

# Examination of Symptoms Management Experiences of Nursing Working in the Palliative Care Clinic: A Qualitative Study

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**Abstract:** ***Purpose:** This study aimed to describe symptoms management experiences of nursing working in the palliative care clinic. **Method:** The qualitative phenomenological approach and purposive sampling amongst nursing working in the Palliative Care Clinic was applied. Permission was obtained from a non-invasive ethics committee of a university and from the nurses was obtained consent. Researchers obtained permission from the Palliative Care Clinic of University Hospital and the nurses individuals who agreed to participate in the research. The population of the research consisted of nurses working in the Palliative Care Clinic in the oncology department of a university hospital. The data of the research were collected with “Descriptive Characteristics Form” and “Semi-structured Interview Form”. Fifteen nurses were interviewed using semi-structured research questions. Interviews were conducted in a private room on the palliative care clinic and lasted between 60 and 90 minutes. Colizzi’s method was used for data analysis and the rigor was based on transferability and credibility. The descriptive characteristics form comprised of questions on age, gender, education status, time of working in palliative care clinic. **Results:** All of the nurses participating in the study were female and the mean age was  $33.16 \pm 7.98$  years. Participants were 50% of the participants are postgraduate, 33.3 % are undergraduate and 16.7 % are high school graduates. Nurses how many 83.3%, have been working as nurses for more than 5 years, and 50% of these nurses have been working in the palliative care clinic for more than 5 years. Following the analysis of the data, the expressions made by nurses during the interviews were grouped under 4 themes. Four clusters of themes were identified. Consistent with the questionnaire format, 4 themes and 8 subthemes were determined describing. **Conclusion:** Palliative care nurses experience some difficulties in physiological and psychosocial symptom management due to the patient group they work with. nurses should support the symptom management processes of patients, with different perspectives of nursing care practices and nursing interventions.*

**Keywords:** Symptom management, palliative care, nursing

## 1. Introduction

Palliative care is the care that provides comprehensive evaluation of physical, psychological, social and spiritual symptoms experienced by patients.<sup>[1]</sup> The goal of palliative care is to offer a person-centred approach that stresses each patient's right to be involved in the care process. Palliative care throughout the illness continuum involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice. In addition, palliative care is a human right where death is not accelerated or postponed.<sup>[2,3,4]</sup>

The group of patients requiring palliative care; motor neuron diseases, progressive neuronal diseases, advanced organ failure, HIV / AIDS, non-responding to treatment, cancer diagnosis, genetic/ congenital, progressive diseases in children.<sup>[5,6]</sup> Therefore, includes key elements of palliative care providing relief from pain and other distressing symptoms, regarding dying as a normal process, intending neither to hasten or postpone, integrating psychological and spiritual aspects of patient care offering a support system to help patients live as actively as possible until death, providing support to help the family cope during the patient's illness.<sup>[3,7,8]</sup> In this context, palliative care requires an interdisciplinary treatment and care process approach.

The practitioners of the entire team, established with an interdisciplinary approach, can manage the basic symptom management in palliative care patients.<sup>[9]</sup> Palliative care patients often experience symptoms such as pain, depression, anxiety, confusion, fatigue, breathlessness, insomnia, nausea, constipation, anorexia, diarrhea, and vomiting. Some patients experience most of these symptoms together. At this point, the symptom load of the patients becomes heavier and the symptom management becomes more difficult.<sup>[10,11,12,13]</sup> It is very important that the palliative care team provides services in the direction of the common goal of managing and managing the symptoms of palliative care patients. Palliative care nurses who work in coordination with health professionals such as oncologists, algologists, neurologists and surgeons in the effective management of these processes are of great importance.<sup>[14]</sup> The palliative care nurse manages the patient's care process with a holistic and humanistic approach. In this context; It allows the patient to express the physical and psychosocial difficulties experienced by the patient.<sup>[15]</sup>

In the management of symptoms of palliative care patients, nurses have important responsibilities. Therefore, it is important to determine the experiences of the nurse in the symptom management of palliative care patients. A few phenomenological studies have investigated nurses' experiences of symptom management of palliative care

patients. To our knowledge, a qualitative study has not been made on this subject in Turkey.

