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Research Article

Evaluating end-stage cancer patients' preferences for spending their final days at home or in hospital

Son evre kanser hastalarının son günlerini evde veya hastanede geçirme tercihlerinin değerlendirilmesi

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Abstract

Introduction: This study aimed to explore the preferences of end-stage cancer patients regarding spending their final days at home or in a hospital, focusing on the impact of cancer types and symptoms necessitating palliative care admission during this period.

Methods: The study was conducted with 274 patients diagnosed with end-stage cancer and admitted to the palliative service of Dr. İFC City Hospital in Tekirdağ province. Opinions were collected from all patients while they were fully conscious. The relationships between patients' preferences for their place of death and their age, gender, socioeconomic status, duration of stay in palliative care, admission complaints, and diagnoses were examined. A significance level of p<0.05 was considered statistically meaningful.

Results: Approximately one-third of the participating patients preferred to die at home under home care supervision. It was found that these preferences were not influenced by the patients' age, gender, socioeconomic status, or duration of stay in palliative care but were affected by their cancer diagnoses and symptoms leading to admission. Patients with pancreatic cancer preferred to die in the hospital, while those with prostate and breast cancer were more likely to choose home death.

Conclusion: If a system equipped with an effective planned home care program, managed by a multidisciplinary team in palliative care services, can be provided to meet the needs of patients and caregivers when they approach hospitals in their final stages, it could enable the right group of patients to spend their end-of-life at home, in accordance with their preferences.

Keywords: Terminal cancer, home care, palliative care, place of death

Öz

Giriş: Bu çalışma, son evre kanser hastalarının son günlerini evde veya hastanede geçirme tercihlerini, bu tercihlerinde palyatif servisine yatış semptomlarının ve kanser türlerinin etkisine odaklanarak araştırmayı amaçlamaktadır.

Yöntem: Araştırma, Tekirdağ ilinde bulunan Dr. İFC Şehir Hastanesi'nin palyatif servisine kabul edilen 274 son evre kanser tanısı almış hasta ile yürütülmüştür. Tüm hastalardan tamamen bilinçli oldukları sırada görüşler toplanmıştır. Hastaların ölüm yerine ilişkin tercihleri ile yaşları, cinsiyetleri, sosyoekonomik durumları, palyatif serviste yatma süreleri yatış şikayetleri ve tanıları arasındaki ilişkiler incelenmiştir. Anlamlılık düzeyi olarak p<0,05 değeri istatistiksel olarak anlamlı kabul edilmiştir.

Bulgular: Katılan hastaların yaklaşık üçte biri son günlerini evde, evde bakım gözetimi altında ölmeyi tercih etti. Bu tercihlerin hastaların yaşları, cinsiyetleri, sosyoekonomik durumları veya palyatif bakımda yatma sürelerinden etkilenmediği; ancak kanser tanıları ve palyatif servise yatışlarına neden olan semptomlardan etkilendiği tespit edildi. Pankreas kanseri olan hastalar hastanede ölmeyi tercih ederken, prostat ve meme kanseri olan hastalar evde ölümü daha fazla tercih ettiler.

Sonuç: Eğer, son evrelerinde hastanelere başvuran kanser hastalarının ve bakım verenlerin ihtiyaçlarını karşılayabilecek şekilde, palyatif servislerde multidisipliner bir ekip tarafından yönetilen etkili ve planlı bir evde bakım programı sağlanabilirse, saptanan doğru hasta grubunun, tercihlerine uygun olarak, hayatlarının son dönemlerini evde geçirmelerini sağlanabilir.

Anahtar Kelimeler: Terminal kanser, evde bakım, palyatif bakım, ölüm yeri

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Key Points

1. The right group of terminal cancer patients can be enabled to spend the final days of their lives at home, in accordance with their own preferences.
2. If pain symptoms can be managed in the final stages for patients with prostate and breast cancer, and their care can be effectively planned with a home care system, it is possible to enable these patients to achieve their preference of dying at home.

