

Initial experience with delivery of palliative care to terminal cancer patients

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Background/aim: We investigated the symptoms and needs of terminal cancer patients in a region where formal palliative care is limited. Here we present the demographic features and symptoms of end-stage cancer patients living in a city in northern Turkey.

Materials and methods: The study was conducted at Gaziosmanpaşa University (Tokat, Turkey), in 2011 and 2012. End-stage cancer patients admitted or referred by various departments to our outpatient pain unit were included. Demographic data, treatment histories, primary tumor sites, patient complaints, and symptom intensities measured using the Edmonton Symptom Assessment System Scale were prospectively entered into a database.

Results: A total of 107 patients (36 female and 71 male) were included. Gastrointestinal cancer was the most common form of cancer (43%), followed by genitourinary (25.3%) and lung cancer (15%). The most common symptom was fatigue (98.1%). The other symptoms (in decreasing order) were pain (92.5%), insomnia (92.5%), loss of appetite (76.6%), constipation (71%), dyspnea (63.6%), nausea (60.7%), cough (57.9%), and vomiting (48.6%). Eighty-six percent of the patients (n = 92) had metastases. Most lived in the city (59.8%) and 84 (78.5%) lived with their spouses.

Conclusion: Patients were referred at the late stages of disease with pain as the principal presenting symptom. Family members were the principal caregivers.

Key words: Pain, palliative care, symptoms, cancer

1. Introduction

Palliative care (PC) is defined by the World Health Organization as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual” (1). PC is a humanitarian need that must be prioritized when cancer patients are in their terminal stages (2). Recently, a study in lung cancer patients emphasized the critical role played by early PC. The patients were less depressed, had a better quality of life, and survived 2.7 months longer than a group receiving standard oncological care (3).

Although PC is accepted worldwide to be an important aspect of cancer therapy, the organization of PC differs among countries. Therefore, findings in one country cannot be directly applied to another; it is necessary to consider the patient's needs, the resources available, and the PC capacity of the particular country (2,4–6).

Here, we present our initial findings on the presentations, symptoms, and needs of terminal cancer patients living in a city in northern Turkey.

2. Materials and methods

2.1. Study design

The study was performed in 2011 and 2012 at the Department of Anesthesiology and Reanimation Gaziosmanpaşa University (Tokat, Turkey). End-stage

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cancer patients aged over 20 years who were either referred to our pain unit from various departments (including surgery, urology, oncology, emergency, or chest surgery) or who were admitted directly to the pain unit were included. Those who agreed to participate completed the Edmonton Symptom Assessment System Scale (ESAS). Demographic data, medical and social histories, primary tumor sites, treatment histories, and presenting symptoms were prospectively recorded using a standardized form. The evaluation was performed retrospectively.

The ESAS is a nine-item self-rated numeric rating scale designed to assess symptom severity in patients receiving PC (7,8). In short, patients rate the severity of nine symptoms, namely pain, inactivity, nausea, depression, anxiety, drowsiness, lack of appetite, well-being, and shortness of breath, on a scale from 0 to 10. An optional tenth symptom can be added by each patient.

The sum of all items, in numerals, constitutes the ESAS distress score.

2.2. Statistical analysis

Quantitative data are presented as means with standard deviations, and qualitative data are presented as frequencies with percentages. All analyses were conducted using SPSS (SPSS Inc., Chicago, IL, USA). Statistical significance was set at $P < 0.05$.

3. Results

A total of 107 patients (66.4% male, 33.6% female) were included. Mean patient age was 64.90 ± 10.61 years (Table 1) and the mean body mass index was 23.65 ± 4.78 kg/m². Most patients were referred from surgical clinics (57.1%, $n = 61$). The primary tumor was of gastrointestinal origin in 46 patients (43%); the other tumors were genitourinary (25.3%, $n = 27$), lung (15%, $n = 16$), hematological (5.6%,

Table 1. Characteristics of the patients.

Age (years)		Mean \pm SD
	Female	65.77 \pm 12.95
	Male	64.46 \pm 9.27
	Total	64.90 \pm 10.61
Primary cancer site	Number	%
Stomach	17	15.9
Lung	16	15.0
Pancreas	13	12.2
Colon and rectum	11	10.3
Prostate	10	9.4
Kidney	6	5.6
Lymphoma	6	5.6
Bladder	6	5.6
Nasopharynx	4	3.7
Gallbladder	4	3.7
Ovary	2	1.9
Uterus	2	1.9
Limb	2	1.9
Breast	2	1.9
Esophagus	1	0.9
Cervix	1	0.9
Spine	1	0.9
Brain	1	0.9
Rhabdomyosarcoma	1	0.9
Myeloma	1	0.9

n = 6), brain (0.9%, n = 1), and other (10.2%, n = 11). Metastasis was present in 86% of the patients (n = 92) on admission, with 19.6% (n = 21) being in the liver, 18.7% (n = 20) in the bone, 16.8% (n = 18) in the lung, 9.3% (n = 10) in the peritoneum, 7.5% (n = 8) in the brain, 5.6% (n = 6) in the lymph nodes, 1.9% (n = 2) in the bladder, and 6.6% (n = 7) in other organs. Of all patients, 70.1% were of low-income status. Most patients lived in the city (59.8%, n = 64). Eighty-four (78.5%) patients lived with their spouses. Another 15% (n = 16) lived in big families (with their children, and thus as grandparents), and the remaining 6.5% (n = 7) lived alone or with relatives. No patient lived in a nursing home or care facility.

