' core characteristics and needs in a clear, data-driven manner[14]. Consequently, Based on the Ottawa Decision Support Framework, this study adopts a descriptive qualitative research design, utilising semi-structured in-depth interviews to construct a profile of caregivers' decision-making characteristics, thereby providing a theoretical basis for the development of personalised decision-support interventions in clinical settings.

2. Methods

2.1 Study design and participants

This study employed a descriptive qualitative research design to explore the palliative care decision-making process among caregivers of patients with end-stage heart failure. Using purposive sampling guided by the principle of maximum variation, caregivers of patients with end-stage heart failure admitted to the cardiology departments of two tertiary hospitals in Shanghai between April and May 2026 were selected to participate in this study.

2.1.1 Inclusion and exclusion criteria

Patient inclusion criteria: (1) The patient fulfilled the 2022 American College of Cardiology criteria for end-stage heart failure, with severe symptoms that persisted or progressed despite optimised medical therapy, and had experienced repeated hospitalizations or emergency department visits for heart failure during the previous 12 months[6]; (2) Aged 18 years or older; Caregiver inclusion criteria: (1) Aged 18 years or older; (2) Was a relative of the patient; (3) Providing care for ≥ 4 hours per day, with care provision lasting ≥ 1 week; (4) Involved in the decision-making process regarding the patient's palliative care and acting as the primary decision-maker; (5) Cognitively intact and able to communicate effectively; (6) Signed an informed consent form and voluntarily participated in this study. Caregiver exclusion criteria: Those with severe cognitive impairment, mental illness, or an inability to communicate effectively.

2.1.2 Determination of sample size

The sample size for this study was determined in accordance with the principle of data saturation in qualitative research. Analysis was conducted on an ongoing basis during data collection; data saturation was deemed to have been reached, and sampling and interviews were terminated, when no new themes emerged in three consecutive interviews. We recruited participants from the inpatient wards of two tertiary hospitals in Shanghai, all of which had extensive experience in providing palliative care. We invited caregivers who met the inclusion criteria to participate in this study. A total of 25 invited participants agreed to take part and were interviewed. We first conducted three pilot interviews; as these were intended to test the scientific validity, rationality and feasibility of the interview guide, the content of these interviews was not included in the final research findings. By the 19th formal interview, the data no longer yielded any new significant information; no further valuable insights were identified during interviews with the subsequent three participants, and the study was discontinued after the 22nd interview. Ultimately, 22 caregivers were included in the formal analysis.

2.2 Data collection

Data were collected through face-to-face, in-depth semi-structured interviews. Prior to the interviews, the researchers collected general socio-demographic information, such as gender, age, educational attainment, marital status, employment status, place of residence and duration of caregiving. The interviews were conducted by two researchers, both of whom were postgraduate students and had received training in qualitative research methods. The first author was responsible for conducting the interviews, whilst the second researcher was responsible for audio recording and note-taking. Interviews

were conducted in quiet, private, separate rooms to reduce environmental disturbances and protect participants' privacy. Before each interview began, the researchers reiterated the purpose, significance and voluntary nature of the study to the participants. Each interview lasted between 30 and 60 minutes. The researchers used open-ended questions and probing questions to guide participants in fully expressing their genuine feelings, whilst avoiding leading language. They also briefly recorded non-verbal cues such as facial expressions and body language. With the interviewee's consent, the entire session was audio-recorded whilst field notes were taken simultaneously to ensure the accuracy and completeness of the data. Within 24 hours of each interview, the audio recording was transcribed verbatim to form the raw data, which was then cross-checked against the audio recording and field notes to guarantee the authenticity and integrity of the data.

2.2.1 Interview guide

This study drew upon the Ottawa Decision Support Framework to draft an initial interview guide, incorporating an extensive literature review, team discussions and consultations with five experts in the fields of cardiovascular nursing and palliative care. Following preliminary interviews with three caregivers who met the inclusion criteria, the interview guide was further revised and refined based on the findings. The final interview guide is as follows: (1) What do you know about end-stage heart failure? What do you know about palliative care? What are your views on palliative care? (2) How do you feel when making decisions regarding palliative care? How do you usually manage your emotions? (3) During the decision-making process, who is able to offer you the most support? (4) When making decisions, what aspects do you consider? What factors influence your decisions? (5) What are your needs? (6) Is there anything else you would like to add?