## 2. Purpose of the Study

This study aimed to describe symptoms management experiences of nursing working in the palliative care clinic. The purpose of the phenomenological approach was to avoid generalizations and quantification and to understand the phenomenon as a human being experiences it.

## 3. Methods

### 3.1. Design

The qualitative phenomenological approach and purposive sampling amongst nursing working in the Palliative Care Clinic was applied. Phenomenology (from the Greek, phenomenon, which means to show itself) was the methodological basis for this qualitative study. This approach is one of discovery and description, and emphasizes meaning and understanding in the study of the lived experience of individuals. Phenomenology aims to translate personal lived experience into consensually validated social knowledge (Coyle, 2004). To reach this aim of transforming private experience into public knowledge, phenomenological research requires active involvement from the researcher, the study participants, and the audience who eventually read and evaluate the research report. The study was conducted in the palliative care department of a university hospital between December 2018 and March 2019.

### 3.2. Ethical considerations

Permission was obtained from a non-invasive ethics committee of a university. Researchers obtained permission from the Palliative Care Clinic of University Hospital and the nurses individuals who agreed to participate in the research. Verbal consent was obtained from each participant. Assurance of participant anonymity was given.

### 3.3. Research Questions

The research was designed to explore the effects of symptoms management experienced by nurses on their nursing care. Data was collected using a semi-structured interview form including 9 questions exploring symptoms management experiences of the nurses. Specifically, the investigation sought to answer the following questions:

- 1) What is palliative care in your opinion?
- 2) Would you define the palliative care you experience?
- 3) Can you say something about nursing caring for palliative care patients?
- 4) Did you want to care for your palliative care patients yourself?
- 5) How does giving care to palliative care patients affect you?
- 6) How do you feel when giving care to palliative care patients?
- 7) What symptom management do you do in palliative care patients?

- 8) What are the difficulties of palliative care patients in symptom management?
- 9) What is the most difficult symptom you experience when managing the symptoms of palliative care patients? Why?

### 3.4. Participants

The population of the research consisted of nurses working in the Palliative Care Clinic in the oncology department of a university hospital. Nurses who had experiences associated with palliative care to be working as a nurse in the palliative care clinic for at least 6 months, and who agreed to take part in the study and to have their words recorded on a tape were included in the study.

### 3.5. Colaizzi's phenomenological methodology

The current study utilized a qualitative method, Colaizzi's method (1978) to approach the subject. According to this method, the researcher must first write a presupposition based on his/her own experiences in the area of interest, because "it was seen that the phenomenologist must initiate his [or her] inquiry by an examination of his approach in order to uncover his [or her] presuppositions about the investigated topic". Then, the researcher asks a few people about the phenomenon and adds new ideas to the original presupposition. Research questions are formulated based on this presupposition; the researcher interviews participants who have abundant experiences regarding the topic. The content of the interview is written down, and these interviews are analyzed in depth. Lastly, the researcher formulates a statement of identification of the fundamental structure of the investigated phenomenon.

### 3.6. Data Collection

The data of the research were collected with "Descriptive Characteristics Form" and "Semi-structured Interview Form". Fifteen nurses were interviewed using semi-structured research questions. As for the semi-structured interview form, a total of nine questions were prepared and grouped under two titles, namely; "for experiences with symptoms management", "for the feelings symptoms management", "for the difficulties symptoms management". To improve the reliability of the data and to facilitate a trusting relationship, one researcher conducted all the interviews. Data were collected using audio taped semi-structured interviews. Interviews were conducted in a private room on the palliative care clinic and lasted between 60 and 90 minutes. The data was collected with in-depth, open-ended interviews and participant observation and field notes. The interviews were conducted in a silent venue and not interrupted. During the interview, the interviewer and the interviewees were seated at the same level and the participants were actively listened to and guided with the questions. During the interview, noticeable situations were recorded as observation notes. Colaizzi's method was used for data analysis and the rigor was based on transferability and credibility. The descriptive characteristics form comprised of questions on age, gender, education status, time of working in palliative care clinic.

### 3.7. Data analysis

We reviewed all interview reports multiple times to analyze the data with the Colaizzi method of analysis (Table 1). We organized the formulated meanings in to categories and themes as described by Colaizzi (Colaizzi, 1978). Maxqda was used for qualitative data analysis. When differences existed between the investigators regarding the appropriate categories and themes, they were discussed until a consensus was reached.

