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Views of nurses regarding palliative care and their roles in the bereavement process

Hemşirelerin palyatif bakıma ilişkin görüşleri ve yas sürecindeki rolleri

Ayşe Gülay Şahan[1] Yasemin Yıldırım[2] Sevnaz Şahin[3]

[1]Balıkesir University, Faculty of Health Sciences, Department of Gerontology, Balıkesir-Türkiye

[2]Ege University, Faculty of Nursing, Internal Medicine Nursing, İzmir-Türkiye

[3]Ege University Faculty of Medicine, Department of Internal Medicine, İzmir-Türkiye

ABSTRACT

Aim: The role of nurses in improving patients' quality of life in palliative care is expanding with changes in the healthcare system and scientific advancements. These roles focus on symptom management, education and communication, care coordination, and providing psychosocial and ethical support. Our study aimed to identify nurses' perspectives on their role in the bereavement process in palliative care.

Materials and Methods: This research is a descriptive and qualitative study aimed at establishing an in-depth and detailed understanding of the current situation. It was designed as a case study, a qualitative research design, and an explanatory/descriptive case study, a case study type. The study group consisted of 12 participants selected using easy accessibility and criterion sampling methods. Descriptive and content analysis methods were used to analyze the data obtained through semi-structured interviews.

Results: The roles in the study were defined primarily within the scope of symptom management and care, followed by roles related to coordination, effective communication, spiritual support, and ethical and psychosocial support. This study determined that some nurses considered themselves competent in terms of communication and empathy, while others considered themselves partially competent in terms of empathy, and others considered themselves inadequate in terms of communication skills.

Conclusion: The findings indicate that nurses' roles in the palliative care and bereavement process are multidimensional and that communication and emotional support skills may vary among nurses. These results highlight the need for institutional support and structured training programs to strengthen nurses' competencies in this field.

Keywords: Nurse role, nurses in palliative care, nurses in bereavement

ÖZ

Amaç: *Hemşirelerin palyatif bakımda hastaların yaşam kalitesini iyileştirmedeki rolleri, sağlık sistemindeki değişimler ve bilimsel gelişmelerle birlikte genişlemektedir. Bu roller, semptom yönetimi, eğitim ve iletişim, bakım koordinasyonu ve psikososyal ve etik destek sağlamaya odaklanmaktadır. Çalışmamızda, hemşirelerin palyatif bakımda yas sürecindeki rollerine ilişkin görüşlerini belirlemek amaçlanmıştır.*

Gereç ve Yöntem: *Bu araştırma, var olan durumun derinlemesine ve ayrıntılı olarak saptanmasına yönelik olarak betimsel ve nitel bir çalışmadır. Nitel araştırma desenlerinden durum çalışması, durum çalışması türlerinden ise açıklayıcı/tanımlayıcı durum çalışması olarak tasarlanmıştır. Araştırmanın çalışma grubunu, kolay ulaşılabilirlik ve ölçüt örnekleme yöntemleri kullanılarak belirlenen 12 kişilik katılımcı grubu oluşturmuştur. Yarı yapılandırılmış görüşmeler yoluyla elde edilen verilerin analizinde tanımlayıcı ve içerik analizi yöntemleri kullanılmıştır.*

Corresponding author: Ayşe Gülay Şahan
Balıkesir University, Faculty of Health Sciences, Department of Gerontology, Balıkesir-Türkiye
E-mail: *gulay.sahan@balikesir.edu.tr*
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Bulgular: *Çalışmadaki roller öncelikle semptom yönetimi ve bakım kapsamında, ardından koordinasyon, etkili iletişim, manevi destek ve etik ve psikososyal destek ile ilgili roller olarak tanımlanmıştır. Bu çalışmada, bazı hemşirelerin iletişim ve empati açısından kendilerini yeterli gördükleri, bazılarının empati açısından kısmen yeterli gördükleri, bazılarının ise iletişim becerileri açısından kendilerini yetersiz gördükleri belirlenmiştir.*