2.3 Data analysis

2.3.1 Establishing caregiver persona label dimensions

The construction of caregiver personas primarily involves three steps: the extraction of tag dimensions, feature clustering analysis, and the visual representation of personas[15]. In this study, NVivo 14.0 software was utilised to organise and code the interview data, and content analysis was employed to analyse the data. Firstly, two researchers read through all transcribed texts repeatedly to familiarise themselves thoroughly with the content and identify statements relevant to palliative care decision-making characteristics. Secondly, meaningful units were open-coded; similar content was summarised using the constant comparative method to form thematic clusters, which were then integrated into shared characteristics of caregivers. These shared characteristics constitute the core dimensions of caregiver personas, which are used to describe the palliative care decision-making characteristics and needs of caregivers, reflecting the heterogeneity among different caregivers. To enhance the reliability of the analysis results, the two researchers conducted independent coding followed by cross-checking; where discrepancies in coding arose, the research team discussed the matter to reach a consensus.

2.3.2 Construction of caregiver personas

After establishing the dimensions of the caregiver personas, this study employed a manual extraction approach to construct the caregiver personas. Based on the interview data, the research team systematically organised and synthesized the characteristics of each caregiver across five dimensions: cognitive level, psychological state, value preferences, social support, and resource needs. The constant comparative method was then used to examine similarities and differences in the combinations of characteristics across participants, with the aim of identifying groups of caregivers who shared similar decision-making characteristics. To ensure the authenticity and representativeness of the personas, the research team repeatedly reviewed the original interview transcripts throughout the analytic process and continuously refined the preliminary classifications. The emerging personas were subsequently shared with a subset of participants for validation to ensure that the classifications accurately reflected their actual experiences. Any discrepancies in classification were discussed among the research team until consensus was reached. Through repeated comparison and validation, the final personas were developed based on stable and recurring patterns of decision-making characteristics demonstrated by caregivers across multiple dimensions. These personas captured the heterogeneity of palliative care decision-making among caregivers of patients with end-stage heart failure.

2.3.3 Description of caregiver personas

Profiling is the process of presenting different groups of individuals with specific characteristics in a visual format. To ensure that the caregiver personas are clear, intuitive and suitable for clinical use, each profile is presented as a character illustration accompanied by descriptive labels, summarising their palliative care decision-making characteristics across multiple dimensions.

2.4 Rigour

To ensure the quality of the study, this research adhered to the guidelines for qualitative research reports[16], implementing rigorous quality control measures throughout the entire process, from research design and data collection to data analysis and validation of results. Firstly, all researchers had completed systematic training in qualitative research methods and possessed sound qualitative research skills; furthermore, none of the researchers had any prior relationship with the participants. The study included caregivers from two different hospitals to ensure the diversity and representativeness of the sample. Secondly, the entire research process was documented, including records of the development and revision of interview guide, the archiving of original audio recordings and transcribed texts, and coding records. All original data were securely stored and made available for independent review. To reduce the impact of researcher bias on the results, the research team adopted a reflective practice strategy. Each interviewer wrote reflective notes within 24 hours of conducting an interview. Finally, this study employed triangulation, comprising researcher analysis, participant validation and expert assessment, to further enhance the reliability of the research. During the interviews, the researchers anonymised the participants' personal identifying information, audio recordings and transcribed texts, and stored them in encrypted form. All data were used solely for the purposes of this study and was not disclosed to any third parties. The research findings were reported in aggregated form, without any personally identifiable information, thereby fully safeguarding the privacy and data

security of the participants. Data collection for this study was conducted only after obtaining approval from the hospital's Ethics Committee, and no physical or psychological harm was caused to any participant.