Introduction

In patients with incurable diseases, the primary objective is to alleviate symptoms, provide psychosocial support, and fulfill the patient's end-of-life desires as much as possible. It has been established through numerous studies that, particularly as cancer progresses to its final stages, the need for symptom relief and psychosocial support increases for both patients and their families [1]. Palliative care services and hospital palliative units have been developed to meet this need, becoming more crucial in recent years due to the rapid aging of the population and the extension of life expectancies linked to advances in medical treatments [2]. The World Health Organization (WHO) defines palliative care as a holistic approach that addresses not only physical but also psychological, social, and spiritual issues in life-threatening illnesses [3]. As incurable patients approach the end of life, the progression of their disease increases the burden of symptoms. This process accentuates the need for palliative services by a multidisciplinary team due to the rising physical and psychological needs of both the patients and their caregivers. In 2020, the International Association for Hospice and Palliative Care expanded the definition of palliative care to emphasize the importance of quality of life for both the patient and their family [4]. The palliative care of end-stage cancer patients should be approached holistically, including physicians, nurses, psychologists, physiotherapists, social service specialists, and caregiving family members. During this period, centering the approach on the patient's final wishes to alleviate the hardships experienced by the patient and their relatives is a significant goal [5].

The choice of death location for end-stage cancer patients is complex and influenced by numerous factors. This preference process is dynamic, changing based on the evolving needs of patients and their families as death approaches [6]. These needs extend beyond the patient's biological requirements, encompassing psychological, social, and economic conditions affecting the caregivers. Regardless of these factors, nearly every patient desires to spend their last days at home, in familiar surroundings with loved ones, seeking what is often referred to as a "good death" [7]. However, there are many reasons why this preference is not realized for all cancer patients in their final stages. This study aims to examine only the reasons related to the type of cancer and the symptoms requiring hospital admission. It seeks to explore whether end-stage cancer patients prefer to spend their final days at home or in a hospital and how these preferences are influenced by the type of cancer and symptoms leading to palliative care admission.

Methods

The study was conducted with a total of 274 patients diagnosed with end-stage cancer who were admitted to the palliative care service of Tekirdağ DrIFC State Hospital in Tekirdağ province from January 1, 2023, to the end of December over a one-year period. All of these patients agreed to participate in the study; however, only 184 of them could be provided with the clinical comfort to medically confront their end-of-life at home under home care supervision. The study was structured around these 184 patients' preferences for their place of death, either at home or in the hospital. The palliative service where the study was conducted was also responsible for providing home care services throughout Tekirdağ province. The home care team offered to patients preferring to die at home consisted of two doctors, two nurses, four home care technicians, one psychologist, one dietician, and one social worker, making regular visits to patients with two separate teams and vehicles. This was the organization of home care provided to end-stage cancer patients in the palliative service who preferred home death.

Consent was obtained from all willing participants while they were fully conscious, and the opinions of family members who would be taking over the home care were also collected. If a consensus could not be reached between the patient and their relatives, the patient was not included in the study. During the collection of these opinions, a full-time psychologist, social service specialist, and home care technician in the palliative service accompanied the patients and their relatives. Patients' cancer diagnoses were categorized by organ and system, without using pathological diagnoses for classification. For the grouping of patients' socioeconomic statuses, those who owned their home or were staying in a property owned by immediate family members and had a monthly income of over 40,000 TL were considered to have a good socioeconomic level. If the patient was staying in a rented home or with an immediate family member and the household's monthly income was between 20,000 and 40,000 TL, they were classified as having a medium income level. If the total monthly income of the caregiver and patient living in the home where care would be provided was below 20,000 TL, they were considered to have a poor socioeconomic status. The reasons for admission to the palliative service were categorized as pain, malnutrition, respiratory distress, and bedsores. While each patient could be admitted for a single specific complaint, many patients presented with several or all of these complaints concurrently.

Ethical approval

a. For this study, ethical approval was obtained from the Tekirdağ Dr. İFC City Hospital Clinical Ethics Committee with the decision number 68, dated 01.12.2023.
b. For this study, informed consent forms have been obtained from all patients.
c. All permissions for conducting this study have been obtained from both patients and institutions.

Statical analysis

All data from participating patients were entered into the SPSS (SPSS Inc, Chicago, IL, USA, version 25.0) program. Regression analysis was used to explore the relationship between patients' ages and the duration of stay in the palliative service with their preferences for the place of death. Binary logistic regression analysis was utilized to examine the relationship between patients' gender, socioeconomic status, diagnostic groups, and reasons for admission with their end-of-life preferences. A significance level of $p<0.05$ was considered statistically significant.