Sonuç: *Bulgular, hemşirelerin palyatif bakım ve yas sürecindeki rollerinin çok boyutlu olduğunu, iletişim ve duygusal destek becerilerinin değişkenlik gösterebildiğini ve bu alanlarda kurumsal destek ile yapılandırılmış eğitim programlarına ihtiyaç duyulduğunu ortaya koymaktadır.*

Anahtar Sözcükler: *Hemşire rolü, palyatif bakım hemşireleri, yas hemşireleri*

INTRODUCTION

Palliative care, among the values related to human rights, is accepted as a caring approach aiming to improve the quality of life by easing the pain and suffering of patients (1). This approach is based on the principle that life and death are normal processes and that every patient has the right to spend the last days of his/her life in peace (2). From the moment of diagnosis to treatment, or in the bereavement process after death, as a multidisciplinary and holistic approach, palliative care aims to meet the physical, psychosocial, and spiritual needs of patients and their relatives, especially in patients to whom therapeutic approaches have been ineffective (3, 4, 5). The team providing palliative care includes professionals from various disciplines such as physicians, nurses, physiotherapists, nutrition and diet specialists, social workers, and clergy (6, 7).

The roles of nurses, who are important health professionals in improving the quality of life of palliative care patients, are gradually expanding in the palliative care process with the changes in the health system and new scientific developments. These roles with intricate features can be grouped as symptom management and care, education and effective communication, coordination, and psycho-social and moral support (8, 9, 10, 11). The symptom management and care of the dying patient should continue, and the pain and respiratory distress should be controlled. Measures should be taken to maintain the integrity of the skin and mucous membranes. The necessary interventions to ensure and maintain patients' comfort should be planned and implemented. In addition, families should be informed about the situation, signs, and symptoms that may occur at the time of death, and their concerns and fears should be relieved. If there is a reasonable and feasible religious or cultural practice that the family wishes to implement, necessary help should be provided. Family members should be supported to have a positive bereavement process and directed to appropriate support resources (8).

Nurses should make the necessary environmental arrangements to ensure the comfort of the patient and family for a peaceful/good death and provide an environment where privacy can be protected, and close relations can be established. In addition, they have important roles and responsibilities such as directing the patient and family to health care services and related specialists to increase the quality of life and to ensure death in a more comfortable and peaceful way (8, 9, 12, 11).

Although studies on palliative care nursing in Turkey have increased since 2005, research specifically focusing on nurses' roles in the bereavement process remains limited (8,12,13,14). In particular, qualitative studies examining how nurses perceive and evaluate their roles before, during, and after death are scarce. Therefore, this study aims to provide an in-depth understanding of nurses' roles in the palliative care and bereavement process and to contribute to the development of clinical practice, nursing education, and palliative care service planning.

Study Purpose, Objectives, and Design

In this context, the study aims to determine the views of nurses about their roles in the palliative care and bereavement process. In line with this main purpose, the study sought answers to the following questions:

1. What are the views of nurses on the roles of symptom management and care, ethics, coordination, effective communication, and psycho-social and moral support in the palliative care and bereavement process?
2. What are the views of nurses regarding self-evaluation of fulfilling their roles in the palliative care and bereavement process?

3. What are the suggestions of nurses to fulfill their roles more effectively in the palliative care and bereavement process?

MATERIALS and METHODS

Research Model

This qualitative study, which is in the scanning model, aims to determine the existing situation in depth and detail. Accordingly, the case study design from qualitative research designs and the explanatory/descriptive case study among case study types were preferred.

Participants

Convenience and criterion sampling methods were used to determine the study group of the research. The sample consisted of 12 individuals working in palliative care centers in the city where the research was conducted and who voluntarily agreed to participate in the study. Personal information about the participants is presented in Table-1.