3. Results

3.1 Demographic characteristics of participants

This study ultimately included 22 caregivers of patients with end-stage heart failure who met the inclusion criteria, comprising 15 women and 7 men.(Supplemental File 1). Their ages ranged from 45 to 72 years, with a mean age of 61.31 years. In terms of educational attainment, 77.27% of the respondents had completed secondary education or higher; 81.81% were married; 68.18% were retired; 77.27% resided in urban areas; and 81.81% had been providing care for more than one year, as shown in Table 1.

Table 1 General characteristics of the participants (n = 22)

Variable		Frequency (n)	Percentage (%)
Age	< 60	8	36.36
	60-70	12	54.54
	> 70	2	9.09
Gender	Male	7	31.81
	Female	15	68.18
Educational level	Uneducated	2	9.09
	Primary education	3	13.63
	Secondary education	8	36.36
	Higher education	9	40.90
Marital status	Married	18	81.81
	Divorced	2	9.09
	Widowed	2	9.09
Employment status	Employed	2	9.09
	Retired	15	68.18
	Unemployed	5	22.72
Residential address	Town	17	77.27
	Village	5	22.72
Care duration (years)	< 1	3	13.63
	1 ≤ Duration < 2	12	54.54
	2 ≤ Duration < 3	6	27.27
	≥ 3	1	4.54

3.2 Personas of caregivers for patients with end-stage heart failure regarding palliative care decision-making characteristics

Based on the Ottawa Decision Support Framework, five dimensions were identified to characterise the palliative care decision-making personas of caregivers of patients with end-stage heart failure: cognitive level, psychological state, value preferences, social support, and resource needs. Through further integrating these characteristics, four caregiver personas were established: the proactive, the anxious-conflicted, the resistant-avoidant, and the isolated-helpless. See Table 2 for details.

3.2.1 Theme 1: proactive caregivers

Caregivers of this type are proactive in seeking information about the disease and palliative care, and have a good understanding of disease progression and changes in treatment goals. They actively participate in the decision-making process, prioritise the patient's comfort and dignity, and are able to approach issues related to the end of life and death in a rational manner. During the decision-making process, they are adept at utilizing support from family, the healthcare team, and community resources to inform their decisions.

C2: *At first, I was very afraid to talk about palliative care; I wondered if it meant giving up. But as I learned more, I realised that in the later stages of the illness, what matters most is sparing my wife as much suffering as possible. I came to understand that palliative care is simply a different approach to helping patients live comfortably and with dignity. Now I take the initiative to discuss these matters with my family, and I actively ask the doctors what approach is best for my wife at this stage, rather than insisting on aggressive resuscitative measures.*

C4: *When the doctor first mentioned palliative care to me, I took the initiative to look up a lot of information, and I regularly keep an eye out for educational content on heart failure and palliative care. I've also joined a support group where we share caregiving experiences and offer each other encouragement.*

C18: *Although it breaks my heart to see my wife's health deteriorating, I know that the natural cycle of life is the natural order of things. There's no point in crying about it; I must face it with a clear head. Our children are all very dutiful and considerate, and we have no financial worries; we can discuss and resolve all household matters together.*

3.2.2 Theme 2: anxious-conflicted caregivers

Caregivers of this type commonly experience significant emotional conflict and hesitation when making decisions regarding palliative care. On the one hand, they wish to alleviate the patient's suffering; on the other hand, they worry that choosing palliative care implies giving up on treatment, which leads to moral distress and guilt. Disagreements among family members further exacerbate their decision-making difficulties.

C5: *On the one hand, seeing him struggling to breathe, I can't bear to let him suffer any longer; I want him to be more comfortable. Besides, we've spent a great deal of money on medical treatment over the years, and the financial burden on the family is quite heavy. But on the other hand, if I do agree to palliative care, I'm afraid my relatives will accuse me of failing to fulfill filial obligations, thinking I'm abandoning him just to save money.*

C6: *What's hardest for me is that my family can't agree. Some think we should continue with the treatment, whilst others feel we shouldn't put the elderly person through any more suffering. I'm caught in the middle and under a lot of pressure; I just don't know what to do.*

C7: *The doctor said his heart function had deteriorated so badly that further resuscitation would be pointless, and suggested we consider palliative care. I knew that continuing resuscitation might not make*

much difference, but when it actually came to signing the consent form, I was still torn. I just couldn't bring myself to do it, fearing I would have regrets later on.

