# **Original Article**

# **Examination of the Perceptions of Nurses Working in a University Hospital** towards the Palliative Care and the Obstacles in Practices

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#### Abstract

**Objectives:** There are barriers related to the clinical use of palliative care. The aim of the study is to examine the nurses' perceptions of palliative care and the obstacles in practices.

Methods: The sampling of the study was composed of 120 nurses who accepted to participate in the study. In order to collect the data, a questionnaire was used, which contained questions and expressions about the demographic data and palliative care. Our study demonstrated that most of the participants emphasized that they would like to receive training about palliative care. The data were analyzed with SPSS version 15.00 for Windows. Descriptive statistics were presented as frequencies, percentages, means and standard deviations. A p value <.05 was considered statistically significant.

**Results:** The most important obstacles were insufficient education, communication and health policies. %57.5 of them state that nurses do not realize the palliative care requirements; %66.6 of them think that doctors do not realize the palliative care requirements; %55 of them think that nurses and %65 of them think that doctors do not have enough knowledge about palliative care; %60.9 of them state that nurses and %68.3 of them state that doctors have lack of communication with patients/families; %78.3 of them specify that the number of health professionals is insufficient

Conclusion: It has been recommended that in-service palliative care training should be planned for nurses at regular intervals and health policy should be organized.

Key Words: Palliative Care, Nurses' Perceptions, Obstacles

#### Introduction

Approximately 1.4 million people are diagnosed with cancer each year and more than 560.000 individuals die due to cancer (Beckstrand et al., 2009). The scientific and medical advances extend the life as well as delay the death (Ahmedzai et al., 2004; McIlfatrick, 2006). World Health organization (WHO, 2002) has reported that the need for palliative care services will increase in the next 20 years with the rising age limit (Oakley et al., 2005). Palliative care is known as family and patient centered and the education priorities of palliative care are set according to the needs of patients and their families (Watson et al., 2006). Furthermore, it can be given to the patients according to their choices such as at home, hospital, clinics or health care institutions (www. national consensus project.org, 2009; Moore, 2005). Palliative care was used primarily for patients dying of cancer who were at the beginning of 1990. Then, the area of palliative care has been expanded due to the alterations in populations and technological developments (Kuebler et al., 2005, Pavlish et al., 2009) and it can be given to individuals in each steps of complex, chronic and life limiting diseases such as heart failure and lung diseases (Currow et al., 2005, Pavlish et al., 2009).

Generally, health professionals consider that family is in the center during the palliative care in which the aim of the treatment and health care plans frequently change. It is also evaluated that symptom management, holistic care and the quality of life are the main focus of palliative care. Besides, nurses perceive that the palliative care focuses on the physical, psychosocial, spiritual well-being and comfort of patients (Pavlish et al., 2009). There should be a multidisciplinary team and experienced health professionals who have sufficient knowledge related to their roles in the efficient palliative care (Reville et al., 2009; Nordgren ve Olsson, 2003).

During this period, health care team is responsible for the coordination of the health care service that will be given to patients and families, they should inform them about the health care and supportive care services (www.nationalconsensusproject.org, 2009; Moore, 2005).

There are limitations and barriers related to the clinical use of palliative care (Pavlish et al., 2009). It has been shown that the health professionals who do not have sufficient experience, knowledge skills and difficulties to understand the status of patients and they may not be aware of the changing needs of patients and families (Wyatt et al., 2000; Hudson et al., 2004). Ahmed et al. (2004) have reported the obstacles which negatively affect the roles of nurses in the palliative care. For instance; the family may not have sufficient income in order to afford the end of life care, the patient's prognosis can get worse, patients and their families may have negative or positive thoughts about the treatment; and there can be an excess amount of technical aspects in the

treatment. The idea of the family regarding the life support can also influence the palliative care. Furthermore, anger of family members who do not accept the treatment as well as poor communication between doctor patient/family or nurse and patient/family can also be important obstacles in the palliative care process. According to a study performed in order to detect the level of knowledge of health professionals in Lebanon, it has been shown that the level of knowledge of nurses is lower compared to doctors (Abu-Saad et al., 2009). It has also been emphasized that doctors have insufficient education on the hospice care and health care of the patient in the terminal period of the life (Ahmed et al., 2004). Alterations in the family during the disease and issues due to the health system are other limitations that can lead to application problems in palliative care in clinics (Hudson et al., 2004).

Additional to these obstacles, studies on palliative care perception of health professionals and the definition of the palliative care requirements are insufficient in number in Turkey (Turgay and Kav., 2012). The studies have been generally performed on aims, goals and obstacles of the palliative care (Aydogan et al., 2011; Elcigil, 2012; İnci et al., 2012). Therefore, this study will lead us to understand better the palliative care perceptions of nurses as well as obstacles in the application of palliative care in our country. Furthermore, our findings will be beneficial to find solutions for this issue. Additionally, this study will also help to increase the life quality of both the patient and the family.

