



ARAŞTIRMA / RESEARCH

Palliative care experiences of the patient family

Hasta ailesinin palyatif bakım deneyimleri

Nazan Torun¹

¹Health Institutions Management, Faculty of Health Sciences, Ankara Yıldırım Beyazıt University, Ankara, Turkey

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Abstract

Purpose: In order to provide patient-centred and high-quality palliative care services, it is crucial to acknowledge the perspectives and experiences of patients and their families; yet, there are not adequate number of studies about this subject. The aim of this study is to identify the perceptions of patient families of palliative care and to determine the challenges they have encountered based on their experience in the palliative care service.

Materials and Methods: Qualitative and semi-structured interviews were conducted with 21 patient relatives of patients in the palliative care service. Content analysis method was used for the analysis of qualitative data. Giorgi's four-step qualitative analysis method was used in qualitative data analysis process.

Results: It has been determined that patient relatives who had had no prior knowledge on palliative care perceived palliative care services as “the place in which patient care is taught”, “a fundamentally crucial assistance service”, “a service which has recently been introduced to public knowledge and which must be proliferated”.

Conclusion: Providing care services for end-of-life patients might be burdensome for caregivers. Therefore, the expectations and attitudes of patient families and the difficulties they experience in the palliative care process might provide beneficial insight to inform policy decisions in palliative care interventions.

Keywords: Palliative care, caregivers, patient families, burden, perception/attitude, qualitative research

Öz

Amaç: Hasta merkezli ve kaliteli palyatif bakım hizmetleri sunmak için, hastaların ve ailelerinin bakış açılarının ve deneyimlerinin bilinmesi büyük öneme sahiptir; ama ne yazık ki bu konuda fazla çalışma bulunmamaktadır. Bu çalışmanın amacı; hasta yakınlarının palyatif bakım hakkındaki algılarını belirlemek ve palyatif bakım merkezlerinde yaşadıkları deneyimleri üzerinden yaşamış oldukları güçlükleri belirlemek amacıyla yapıldı.

Gereç ve Yöntem: Niteliksel yarı yapılandırılmış görüşmeler, palyatif bakım merkezlerinde hastası bulunan 21 hasta yakını ile gerçekleştirildi. Niteliksel verilerin analizinde ise içerik analizi (content analysis) yöntemi kullanıldı. Verilerin çözümlenmesinde Giorgi'nin geliştirmiş olduğu dört aşamalı niteliksel analiz adımları kullanıldı.

Bulgular: Daha önce palyatif bakım konusunda hiçbir bilgisi olmayan hasta yakınları palyatif bakımı “hastanın bakımının öğretildiği yer”, “çok önemli bir yardım hizmeti”, “ilk defa duyulan ancak yaygınlaştırılması gereken bir hizmet” olarak algıladıkları belirlendi.

Sonuç: Yaşamın sonuna yaklaşan hastalara bakım sağlanması, bakım verenlere önemli bir yük getirebilir. Bu nedenle, hasta yakınlarının bu süreçte yaşamış oldukları zorluklar, beklentileri ve algıları palyatif bakımdaki müdahalelerle ilgili politika kararlarının yönlendirilmesi konusunda yararlı bilgiler sunabilir.

Anahtar kelimeler: Palyatif Bakım, bakım verenler, hasta ailesi, zorluk, algı/tutum, niteliksel araştırmalar

INTRODUCTION

Palliative care is an approach which aims to maximize the quality of life for patients with serious illnesses, and their families¹. Determining the caregiver's palliative care needs is very important for developing

and implementing palliative services for families². Therefore, within the context of evaluation and organization of palliative care services, inclusion of the experiences of patients and patient relatives in palliative care services has become a fundamental component in palliative care applications³. In order

Yazışma Adresi/Address for Correspondence: Dr. Nazan Torun, Health Institutions Management, Faculty of Health Sciences, Ankara Yıldırım Beyazıt University, Ankara, Turkey E-mail:nazansf@gmail.com

