Original Article

Characteristics of Advanced Cancer Patients Admitted to the Palliative Care Unit from the Emergency Department

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Abstract

Aim: People with cancer frequently present to emergency departments (EDs) because of exacerbation of the existing problems and new symptoms, complications of treatments, or difficulties with care and support systems. The aim of the study was to determine the presenting symptoms and demographic characteristics of advanced cancer patients and their caregivers admitted to the palliative care (PC) unit from the ED. **Methods:** After approval, 139 cancer patients admitted to the ED and referred for PC consultation were included in the study. The medical records of PC unit for all patients and their primary caregivers were retrospectively evaluated. Demographic characteristics, cancer site and metastasis, reasons and frequency for ED admissions, symptoms, duration of hospitalization, and outcomes were recorded. The association between the characteristics of caregivers and emergency visits was also evaluated. **Results:** Among all patients, 61.9% were >60 years old, 58.3% were male, and 71.2% were married. The most frequent site of cancer was gastrointestinal system (39.6%), lungs (18.7%), and genitourinary system (12.2%). The reasons for emergency visits were found as inadequate symptom control (65.5%), dying patient (30.2%), lack of psychosocial support (3.6%), and symptom of other comorbidities (0.7%). The most frequent symptoms were feeling of not well-being, tiredness, and lack of appetite. There was no difference in the number of admissions according to caregivers. Ninety-seven patients (69.8%) died at the PC unit and 42 (30.2%) were discharged. **Conclusion:** PC system needs to be integrated into all health-care disciplines including EDs. While improving a community- and home-based PC, education of patients, caregivers, and health professionals must also be provided.

Keywords: Advanced cancer, caregiver, consultation, emergency department, palliative care

Introduction

Palliative care (PC) is a comprehensive and integrated care of patients and their families who are facing problems associated with life-threatening illness. Cancer patients often experience several symptoms together, which may be difficult to manage from the diagnosis to the treatment or terminal phase of the disease. Combined standard oncology care and PC should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden.[1]

People with cancer frequently present to emergency departments (EDs) because of exacerbation of the existing problems and new symptoms, complications of treatments, or difficulties with the care and support systems.[2,3] The distress of family members while managing the end-of-life symptoms may also contribute to the increase in admissions.[4] Although patients with advanced illness who are near the end-of-life report wanting to be cared for and die at home, most of them contradictorily present to the EDs in the last weeks or days of life.[2,5,6] Barbera *et al*. have shown that about 34% of patients with cancer visited ED during the final 2 weeks of life.[2] Multiple ED visits are considered an indicator of poor-quality cancer care, along with chemotherapy in the last 14 days of life, multiple hospitalizations, intensive care unit admissions, and death in an acute care institution.[7] ED visits may be associated with prolonged and exhausting waits, which can distress vulnerable patients at the end of life and their families.[8] It is also time-consuming and clinically challenging

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for the emergency staff. Although delivering appropriate PC to the patients with advanced cancer is extremely important, identifying the causes of ED visits and preventing potentially avoidable ones might be important as well.[9] In the general population, more than 50% of the ED visits were for nonurgent care or for conditions that could have been treated in a primary care setting.[10] Delgado-Guay *et al*. have found that nearly one-fourth of ED visits by patients with advanced cancer receiving PC were potentially avoidable.[9]

The primary objective of the present study was to determine the presenting symptoms and demographic characteristics of advanced cancer patients admitted to the PC unit from the ED. The secondary objectives were to evaluate the outcomes of patients and identify any association between the characteristics of primary caregivers and emergency admission.

Methods

With the approval of the hospital's research committee, cancer patients admitted to the ED of the hospital between April 2016 and April 2017 and referred for PC consultation were evaluated. A total of 142 patients who were hospitalized in the PC unit after consultation were included in the study. All procedures performed in the present study were in accordance with the ethical standards of the institutional and/or national research committee and with the Helsinki declaration.

