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**Qualitative Research** 



# Experiences related to grief and death from the perspective of nurses caring for individuals approaching the end of life: A qualitative study

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#### Abstract

**Objectives:** It is known that it is important to determine the needs of individuals and their life experiences to improve the quality of respected care for individuals with life-threatening illnesses. This qualitative study aimed to identify experiences related to grief and death from the perspective of nurses caring for individuals approaching the end of life. **Methods:** This study is based on a qualitative research design. The sample of the study consisted of 15 nurses working in the palliative care and intensive care clinics of a training and research hospital in the Central Anatolia Region, caring for terminally ill individuals. The findings of the study were collected through semi-structured, in-depth individual interviews with audio recordings. The findings were analyzed thematically using the N-Vivo12 program.

**Results:** The average age of the nurses who participated in this study was 35 years. As a result of this study, four main themes and 13 subthemes emerged. Main theme I: End-of-life care needs (Subthemes: Support systems, preference for place of death, information, and spiritual needs); Main theme II: Reactions to death (Subthemes: Denial, anger, blame, and acceptance); Main theme III: Difficulties experienced in nursing care (Subthemes: Continuous requesting individual, difficulties in talking about death, and difficulties created by the nurse's death anxiety); Main theme IV: Facilitators in nursing care (Subthemes: Therapeutic communication and acceptance of death).

**Conclusion:** This qualitative study is thought to contribute to nurses' understanding of grief and bereavement experiences so that individuals can receive dignified and quality care at the end of life.

Keywords: Dignified care; end-of-life care; nurse; palliative care

**G**rief is a natural reaction to death, experienced not only by families when a patient dies but also by nurses responsible for the patient's care.<sup>[1]</sup> Especially in environments where patient death is common, such as intensive care and palliative care services, nurses have to face the difficulties brought by grief and death.<sup>[2-7]</sup>

Nurses play a vital role in helping individuals approaching the end of life to cope with the psychosocial challenges of a terminal illness diagnosis and in supporting families before and after the death of their dying relatives. According to the results of a systematic review by Johnston and Dönmez,<sup>[8]</sup> lack of emotional preparation for death, ineffective communication about death, ambivalent relationship with the deceased, difficulty in accepting the reality of death, and negative attitudes toward death are risk factors for prolonged grief disorder. In addition, the results of this study emphasize that grief begins before the death of the individual approaching the end of life, the importance of preparing individuals for grief before death,

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and the importance of nurses using appropriate therapeutic communication techniques with patients and their families on death-related issues.<sup>[8]</sup> However, many studies report that nurses are not comfortable or unprepared to provide bereavement care.<sup>[1,3,6,9]</sup> In a study conducted to investigate the perceptions and experiences of bereavement care among nurses and bereaved family members in an oncology unit in Hong Kong,<sup>[6]</sup> nurses stated that they needed more training to improve their knowledge and skills in providing bereavement care. In a study on the grief experiences of nurses caring for patients who died in intensive care, it was stated that nurses should have more knowledge about end-of-life.<sup>[1]</sup> Similarly, Mir et al.<sup>[9]</sup> study on nurses facing sudden deaths in intensive care and emergency units emphasized that nurses need training to identify the care needs of bereaved individuals. In a gualitative study by Khalaf et al.<sup>[3]</sup> on the effect of patient death on nurses' grief experiences, it was stated that nurses need support in understanding the grief experiences of patients after their deaths and coping with the grief they experience.

Ineffective end-of-life care by the nurse can cause many problems for family members in the following weeks, months, or years. These problems include prolonged bereavement disorder, chronic insomnia, post-traumatic stress disorder, anxiety, depression, hypertension, and risk of sudden cardiac death.<sup>[10-12]</sup> In addition, at the societal level, unresolved bereavement can place an additional burden on the health-care system by causing the bereaved person to experience long-term coping problems and associated health problems.<sup>[12]</sup> Effective end-of-life and bereavement care that focuses on the needs of individuals with terminal illness and their families and includes pre- and post-death preparation has a key role in reducing this burden.<sup>[9,13]</sup> Therefore, it is thought to be important to identify the needs and experiences of individuals at the end of life to improve the quality of person-centered dignified care of people with life-threatening illness and their families.[12,8,14,15] Because the care of bereaved individuals can only be possible by planning in line with the determination of the unique experiences of nurses, focusing on individual-centered needs, and providing respectful and quality care.<sup>[15]</sup> However, while there are studies in the literature focusing on nurses' feelings, thoughts, attitudes, and experiences related to grief, death, and end-of-life care, gualitative studies on the experiences of individuals with life-threatening illnesses regarding grief and death from the perspective of nurses were not found.<sup>[5,12,16-18]</sup> Therefore, it can be said that this gualitative study is important in terms of determining the needs of individuals approaching the end of life from the perspective of nurses regarding grief and death and contributing to increasing the quality of person-centered, respectful care in line with these needs. The themes revealed by the study

#### What is presently known on this subject?

- In the literature, nurses who care for individuals approaching the end of life have difficulty discussing death with patients and need training on this issue
- Nurses need to protect the psychological, social, and spiritual well-being of individuals approaching the end of life while trying to cope with the diagnosis of a terminal illness and
- Families are reported to play a vital role in supporting their near-death relatives before and after their death.