Table-1. Personal information about the participants (n=12)

Personal Information	n	%
Age		
20-30	5	41.7
31-40	2	16.6
41 and older	5	41.7
Gender		
Male	1	8.3
Female	11	91.7
Education		
High School	3	25.0
Associate and Undergraduate Degree	9	75.0
Marital Status		
Single	4	33.4
Married	6	50.0
Divorced	2	16.6
Seniority / Working Year		
0-10	5	41.7
11-20	2	16.6
21 and over	5	41.7
Training		
Palliative care training	4	33.4
No palliative care training	8	66.6
Relatives Receiving Palliative Care		
Yes	3	25.0
No	9	75.0

In qualitative research, the aim is not generalization but to obtain in-depth information about the phenomenon being studied. Therefore, sample size is determined according to data saturation rather than numerical adequacy. During the interviews, it was observed that the data began to repeat and no new themes emerged, indicating that thematic saturation had been reached. For this reason, data collection was terminated after twelve participants, and this number was considered sufficient to address the research aim.

The inclusion criteria for the study were being a nurse working in a palliative care unit and volunteering to participate in the study. Nurses who were on leave during the data collection period or who did not consent to audio recording were excluded from the study.

Data Collection

The data of the study were obtained with personal information and semi-structured interview forms developed by the researchers. The personal information form was used to determine the characteristics of the data sources to be used in the research (age, gender, education, marital status, seniority/working years, being a permanent member in the palliative care service, receiving training for those working in different services, and having relatives receiving palliative care). The views of nurses on their roles in the palliative care bereavement process were obtained using a semi-structured interview form.

In creating the interview forms, first the questions to be included in the forms were determined. In order to ensure content validity, it was submitted to expert opinion and necessary corrections were made within the framework of expert opinions.

During the data collection process, the purpose, importance, and participation of the study were explained to the study group, thus ensuring that the study group made a sincere and scientific contribution to the research process. Interviews were recorded with the consent of the interviewee, thus eliminating the risk of data loss. The interviews lasted between 30-40 minutes.

Data Analysis

Descriptive and content analysis methods were used to analyze the data. In the analysis, developing the conceptual framework, coding the data in the conceptual framework, presenting the data, and interpreting the data steps were

followed. Findings were supported by direct quotations using the numbering system (P1, P2 … P12) representing the order of the participants during the analysis process.

Validity and Reliability

In this study, the research methods and designs, the reasons for their use, the sampling techniques used in the determination of the study group, the characteristics of the study group, and the data collection and analysis process were explained in detail. Thus, it was aimed to provide the "confirmability" and "credibility" features of the research. To ensure reliability, Miles, and Huberman's formula [Reliability = agreement / (total agreement + disagreement)] was used (10). The percentage of agreement in the coding was calculated as 89% by using the relevant formula. According to Yıldırım and Şimşek (15), when the percentage of agreement in the reliability calculation is 70%, it is considered to be reliable.

RESULTS

The findings are presented in tables and interpreted in line with the research questions. Participants' demographic characteristics are presented in Table-1. Nurses' views on their roles in the palliative care and bereavement process are summarized in Table-2. As shown in Table-2, nurses defined their roles within the themes of symptom management and care, ethics, coordination, effective communication, psychosocial support, and moral support across the pre-death, death, and post-death periods. Representative participant statements related to these themes are presented below.

Table-2. Views of nurses on palliative care and their roles in the bereavement process