The medical records of the PC unit, both electronic and written files for all patients and their primary caregivers, were retrospectively evaluated. The data of the caregivers of three patients were missing. From the eligible data of 139 patients, the following information was collected: demographics (age, gender, marital status, number of children education, and monthly income), primary cancer site and diagnosis, presence of metastasis at the time of PC consultation, time of diagnosis, types of treatments received for cancer (surgery, chemotherapy, and radiotherapy), time of last treatment, the hospital that the patient was followed, number of previous ED visits, and knowledge about the disease and prognosis. The main reasons for ED visit were categorized as inadequate symptom control, lack of psychosocial support, complication of treatment, dying patient, or symptom of other comorbidities. The presenting symptom at admission and severity of the symptom was determined using the Edmonton Symptom Assessment Scale (ESAS). ESAS is a visual analog scale developed for use in symptom assessment of PC patients. Its Turkish validity and reliability study has been performed by Yeşilbalkan *et al*.[11] The duration of hospitalization at the PC unit and outcomes (discharge/exitus) of patients were also noted.

The primary caregivers of patients were assessed in terms of demographics, the existence of comorbidities, and previous experience of cancer patient care. The relation between the characteristics of caregivers and the number of ED visits was evaluated.

Statistical analysis

All categorical variables such as gender, educational status, or reason for ED visit were presented as frequency (%). The distribution of duration of hospitalization in the PC unit was examined using Shapiro–Wilk test and the variable was reported by median (interquartile range [IQR]: 25th–75th percentile). The number of ED visits according to the patients' and caregivers' characteristics and the reason of ED visits based on the patients' characteristics were compared by either Pearson's Chi-square test or likelihood ratio test. Cochrane-Q test was used to detect the differences of observed symptoms among patients and Friedman test to determine the differences between the severity of symptoms. $P < 0.05$ was accepted as statistically significant.

IBM SPSS Statistics 21.0 (IBM Corp. Released 2012. IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY, USA) program was used for statistical analysis and calculations.

Results

During the study period, a total of 187 patients admitted to ED were found to receive PC consultation. Twenty of them were for pain management, 16 patients returned to their homes after palliation of other acute symptoms, and 12 could not be hospitalized in the PC unit due to lack of empty bed. A total of 142 patients had inpatient PC after consultation, and only the data of 139 patients were eligible for the statistical analysis.

The demographic characteristics of the patients and their primary caregivers are presented in Table 1. Among the 139 patients, 61.9% (n = 86) were aged above 60 years, 58.3% (n = 81) were male, and 71.2% (n = 99) were married. It was found that 58.3% (n = 81) of the primary caregivers were the patient's child or sibling, 64.7% (n = 90) was between ages 41 and 60 years, and 68.3% (n = 95) had no previous experience of caregiving to a patient.

The median duration of hospitalization was 6 days (IQR: 2–11). The most frequent sites of cancer were gastrointestinal system (39.6%, n = 55), lungs (18.7%, n = 26), and genitourinary system (12.2%, n = 17). Metastasis was present in 96.4% of the patients (n = 134). The number of ED visits was found to be once in 56.1% of patients (n = 78), twice in 25.9% (n = 36), and thrice or more in 18% (n = 25). The reasons for ED visits were found as inadequate symptom control (65.5%, n = 91), dying patient (30.2%, n = 42), lack of psychosocial support (3.6%, n = 5), and symptom of other comorbidities (0.7%, n = 1). Ninety-seven patients (69.8%) died at the PC unit and 42 (30.2%) were discharged [Table 2].

The distribution and severity of symptoms at admission to the ED are presented in Table 3. The most frequent symptoms were detected as feeling of not well-being, tiredness, and lack of appetite, and those were found to be statistically different from other symptoms ($P < 0.05$). Pain was the fourth frequent symptom at admission. The median severity of not well-being and tiredness was 9 (IQR: 9–10) and 9 (IQR: 8–9), respectively.