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to provide a patient-centred and high-quality palliative care, there is an immediate need for an extensive acknowledgment of the attitude and experiences of patients and patient relatives⁴. Without a consideration of the attitudes of palliative patients and patient relatives, it is difficult to understand the essential information for clinical decision-making processes and for the improvement of evidence-based care implementations⁵. Therefore, patients and patient relatives are important partners in terms of responding against problems in palliative care. Further studies are required to evaluate the needs of the patients who have no access to palliative care services⁶. Moreover, in the literature, there is very little information about the experiences of palliative care patients and caregivers^{7, 8}. In Turkey, there are not any studies on this subject matter. In order to proliferate and efficiently provide palliative care services, which have recently been launched in Turkey, it is required to identify problematic issues. Hence, this study has been conducted in order to identify the opinions and attitudes of patient families through an analysis of their experiences in the palliative care service. Also, it has been aimed to provide an insight into intervention and policies, which could contribute to the improvement in palliative care services through identification of the problems in palliative care applications.

MATERIALS AND METHODS

This study is designed as a qualitative study through a phenomenological framework. In the study, purposive sampling method is used. The study was conducted with patient families whose relatives are in the biggest palliative care centre in Turkey. The participants of the study were interviewed through face-to-face, semi-structured questionnaires. Interviews were continued until data saturation was achieved (n=21). The length of interviews varied between 15 to 40 minutes. The interviews were conducted by a PhD female researcher who had previous experience in qualitative studies and working in the field of healthcare. The participants were interviewed about whether they had previously heard of palliative care services, and their ideas of palliative care, their experiences during the time their patient stayed in the palliative care centre and the challenges they faced during that time.

The ethical consent for the present study was obtained from the Ethical Committee of Ankara Yıldırım Beyazıt University (31.07.2017 and 21

number). All procedures were applied in accordance with the principles of the World Medical Association Declaration of Helsinki. The study was conducted with voluntary participants. Interviews were conducted in a private room in the hospital with an audio recording device, between August 10 and 23, 2017. Prior to the interviews, the participants had been informed about the nature of the study. Then, the participants signed a "Voluntary Consent Form", which verified their voluntary participation to the study. In the study, the participants were kept anonymous and the quotations from the interviews were given labels, which had been determined by the researcher (N1, N2, N3, etc.)

Statistical analysis

The compliance of the continuous variables (age, total amount of professional experience in intensive care and in the profession) to the normal distribution was analysed graphically and with Shapiro-Wilk test. Patient and patient relative age variable was determined to be distributed normally; however, the duration of patient relatives' care for the patient, the duration of patient relatives' visit in the care centre and the duration of illnesses were determined not to be distributed normally. For the age variable, determinant statistics were shown with \pm Standard Deviation; the duration of patient relatives' care for the patient, the duration of patient relatives' visit in the care centre and the duration of illnesses variables were shown with median [Inter Quartile Range (IQR)]. Actual numbers and percentages were used in order to illustrate categorical variables (gender, education level, marital status, diagnosis, nutrition and catheter use).

In the analysis of qualitative data, content analysis method is used. Audio recordings from the interviews were transferred to the computer. During the analysis of the data, the four-step qualitative analysis, which was designed by Giorgi, were used; (1) the entire descriptions were read in order to understand get the overall sense of the statement. (2) After grasping the meaning of the whole response, the researcher went back to the beginning and read all of the statements once again in order to identify 'meaning units', with a focus on the phenomenon in question through a psychological perspective. (3) After identifying the meaning units, the researcher expressed the psychological insights in these meaning units more directly. This process is especially true for the meaning units revealing the analysed

phenomenon in the most efficient manner. (4) Lastly, the researcher synthesized all identified meaning units into a consistent statement regarding the experience of the participant⁹. The analyses of the qualitative data were done in six steps; (1) preparing and arranging the data for the analysis (transferring the scores to the computer and analysis of the data), (2) reading the transcribed data carefully, (3) coding the data manually (Nutrition support, train medical care in the house environment, education, patient relatives, lack of experience of homecare, critical conditions, challenges, fundamental service), (4) designing the themes (the place in which patient care is taught", "a fundamentally crucial assistance service", "a recently discovered service which must be proliferated.), (5) establishing connections between themes (using quotes), (6) interpreting the meanings of the themes (what lessons have been taken) ¹⁰.