Theme	Sub-theme	Codes and Frequencies
Symptom Management and Care	Before Death	Reducing pain and suffering (8), Care (8), Nutrition (6), Medication and follow-up (6), follow-up fluid balance (6), fever, pulse, blood pressure, respiratory rate follow-up (6), Catheter insertion (6), Increasing the quality of life (4), Teaching care and nutrition to relatives (4)
	During Death	Monitoring the patient (4), Connecting oxygen (4), CPR (4) Giving narcotic drugs (2), Non-intervention (2)
	After Death	Preparing for morgue (7), Probe removal (4), Drain extraction (4) Cannulation removal (4)
Ethics	Before Death	Informing the guardian (3), Respecting privacy (2), Protecting the patient rights (2), Informing the relatives (2), Respecting the death place request (2)
	During Death	Not to interfere with DNR patients (4), Intervention according to the wishes of the patient or his/her relatives (2)
	After Death	Preparing official documents (1), Information (1)
Coordination	Before Death	Coordination with palliative staff (8), Coordination with relatives (4)
	During Death	Giving the blue code (8), Taking the relatives to the bereavement room (1), Calling security (1), Coordination with the palliative staff (1)
	After Death	Referring relatives to funeral procedures (5), Referring relatives to relevant specialists (3)
Effective Communication	Before Death	Informing (9), Empathizing with the patient (2), Communicating with relatives (2), Persuading (1), Respecting (1), Communicating with experts (1)
	During Death	Empathizing with relatives (6), Comforting (2), Contact (1)
	After Death	Informing (1), Persuading (1)
Psycho-Social Support	Before Death	Referral to specialists (5), Preparing for the bereavement process (1), Ensuring unity with relatives (1)
	During Death	Ensuring unity with relatives (2), Distancing relatives during the intervention (1)
	After Death	Referring relatives to relevant experts (3), Ensuring unity with relatives (1), Referring to religious officials (1)
Moral Support	Before Death	Allowing religious rituals (4), Providing the last meeting with relatives (1)
	During Death	Allowing faith rituals (6), Ensuring good death (1)
	After Death	Allowing faith rituals (8), Condolences (3)

Before Death

If the patient can be fed orally and there is no difficulty in swallowing, he/she is fed with watery and soft foods. Additionally, NG tubes are placed. After the doctor's examination, we organize drug treatment and follow-up. (P1)

During death

We monitor the patient at the time of death. We give oxygen, narcotic drugs, and a durogesic transdermal patch. (P5)

After Death

After death, we perform preparations for the morgue, such as removing the patient's catheter and clamping the foot and jaw. (P5)

Within the ethical theme, nurses emphasized informing relatives before death, respecting patient rights and privacy, following DNR decisions when appropriate, and completing necessary official procedures after death. Representative participant statements are presented below.

Before Death

We give information to the guardian. No information is given to anyone but the guardian. Patient rights are protected. (P11)

During death

If our physicians deem it appropriate, we can intervene according to the wishes of the patient's relatives or guardians (P2)

After Death

In the event of a death, I provide information by trying to answer the questions within my authority. (P12)

Within the coordination theme, nurses reported ensuring coordination with the palliative care team before death, initiating a blue code when necessary, during death, and guiding relatives regarding post-death and funeral procedures. Representative participant statements are presented below.

Before Death

Before death, we coordinate with the code blue team, dietitians, social service specialists, psychologists, physicians, and religious officials. (P4)

During Death

We give a blue code at the time of death or when the general condition of the patient worsens. (P3)

After Death

We provide guidance to the relatives of the patients about the funeral procedures. (P4)

Within the theme of effective communication, nurses stated that they informed patients and relatives before death, maintained empathy with relatives during and after death, and provided information and persuasion when necessary. Representative participant statements related to this theme are presented below.

Before Death

I inform patients and their relatives within the scope of my authority. (P12)

During Death

The empathy I have with the relatives of the patient at the time of death can last for a very long time (P7)

After Death

When there is a death, I give information by trying to answer the remaining questions within my authority (P12)

Within the theme of psychosocial support, nurses reported referring patients and their relatives to relevant specialists before death, ensuring togetherness with relatives during death, and guiding relatives after death. Representative participant statements related to this theme are presented below.

Before Death

Especially in cancer patients, there are problems due to the fear of death. In this case, we refer them to psychologists or related specialists. (P2)

During Death

While intervening during death, we take the relatives of the patients out of the room. (P8)

After Death

When necessary, we refer patients' relatives to our psychologists and physicians in psycho-social terms. (P4)

Within the theme of spiritual and moral support, nurses stated that they allowed religious and cultural practices before, during, and after death

and tried to ensure that patients spent their final moments comfortably. Representative participant statements related to this theme are presented below.