#### What does this article add to the existing knowledge?

- This study emphasizes that the most important end-of-life needs of patients are: Accurate/timely information and strengthening spiritual resources and support systems
- The findings of the study reveal the specific difficulties that nurses experience in communicating with patients on issues related to grief and death (e.g., difficulties in caring for angry patients and patients with constant requests)
- In addition, this study contributes to the literature with a conceptual schema of experiences related to grief and death from the nurse's perspective.

#### What are the implications for practice?

- This study aims to increase nurses' insights into their feelings and attitudes toward death, loss, and grief in the clinical setting
- To improve the quality of person-centered, dignified end-of-life care in line with the needs of people with terminal illnesses and
- It may contribute to the creation of end-of-life care guidelines in the light of facilitators and challenges in end-of-life nursing care
- The "Schema of experiences of grief and death from the nurse's perspective" developed as a result of the research findings can be integrated into the end-of-life care education of nurses and help to provide a comprehensive view to improve the quality of care.

are important in terms of (i) increasing nurses' insights into their feelings and attitudes toward the terminally ill patient in the clinical environment; (ii) providing person-centered respectful care quality in line with the needs of people with terminal illness; and (iii) helping to identify facilitators and challenges in end-of-life nursing care. In addition, it is thought that the "Schema of experiences related to grief and death from the nurse's perspective" developed as a result of the research findings can be integrated into the endof-life care education of nurses and help to provide a comprehensive view to improve the quality of care. In addition, this study may contribute to (i) determining the difficulties and facilitators experienced by nurses while caring for individuals with life-threatening diseases, (ii) improving nursing practices in palliative care and intensive care services, (iii) creating end-of-life care guidelines in line with these recommendations, and (vi) increasing the awareness of nurses who do not have the opportunity to learn experientially about end-of-life care about death and grief.

#### **Materials and Method**

#### **Overall Objective**

This qualitative study aimed to identify experiences related to grief and death from the perspective of nurses caring for individuals approaching the end of life.

#### **Subobjectives**

- To determine the experiences of individuals approaching the end of life regarding mourning and death from the perspective of nurses
- To determine the facilitators and difficulties experienced by nurses while providing end-of-life care.

#### **Research Type**

In this study, the in-depth interview method was used in a descriptive, qualitative research design. This method is the most appropriate research type for this research design as it is used to explore the meanings of social phenomena that individuals experience in their natural contexts.<sup>[19]</sup>

#### Sampling Number and Method

This study was conducted with 15 nurses working in palliative care and intensive care clinics in a training and research hospital in the Central Anatolia Region. According to the literature, 12 interviews are reported to be sufficient in qualitative studies aiming to understand common perceptions and experiences among a group of homogeneous individuals.<sup>[20,21]</sup> In this study, satisfaction was reached with 15 nurses working in adult intensive care and palliative care. In addition, purposive and snowball techniques were used among the research sampling methods. The purposive sampling technique is appropriate for this qualitative research as it is pragmatically guided based on the research questions and study objectives. In addition, through snowball sampling, after a participant was included in the study, other individuals experiencing a similar situation were enabled to participate in this research.<sup>[9]</sup>

The study included nurses who provided care to patients aged 18 years and older with end-of-life and/or palliative care needs, who worked in intensive care and palliative care services in the Central Anatolia Region, where death is frequently encountered, and who gave consent before starting the interview.

#### **Ethics Committee**

Institutional Permission was obtained from Çorum Provincial Health Directorate and Hitit University Erol Olçok Training and Research Hospital, and Ethics Committee permission was obtained from Demiroğlu Bilim University with the decision number 24.11.2020/2020-22-02. Participation in the study was voluntary, informed consent was obtained from all participants, and it was undertaken that the information belonging to the research would be kept confidential. The study was conducted in accordance with the Declaration of Helsinki.