RESULTS

The 21 caregivers included in this study comprised 12 (57%) males and 9 (43%) females, with a mean age of 39.4 ± 3.2 years and 11 of them (52%) were primary school graduates. 8 participants (38%) were the spouses of the patients, and 17 of the participants (81%) were married, and they had been looking after the patients for Median 150 days (IQR=275) (Table 1).

Table 1. Participant characteristics

Variable		
Age (years) (mean \pm SD) (min-max)	49 \pm 3.2 (23-70)	
Caring period (days) (mean \pm SD) (min-max)	150 (275) (10-1200)	
		n (%)
Gender*	Female	9 (43)
	Male	12 (57)
Education status *	Illiterate	2 (10)
	Primary School	11 (52)
	Middle School	1 (5)
	High School	2 (10)
	University	5 (24)
Marital status *	Single	4 (19)
	Married	17 (81)
Relative status	Brother/Sister	2 (10)
	Daughter	7 (33)
	Son	4 (19)
	Spouse	8 (38)

*n (%) **Mean \pm Standard deviation ***Median (Interquartile range (IQR))

The 21 patients included in this study comprised 13 (62%) males and 8 (38%) females, with a mean age of 66 ± 3.1 years. Six of the patients (29%) had Cerebrovascular System (CVS) and 17 (81%) of them had been fed by Percutaneous Endoscopic Gastroscopy (PEG) and 19 (90%) of them had catheters. Patients who had been suffering for Median 365 days (IQR=940) had been in palliative care service for Median 33 days (IQR=39) (Table 2).

From the interviews with participants, three major themes were obtained. These themes were "the place in which patient care is taught", "a fundamentally crucial assistance service", "a recently discovered service which must be proliferated".

The Place in which Patient Care is Taught; 3 of the interviewees expressed their ideas about the definition of palliative care simply as "I do not know (N1), (N7)". Although other participants defined palliative care in different terms; "Nutrition support (N2)", "...the nourishment procedure through catheter or intravenous route for patients who cannot be fed orally (N5)", "final destination (N14)", "I suppose it is the cleaning of phlegm (N18)", most of the participants defined palliative care as "the place in which bedbound patients are provided with medical care and patient relatives are trained in order to continue this medical care in the house environment"

Table 2. Patient characteristics

Variable		
Age** (years) (mean \pm SD) (min-max)	66 \pm 3,1 (37-83)	
Duration of stay at palliative care service ***	33 (39) (2-252)	
Period of illness (days)***	365 (940) (30-3650)	
Gender*	Female	8 (38)
	Male	13 (62)
Diagnosis of the illness*	Cancer	5 (24)
	Pneumonia	2 (10)
	Heart Failure	2 (10)
	Alzheimer's	2 (10)
	CVS	6 (29)
	Dementia	1 (5)
	Amyotrophic Lateral Sclerosis	1 (5)
	Meningitis	1 (5)
	Gastrostomy	1 (5)
Feeding status *	PEG	17 (81)
	Oral Feeding	3 (14)
	IV	1 (5)
Catheters *	Available	19 (90)
	None	2 (10)

*n (%)**Mean \pm Standard deviation ***Median (Interquartile range (IQR))

"The place in which bedbound patients are under medical care (N3)", "I do not know, their patient care is beneficial", "Enthusiastic medical care for older patients, not older but rather these kinds of patients... (N10), "...patients who suffer from cancer, that is to say; patients who progress slowly in terms of recovery process are in palliative care (N11)"

"...medical care without any expectation of recovery; I would say medical care in which treatment options are absent. It is a form of care which aims to stabilize the patient's condition, rather than improve it (N6)", "To only provide care for terminally ill patients, not to treat them (N16)".

"I think it is a place in which they teach you how to provide home care for patients which have no chance of being treated (N8)", "to meet the needs of the patient... they try to ensure that we will know how to take care of our patients and then they will send us home (N9)", "it is great and training-based (N13)", "Training. How to provide care for the patient. What to do (N14)", "It is training-based, such as night care, and the maintenance of medical devices (N19), "to teach how to take care of bedbound patients (N20)".