Table 1: Demographic characteristics of the patients and their caregivers

Patients' characteristics	*n* (%)
Age	
18- 40	3 (2.1)
41- 60	50 (36.0)
>60	86 (61.9)
Gender	
Female	58 (41.7)
Male	81 (58.3)
Marital status	
Married	99 (71.2)
Single	2 (1.4)
Separate/divorced	9 (6.5)
Died spouse	29 (20.9)
Number of children	
None	2 (1.4)
1	11 (7.9)
2	34 (24.5)
+3	92 (66.2)
Educational status	
Non illiterate	21 (15.1)
Primary/secondary school	99 (71.2)
High school	14 (10.1)
University	5 (3.6)
Financial status	
Low	54 (38.8)
Middle	75 (54.0)
Good	9 (6.5)
Very good	1 (0.7)
Family history of cancer	
Yes	88 (63.3)
No	51 (36.7)
Caregivers' characteristics	***n* (%)**
Age	
18- 40	29 (20.9)
41- 60	90 (64.7)
>60	20 (14.4)
Gender	
Female	90 (64.7)
Male	49 (35.3)
Relationship	
Spouse	49 (35.3)
Child/sibling	81 (58.3)
Relative	9 (6.4)
Occupational status	
Occupied	40 (29.0)
Unoccupied	98 (71.0)
Support for care	
Supported	71 (51.1)
Unsupported	68 (48.9)
Educational status	
Nonilliterate	5 (3.6)
Primary/secondary school	79 (56.8)
High school	32 (23.0)
University	23 (16.5)
Financial status	
Low	40 (28.8)
Middle	81 (58.3)
Good	18 (12.9)
Very good	0 (0.0)
Experience of caregiving	
Yes	44 (31.7)
No	95 (68.3)
Comorbidity	
Yes	57 (41.0)
No	82 (59.0)

The symptom of not well-being was more severe than other symptoms except tiredness ($P < 0.05$).

When the symptoms were evaluated according to the diagnosis of cancer, the most frequent symptoms were found to be pain in head-and-neck cancers (71.4%); nausea (54.5%), depression (34.5%), and insomnia (36.7%) in gastrointestinal cancers; anxiety (69.2%) and shortness of breath (73.1%) in lung cancers; and drowsiness in hematologic cancers (100%).

The rate of previous PC consultation was 58% ($n = 81$), and hospitalization in PC unit was 23% ($n = 32$). The patients with a previous history of PC consultation were found to visit ED for once (44.4%, n = 36), twice (28.4%, $n = 23$), and thrice or more (27.2%, $n = 22$). The visit for once was lower and the visit for thrice or more was higher in the patients with previous consultation history when compared with patients who were not previously consulted to PC ($P < 0.05$). The other characteristics of the patients did not reveal any statistical difference in terms of the number of ED admissions ($P > 0.05$). The patients who were cared by their spouses had one visit for 57.1% and two visits for 24.5%. There was no difference in the number of admissions according to the caregiver ($P = 0.961$). The distribution of admissions was also similar in terms of other caregiver characteristics ($P > 0.05$).

It was shown that 70.7% ($n = 70$) of the married patients were admitted for inadequate symptom control and 1% ($n = 1$) for lack of psychosocial support. The results were 52.5% ($n = 21$) and 10% ($n = 4$) in unmarried patients, respectively. The married patients presented to the ED with inadequate symptom control more than unmarried ones, while the admissions were lower for lack of psychosocial support ($P < 0.05$).

Discussion

In the present study, we found that advanced cancer patients have visited ED frequently for inadequate symptom control at home (65.5%) or when they are very close to dying (30.2%). The most frequent symptoms were feeling of not well-being, tiredness, lack of appetite, and pain. Gastrointestinal tumors constituted the primary site of cancer (39.6%, $n = 55$) followed by lung tumors (18.7%, $n = 26$).

Table 2: The characteristics of cancer, emergency department visits, palliative care consultations, and outcomes of the patients

Characteristics	*n* (%)
Diagnosis of cancer	
Brain	10 (7.2)
Head and neck	7 (5.0)
Lung	26 (18.7)
Breast	12 (8.6)
Gastrointestinal	55 (39.6)
Genitourinary	17 (12.2)
Hematologic	3 (2.2)
Others	9 (6.5)
Metastasis	
Yes	134 (96.4)
No	5 (3.6)
Continuity of treatment	
Yes	11 (8.5)
No	119 (91.5)
Information about disease	
Absent	113 (81.3)
Present	26 (18.7)
Characteristics	***n* (%)**
Number of visits	
1	78 (56.1)
2	36 (25.9)
+3	25 (18.0)
Reason of visits	
Inadequate symptom control	91 (65.5)
Lack of psychosocial support	5 (3.6)
Dying patient	42 (30.2)
Symptom of comorbidity	1 (0.7)
Previous consultation	
Yes	81 (58.3)
No	58 (41.7)
Previous palliative care hospitalization	
Yes	32 (23.0)
No	107 (77.0)
Outcome	
Discharge	42 (30.2)
Exitus	97 (69.8)