**Aims**: The aim of the study is to examine the nurses' perceptions of palliative care and the obstacles in practices.

# The study questions are:

How are the perceptions of nurses towards palliative care?

How is the perception of obstacles to the implementation of palliative care for nurses?

# Methodology

## **Design**

The universe of the study was composed of health professionals who were working as a nurse in a University, Research and Application Hospital. This study employed a prospective descriptive study design.

#### **Participants**

The universe of the study was composed of health professionals who were working as a nurse in Dokuz Eylül University, Research and Application Hospital. The study samples were randomly selected among nurses who were at the clinic at the time of data collection and who were voluntary to participate in our study. Sample calculation method for the known universe was used to determine the size of the samples, and the number of samples was accordingly fixed to 261 individuals. Type I error was accepted as 0.05. The sampling of the study was composed of 120 nurses who accepted to participate in the study. The participation rate was %45.97.

#### **Data Collection Tools**

In order to collect the data, a questionnaire was used, which contained questions and expressions about the demographic data and palliative care. This form was prepared by researchers with the help of the literature (Steinhauser et al., 2000; Kreating, 2009, Steinhauser et al., 2001, Ogle et al., 2003, Turgay&Kav., 2012). The expert views were obtained before the onset of the study and the interprofessional compliance between experts was evaluated by using the content validity rate. According to the results, the compliance was 0.99. The questionnaire was applied to the five nurses who were outside the sample and it was also applied to study group since these was no negative feedback.

#### **Data Collection**

The data of the study was obtained via face-to-face meetings with nurses who were working in Dokuz Eylül University Research and Application Hospital and who met criteria. During the data collecting period, the researcher determined the individuals who met criteria, explained them the aim of the study and continued to face-to-face meetings with nurses who accepted to participate in the study. No financial support has been received from any institutions or organizations.

## **Data Analysis**

SPSS program was used in order to analyze the data. The independent variables such as age, gender, education and occupation status and duration of the profession of the nurse were evaluated with descriptive statistics (mean,

number and percent). Concept Validity Index (CVI) was used to evaluate the views of experts, and Lawshe table was used to understand whether or not there was compliance between experts. Percentage calculations were done in order to assess the views of nurses. The significance level was accepted as 0.05.

#### **Research Ethics**

The written consents were obtained from the Ethical Committee at Dokuz Eylul University, the chief physician at Dokuz Eylul University and individuals who were voluntary to participate in the study.

#### Results

The mean age of nurses who participated in the study was 33.8+ 6.9. The average working time of nurses was  $10.8 \pm 7.4$  years, duration of the occupation in the current clinic was 5.75 + 4.77years and average weekly working hours was  $45.5 \pm 6.4$ . The %99.2 (n:119) of the participants were female and %86.7 (n:104) of them were graduated from undergraduate program. The %42.5 (n:51) of them received the palliative care education. Participants specified that they had the palliative care education in congresses (%3.3 of them), in courses (%5 of them), in conferences (%6 of them), in workshops (%0.8 of them), in lectures (%23.3 of them), in DEU Palliative Care Group meetings (%1.7 of them) and in various activities (the rest of the nurses). Individuals stated that the palliative care training was sufficient (%16.6 of them), partially sufficient (%55 of them) and insufficient (%28.4 of them). The %75.9 of the participants emphasized that they would like to receive training about palliative care. It has been detected that %19.2 of them needed to receive palliative care training in their families. According to the participants, the palliative care should be given in hospital (%2.5 of them), at home (%6.7 of them), in nursing home (%0.8 of them), in hospice (%19.2 of them) and in all of these places (%64.2 of them).

The %20.8 of the nurses thought that they were sufficiently equipped to perform the palliative care, %64.2 of them considered themselves as partially sufficient in palliative care and %15 of them stated that they were not sufficient in palliative care. The perceptions of nurses towards palliative care can be seen in Table-1.