#### **Data Collection**

This study, which was designed with a qualitative research design, was conducted through individual interviews with

nurses working in intensive care and palliative care wards using a face-to-face, in-depth, semi-structured interview form. After obtaining institutional permissions from Erol Olcok Training and Research Hospital, a meeting was organized by the Health-Care Services Manager of the hospital with the nurses in the wards, and appointments were made by determining the time and place where the nurses were available. The participants were informed in detail about the confidentiality of the study, that they could leave the study at any time, and that the voice recording could be stopped. All interviews lasted an average of 45 min after the participants were informed about the research and their informed consent was obtained (interviews were conducted for a minimum of 30 min and a maximum of 60 min). The interviews were conducted in hospital interview rooms where the privacy of the nurses was ensured or in the nurses' homes. Nurses' facial expressions, emotions, and reactions were noted during the interviews. The open-ended guestions to be asked in the interviews were designed to determine the participants' experiences of grief and death and to reveal the facilitators and difficulties they experienced while providing end-of-life care. In this context, nurses were asked two main questions: "From your perspective, what are the experiences of individuals with life-threatening illnesses that you care for regarding grief and death?" and "What are the difficulties and facilitators you experience when caring for individuals approaching the end of life?" and "Can you explain this a little more?" In-depth interviews were conducted with questions.

#### **Data Analysis Method**

The thematic analysis method developed by Clark and Braun<sup>[22]</sup> in 2006 and updated in 2022<sup>[4]</sup> was used to analyze the research. The six stages of Braun and Clarke's analysis (1. Recognition [familiarity with the data], 2. Creating initial codes, 3. Searching for themes, 4. Reviewing themes, 5. Identifying and naming themes, and 6. Creating the report) were used to analyze the data. This thematic analysis involves in-depth recording to consolidate codes and themes. These were reviewed and refined by the research team to arrive at final themes and sub-themes. The themes were coded to reflect the data collection questions. In addition, NVivo 12.0 software was used to facilitate data management and systematically code the transcriptions into themes and subthemes. The themes were independently constructed by the 1<sup>st</sup> and 2<sup>nd</sup> researchers (YY) and (CFD) to increase the reliability and validity of the study. In addition, the themes obtained by the third researcher (NA) were reviewed to reach the final report. In addition, the COREQ list (list of criteria for reporting qualitative research) was used to help ensure that qualitatively designed research is conducted according to appropriate criteria.[23]

### Results

#### **Sociodemographic Characteristics of Participants**

Among the nurses who participated in the study, 53.3% were married. The mean age of the nurses was 32.13±7.07 years, and they had an average working experience of 16 years or more (Table 1).

#### Themes

Four main themes and 13 subthemes emerged with the thematic analysis method through the N-Vivo program. These themes are presented in detail in Table 2, and a visual presentation of the results is presented in Figure 1. Below, the themes of patient needs, reactions to death, difficulties in nursing care, and facilitators in nursing care are reported with examples, respectively.

#### Theme 1: End of Life Care Needs

The main theme of "End-of-Life Care Needs" that emerged in this study has four sub-themes: place of death preference, support systems, information, and spiritual needs (Table 2).

Two nurses who participated in the study emphasized the patients' preference for the place of death and stated that individuals with terminal illnesses do not want to die in a hospital and want to die at home where they feel good and peaceful:

"...He was saying I miss my village so much, take me to my village. He said he wanted to die next to his family. There was a hazelnut tree in his garden and he said he would break it and eat it. We told his relatives to bring him nuts and he was very happy...." (Nurse 4)

In addition, four nurses who participated in the interviews stated that individuals approaching death do not want to die alone and that the support of their relatives at the end of life is very important for them:

"I can never forget a patient... The patient was dying and could not die. He kept asking to see his son but his son wouldn't come. His son came, saw his son, talked to him and died... He waited for him and died next to him..." (Nurse 5)

However, two nurses emphasized the importance of meeting the spiritual needs of patients in providing quality end-of-life care for them, saying: "A patient I care for said, I am not rebelling, but I want to go to the toilet and pray myself, so I want to leave this place." (Nurse 13)

Finally, three nurses emphasized that they experienced difficulties in the process of informing patients and their families about the terminal illness. While describing the difficulties she experienced in preparing individuals approaching death and their families for death, a nurse said the following:

(n=15)				
Participant no status	Marital	Age	Professional life (years)	
H1	Married	42	23	
H2	Single	26	8	
H3	Single	33	15	
H4	Single	22	6	
H5	Married	46	28	
H6	Single	35	17	
H7	Married	27	12	
H8	Married	24	10	
H9	Married	38	22	
H10	Single	29	18	
H11	Married	26	13	
H12	Married	31	11	
H13	Single	40	23	
H14	Married	28	12	
H15	Single	35	24	

Table 1. Distribution of sociodemographic findings of nurses

"...We need to prepare the patients and their relatives when they ask if they will be able to stand up (Will I get better?) We cannot say that they cannot stand up, but we say it is very difficult, on the one hand you need to prepare them that the situation will not change, on the other hand it is very painful and difficult to tell them this... We do not want to destroy their hopes." (Nurse 15)

#### **Theme 2: Reactions to Death**

The main theme of "*Reactions to Death*" that emerged in this study has four subthemes: *anger, denial, blame, and acceptance* (Table 2).