Although patient relatives mostly perceived palliative care as a patient-focused service, some participants considered patient relatives as part of this service; *"patient care in which patient relatives are also present, similar to intensive care (N12)", "To provide an attendant-focused care. To teach the attendant how to provide nursing for the patient (N17)".*

A Fundamentally Crucial Assistance Service;

Patient relatives stated that household environments were not as adequate as hospital conditions and they would have challenges due to their lack of experience with their bedbound patients who were unable to maintain their needs on their own. Therefore, they also underlined the fact that it was crucial to learn how to provide nursing for the patients under the supervision of medical staff for patients and relatives; *"palliative care is like some kind of a lifesaver (N13), "this place is like an oasis in the desert (N6)".*

16 of the patient relatives who participated in the study underlined that "their patients must be provided with medical care in hospitals"; 5 of the participants stated that home care would be better *"This place is boring, the house would be more comfortable (N7)", "We would be more comfortable at home, it is more suitable for the health and mental state of the patient (N14), as long as there is no infection risk; "as long as there is no infection, it is more suitable to care for the patients in the household environment (N11)", "maybe patients would not get infected in the household environment (N13)" and when they have adequate facilities; "household environment is always better, but if there are no adequate facilities, one might have difficulties. For example, I will have great difficulties, really (N20)."*

Participants who considered hospital-care is better for their patient stated that it would be better for the

patients who were bedbound, could not be orally fed and were in constant critical conditions for various reasons; due to continuous patient care, “they give regular and analgesic infusion two times a day; morning and evening (N1)”; due to the fact that they were alone and could not provide adequate care; “Still, I cannot look after the patient on my own. Since I am illiterate, I cannot know necessary things to do (N4)”, “I am also afraid that something would happen (to the patient), something that might be because of us (N8)”; due to the fact that they did not know what to do in a possible emergency situation; “How am I going to cope with possible crises? (N6)”, “I mean, if anything happens, they can immediately respond to the problem (N9)”, “The only thing (concern) is emergencies (N15)”, “We cannot resuscitate (the patient) (N19)”, due to the fact that they lived in rural areas, and thus they did not have the adequate environment and facilities; “I live in a village; where am I supposed to take (the patient)? (N10), “it (the place where they live) is even farther than the village, it is in the arable field (N11), due to the fact that their spouses would object and their children might be psychologically affected; “There will be visitors to the house and my spouse would not want that. I will have more and more problems (N12)”, “I would not like my child to be around (the patient), also... (N16)”.

13 patient relatives reported that they did not experience any challenges/problems during their stays in the palliative care centre. Also, four of the other 8 patient relatives noted that they had difficulties to change patients’ diapers on their own; one relative reported that there had been communication problems with nurses; two patients underlined that they also had other things to be occupied with, they left their spouses and children at home and thus they had been unable to remain in the centre constantly; one participant stated that constantly being with the patient was tedious and one participant noted that he/she experienced financial problems since the government did not cover all the expenses (wound care barrier creams).

A Recently Discovered Service Which Must Be Proliferated;

All of the patient relatives noted that they had not previously known what ‘palliative care’ meant. Moreover, despite the fact that they had not realized there had been such a service, they expressed that palliative care was a fundamental service; *In that sense, this place is like an ointment (suggesting the usefulness of the centre for the patients) (N6)*”. Moreover, patient relatives also underlined the necessity that these centres must be deployed in every city, especially

metropolitan cities, and in every hospital in order to enable patients to have access to this service.

“We have not heard (of palliative care service) ... We would like to have more centres for the medical supervision of such patients (N8)”.

“I have never heard of it (the palliative care service). I genuinely want it to be everywhere. Those who do not know (about patient care) must learn, they must realize such things can happen to anyone (N10)”.

“I have not heard (of the palliative care) but it is a good thing since you cannot care for the patient at home, at least you can be close to the patient in the hospital... if these centres are opened in every region... Adana, İstanbul, Samsun, Giresun, I mean opening such centres in every region for training and education purposes... There are people (patients) whose spouse/children cannot even look after them. They have jobs to go to but cannot (go to work). They cannot leave their jobs to be with their mothers, and even if they can, they have great difficulties (in terms of their job requirements) (N13)”.