The principal symptom was fatigue (98.1%, n = 105). The other symptoms (in decreasing order) were pain (92.5%, n = 99), loss of appetite (76.6%, n = 82), constipation (71%, n = 76), dyspnea (63.6%, n = 68), nausea (60.7%, n = 65), cough (57.9%, n = 62), and vomiting (48.6%, n = 52). The prevalence of the symptoms is shown in Table 2.

4. Discussion

Great variations in PC facilities worldwide are associated with political, cultural, and socioeconomic differences among countries (2–6,9). In certain countries, such as the USA and the UK, hospices and nursing home care services are common. Moreover, PC is either a medical subspecialization or a full specialization in these countries. The importance of PC cannot be overemphasized; recent work has shown that PC prolongs survival if combined with adjuvant chemotherapy (3,10,11). Home care PC has commenced very recently in Turkey and coordination among the various PC organizations has yet to be achieved (12,13). Patient needs are usually met by physicians and patient families. The traditional family remains strong in Turkey and most social and psychological support

is provided by the nuclear family and close relatives (5,6,12,14).

Although symptoms of pain and insomnia were common, our patients were referred principally because of fatigue (98.1%) (Table 2). Pain was the second most common complaint that most severely compromised the quality of life. However, all symptoms were severely debilitating. Cancer patients do not deal with a single symptom, but rather with assemblies of mutually aggravating symptoms, rendering management difficult (15–17).

As pain is an important symptom, it might be logical to suggest that, in the absence of true PC, pain units could be created in hospitals (18,19). Effective pain management requires a coordinated effort by the patient, the physician, and healthcare officials. Patients often find it difficult to verbalize pain and may not understand the side effects of painkillers. Physicians can be inadequately trained to manage pain, may maintain negative convictions or prejudices about cancer pain, and may fail to adequately evaluate pain. The healthcare system can sometimes refuse to take pain treatment seriously and make it difficult for patients to access certain opioids. Opioids are the mainstay of cancer pain management; they have come under strict international control since 1961 because of their highly addictive potential (20,21). Fear of abuse has caused most countries to overlimit the medical use of opioids. Hence, patients in such countries cannot readily obtain them and thus are ineffectively managed (21). Therefore, very serious and greatly underestimated causes of disability in cancer patients may be virtually ignored (21,22).

Patients usually present to emergency departments seeking relief from pain and other symptoms, and it has been suggested that “advanced adjunctive therapeutic approaches” offered in outpatient clinics might reduce the

Table 2. Prevalence of symptoms.

Symptom	Number	%
Fatigue	105	98.1
Pain	99	92.5
Insomnia	99	92.5
Loss of appetite	82	76.6
Constipation	76	71.0
Dyspnea	68	63.6
Nausea	65	60.7
Cough	62	57.9
Vomiting	52	48.6

number of such presentations (19). However, considering the variety of presenting symptoms and the great variation in psychological, spiritual, and medical needs of patients, PC must be delivered in a multidisciplinary manner until dedicated PC specialists are trained (6,23).

Referral to a PC organization often occurs late in the course of disease; most patients are terminal on admission (86%). Possible explanations for this include the lack of formal PC units, underestimation by physicians of the roles potentially played by PC, and misconceptions of such roles (in that PC is inappropriately reserved for terminal patients rather than serving as an adjunct to the standard therapies of surgery, chemotherapy, and radiotherapy). In the present study, no patients lived in nursing homes; all lived with their spouses or their children and grandchildren in big families. Most needs, including psychological, social, and economic support, were satisfied by the families. This may explain why formal PC is so slow to develop in Turkey; first-degree relatives assume the burden of terminal care. Although intimate support by the family is invaluable, such support can be variable in extent, inconsistent, and unreliable. An organized healthcare approach featuring PC is essential to bolster family support (6).

Our study had some limitations. We studied only a relatively small number of patients from a single geographic region in Turkey. However, the fact that we conducted

our study in a region lacking any formal PC services is important. We found that terminal cancer patients come in contact with pain units only in the later stages of their disease. Although the most bothersome symptom was pain, fatigue was evident in nearly all patients. Many patients still lived in big families and were primarily cared for by first-degree relatives. Such findings may help healthcare facilities organize appropriate PC services that allow family members to play pivotal roles in patient care, with a focus on the most debilitating symptoms to improve patient quality of life. Carefully planned multicentric prospective studies featuring large numbers of patients from different regions in Turkey are required to determine whether our findings can be generalized to the whole country. The results could aid policymakers to organize PC in the most efficient manner, given that financial and personnel constraints will inevitably be in play.

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