Two nurses who participated in the study emphasized patients' feelings of anger about death:

"An uncle in his 60s was in the terminal stage of Lung CA... He was always angry and aggressive. Always questioning the treatment... Every time he had a symptom he would ask why it happened, when will it go away, why is this happening, and at the slightest distress he would panic, get tense and aggressive... Both to us and to his family... If she had a fever, why did it happen? When will it pass? Isn't this the end?" (Nurse 11)

Three nurses who participated in the research stated that patients and relatives of patients approaching death were particularly in denial:

"The relatives of the patient never accepted... They told me that we found a doctor, and they said that we could get the patient back on his feet in 1 month. I said if there is such a hope, don't leave the door of that doctor, we don't expect such a thing. I had to make this clear, the patient was hos-

Table 2. Thematic display of research findings				
Themes	Sub-Themes	Participant testimonies		
End of life care needs		He said "I missed my village so much, take me to my village". He said he wanted to die with his family. There was a hazelnut tree in his garden and he said he would break it and eat it. We told his relatives to bring him nuts and he was very happy (Nurse 4)		
		"Uncle Talip was about 70 years old. He used to be a wrestler. He was generally a cheerful uncle, he always chatted with me. He used to tell me about his village, he used to ask if there was this or that in my village. He used to say that he would rather die than live like this. He always wanted to go to his village and die there." (Nurse 7)		
	Support systems	"I can never forget a patient The patient was on his deathbed and could not die. He constantly wanted to see his son but his son would not come. His son came, saw his son, talked to him and died. He waited for him and passed away next to him" (Nurse 5)		
		"Nobody looked after him, his nephew was looking after him only when he was not capable of taking care of his personal needs. When no one wanted to look after him near the holiday, they would send the patients to us. He stayed with us for 3 months. The relatives of the patients next to him would come. His eyes would fill with tears when I saw him like that after the visiting hours, I would get very upset. When the other patients kept saying to him, "Don't you have anyone, our people brought this and that, these people came to visit" (Nurse 2)		
		"His mother was looking after him, his children would come very rarely, maybe she didn't want them to see him like that, they came very rarely. He started to get worse during the visiting hours. He asked for forgiveness from us" (Nurse 15)		
		"He trusted me and a friend much. He used to call us from home in the evening saying, "I'm very bad, come please, I'm going to die, I can't breathe". We were trying to calm him down by saying, "Take a deep breath, it will pass." He was afraid of death…" (Nurse 10)		
	Spiritual needs	"A patient I was taking care of said, I'm not rebelling but I want to go to the toilet and pray myself so I want to leave here…" (Nurse 13)		
		"One day I entered the room and found her holding her father's hand, caressing and loving him Her father was asking her why she was in so much pain, why she was experiencing these things, and her daughter was telling her that God hurts those he loves, you will go to the other side completely clean…" (Nurse 8)		
	Being informed	"The relatives of the patients did not want to accept the patient's condition and were causing problems. The relatives of the patients had no tolerance for delays or waiting. The nurses were saying that these relatives of the patients would cause us trouble, and when they saw the attitude of the relatives of the patients, they wanted the patient to be discharged and leave as soon as possible. The reason for the attitude of the relatives of the relatives of the relatives of the patients is generally ignorance" (Nurse 15)		
		"If they do not know what will happen and are not informed enough about how the process will proceed, they become very aggressive. However, if they see that they are being followed up regularly and dealt with, they become more compliant and accept the situation more easily." (Nurse 8)		
		"When they ask, "Will I be able to get up (Will I get better?); we need to prepare the patients and their relatives. We cannot say that it will definitely not be, but we say that it is very difficult, on the one hand you need to prepare them that the situation will not change, on the other hand it is very painful and difficult to tell them this. We also do not want to destroy their hopes." (Nurse 11)		
Reactions to death	Anger	"This patient experienced serious difficulties, he suffered a lot. His consciousness was in and out. He was a childish, likeable person. Sometimes he would be aggressive, sometimes he would shout at night." (Nurse 15)		
		"A 60-year-old uncle was in the terminal stage of Lung CA. He was always angry and aggressive. He constantly questioned the treatment. He would ask "Why did it happen, when will it pass, why is it like this" for every symptom in his body and would panic, get tense and aggressive at the slightest trouble. When he had a fever, he would ask both us and his family "Why did it happen? When will it pass? Isn't this the last one?" (Nurse 11)		

pitalized with us for 3 months, and the family never entered the acceptance process. He believed that he would get better so much that he started to say that he gave reactions that his mother did not give. For example; he blinked his eyes, he squeezed my hand – he was not reproachful because the cortex was deactivated – and he said he would get better. When he couldn't hear what he wanted to hear from me, he would cry, shout, and become irritable." (Nurse 15)

"When I came to the ward, I asked how are you? The patient said, Why am I here? I came on foot, look at the state I am in,

I want to go. When I prepared his treatment and went to him, he kept telling me, "I came on foot, I'm fine, I'm fine, I'm fine, I want to go, I'm fine." (Nurse 13)

However, three nurses stated that patients and relatives of patients approaching death were accusatory when expressing their reactions.