Results

The study included a total of 184 patients with an average age of 68.68±11.97 (min 31, max 99). Of these, 62.5% were male (n=115). Sixty-two patients (32.6%) chose to spend their final days at home and successfully did so under home care supervision after all arrangements were made. The remaining patients (77.4%) preferred to spend their end-of-life in the hospital palliative service. The average number of days all participating patients spent in the palliative service was 13.95±12.41 (min 1, max 77). Twenty-four patients (13.0%) were classified with a poor socioeconomic status, while the remaining 160 patients (87.0%) had a medium or good socioeconomic level. It was determined that the choice of spending the end of life at home was not significantly influenced by age, gender, socioeconomic status, or duration of stay in the palliative care service. Consecutively (p=0.742,0.864,0.762,0.911).

The categorization of patients based on their admission diagnoses revealed that lung cancer was the most common group admitted to the palliative service, with malnutrition being the most frequent reason for admission. The clinical descriptive statistics of the patients participating in the study are provided in Table 1.

Table 1. Clinical descriptive characteristics of participating patients

	n (%)
Primary Cancer Diagnosis	
Lung Cancers	41 (22.3%)
Stomach-Esophagus Cancers	23 (12.5%)
Pancreatic Cancers	22 (12.0%)
Liver-Biliary Cancers	19 (10.3%)
Colorectal Cancers	16 (8.7%)
Gynecological Cancers	16 (8.7%)
Brain Tumors	11 (6.0%)
Head and Neck Cancers	10 (5.4%)
Prostate Cancers	9 (4.9%)
Hematological Cancers	8 (4.3%)
Breast Cancers	6 (3.3%)
Skin Cancers	3 (1.6%)
Total	184 (100.0%)
Reason for Palliative Admission	
Malnutrition	147 (79.9%)
Pain	138 (75.0%)
Respiratory Distress	50 (27.2%)
Bedsores	17 (9.2%)

The information provided highlights a significant finding from the study regarding the relationship between the reasons for admission to palliative care and the preferences of patients to spend their end-of-life at home. Specifically, it was found that patients admitted to the palliative service due to pain had a significantly higher preference to spend their final days at home once their pain was managed effectively (p<0.001). Furthermore, the symptoms leading to palliative care admission significantly influenced patients' preferences to spend their end-of-life in the hospital (p<0.001). (Table 2)

Table 2. Relationship between palliative care admission complaints and end-of-life location preferences

Symptom	**Score**	**B**	**Degrees of Freedom (df)**	**P-Value**
Pain	52.76	2.84	1	***<0.001***
Malnutrition	0.66	0.64	1	0.18
Respiratory Distress	3.52	0.66	1	0.15
Bedsores	0.70	0.88	1	0.22
Total	56.26	***-2.99***	4	***<0.001***

Binary logistic regression test, significance level p<0.05.

A total of 67.4% of the end-stage cancer patients participating in the study preferred to die in the hospital (n=124). According to their diagnoses, a significant majority of patients diagnosed with pancreatic cancer preferred hospital death (p=0.024), while a significant majority of patients with prostate cancer preferred to die at home (p=0.039) (Table 3).

Of the patients admitted to the palliative service, 32.6% preferred to die at home (n=60). Patients who preferred to spend their final days at home at a rate higher than this average included, in descending order, those with prostate cancer (66.7%), brain tumors (54.5%), head and neck cancers (50.0%), and gynecological cancers (43.7%) (Table 3).

Table 3. Evaluation of end-of-life location preferences (home vs. hospital) of participating patients based on their diagnoses at admission to the palliative service.

Diagnosis	Hospital n (%)	Home n (%)	Total n (%)	p-value
Lung Cancers	27 (65.9)	14 (34.1)	41 (100)	0.811*
Stomach-Esophagus Cancers	16 (69.6)	7 (30.4)	23 (100)	0.814*
Pancreatic Cancers	***20 (90.9)***	***2 (9.1)***	***22 (100)***	***0.024****
Liver-Biliary Cancers	13 (68.4)	6 (31.6)	19 (100)	0.923*
Colorectal Cancers	14 (87.5)	2 (12.5)	16 (100)	0.091*
Gynecological Cancers	9 (56.3)	7 (43.7)	16 (100)	0.323*
Brain Tumors	5 (45.5)	6 (54.5)	11 (100)	0.121*
Head and Neck Cancers	5 (50.0)	5 (50.0)	10 (100)	0.237*
Prostate Cancers	***3 (33.3)***	***6 (66.7)***	***9 (100)***	***0.039****
Hematological Cancers	5 (62.5)	3 (37.5)	8 (100)	0.763*
Breast Cancers	4 (66.7)	2 (33.3)	6 (100)	0.969*
Skin Cancers	3 (100.0)	0 (0.0)	3 (100)	0.999*
Total	**124 (67.4)**	**60 (32.6)**	**184 (100)**	**<0.001****