“No, I have just heard of it (palliative care) ... I have overheard people talking to each other... They say there are patients who are far worse (in terms of their medical condition) ... They say these patients must also remain in such centres, but they cannot. The number of these centres might be increased (N16)”.

“I have never heard of it before, I did not know (about palliative care service). Of course.. I have searched everywhere up to Polatlı. If we could, we would have gone there, also. Here, not every hospital has it (palliative care centre) (N20)”.

“It is a necessary institution, indeed. There are a lot of patients who die without any care (since these centres are scarce in number and are not known by patient relatives) (N21)”.

Some patient relatives suggested that the provision of care for the patients who are in similar conditions with their patients, is not a luxurious investment for the government; as a matter of fact, they suggested that palliative care service would reduce the patient-care expenses. They also noted that thanks to these centres, patient relatives could provide a better care for their patients, would not consider them as a burden, would care for their patients with pleasure, and would not occupy other hospital units (intensive care, emergency unit) unnecessarily.

“As far as I can understand, there must be new palliative care service units. This is also a financial relief for the government because there are patients who visit emergency units... (There are) patients who excessively occupy intensive care units... They (Palliative care service units) must be the primary concern of the

government, but the official approach is exactly the opposite, as far as I can observe, they (officials) prefer to send patients home... Patient relatives begin to hate their patients (N6)".

"I think the number of these centres must be increased. This is not a luxurious form of investment; the budgetary concerns are not an excuse. In one way or another, the number of these centres must be increased, especially in metropolitan cities (N17)".

DISCUSSION

Learning about the experiences of caregivers might make it easier to identify and evaluate the satisfaction levels, problems, and unanswered needs of both patients and caregivers and thus it might contribute to the understanding, measurement, and improvement of the quality of the care provided¹¹. Moreover, the perceptions of caregivers of palliative care might contribute to the provision of human-centred healthcare by causing an improvement in the quality of life for patients¹². Although patients and caregivers are critical shareholders regarding the tackling of these issues, few studies focused on the perceptions of patients and caregivers⁷.

As a result of the present study, which focused on identifying the perceptions of relatives of patients hospitalized in a palliative care centre of palliative care, it was inferred that for patient relatives, 'palliative care' was perceived as "the place in which bedbound patients are nursed and patient relatives are trained in order to continue such nursing-oriented treatments". While in a study, patient relatives associated 'palliative care' with 'death, hopelessness and dependency' through a negative and frightening relationship¹³, in another study, relatives defined it as a 'holistic support, guidance for decision-making and preparation for future challenges'⁷. In the present study, only two of the participants perceived palliative care service as a holistic support, which also included patient relatives. However, similar to the findings of our study, in the literature, palliative care is often related to the notion of 'nursing' by the patient relatives. Patient relatives also defined palliative care as a 'nursing service without treatment', 'care for terminally ill patients', "care for the patients who are unable to show any progress"¹⁴. The notion of palliative care was reported as "a nursing-oriented care in an institution" by the patient relatives and it was defined as 'elemental care' or only 'pain-easing' or 'convention' for the patient¹. In another study, although the majority of the participants reported

that they were familiar with the term, few of these participants actually had proper knowledge about palliative care².

What is more, doctors must acknowledge that their attitudes towards the patient relatives in terms of providing information about palliative care also influence patient relatives' perception of the definition and importance of palliative care¹³. The finding that patient relatives defined palliative care as a service which "teaches patient relatives about the nursing-oriented treatments in order to transfer this care to the household, from the hospital' is also related to the fact that doctors inform patient relatives in this manner before accepting the patients. That the information given to the patient relatives is understood clearly depends on how the information is presented, where, when and how much it is shared, and who shares the information, and it is critically important¹⁵. In their study, Josland et al. suggested that it is significant that regular deliberative meetings be held with patients and patient relatives during the illness, and that professionals be aware of the burdens of the family caregivers resulting from the nursing of the patient¹⁶.