**Table 1:** The steps in Colaizzi's phenomenological data analysis.

1. Read all the participants' description of the phenomenon under study.
2. Extract significant statements that pertain directly to the phenomena.
3. Formulate the meaning of these significant statements.
4. Categorize the formulated meanings into clusters of themes.
5. Integrate findings into an exhaustive description of the phenomenon being studied.
6. Validate the exhaustive description by returning to some of the participants to ask the how it compares to their experiences.
7. Incorporate any changes offered by the participants into the final description of the essence of the phenomenon.

## 4. Results

When the sociodemographic data distribution of the nurses working in palliative care was analyzed, their mean age was found to be 33,16±7,98. All participants were female, and 50 % of them were graduates of postgraduate. Nurses how many 83.3%, have been working as nurses for more than 5 years, and 50% of these nurses have been working in the palliative care clinic for more than 5 years. Following the analysis of the data, the expressions made by nurses during the interviews were grouped under 4 themes. Four clusters of themes were identified. Consistent with the questionnaire format, 4 themes and 8 subthemes were determined describing.

### Theme 1. The most common symptoms

#### Subtheme 1. Physiological symptoms

"We have added pain to our system as the fifth vital finding"

"The biggest challenge is pain"

"We see the most pain here."

"Sometimes we can see constipation."

"We can also see neurological symptoms, for example delirium."

"Nausea and vomiting are also common symptoms."

"Generally, pain, nausea, vomiting and feeding problems occur in the first place."

#### Subtheme 2. Psychosocial symptoms

"Fear of death is a condition frequently encountered by patients in the terminal period."

"In our patients, the most anxiety is seen."

"Interventional procedures are performed here. This situation also creates agitation in patients."

"Patients have a lot of fear of death."

### Theme 2. Symptom management

#### Subtheme 1. Drugs

"First, we usually use nonsteroidal anti-inflammatory for pain. Then we switch to strong opioids."

"First of all, we cooperate with the dietitian. We're letting the patient eat his favorite things. Because it doesn't make nausea and vomiting. Because it doesn't make nausea and vomiting. Except for that, the antiemetics smell bad."

"We are constantly doing evaluation. However, since pain relievers are applied, we cannot see the patient's pain clearly."

#### Subtheme 2. Non-pharmacological methods

"As a nurse, we don't do anything non-pharmacological."

"We do not have time to do non-pharmacological interference."

"We wanted to build a music system. However, the hospital management did not allow this."

### Theme 3. Difficulties experienced by nurses

#### Subtheme 1. Job satisfaction of nurses

"The fact that an uncle or aunt say thank you is enough for us. that way we can get satisfaction. As a general nurse, I feel a sense of satisfaction."

"I thought I was going to get job satisfaction, but there's insufficient satisfaction. I think I'm disappointed when the patients' lives seem to end."

#### Subtheme 2. Emotional status of nurses

"I think this is a special unit, so it's very different from other units. This process is also very important for our patients and our. What they share with us can be their last sharing and their last memories."

"Relationships are different and we are starting to build a strong bond. She's wearing it down."

"I think this is a special unit, so I think it's very different from other units."

“I think it leaves deep marks. So we're listening to their stories. And we are inevitably involved in their lives. We're suffering when we're involved in their lives and empathy.”

#### Theme 4. Cooperation

##### *Subtheme 1. Patients' relatives*

“As long as their relatives help, our work is getting easier.”

“Patient relatives benefit more. So they're going to the stage of acceptance. Because when they first arrive, they become more agitated. They cannot accept this process. They adapt later.”

“Especially when the patients do not want to eat, the relatives of the patients support us by motivating the patient.”

##### *Subtheme 2. Health professionals*

“We cooperating with dietitian.”

“We're cooperating with physiotherapists.”

“We work in cooperation with spiritual support specialist and psychologist in support of their families.”

“Unfortunately, the group of physicians can ignore other problems of patients while dealing with pharmacological treatment. We are always directing physiotherapy and dietitian cooperation.”

#### 5. Discussion

The aim of this phenomenological study is to describe symptoms management experiences of nursing working in the palliative care clinic. The study was conceptualized on the basis of the experience of the nurses on symptom management and their difficulties. The results of this study reveal the experience of symptom management of nurses working in the palliative care clinic. When the literature is examined; it is seen that the studies related to the subject matter are very limited.