"But some patients think that they are not getting better because the physician does not take good care of them and the nurse does not come on time, and they think that they will get better with proper treatment. For example, you said



Figure 1. Schematic of experiences of grief and death from the nurse's perspective.

you would give me medicine for the edema and it didn't go away, you gave me medicine and I still can't walk, etc. They constantly show attitudes and discourses that are accusatory and expect a full recovery..." (Nurse 3)

"They want to get what they want immediately, and when they don't, they cause problems. For example, if the physician speaks briefly, this is a problem, if there is a fever, they want the doctor to see the patient immediately, if he/she does not come, they constantly go to the nurse and complain that it has been so long and he/she has not come yet and put pressure on him/her. They do not consider your care and treatment sufficient. They are looking for a responsible person, they believe that they would get better if they were in a better place, if they had better treatment..." (Nurse 15)

Finally, in the interviews, five nurses stated that patients and relatives of patients approaching death accepted the situation

and that various factors were effective in the patient's transition to the acceptance stage as follows;

"Another thing I have observed about the acceptance process of patients is that if there is a sudden situation, if it happens suddenly and the process progresses quickly, acceptance is difficult. If the process is prolonged, acceptance is easier, the patient gets used to it and accepts the situation." (Nurse 15)

"I have observed that people who do not have many regrets in life, who have not made big mistakes, accept death more quickly..." (Nurse 5)

"Also, those who are religious, but truly religious, accept the situation more easily. Those who have inner peace, those who have completed their inner reckoning face the situation more easily, and people who have done and lived most of what they want to do in life face death more easily. They accept it more easily." (Nurse 11)

#### **Theme 3: Difficulties Experienced in Nursing Care**

The main theme of "*Difficulties in Nursing Care*," which emerged in this study, has three subthemes: the individual with continuous wishes, difficulties in talking about death, the nurse's acceptance of death, and the difficulties created by death concerns (Table 2). Regarding the difficulties experienced in nursing care, three nurses stated that they had difficulties in caring for individuals with continuous requests:

"...They react seriously when they don't get their way... They insult and curse... As health personnel, we want them to leave. We are already tense... We cannot look at it emotionally... When the patient or the patient's relatives are aggressive, we try to understand at first, but as time passes, if they still do not accept the situation and maintain the same attitude, the health personnel cannot tolerate it because they are not our only patients..." (Nurse 15)

"Their relatives were problematic people, they came very rarely and caused problems. Did you feed him/her, did you give him/her food, did you give him/her medicine, did you take good care of him/her? When they came outside visiting hours, they fought when we didn't let them. Uncle was very upset, he was ashamed of us, he was telling us not to look at them, God bless you... He didn't die on my watch, I felt strange when I learned that he had died..." (Nurse 7)

Two nurses who described the difficulties experienced in nursing care stated that they had difficulty in talking about the patient's condition;

"I was saying no, you will get better and then the patient suddenly died... We were very sad, we did't expect it at all. We all cried. The patient was very young and we were very sad. Some friends even shared the death of their patient on their social media..." (Nurse 4)

"We need to prepare the patient's relatives when they ask if he will stand up. We can't say that they absolutely can't get up, but we say it is very difficult, on the one hand you have to prepare them that the situation will not change, on the other hand it is very painful and difficult to tell them this... We don't want to destroy their hopes..." (Nurse 15)

While both nurses who participated in the study emphasized death anxiety and acceptance of death, they stated that it was more difficult for them to care for the patients they identified themselves with:

"We had a 33-year-old male patient with a brain tumor, I was very sad for him, I think I identified myself with him. The patient had a child, he was very sad for his child, he was crying... I thought about myself, I had a child too, how sad I would be if one day my child saw me in this situation..." (Nurse 15)

"I have seen hundreds of deaths, the ones that affect me the most, the ones I identify with, the ones I participate in the care

of our young patients, those with children. I think about what will happen to my children if I die. I think about how I would feel if something like this happened to me when I was 19 or 20. And I think sudden deaths affect me a lot..." (Nurse 10)

#### **Theme 4: Facilitators in Nursing Care**

The main theme of *"Facilitators in Nursing Care"* that emerged in this study has two subthemes: *therapeutic communication and acceptance of death* (Table 2).