**Table 1. Perceptions of Nurses towards Palliative Care** 

Palliative Care	I agree	I partially agree	I do not agree
	n %	n %	n %
The process begins with the diagnosis of life-threatening diseases.	59 49.2	39 32.5	22 18.3
The process begins with the terminal stages of the life threatening disease.	33 27.5	31 25.8	56 46.7
It provides an effective health care to the patients according to the patient's changing condition	105 87.5	13 10.8	2 1.7
It focuses on the patient and her/his family.	99 82.5	21 17.5	
It supports the physical, emotional and spiritual comfort of the patient and the family.	107 89.2	12 10.0	1 0.8
It gives importance to cultural differences in patient care.	91 75.8	19 15.8	10 8.4
It improves the quality of life of patient and the family.	107 89.2	13 10.8	
Symptom control is not the goal of palliative care.	90 75.0	22 18.3	8 6.7
It allows patients and their families about their preference about the death and the last period of the disease.	85 70.8	28 23.3	7 5.8
It does not cover the mourning process.	53 44.2	28 23.3	39 32.5
It provides social support for the patient and the family.	101 84.2	15 12.5	4 3.3
It is carried out by an interdisciplinary team with the appropriate skills and training.	101 84.2	15 12.5	4 3.3
The team should be managed by a medical doctor.	40 33.3	39 32.5	41 34.2
Patients and health care providers should reach the palliative care team at any time.	79 65.8	28 23.3	13 10.8
Palliative care services should be provided only in hospital.	19 15.8	26 21.7	75 62.5
Legal arrangements should be made for patients who have the right not to want the resuscitation.	80 66.6	32 26.7	8 6.7
There should be meetings.	98 81.7	22 18.3	
Receiving a palliative care is a human right.	110 91.7	9 7.5	1 0.8
Palliative care members may live burn-out since they are always in a work environment with the continuous loss.	104 86.6	14 11.7	2 1.7
Palliative care services should be supported by social security institutions.	108 90.0	12 10.0	
Palliative care should be a compulsory subject in the curriculum.	95 79.1	23 19.2	2 1.7

Table 2. Obstacles that were perceived by Nurses in the development of Palliative Care Services

	Very		Important	Not	
	important		n %	important	
	n	%		n %	
Nurses do not realize the requirements for palliative care.	69	57.5	48 40.0	3 2.5	
Doctors do not realize the requirements for palliative care.	80	66.6	38 31.7	2 1.7	
The lack of education of nurses	66	55.0	52 43.3	2 1.7	
The lack of education of doctors	78	65.0	41 34.2	1 0.8	
The lack of communication of nurse with the family/patient	73	60.9	46 38.3	1 0.8	
The lack of communication of doctor with the family/patient	82	68.3	38 31.7		
The insufficient number of health professionals	94	78.3	25 20.7		
Obstacles in the health politics	85	70.8	34 28.4	1 0.8	
Disbelief in the efficiency of the palliative health care	69	57.5	45 37.5	6 5.0	
The insufficient number of places for providing the palliative health care	82	68.3	35 29.2	3 2.5	
The lack of quality of the environment for providing the palliative health care	79	65.8	41 34.2		

The most important obstacles that were perceived by participants in terms of palliative care can be summarized as follows can be seen in Table-2: %57.5 of them state that nurses do not realize the palliative care requirements; %66.6 of them think that doctors do not realize the palliative care requirements; %55 of them think that nurses and %65 of them think that doctors do not have enough knowledge about palliative care; %60.9 of them state that nurses and %68.3 of them state that doctors have lack of communication with patients/families; %78.3 of them specify that the number of health professionals is insufficient; %70.8 of them think

that there are limitations in the healthy policies; %57.5 of them state that individuals do not believe in the efficiency of the palliative care; %65.8 of them think that there is an inadequacy in the number of palliative care practice places; and %65.8 of them think that palliative care practice places are unqualified.

#### **Discussion**

It is important that how the palliative care is perceived by health professionals and whether or not the obstacles regarding palliative care are known. In our study, it has been shown that majority of the nurses consider the palliative care as a human right. According to our results, nurses think that palliative care starts with the diagnosis and it is not provided only for the symptom control but also for the efficient care according to the changing health conditions. Furthermore, it has been considered that it supports the physical, emotional, spiritual comfort of patients, enhances the life quality of them, emphasizes the cultural differences during the health care and ensures that the patient and the family can discuss about the end of life and the death (Table-1). Our results are similar to the literature (Watson et al., 2006, Turgay& Kav, 2012, Aydogan & Uygun, 2011). In our study, majority of nurses (%44.2) think that the palliative care does not contain the mourning process. There are other studies that support our findings and show that palliative care given by nurses are similar to the end of life care (Pavlish et al. ,2009; Mahon & Mc Auley, 2010). However, WHO considers that palliative care is a service which should be given multidisciplinary team to meet the requirements of the families when they need and to give also consultancy mourning (http://www.who.int/cancer/palliative, 2014: Reville et al., 2009; www. national consensus project.org, 2009; Moore, 2005). Furthermore, nurses who participated in our study (%34.2) support the idea that a doctor should be the group leader of the palliative care team. However, it has been reported according to other studies that the multidisciplinary palliative care team should have common meetings to direct the health care, new members can participate in this team according to the patient population, and members who have sufficient knowledge and clinical skills coordinator can be the team (http://www.nccn.org,2014; Ozcelik et al., 2014; Reville et al., 2009; www. national consensus project.org, 2009; Moore, 2005).