Patient relatives expressed that 'palliative care' must be proliferated in order to enable everyone to have access to this service, even though they had not heard of it beforehand. In a study which was conducted in Italy, more than 40 percent of the interviewees had already known about palliative care and only 23.5 percent of these interviewees reported that they had adequate knowledge about palliative care¹⁴. Caretakers of patients with Parkinson disease also did not know what palliative care was; however, when they were informed about the role of palliative care, most of them also noted that they could benefit from palliative care¹⁷. In a study conducted to examine the perceptions of Australian family caregivers of palliative care, it was aimed to develop training interventions/strategies which would increase early integration, access and community participation in palliative care¹.

Although patient relatives reported that they had not experienced any problems throughout their visiting times in the palliative care centre, some participants reported problems regarding their personal communication with the personnel, their ability to provide the same care on their own, and their disconnection from their social lives and economic problems. In the palliative care service, medical care providers must have the skills to listen to and interact

with patients/patient relatives and to be graceful and empathetic towards them⁴. The benefits of palliative care from the perspective of patient relatives have also been studied and it has been found that palliative care also supported patient relatives' coping mechanisms, strengthened them and reinforced their sense of support and trust¹⁸. Moreover, patient relatives often have to juggle multiple responsibilities at the expense of their own needs in order to care for the patients¹⁹. Besides, the multi-factor nature of the notion of 'caregiver' includes social isolation, excessive workload inside and outside the household, changes in patient relatives' attitudes towards their patients, being exclusively 'responsible', economic challenges and withdrawal from employment^{20,21}. At the same time, palliative care must not only focus on patient comfort in terms of eradicating the symptoms, but it must also include patient relatives who take the responsibility of looking after their patients for years²².

Patient relatives claimed that it would be a challenge for them to provide care for their patients without any prior experience and thus staying in these centres and learning how to provide care for their patients were fundamentally important for them. In another study, it was found that palliative care was important for both patients and relatives³. In the present study, patient relatives suggested that it was better for patients to stay in the hospital due to the fact that their conditions might be worsened at any time. In another study, patient relatives were found to be unprepared for emergencies (for example; falling, CPR, or psychosis)². This situation also became a source of uncertainty about the progress of the illness and stress and anxiety. The primary needs of relatives were defined as follows; medical and nursing care in the household, then care and psychological support which is provided by volunteers. It has been determined that the optimal environment for these patients is their home, with professional assistants¹⁴. Home-based palliative care programs, which would provide the patients nearing the end of their lives with the comfort of their own homes, were developed since they increased quality of life for patients and satisfaction, and since they eased the burden of healthcare system²³.

Patient relatives' idea that palliative care would relatively be less of a financial burden for the government is also supported by the previous literature on this subject²⁴. In addition, community-based palliative care is related to the reduction of

hospital expenses under the life-constraining conditions^{1, 25}. A comprehensive literature review about the existing international findings and evidence about the palliative care expenses between the years of 2002-2011 was conducted. Within the scope of this review, 46 articles were reviewed and it was found that palliative care was less expensive with respect to comparative groups²⁶. Moreover, it is also anticipated that relatively low expenses and multi-disciplinary support provided through palliative care also ease the burden on caregivers²⁷.

The present study stands out as being the first study that sheds light on the development of palliative care centres in Turkey; however, one limitation of the study is that it focused only on one palliative care centre and on the opinions of patient relatives alone. Further studies which examine other palliative care centres including the perceptions of service providers and policy makers, as well as of patient relatives would significantly contribute to the present study.

The fact that palliative care is perceived differently on a global scale is related to the healthcare and social policies of the states. However, these differences might cause theoretical gaps in palliative care services, and thus cause problems. In order to fill in these gaps, the experiences of patients and patient relatives must be utilized throughout the decision-making processes about palliative care services. Moreover, doctors' approach towards their responsibility to inform patient relatives about palliative care also influence relatives' perceptions of this service. Therefore, doctors must inform patient relatives with respect to healthcare policies. Lastly, it has been revealed by the present study that palliative care is fundamentally beneficial for patients and their relatives, and policy-making decisions must be made to make palliative care services more accessible to persons who are in need of such services.

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