*Binary logistic regression analysis. **Single-sample t-test. Significance level at p<0.05*

Discussion

In the study, approximately one-third of cancer patients preferred to die at home under home care supervision. It was concluded that these preferences were not influenced by the patients' age, gender, socioeconomic status, or duration of stay in the palliative service. The findings suggest that the type of cancer diagnosis played a significant role in these preferences, with a notable majority of patients with prostate cancer preferring to die at home, while a significant majority of those with pancreatic cancer chose to die in the hospital. It was also determined that the symptoms experienced by cancer patients in their terminal phase influenced these preferences. Specifically, pain was identified as a symptom that significantly influenced the preference for dying in the hospital.

In the Western world, the desire among cancer patients to be cared for and to die at home in their final stages is widespread. A study by Nysaeter and colleagues revealed that patients prefer to maintain control over their lives, remain autonomous, and be seen as they always have been during their final days [8]. Factors influencing the preference of terminally ill cancer patients to die at home and the facilitation of this desire have been examined. According to this study, living in an affluent area and an increase in socioeconomic status make it easier to fulfill this wish [9]. In a study conducted in Turkey, although patients and their families were satisfied with palliative care clinics, about half of the participants expressed a desire to spend their end of life at home, provided that necessary measures were taken and home care was ensured [10]. Despite this, in recent years, alongside an increase in treatment options, the number of home deaths has decreased, with only a few countries (such as Canada, the United Kingdom, and the USA) reporting an increase in home deaths due to the strengthening of home care services [11]. There is a discrepancy between the desire of cancer patients to spend their final days at home and actual home deaths. A systematic review found that while the desire for home death among cancer patients can reach 60%, actual home death rates fall to around 40%. This decrease is attributed to many significant factors, ranging from the level of socioeconomic development to the provision of home care health services, patients' age and gender, disease diagnosis and symptoms, and the period when this preference is asked [12]. Consistent with the literature, our study also examined some of these factors. Unlike the literature, we found that patients' age and gender did not significantly influence these preferences, which we attribute to the low number of participants in our study. We believe that if this study were conducted with a much larger sample size, the outcome might differ. Contrary to the literature, the impact of socioeconomic level was not significant in our study. We speculate that this may be due to the socioeconomic income levels of patients who can access the palliative service of the State hospital in the province where the study was conducted being relatively similar. Patients with much lower socioeconomic levels might struggle to access this service, while those with much higher socioeconomic levels might opt for private hospitals.

In the literature, age has been shown to influence the desire of cancer patients to spend their final days at home, with patients over the age of 80 particularly preferring to die at home. Studies also indicate that women are more likely to prefer the hospital as their place of death [13]. However, this study found that, contrary to the literature, patients' age and gender did not significantly influence their end-of-life location preferences. This discrepancy may be attributed to the higher average age of patients admitted to the palliative service during the study period and the study being conducted with patients in similar age groups.

Approximately ninety percent of cancer patients are hospitalized at some point following their diagnosis. The frequency of symptoms and problems with nutrition significantly increase the frequency of hospital admissions, especially in patients with advanced-stage cancer [14]. A study encompassing seven countries (Belgium, Canada, England, Norway, the Netherlands, the United States, and Germany) showed that about 70-90% of patients were hospitalized for any reason during the last six months of their life [15]. Another study analyzing the symptoms observed during the admissions of end-stage cancer patients found that depression was the most common symptom, followed by fatigue, insomnia, and other symptoms. However, when considering the severity of symptoms and their role in necessitating hospital admission, pain, shortness of breath, and problems with nutrition were identified as the primary reasons [16].In Türkiye, another study examining the reasons for hospital admissions during the terminal phase of cancer patients categorized these reasons into physical symptoms, psychological problems, and care support needs. Pain, fatigue, malnutrition, sleep disorders, respiratory difficulties, and depression were highlighted in these studies [17]. Consistent with the literature, the most common reason for hospital admission in this study was malnutrition. Approximately eight out of ten patients were admitted to the hospital due to this problem, followed by pain, respiratory distress, and bedsores due to prolonged bed rest. The absence of symptoms such as sleep disorders, depression, and fatigue as reasons for admission to the palliative service in this study was because, although these symptoms were present, they were not the reasons for admission. Although many symptoms identified in the literature as reasons for hospital admission accompanied the admitted symptoms, only the primary reasons for admission were included in the study design. The study found that all symptoms leading to hospital admission influenced the preference for dying in the hospital. However, when examining the symptoms individually, pain was identified as the most significant and the only statistically significant symptom influencing the preference for hospital death. This finding suggests that the relationship of patients and their families who prefer home death with pain should be carefully reconsidered, and the pain management of end-stage cancer patients receiving home care should be well-planned.