Two nurses who participated in the study emphasized the importance of therapeutic communication and stated that this facilitates patient compliance and acceptance:

"After 35 days in intensive care, we were taking him to the ward. In the ward, he needs to be mobilized in order for his circulation to return to normal, but he comes back to the intensive care unit because he cannot walk for fear of dying. When he came to us, he recovered and walked because he trusted us." (Nurse 10)

"A female patient in her 40s was hospitalized with us in the terminal stage of Lung CA. She had respiratory distress. The patient had anxiety about not being able to breathe. Dying and not being able to breathe. Because most of the time the patient was screaming that she was suffocating and calling us, but when we looked at her oxygen saturations, we saw that they were normal. The patient relaxes when we say, "Take deep breaths, you are fine, we are with you, there is no problem." (Nurse 15)

"Patients with whom we communicate well are calmer, they do not act agitated, they do not pull the intravenous line, they are more compliant in their work, both they are comfortable and we are comfortable... They do what we want and make an effort to get better..." (Nurse 13)

In addition, a nurse participating in the interviews stated that acceptance of death facilitates care:

"Patients hospitalized with us show different reactions. If they accept that they are going to die, they don't react at all, they don't talk, they are harmonious. But patients who cannot accept death are aggressive... They find excuses for everything they do, complain, are aggressive and belligerent toward us and their family. For example, because the veins of the patients are thinned due to chemotherapy, it is difficult to open an IV. Patients who have accepted death do not react much, even if it hurts, they say it is not your fault. But the patient who has not accepted death gets very angry, reacts like you hurt me, you can't do it, let someone else do it, do you know what I am going through..." (Nurse 11)

## Discussion

Four main themes were identified in this qualitative study, aiming to identify experiences related to grief and death from the perspective of nurses caring for individuals approaching the end of life. These themes are: End-of-life care needs, reactions to death, difficulties in nursing care, and facilitators in nursing care (Table 2).

The main theme of "End of Life Care Needs" that emerged in our study has four sub-themes: Preference for place of death, informing support systems, and spiritual needs.

Two nurses who participated in our study emphasized the patients' preference for the place of death and stated that terminally ill individuals do not want to die in a hospital and want to die in a home environment where they feel good and peaceful. When caring for a dying patient, it is very important for the nurse to plan a care strategy that focuses on making the patient's last moments of life as comfortable as possible.<sup>[24]</sup> This plan should include the assessment of not only the patient's physical presence but also their emotional and psychosocial well-being.<sup>[3]</sup> In this context, Södörman et al.'s<sup>[17]</sup> emphasize the importance of the place of death choice at the end of life as "Choice and preference are essential for person-centered care and supporting personal choice at the end of life should be a priority for the nurse." supports the results of this qualitative study. In addition, one of the nurses who participated in the study by Glies et al.<sup>[12]</sup> focusing on nurses' perceptions and experiences of caring for patients who died in the emergency department environment; expressed the importance of the place of death preference by saying, "Patients die in the emergency department because of the lack of clear end-of-life care guidelines, but if the patient could be asked, I am sure they would want to die at home, in a familiar place where they feel safe, not in the emergency department. " In a qualitative study conducted by Skorpen Tarberg et al., [23] the nurses participating in the study emphasized the need to create a space for dying and to provide the opportunity to die at home for patients who are hospitalized for a long time. In another study<sup>[21]</sup> on the perceptions and experiences of patients and bereaved families in an oncology unit regarding bereavement care, the choice of the place of death and the creation of a space for death were emphasized among the elements of good bereavement care, and the following statement of a patient relative was included; "If we were in a place where we could be quiet alone with my husband, we would not think about whether we were disturbing other people." Similarly, in the study of Donesky et al.[25] it was stated that patients generally wanted to be at home in their last period and wanted to share special moments that would help their loved ones remember them after death.

In our study, it was determined by nurses that patients approaching death do not want to die alone and that support systems are important. Similar to these results, Giles et al.<sup>[12]</sup> stated that nurses consider the presence of the family as a vital element of effective end-of-life care and expressed the difficulties experienced in this regard as follows: *"Many staff* 

are reluctant to have the family of a dying patient present and make excuses for the family not to be with the patient, but this opportunity should be offered to the family without hesitation." In a study<sup>[26]</sup> examining emergency nurses' perceptions of end-of-life caregiving in Hong Kong, nurses emphasized that; "The final farewell is a very meaningful sharing that affects the grief and mourning of family members." These results are similar to the following statements in our study; "It is important to allow them to stay with the dying patient, if you do not allow them to stay with the patient, they will feel something missing throughout their lives, and being with the patient can lead to a better grieving process." In a qualitative study,<sup>[27]</sup> in which the grief needs of individuals with cancer and their families were examined from the perspective of health-care professionals, the importance of family support and the trust relationship established with caregivers for the control of physical and mental symptoms and grief management in the later stages of the individual's life at the end of life was emphasized. In our research result, nurses frequently stated that the patient's trust in the nurse would affect the treatment process. Establishing support systems and trust in end-of-life care practices provided by nurses in a way that includes compassion and takes into account the cultural characteristics of individuals has an important place in providing quality bereavement care.<sup>[28]</sup>