3.2.3 Theme 3: resistant-avoidant caregivers

Caregivers of this type find it difficult to accept the reality that the patient has entered the terminal stage of the illness. They often hold misconceptions about palliative care, often viewing it as a form of giving up on treatment. They tend to avoid topics related to death and insist on aggressive treatment, maintaining hope that the patient's condition will improve even as it clearly worsens.

C3: *Last time, the doctor said we could scale back the treatment a bit, claiming that further resuscitation wouldn't do him much good anymore. I was absolutely furious. Isn't it a doctor's duty to do everything in their power to save a life? How can they possibly advise the family to give up on treatment? As long as my husband still has a breath left in him, we must continue with resuscitation—how can we give up so soon? I insist on continuing with the best medication available; even if it's a bit more expensive, it's worth it—every extra day counts.*

C14: *The doctor says he's in the final stages, but the last time he took that medicine, he clearly improved for a while. Who's to say he can't get better again? As long as there's even a one percent chance, I won't give up. It feels as though, the moment I mention this, I'm just waiting for him to pass away—and I can't accept that.*

C21: *I never say these things in front of him—not a word about funeral arrangements or the end of life. If he were to hear them, it would only make him feel worse, and it would certainly have a negative impact on his condition. I've also made it clear to the family that they must never mention such things in his presence. He's still with us, so it's far too early to be talking about this; there's no rush to discuss it until the time actually comes.*

3.2.4 Theme 4: isolated-helpless caregivers

Caregivers in this category bear long-term caregiving responsibilities, lack sufficient family and social support, and face significant financial pressures. They tend to rely heavily on the opinions of healthcare professionals when making decisions and often exhibit feelings of helplessness, exhaustion, and passivity.

C16: *Having looked after him for so long, I feel I'm reaching my limit. I can't sleep properly at night, and during the day I have to be by his side constantly—taking him to appointments, collecting his medication and making sure he eats—it's all down to me. Sometimes when the doctor asks if I want to go ahead with a particular treatment, my mind goes blank and I simply don't know how to decide.*

C10: *We live in the countryside and didn't receive much education, so there's a lot we don't understand. We don't know what palliative care is either; we just thought the doctor was talking in a very complicated way that I couldn't quite follow. All I know is that his condition is getting worse and we don't have much money. I have absolutely no idea what we're supposed to do next.*

C20: My father passed away when I was young, so I'm the only one left to look after her. My children all live far away, so there's no one to turn to for advice. Sometimes she gets really upset, and I don't know what to do; I just have to cope on my own.

4. Discussion

Based on user profiling, this study conducted an in-depth exploration of the characteristics of palliative care decision-making among caregivers of patients with end-stage heart failure. The results indicate significant heterogeneity in the palliative care decision-making processes of caregivers for patients with end-stage heart failure, with differences manifesting across multiple dimensions, including cognitive level, psychological state, value preferences, social support, and resource needs. By integrating these decision-making characteristics, four distinct caregiver personas were established. These personas facilitate a clearer identification of the core dilemmas and underlying needs in the decision-making processes of different types of caregivers, thereby providing a theoretical foundation for the implementation of personalised palliative care decision support in clinical practice.

This study found that proactive caregivers are the group with the exhibited relatively higher decision-making readiness; they generally have a higher level of education, strong information-gathering skills, and a lighter financial burden on the family. This group of caregivers is able to view the shift in treatment goals during the terminal stage of illness rationally, communicates actively with healthcare professionals, and places great importance on the patient's comfort, dignity and quality of life; once the patient's illness has progressed to the terminal stage, they demonstrate a high level of engagement in shared decision-making. Ong et al.[17]found that caregivers with higher levels of health literacy are better able to understand the principles of palliative care and effectively synthesise medical information, thereby improving the quality of decision-making. At the same time, strong social support and psychological resilience also help them cope more effectively with the patient's deteriorating condition and death[18]. According to health literacy theory, an individual's ability to access, understand, evaluate and apply health information influences their health decision-making behaviour[19]. Proactive caregivers help to facilitate earlier acceptance of palliative care by patients, reduce futile medical interventions and excessive resuscitation, improve patients' quality of life, and uphold their dignity. However, such caregivers may also experience anticipatory grief, decision fatigue and emotional exhaustion during the long-term care process. Therefore, for proactive caregivers, healthcare professionals can help them further clarify the patient's values and care goals through advance care planning discussions, ongoing updates on the patient's condition, and multidisciplinary consultations. At the same time, they should provide ongoing psychological support, such as counseling for anticipatory grief, to help maintain the caregivers' decision-making capacity and ability to provide care.