EDs are increasingly being utilized as care units for patients with advanced life-limiting diseases. The main reasons for referral were reported as management of worsening symptoms, a pathway for admission to an oncology or PC ward, not further coping at home, or directives of the primary oncologist for preemptive management of treatment complications.[12] Although multiple visits to ED and subsequent hospital admissions in the last months or days of life reflect poor quality of care, cancer patients frequently visit EDs because of unplanned end-of-life care and inadequate management of dying.[7] In the UK, 60% of people die in hospital and most of them follow an emergency admission after multiple hospital stays.[13] Yildirim *et al*. reported in their study that 60% of 107 Turkish cancer patients made at least one visit to ED within 1 month before death.[14] The most common site of the primary tumor was lung and symptom dyspnea as well. In our study, cancer patients with gastrointestinal tumors were admitted more frequently, and lung tumors were the second. These results are similar to several other studies indicating gastrointestinal and lung cancers as the first two diagnoses.[2,8,15,16] Delgado-Guay *et al*. detected that the main reasons for the referral to PC service from EC and the primary oncology team were uncontrolled pain, gastrointestinal symptoms, and dyspnea.[8] In another study, the highest mean intensity scores on the ESAS at emergency admission in advanced cancer patients were for fatigue, poor appetite, oral dryness/xerostomia, and pain upon movement.[15] Grudzen *et al*. found that older adults with PC needs at the ED mostly reported moderate-to-severe fatigue, pain, dyspnea, and depression.[17]

In the present study, 65.5% of the patients were admitted for the management of uncontrolled symptoms. The most frequent symptoms were detected as feeling of not well-being, tiredness, lack of appetite, and pain, with not well-being being the most severe one except tiredness ($P < 0.05$).

The pain symptom was more prominent in head-and-neck cancers; nausea, depression, and insomnia in gastrointestinal cancers; anxiety and shortness of breath in lung cancers; and drowsiness in hematologic malignancies. Although the number of patients was not comparable for all cancer types, symptoms were found as expected. In 30.2% of the cases, the reason for ED visit was the end-of-life care of the dying patient. Approximately 70% of all patients died in the PC unit after a duration of hospitalization. Turkish people have a traditional family structure. The families are extensive, and majority of the cancer patients prefer to spend their last days with their loved ones caring for them and die at their homes. In contrast, many dying people are admitted to hospital for terminal care and the place of death is most often the hospital. The main reason for this is the inadequate support in the community. Families or caregivers cannot manage to cope with the end-of-life symptoms and bring the patient to the hospital where they feel safer. It was found that 58.3% of the primary caregivers of this study were the patient's child or sibling, and 68.3% had no previous experience of caregiving to a patient. The characteristics of the caregivers did not reveal any difference in terms of the distribution of admissions. Still, the married patients presented to the ED with inadequate symptom control more than unmarried ones while their admissions were lower for lack of psychosocial support ($P < 0.05$). We found that 10% of unmarried patients reported lack of psychosocial support on admission.

ED visits are often a stressful experience for both patients and families. The overcrowded and busy environment can distress and exhaust vulnerable patients at the end of life.[18] A primary focus of ED care is to provide urgent medical treatment in the hope of minimizing morbidity and preventing death. The ED health professionals may feel a conflict between

Table 3: The frequency and severity of symptoms at admission to the emergency department

Symptoms	Present, *n* (%)	Absent, *n* (%)	Severity of symptoms	
			Median	IQR
Feeling of not well-being	138 (99.3)[a]	1 (0.7)	9[a]	9-10
Tiredness	134 (96.4)[a]	5 (3.6)	9[a,b]	8-9
Lack of appetite	131 (94.2)[a]	8 (5.8)	8[b]	7-9
Pain	82 (59.0)[b]	57 (41.0)	7[c]	0-9
Anxiety	68 (48.9)[b,c]	71 (51.1)	0[c,d,e]	0-8
Insomnia	60 (43.2)[b,c,d]	79 (56.8)	0[c,d,e]	0-8
Shortness of breath	59 (42.4)[b,c,d]	80 (57.6)	0[c,d]	0-9
Drowsiness	53 (38.1)[c,d]	86 (61.9)	0[d,e,f]	0-7
Nausea	52 (37.4)[c,d]	87 (62.6)	0[c,d,e]	0-7
Depression	35 (25.2)[d]	104 (74.8)	0[e,f]	0-4
Others	7 (5.0)[e]	132 (95.0)	0[f]	0-0
Test statistics; *P*	Q=514.715; <0.001		χ^2=563.124; <0.001	