In our study, spiritual (spiritual) needs were identified as another important element of end-of-life care. In the studies, it was emphasized that spirituality and spiritual care are other factors in confronting and struggling with the feelings of anxiety, pain, loneliness, and deprivation, and strengthening against these feelings that patients at the end of life and nurses who care for these patients feel at the end of life and that spiritual needs should be determined to provide spiritual care, which is expressed as intuitive, social and integrative situations that reflect the patient's reality. However, studies show that nurses prefer to stay away from issues related to spirituality because they do not consider themselves adequate in identifying spiritual needs and diagnosing mental problems, lack self-confidence, and feel that they lack spiritual care skills.<sup>[18,26,29–31]</sup> Spiritual care, which is a fundamental element of holistic care, also has an important place in end-of-life practices.<sup>[26,32]</sup> In a study on emergency nurses' perceptions of end-of-life care, a nurse's statement is as follows;<sup>[31]</sup> "Nurses should address the psychosocial and spiritual needs of patients and their relatives in accordance with the end-of-life protocol. For example, I provide spiritual care by turning on music in the patient's room in accordance with the patient's cultural preference, or if the patient is unconscious, I give spiritual care by talking and touching the patients to make them feel my presence there." Rassonli and Sajadi<sup>[28]</sup> emphasized that the use of spiritual and religious approaches is very important in dealing with the stress caused by cancer in Iranian society. In a qualitative study by Khalaf et al.<sup>[3]</sup> focusing

on nurses' bereavement experiences after patient death, they stated that nurses generally consider the religious and cultural needs of patients approaching death and their families. For example, a nurse participating in this study described spiritual care practices as follows: "I remember a dying Christian patient; the priest was called, rituals were performed. The relative brought a dress for the deceased patient, put make-up and perfume on it."

Our research results show that patients and their relatives are mostly disturbed by the uncertainty of the process, this uncertainty causes them to behave more aggressively, and nurses have difficulty in managing this process. In a study on nurses' experiences of caring for patients approaching the end of life<sup>[12]</sup> it was stated that to manage the expectations of patients and their families and to cope with the uncertainty experienced, interdisciplinary interviews should be conducted to provide consistent information to the patient and family, and if necessary, a spokesperson should be selected from the family, and consistent information should be given to individuals in a clear and understandable language by allocating sufficient time to this person. Donesky et al.[33] emphasized the importance of communication and sharing of feelings and information between patients approaching death and their families and nurses. In the study on the bereavement experiences of families of children with cancer, in connection with the subcategory of gaining family self-control and awareness of end-of-life care, the participants stated that the reason why the child and family wandered around in different areas despite the provision of care, knew insufficient medical resources, spent too much time to access the service; the patient has problems with the information, that parents such as to be involved in treatment decisions and to know the risks of treatment, that knowledge about the child's condition is necessary for parents to have peace of mind, to keep the situation under control, to remain optimistic and to develop strategies that are in the best interest of the child. In another qualitative study conducted with 15 nurses and 10 bereaved families in an oncology unit, a nurse emphasized the importance of informing patients and their relatives appropriately and in a timely manner: "Bereaved families should be informed regularly about the patient's condition, so that the patient's relatives know that the patient is not neglected and is being followed, they are less worried and thus the management of bereavement care is more comfortable."[6]

In our study, nurses stated that they saw denial, blame, anger and acceptance reactions in patients approaching death and their families. The first of the attitudes toward death is denial. When a person encounters a situation that threatens his/her existence, he/she uses denial to overcome this threat. When there is nothing the person can do, denial can help alleviate the person's pain. Denial buys time for the patient's adaptation process.<sup>[3,34,35]</sup> It has been said that the patient's first

reaction may be a shock reaction that will pass over time, a state of numbness and numbness. In the study of Günay and Özkan;<sup>[36]</sup> "When the doctor told me, I doubted that it could be wrong, I prayed that it would be wrong". When bad news is received, the first reaction to the news, "No, this can't be true, it can't be me," turns into a new reaction, and the reality of "This was not a mistake."[34,37,38] The anger experienced is a normal phase seen in the process of mourning and facing the terminal illness. Underneath anger is the pain felt by the individual.<sup>[38]</sup> Emotions related to this phase include sadness, guilt, shame, helplessness, and hopelessness. Blaming oneself or others leads to feeling anger toward oneself or others.[34,37,38] Nurses can eliminate communication conflicts by accepting the anger of individuals, listening to them compassionately, and confronting their own fears about death while caring for bereaved individuals and their families.<sup>[7,34,37,39,40]</sup>