When examining the preferences for dying at home or in the hospital based on cancer diagnoses, this study found that, in order of frequency, patients with pancreatic cancer, colorectal cancer, stomach-esophagus cancer, and liver and biliary cancers were more likely to prefer dying in the hospital during their terminal phase compared to patients with other types of cancer. We believe that the formation of such a grouping in this study is particularly due to the common occurrence of nutritional problems and pain symptoms among these groups of cancer patients [18,19].

A study in Canada found that patients diagnosed with pancreatic cancer significantly preferred to die at home if effective home care was provided [20]. Another study indicated that as problems increased in the terminal phase for pancreatic cancer patients, their initial preferences could change, leading them to prefer dying in a hospital more [21]. This study, particularly covering the period close to death for terminal cancer patients, aligns with the literature by showing that patients with pancreatic cancer prefer to spend their final days in the hospital and increasingly choose hospital death as time progresses. This preference may be due to pancreatic cancer patients having shorter life expectancies after diagnosis compared to other cancer patients, resulting in less time to adapt to the process.

In a study conducted in two regions of Sweden examining the quality of life in the final stages of patients diagnosed with metastatic prostate cancer, it was indicated that patients with prostate cancer preferred to die at home more frequently, and this preference did not change even if their quality of life deteriorated [22]. Another study examining the final stages and symptoms of patients with prostate cancer found that patients increasingly accepted their illness and prepared themselves more comfortably for death as they lived longer with the disease [23]. In Italy, it has been reported that about 75% of patients with breast cancer preferred to die at home, a significantly higher rate compared to other types of cancer [24]. Consistent with the literature, this study also found that patients with prostate and breast cancer preferred to die at home more than patients with other cancer diagnoses. We believe this may be due to the longer terminal phase durations of these cancer types and their less detrimental impact on quality of life compared to other cancers. Providing quality home care services to this patient group could not only meet the patients' preferences but also reduce the caregiving burden on families and potentially decrease the load on hospitals.

Limitations

The most significant limitation of the study is that, although the palliative care patients were informed about the home care services that would be offered to them if they chose home preference, we believe that their preferences for dying at home were not adequately reflected because they could not live through and experience these services.

Conclusion

The preferences of cancer patients to spend their final days at home or in a hospital are influenced by multiple factors. Despite the strengthening of palliative care services to meet the needs of these patients and their caregivers, especially during the final stages, there remain challenges in adequately addressing these needs. If an effective and planned home care program is integrated with the care managed by a multidisciplinary team in palliative services, it should be possible to facilitate home deaths for patients and their families in accordance with their preferences, without leaving them to face the end of life alone. There is a need for further research to determine which patients, cancer groups, and symptom-burdened families can be prepared and directed towards home care during these processes. Our recommendation with this study is to enhance the analysis of conditions for home death preferences while strengthening palliative services for end-stage cancer patients, and to reinforce preliminary ideas on which symptoms and cancer groups could be more readily prepared for this process. Specifically, we suggest developing arrangements that will enable patients with a longer terminal phase expectation, such as those with breast or prostate cancer, to achieve their preference for home death by addressing challenging symptoms like pain.

Conflict of interest: The author declares that In this study there is no conflict interest.

Author Contributions	Author Initials
SCD (Study Conception and Design)	GÖ
AD (Acquisition of Data)	GÖ
AID (Analysis and Interpretation of Data)	GÖ
DM (Drafting of Manuscript)	GÖ
CR (Critical Revision)	GÖ

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