Caregivers exhibiting conflicting and anxious attitudes constitute the largest group and face the most pronounced decision-making dilemmas; they have a wide range of educational backgrounds and lack systematic understanding of the disease and palliative care. Such caregivers struggle to balance the values of active treatment and comfort care; they are concerned that invasive treatments may

exacerbate the patient's suffering, yet fear that choosing palliative care will lead to moral guilt over being unfilial. They simultaneously rely on and distrust medical advice, whilst significant disagreements exist within the family, often leading to marked psychological conflict and emotional turmoil during the decision-making process. Li et al. [20] found that filial piety is a key factor influencing caregivers' decisions regarding palliative care, with caregivers frequently experiencing a conflict of values between prolonging life and alleviating suffering. Cognitive dissonance theory posits that when individuals hold mutually contradictory beliefs, they experience psychological distress and become trapped in a decision-making dilemma[21]. The decision-making conflict experienced by such caregivers directly impacts the effectiveness of palliative care delivery; persistent anxiety and repeated hesitation may lead to patients receiving unnecessary invasive treatments, thereby increasing their physical suffering and the burden on the healthcare system. At the same time, caregivers themselves are prone to severe anxiety and depression, which affects the quality of care provided. Therefore, for caregivers experiencing conflict and anxiety, healthcare professionals should use structured decision-making tools and family meetings to help them fully understand the disease prognosis and the pros and cons of different treatment options, thereby guiding family members toward reaching a consensus. At the same time, psychological support should be strengthened to alleviate the anxiety and uncertainty stemming from traditional notions of filial piety, thereby enhancing their confidence and efficiency in decision-making.

Resistant-avoidant caregivers were the group with the demonstrated the greatest resistance to palliative care in this study. they were predominantly middle-aged and elderly women with a lower level of education. Such caregivers lack a proper understanding of the illness and palliative care, equating palliative care with giving up on treatment. During the decision-making process, they display marked avoidance and resistance, tending to favour continued active treatment. Even when the patient's condition has clearly deteriorated, they are reluctant to initiate discussions about end-of-life issues and avoid communicating with patients and healthcare staff regarding relevant decisions, leading to delays in the initiation of palliative care and reduced decision-making quality. Abera et al. [22] found that when faced with serious illness, caregivers often adopt avoidance strategies due to emotional distress, fear of discussing death, and communication difficulties; insufficient communication among family members can further exacerbate the avoidance of disease-related decisions. Terror management theory suggests that when faced with the threat of death, individuals often alleviate their inner anxiety through denial, avoidance, and clinging to existing beliefs[23]. Such avoidance behaviours on the part of caregivers frequently result in patients being subjected to extensive ineffective and invasive treatments, enduring unnecessary physical suffering and damage to their dignity. At the same time, as caregivers themselves remain in a prolonged state of emotional suppression and exhaustion, this can easily lead to conflicts in clinician–caregiver communication and medical disputes. Therefore, when dealing with caregivers who are resistant or avoidant, healthcare professionals should first establish a relationship of trust and adopt a gradual approach to communication. By respecting the caregivers' emotional reactions, they can gradually correct misconceptions about palliative care and help caregivers gain a clear understanding of the disease progression and the shift in treatment goals. Through ongoing follow-ups and periodic

communication, healthcare professionals can gradually increase caregivers' acceptance of palliative care and reduce decision-making delays caused by avoidance behaviours.