Before Death

We enable them to meet with relatives whom they have not seen for a long time and would like to see. (P11)

During Death

The important thing is that at the time of death, we relieve the patient's pain and suffering so that he/she can spend his/her last moments comfortably. (P6)

After Death

After death, if the relatives of the patients have requests according to their traditions and customs, we perform them. (P4)

Nurses' self-evaluations regarding the fulfillment of their roles in the palliative care and bereavement process are presented in Table-3. As seen in the self-evaluation theme, some nurses evaluated themselves as sufficient in terms of communication and empathy, some as partially sufficient in empathy, and others as insufficient, particularly in communication. Representative participant statements related to these evaluations are presented below.

Table-3. Self-evaluation of nurses regarding fulfilling their roles in palliative care and bereavement process.

Theme	Sub-theme	Codes and Frequencies
Self-evaluation	Sufficient	Empathy (4), Communication (4), Ethics (1)
	Partly sufficient	Empathy (4)
	Insufficient	Communication (2), Informing (1)

Sufficient

I think we are very good in the communication dimension. We become like family with patients and their relatives (P2).

Partly sufficient

My friends tell me I'm cold because I see so much death. In this situation, I think that my sense of empathy is weakened (P8).

Insufficient

When the relatives of the patients react negatively, I cut off communication with them, I think I cannot overcome the communication problem (P8).

Recommendations of nurses for fulfilling their roles in the palliative care and bereavement process more effectively are presented in Table-4. Within the recommendations theme, expectations such as psychological support, coping training, institutional support, team-based working conditions, and workload reduction came to the forefront. Representative participant statements related to these recommendations are presented below.

Table-4. Recommendations of nurses to fulfill their roles more effectively in palliative care and bereavement process.

Theme	Sub-theme	Codes and Frequencies
Recommendations	Personal Expectations	Psychological support (6), Event organization (3), Coping training (2), Bereavement process training (2), Moral support (1)
	Institutional Expectations	Team evaluation (2), Being a privileged department (1), Extending the team (1), Reducing the workload (1)

Personal Expectations

Psychological support and intermittent coping training can be provided to overcome the bereavement process (P11). For example, this service should be a privileged section. In fact, the burnout here cannot be measured by money. (P8)

Institutional Expectations

Recognition of palliative care staff as a distinct and specialized unit, along with the regulation of their professional rights, accordingly, may enhance their performance; in turn, this could improve the

quality of care provided to patients in the end-of-life period (P7).

DISCUSSION

When the identified themes were evaluated overall, it was observed that nurses predominantly defined their roles in the palliative care and bereavement process within the pre-death period, particularly under the dimension of symptom management and care. This finding suggests that nurses prioritize direct physical care and symptom control throughout the palliative care process. The prominence of statements related to pain management, continuity of care, and maintaining patient comfort reflects the central aim of palliative care, which is to improve quality of life. Similar findings have been reported in the literature, emphasizing that one of the most important roles of nurses in palliative care is the effective management of symptoms such as pain and discomfort (16). In addition, previous studies have shown that the most frequently performed nursing interventions in symptom management include pain relief and wound care (17). Recent studies also emphasize that palliative care nurses play a key role in maintaining patient comfort, managing symptoms, and improving quality of life throughout the disease trajectory (18).

The more detailed articulation of roles concerning the pre-death period further indicates that nurses mainly focus on direct care and symptom management. In contrast, the relatively limited emphasis on communication, psychosocial, and spiritual support roles during and after death suggests that nurses' role perceptions and practices in these areas may require further development. This situation may indicate that while clinical care roles are well established, supportive and bereavement-related roles may not be structured to the same extent in practice.

In our study, the roles within the scope of symptom management and care were followed by the roles related to coordination, effective communication, ethical responsibility, and psychosocial and spiritual support. These findings are consistent with studies in the literature indicating that nurses play a central role in coordinating care, supporting patients and families, and ensuring continuity of care throughout the palliative process. However, previous studies have also indicated that spiritual and moral support may not always be provided

To enhance the patient's comfort, the palliative care process should be evaluated and managed under the coordination of relevant specialists (P5). sufficiently and that healthcare professionals may feel inadequate in this area (19).