The same letters show similar values. IQR: 25th-75th percentiles. IQR: Interquartile range

the perceived lifesaving role and a palliative approach to care.[19] They may also find themselves inadequately trained about implementing the core competencies of PC. One of the most common problems is also limited information available about the patient. PC patients are often time-consuming and clinically challenging for ED health professionals. In PC, the intrinsic value of each person as an autonomous and unique individual is acknowledged and respected.[20] Patients must be empowered to make their self-decision about the type of care, prognosis, treatment, care options, and other relevant aspects of care. In EDs, there is usually no efficient time and trained staff to communicate with the patient, caregivers, and families about the incurable nature of the disease and for end-of-life or advanced care planning regarding the cultural aspects. Besides in Turkey, the decision-making usually shifts to the family members as the patient often do not know anything about the accurate diagnosis. In the present study, 81.3% of the patients were unaware of their cancer diagnosis. Early PC involvement in the ED is important as it provides a patient- and family-centered care, symptom control, and good quality of life, while minimizing futile treatments and inappropriate utilization of health-care resources. Although the present study was performed at a comprehensive cancer center and the staff working in ED are familiar with cancer patients, there is still a need to improve communication and appropriate management of the patient and avoid unnecessary consultations at the same time.

While investigating the reasons for ED referrals of advanced cancer patients and developing optimal caring methods of PC patients in EDs, solutions to prevent the avoidable ones must also be improved. In a French study, the most frequent reasons for ED admissions were generalized weakness, social isolation, and end-of-life care for home-hospitalized PC patients. They also report in their study that half of the transfers to EDs were potentially avoidable for terminally ill patients in home care. For 58% of presentations, the investigations and treatments did not require presentation to an ED; 34% of patients returned home after the visit; and only 20% remained to receive special care.[21] Mercadante *et al*. showed that most of the problems could be solved just by phone explanations or by a simple medical visit at home in a population of patients with advanced cancer.[22] For advanced illness, continuity of care throughout the disease trajectory and across different settings in the health-care system is mandatory. Therefore, an expanded community- and home-based PC with input from specialist physicians enabling the management of complex pain and other symptoms at home can be beneficial.[12] Unfortunately, there is no hospice, community hospice teams, home PC teams, or "hospital at home" organizations in Turkey. The existing home-care teams are not specialized for PC but are expected to give such care. Patient and caregiver education, coordination of referrals, regular home visits, or available telephone counseling and psychosocial support may be other alternatives to prevent PC patients from admitting to EDs with unmet needs. Care organizations must diversify by including institutions offering social services besides health care.

This study may have several limitations. It is designed as a retrospective study and the data were collected from the medical records of the patients who were hospitalized in the PC unit. The patients consulted for other reasons, not hospitalized due to lack of empty bed in the service or return to home after an informative speech and minor interventions, were not included. However, this population constitutes only a small percent of referrals and patients are generally hospitalized in PC unit following consultations. Therefore, we believe that our results reflect the characteristics of the majority of patients admitted to ED in need of PC.

Conclusion

Advanced cancer patients frequently visit EDs in the last days or months of their lives to receive PC for unmanaged symptoms, end-of-life care, or psychosocial support. Identifying the main reasons for admission and preventing the avoidable ones is extremely important to reduce unnecessary ED crowding

and patient exhausting. There is a need to promote access to primary care, increase the number of PC organizations, educate patients in hospital-at-home service, and train caregivers and health-care professionals in palliative medicine. The optimal PC organization and research for consensual definition of goals and quality standards and uniform national criteria at all levels of care must be carried out. A sustainable, quality, and accessible PC system needs to be integrated into all health-care disciplines including EDS, as well as supporting care providers such as family and community volunteers.

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Conflicts of interest

There are no conflicts of interest.

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