Isolated-helpless caregivers are the group with the greatest challenges in decision-making and the most limited support networks. They are predominantly middle-aged and elderly women with low levels of education, living in rural areas, and are mostly unemployed or retired, facing significant financial pressures. This group of caregivers has a severe lack of understanding regarding illness and palliative care; their ability to access information is severely limited; they have no clear decision-making preferences; they bear the full burden of caregiving alone; they are in a state of prolonged physical and mental exhaustion; and they can only passively follow the advice of medical staff. Haya et al. [24] found that a lack of social support is a key factor leading to a sense of helplessness among caregivers, and that significant financial pressure further exacerbates this predicament. Social support theory posits that individuals facing stressful events who lack emotional, informational, material and evaluative support will experience a sense of helplessness and a decline in coping ability[25]. Although the passive decision-making behaviour of this group of caregivers reduces the risk of erroneous decisions to some extent, their lack of active participation and ability to synthesise information may lead to delays in palliative care, treatment choices that do not align with the patient's wishes, and a decline in the quality of decision-making. Furthermore, prolonged isolation and lack of support render caregivers vulnerable to psychological crises, potentially rendering them unable to continue providing care[26]. Therefore, for isolated caregivers, healthcare professionals should proactively assess their caregiving burden, financial pressures, and social support, and provide them with ongoing support by integrating medical, community, and social resources. At the same time, they should provide education on the disease and palliative care in an accessible manner to help caregivers improve their ability to access information and participate in decision-making, thereby reducing feelings of helplessness and passive decision-making.

4.1 Limitations

This study has the following limitations. Firstly, as the sample was drawn from two tertiary hospitals in Shanghai and did not include primary care institutions, the generalisability of the findings is limited. Secondly, the study focused solely on caregivers and did not incorporate the perspectives of patients or healthcare professionals, meaning it cannot fully capture the complexity of the actual decision-making process. Thirdly, the sample size was limited to 22 cases; although the data reached thematic saturation, expanding the sample size of interviews could further enrich and refine the dimensions of the profile. Fourthly, the construction of the profile may have involved subjective interpretations by the researchers, which could have influenced the presentation of details. Finally, this study employed a descriptive qualitative approach to construct the caregiver profile; future research could incorporate multi-centre mixed-methods studies to further validate and refine the findings of this study.

5. Conclusion

Based on user profiling methods, this study identified four distinct decision-making personas among caregivers of patients with end-stage heart failure regarding palliative care decisions: the proactive type, the anxious-conflicted type, the resistant-avoidant type, and the isolated-helpless type. These findings highlight the substantial heterogeneity across dimensions such as disease cognition, psychological state, value preferences, social support and resource needs. The findings of this study provide a theoretical basis for decision support for caregivers of patients with end-stage heart failure and lay the groundwork for subsequent multi-centre, large-scale mixed-methods research.

Declarations

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Author contributions

Qi Wang: Data curation, Formal analysis, Methodology, Validation, Writing - original draft; **Na Liu:** Conceptualisation, Formal analysis, Supervision, Data curation; **Hang Wang:** Validation, Formal analysis, Software; **Leying Li:** Formal analysis, Conceptualization, Validation; **Ye Fei:** Software, Methodology, Formal analysis; **Weiyang Zhang:** Conceptualization, Formal analysis, Funding acquisition, Methodology, Project administration, Supervision, Validation, Writing - review & editing.

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Data availability

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

This study has been reviewed and approved by the Medical Ethics Committee of Shanghai East Hospital, affiliated with Tongji University (2026-092). Prior to inclusion in the study, all participants were informed of the study's objectives, significance, potential risks and benefits, and were made aware of their right to participate voluntarily, to withdraw at any time without conditions, and to do so without incurring any adverse consequences. Each caregiver voluntarily signed a written informed consent form after fully understanding the information relevant to the study. All methods were carried out in accordance with relevant guidelines and regulations and the Declaration of Helsinki.

Consent for publication

Not applicable.

Competing Interest

The authors declare no competing interests.

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Table

Table 2 is available in the supplementary files section

Supplementary Files

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- [Table2Tailoredpersonasofpalliativecaredecision.docx](#)
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