The symptoms of palliative care patients negatively affect the physical, mental and social well-being of the patients and lead to a decrease in the quality of life of patients. As a result of this study, nurses reported that they have the most physiological and psychosocial symptoms in palliative care patients and they manage these symptoms. In this study, nurses listed pain, nausea/vomiting, malnutrition, dyspnea and constipation that physiological symptoms frequently seen in these patients. This result is similar to the literature that in palliative care units, symptoms such as pain, nausea, vomiting, fatigue, insomnia and digestive system are mostly performed.<sup>[16,17,18]</sup> At the same time nurses emphasize that it is not possible to eliminate symptoms completely because they cannot fight the disease, but they provide temporary relief in patients. When the literature is examined, it is stated that palliative care patients experience anxiety due to illness and treatment process and uncontrolled symptoms. It was reported that patients experienced psychological symptoms

such as anger (35%), anxiety (38%), and nervousness (40%).<sup>[19,20,21]</sup> Also in addition to physiological symptoms, psychosocial symptoms that anxiety, depression, hopelessness, and the fear of death reported by nurses in this study. Udo et al (2018) study, when a patient's physical symptoms were not relieved, nurses stated that patients experience anxiety, disappointment and distrust.<sup>[2]</sup> Therefore, these psychosocial symptoms experienced by the patients require the nurses to manage not only the physiological symptoms but also their psychosocial symptoms and approach the patient in a holistic manner.

Management of physiological and psychosocial symptoms of patients is of great importance. In this study, the nurses stated that patients used pharmacological treatment in the management of their physiological symptoms and this treatment was usually directed to the symptom. Similarly, in the literature, pharmacological methods are frequently used in the symptom management of palliative care patients.<sup>[22,23]</sup> When literature is examined, non-pharmacological therapies which yoga, dance therapy, acupuncture, music therapy, massage therapy, reiki, aromatherapy, therapeutic touching provide significant decrease in the perceived pain intensity in palliative care patients.<sup>[24,25,26,27]</sup> However, in this study, nurses stated that although non-pharmacological methods know positive effects on symptom management, they do not apply these methods for environmental reasons. In addition, nurses attempt that there is no specific attempt to manage patients' psychosocial symptoms, but nurses emphasized that they are cooperating with spiritual support specialist and psychologist in order to support not only patients but also families.

Nurses expressed some difficulties in job satisfaction. This may be due to the fact that nurses think therefore that patients are usually in the final stage of life and that the treatments are insufficient and therefore they do not fully develop a well-being. The patients were treated for a very long time in this clinic because of their care and treatment. Therefore, in long-term hospitalizations, nurses stated that they had established good relationships with patients and that a bond was formed between them. As a natural consequence of this, the worsening of the patient's prognosis is quite difficult for the nurses as emotionally.

In the literature, it is emphasized that palliative care should be carried beyond the services in the hospital, and should be implemented with medical practice and social services. In this study, nurses noted that they experienced some difficulties in symptom management and these difficulties were generally caused by lack of cooperation. In this context, it is very important that patient, relatives, physicians, nurses, psychologists, religious officials, social workers and nutritionists, and physiotherapists work in cooperation.<sup>[28,29,30]</sup> It is thought that every member of this multidisciplinary group will fulfill the roles and responsibilities of symptom management, and if it creates and maintains the appropriate conditions, the difficulties of management symptoms will be minimized. In addition the team should not only supportive in situations relating to the care of an individual patient but also acts as a body for learning and education. In this context, it is obvious that team must foster a more collaborative and team-based



work environment to improve the quality of palliative care.

## 6. Conclusion

As a result of this study, nurses explained their experiences as the most common symptoms, symptom management, cooperation and difficulties. The issue that nurses frequently emphasize is the difficulties they experience in symptom management. Palliative care nurses experience some difficulties in physiological and psychosocial symptom management due to the patient group they work with. In this context, nurses must gain a holistic view and shape their care in this direction. In addition, nurses should support the symptom management processes of patients, with different perspectives of nursing care practices and nursing interventions. In the light of all these, it is very important to strengthen of the palliative care servers by educational programs and increase awareness.

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