In our research results, it was found that one of the difficulties experienced in nursing care is "the individual who constantly requests". During the dying process, it is necessary to determine the wishes of the patient and his/her family and to fulfill the needs in this direction. However, due to the workload, sometimes the wishes of patients and their relatives cannot be fulfilled.<sup>[12]</sup> In a study conducted with 16 nurses with experience in providing end-of-life care, nurses stated that they felt tired of answering family members who asked questions over and over again.<sup>[18]</sup> Underneath the constant questioning of the patient and his/her family actually lies anxiety and fear. When the nurse is aware of this situation and the information and psychosocial needs of the patient and family are taken into consideration, when the patient and family feel safe, they will not ask continuous questions, will not make continuous requests, and will pass to the acceptance stage. In a study<sup>[6]</sup> focusing on the perceptions and experiences of nurses in the oncology unit toward the bereavement care of bereaved families, a nurse emphasized that when the needs of individuals are effectively responded to, the needs of patients and their relatives to constantly ask questions can be eliminated by saying "There should be an expert who knows what to say, which door to enter, how to guide them, because they really say such a thing that only an expert team can understand their needs from their words."

In our study, it was found that nurses had difficulty in talking about death. Giving bad news or talking about death is a basic communication skill. When talking about death or giving bad news, it is important to maintain trust, reduce uncertainty, prevent unrealistic expectations, and ensure patient compliance.<sup>[41]</sup> Studies show that nurses are reluctant to discuss issues related to death<sup>[42,43]</sup> and tend to avoid dying patients. <sup>[44]</sup> Although it is difficult for health-care professionals to talk about death, accepting, compassionate, and sincere communication that focuses on the needs of patients and their relatives are key point in overcoming this difficulty.<sup>[34]</sup> In addition, therapeutic communication was identified as one of the facilitators of nursing care in our study. The main function of nurses is to help patients and healthy individuals recognize and meet their unmet needs. Among nurse theorists, King, Travelbee, and Orlando emphasized the importance of patient-nurse interaction and defined nursing as "the process of interpersonal interaction." In the literature, it has been stated that the interpersonal relationship established by the nurse with the patient is an important factor in determining the course and outcome of the disease and that this relationship can be as important and useful as the use of morphine in pain treatment. <sup>[45]</sup> In the studies, it has been stated that nurses working in the wards are mostly task-oriented, but end-of-life care providers should reinforce their competencies related to their professional knowledge and skills, especially therapeutic relationships and patient advocacy.[18,27] Therapeutic communication and compassionate care are considered to be the basic elements of patient-centered care in relieving, reducing, or alleviating the pain and suffering of others.[46]

In conclusion, all these findings are important in terms of contributing to the determination of the needs of individuals approaching the end of life regarding grief and death from the perspective of the nurse and increasing the quality of person-centered, respectful care in line with these needs. In addition, at the societal level, unresolved grief can bring an additional burden on the health system as the bereaved person lives with long-term coping problems and health problems that may arise due to this<sup>[12]</sup> effective end-of-life and bereavement care, which focuses on the needs of terminally ill individuals and their families and includes pre- and post-death preparation, has a key role in reducing this burden.<sup>[13,18]</sup> Therefore, with this study, it is thought that it is important to determine the needs and experiences of individuals at the end of life to improve the quality of person-centered respected care of people with life-threatening illness and their families.

#### Limitations

Since the research data were collected through semi-structured interviews, the generalizability of the results is limited. In future studies, more data should be collected with larger groups and mixed research methods to ensure quality and dignified bereavement support and care.

# **Conclusion and Recommendations**

The themes revealed in this study are important in terms of (i) increasing nurses' insights into their feelings and attitudes towards the terminally ill patient in the clinical setting; (ii) providing a respectable person-centered quality of care in line with the needs of people with terminal illness; and (iii) helping to identify facilitators and challenges in end-of-life nursing care. This gualitative study is thought to contribute to understanding the grief and mourning experiences of nurses, determining the experiences of individuals approaching the end of life regarding grief and death from the perspective of nurses, and ensuring that individuals receive dignified and guality care at the end of life. In addition, the results of this study may contribute to the creation of end-of-life care guidelines for clinical practices that take into account the needs of individuals with terminal illness and their families and the facilitators and challenges in end-oflife nursing care. In addition, the "Schema of experiences of bereavement and death from the nurse's perspective" developed as a result of the research findings can be integrated into the end-oflife care education of nurses to provide a comprehensive view to improve the quality of care. In future studies, it is recommended to conduct studies that include nurses caring for more specific age groups, including dying individuals and their relatives, and focus on the sociocultural dimensions of the issue.

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