Nurses have instructive roles to prepare the patient and the family for the management of symptoms. Besides, they have protective and driving roles to direct the caregivers, coordinators who ensure the intra-team communication, patient as well as the family (Pavlish et al., 2009). In this regard, a nurse can switch to the case manager position. Similarly, Turgay and Kav (2012) stated that palliative care team should be 24 hours accessible. In our study, it has been shown that last period patients have right not to want resuscitation and there should

be legal regulations regarding this issue (%66). Furthermore, it has also been indicated that obstacles in the health policies negatively affect the palliative care services (%70.8). As it is specified and emphasized in the Patients Rights and Regulations, no medical intervention can be performed without permission and patient's consent should be obtained in order to any type of intervention (Hasta hakları yonetmeligi, 1998). In our study, it has been detected that health professionals, who provide palliative care to patients, experience burn-out since they are faced with death permanently (%86.6). This finding is similar to results of others (Turgay and Kay, 2012; Kirchhoff and Beckstrand, 2000). According to our results, participants think that palliative care services should be supported by social security agency (%90); the lectures about palliative care should be included in the curriculum as a compulsory subject (%79.1). Besides, %75.9 of the nurses want to get palliative care training and only %42.5 of them previously got the education on palliative care. Turgay and Kav (2012) emphasized that palliative care services should be supported by the government and health professionals have inadequate knowledge regarding palliative care. In another study performed in Turkey, it has been stated that the lack of training on palliative care is one of the most common obstacles and health professionals should be prepared for the palliative and end of the life care. In order to do that, it has been recommended that there should be certification programs and palliative care and relating subjects should be included in the nursing curriculum (Elcigil, 2012).

According to the perceptions of nurses with respect to the obstacles in the application of the palliative care services, it has been detected that nurses and doctors' awareness of the need for palliative care patients are found to be lower. It has been shown that health professionals who do not have enough knowledge, experience and skills have difficulties in detecting the alterations in the status of patients and the changing requirements of patients and families. These studies have supported that the awareness of these nurses is low (Wyatt et al., 2000; Hudson et al., 2004, Turgay & Kav 2012). In our study, having poor communication doctors/nurses with patients or family members is considered as another obstacle for palliative care. The anger of patients and their families as

well as the poor communication between patients/families with health professionals negatively influence the palliative care process and lead to decrease in home visits (Ahmed et al., 2004; Kirchoff et al., 2000; Beckstrand et al., 2009). Ahmed et al. (2004) have emphasized that doctors have difficulty to direct the negative attitudes of patients/families and doctors have insufficient training in this regard. Similarly, it has been indicated that nurses deal with the care of other patients, reduce the interest in the dying patient, and do not allow time for dying patient's family members when families are nervous about the death of their relative and when they do not accept the worsening prognosis. Furthermore, it has also been emphasized that social worker and a palliative care nurse should be included in the team (Beckstrand et al., 2009). In this regard, the maladjustment of the patients and families negatively affects the process and nurses/doctors are responsible to inform the patients and their families correctly (Hudson et al., 2004). In our study, it has been detected by nurses that other obstacles in palliative care services are as follows: economic shortcomings of the patient and the family (%56.7), culture (%48.3), and religious situation (%45.8). Turgay & Kav (2012) and Ahmed et al. (2004) have also shown that the culture is important in the palliative care service quality and economic shortcomings negatively affect the palliative care process. In literature, it has been specified that nurses should show cultural competence by transferring their culture-specific knowledge and experiences. Nurses should have respect for the culture of the patient and the family, they should use their communication skills effectively and they should provide the palliative care in accordance with the cultural structure of the patient and the family (Huang et al., 2009). In a study performed by Handratty et al. (2002), it has been emphasized that the financial support provided to patients and their families is very important in structured palliative care.

# Conclusion

It has been recommended that in-service palliative care training should be planned for nurses. These training should be renewed and repeated at regular intervals; palliative care and requirements of patients should be included in the syllabus of nursing education; palliative care should be provided according to the cultural differences; the relationship between health care

professionals and patients/families should depend on trust; and sufficient theoretical and practical background should be provided to health care professionals in order to ensure their adaptation on their roles in palliative care.

#### Limitations

Our study was designed to be a single-center study with a limited patient sample. To broaden the sample size, a multicenter study design targeting a larger population with distinct sociodemographic features would be useful.

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