Recent literature highlights that effective communication is one of the core competencies in palliative nursing and is essential for supporting both patients and their relatives during the bereavement process (20). In this study, while some nurses perceived themselves as competent in terms of communication and empathy, others reported that they were only partially competent or insufficient in these areas. This finding suggests that communication skills in the palliative care and bereavement process may vary among nurses.

In addition, previous studies have reported that nurses working in palliative and end-of-life care settings may experience emotional burden, stress, and feelings of inadequacy when supporting patients and their relatives, which may negatively affect communication and coping processes (21,22).

Statements indicating difficulties in communication, particularly in challenging interactions with patients' relatives, underscore the importance of structured training and support programs aimed at enhancing communication and coping skills in this field. Previous studies have reported that nurses working in end-of-life settings may experience emotional burden and communication-related stress, which may influence their coping abilities and professional interactions (23).

Another important finding of the study is that psychosocial and spiritual support roles were frequently expressed in the form of referring patients and their relatives to relevant specialists or facilitating religious and cultural practices. Although such practices are important, strengthening nurses' competencies in providing direct psychosocial and bereavement support may contribute to a more comprehensive and holistic approach to palliative care. Previous studies have reported that nurses may not always feel competent in providing spiritual care and that spiritual support practices may vary (19). Studies examining spiritual care practices have also shown that when nurses provide spiritual support, patients may experience improved spiritual well-being (24).

Similarly, interventions aimed at supporting patients' spiritual well-being have been found to reduce distress levels in patients receiving end-of-life care (25). Furthermore, recent research indicates that high workload, emotional strain, and insufficient institutional support may increase burnout levels among palliative care nurses, highlighting the need for structured support systems and training programs (26).

Moreover, studies have emphasized that institutional and team support play a crucial role in strengthening the resilience and well-being of healthcare professionals working in palliative care settings (27).

In this context, strengthening nurses' communication skills, coping abilities, and access to psychological support mechanisms may enhance both the quality of care provided to patients and the well-being of nurses themselves.

Limitations

This study has some limitations that should be considered when interpreting the findings. The research was conducted in a single center and included a limited number of participants, which may restrict the transferability of the results. In addition, the data were based on the self-reports of nurses and therefore reflect their individual experiences and perceptions. Despite these limitations, the study provides valuable insights into nurses' roles in the palliative care and bereavement process and may contribute to the development of future research, clinical practice, and training programs in this field.

CONCLUSION

As a result of this study, it was determined that some nurses evaluated themselves as competent in terms of communication and empathy skills, some evaluated themselves as partially competent in empathy, and others felt inadequate, particularly in communicating with patients' relatives. These findings indicate that nurses' communication and emotional support skills in the palliative care and bereavement process may vary and that these skills need to be strengthened.

In addition, the study revealed that nurses have expectations such as receiving psychological and moral support, organizing appropriate training and educational activities, strengthening team collaboration, working within a larger multidisciplinary team, and reducing workload in order to fulfill their roles more effectively in the palliative care and bereavement process. This highlights the importance of institutional support and team-based approaches in enabling nurses to carry out their roles effectively in these processes.

In line with these findings, it is recommended to increase nurses' awareness of their roles in the palliative care and bereavement process and to support them through structured communication, coping, and bereavement training programs. Providing psychological and moral support for nurses, strengthening team collaboration, and reducing workload by expanding the healthcare team may contribute significantly to the effective fulfillment of nurses' roles in this process. Furthermore, future studies may examine the self-evaluations of other members of the palliative care team or investigate nurses' roles in the bereavement process from the perspectives of different stakeholders.

The findings of this study may provide guidance for nursing education, clinical practice, and the planning of palliative care services by clarifying nurses' roles in the palliative care and bereavement process.

Ethics Committee Approval

Ethics committee approval was obtained from Ege University (Number: E-99166796-0500.06.04-790351). In addition, the necessary official permissions were obtained from the hospital where the research would be conducted. Before the interview, the nurses were informed about the scope of the study, and an informed consent form was signed. There was no conflict of interest between researchers and nurses. The researchers also assured the participants that the data would not be used for other purposes and that their personal data would be confidential.

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