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Applicability of end of life needs assessment tool at a multicultural Turkish hospital

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ABSTRACT

Improving the quality of life in terminal stage cancer patients and their families are at utmost importance. The End of Life Needs Assessment Form is adapted from Palliative Performance Scale; to assess patients' needs toward the end of their life. We studied for the first time the practicality, applicability and usefulness of this tool in a unique Turkish hospital providing services to patients from extensive number of countries in this region.

1. Introduction

The World Health Organization (WHO) describes palliative care as an approach that can improve the quality of life of patients and their families when facing the problems associated with life-threatening illnesses. This is achieved through the prevention and relief of suffering by means of early identification, impeccable assessment and the treatment of pain and other related problems – i.e., physical, psychosocial and spiritual. The aim of palliative care is to improve the life quality of the patient and his or her family members. Palliative care reaches its aim only if it relieves the patients' pain and other symptoms, provides psychological and spiritual support, helps the patient to lead as active a life as possible despite having a life-threatening disease and it provides support and education for the family.[1–3]

Life and death are normal processes in palliative care. This type of care neither postpones nor hastens death; the aim is to facilitate the transition to death. Palliative care is concerned with the quality of life, rather than its duration. When death approaches, the measures used to comfort the patient and his or her family members become more intense.[4] Palliative care team input has been shown to result in better satisfaction, symptom control and shorter lengths of stay in hospital.[5]

A systematic review has shown the majority (49–78%) of patients with advanced cancer would prefer to die at home.[6,7]

In palliative care, predictions about the outcomes as death approaches may help the patient and his or her family members when making individual decisions to coordinate after-death planning, and to use available resources in an optimal way.[8]

At present, accurate prognostication remains a challenge even for experienced clinicians. Previous studies have shown the high bias in predicting the prognosis of cancer patients.[9] A meta-analysis showed that clinicians' survival prediction was overestimated by at least 4 weeks in 27% of cases. It is necessary to develop new methods to enhance the clinical prediction of survival.[10] Recent research suggests that repeated assessment of patients over time and with the application of prognostic tools and indicators

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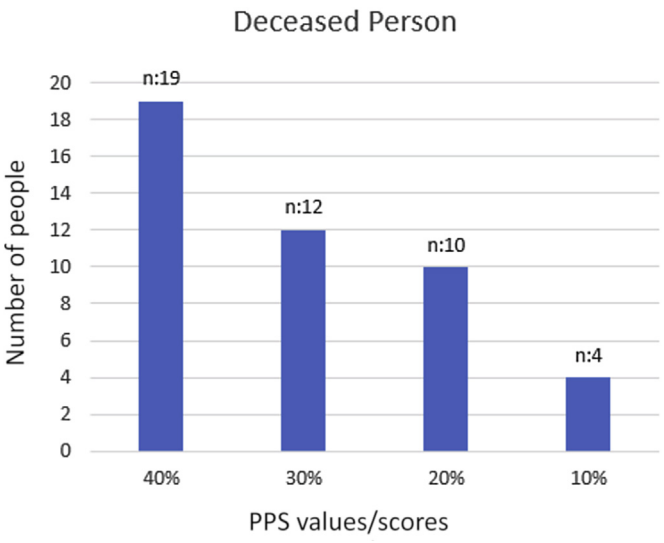
Table 1
Patients with their respective countries.

Country	n	%
Turkey	74	47,13
Romania	24	15,29
Bulgaria	20	12,74
Russia	9	5,73
Azerbaijan	7	4,46
Kazakhistan	5	3,18
Libya	4	2,55
Iran	3	1,91
Bahrain	2	1,27
Georgia	2	1,27
Iraq	2	1,27
Afghanistan	1	0,64
Algeria	1	0,64
Syria	1	0,64
Uzbekistan	1	0,64
Kosovo	1	0,64
Total	157	100



Graphic 1. The 45 patients who died during the follow up period is depicted according to their PPS scores.

improves prediction accuracy.[11]

Crucial to determining prognosis is the demonstration that the patient's primary disease process is progressing over time. There are a number of sources of important information that can help the clinician recognize when the patient's condition is worsening.[12]

Previous studies have shown that the Karnofsky Performance Scale is an important tool in determining the patient's remaining life and prognosis. The Karnofsky Performance Scale was developed in 1947 and serves as the first example of a scale that considers social factors, such as normal daily activities, the ability to provide self-care and the ability to work, in addition to performing a physical and clinical examination to assess one's health status.[13]

The palliative performance scale (PPS) has been adapted from the Karnofsky Performance Scale and it investigates ambulation, level of activity, self-care, oral intake of food and vigilance, in addition to providing a functional assessment. It is divided into 11 categories. Its scores range from 0 to 100; 0 indicates that the patient is dead, while a score of 100 indicates that the patient is perfectly healthy. This palliative care assessment tool was created in 1996 and it is currently used in various countries and health centers around the world.[14]

2. Aim

The aim of our study is to show the benefits of using supportive tools in planning end-of-life care in patients under palliative care.

3. Materials and methods

A total of 345 patients with a diagnosis of cancer were admitted to the oncology in-patient unit in-between December 2013 and December 2014; 247 of these patients, for whom there was no chance for curative therapy, were reviewed retrospectively.

Prognostic tools have been developed to guide to patient-physician communication and decision-making. In our hospital, the assessment of end-of-life care in patients is performed using tools such as the Palliative Performance Scale, which was developed by clinicians. The tool collects information on the patient's sociodemographic information, and there are a total of eight questions that have been developed by a clinician: three questions aim to assess the patient's progression status; one question measures the patient's level of normal daily activities; one question assesses the patient's nutritional status; and three questions pertain to the patient and family's awareness, needs, expectations and preferences. The End of Life Needs Assessment Form (ELNAF) also includes the Palliative Performance Scale. Appendix 1.

Psychosocial assessment is performed by routine psychologist visits and interviews. Consciousness, attention, general status, mood, emotional status, psychomotor activity, structure, content and speed of thought, speech and comprehension are assessed during the psychological assessment. Additionally, the patient's awareness (insight), support from the family and social environment, as well as the status of the family during the bereavement process are also assessed.

Data were evaluated using the SPSS software program. The demographic data are presented in terms of percentages and mean values. One-way analysis of variance was used to determine whether the PPS values differed according to diagnosis.

Table 2
The average lifetimes of the deceased patients according to their diagnosis.

Diagnosis (according to affected systems)	Time from the beginning of the disease until death (months)	Time after completing the ELNAF until death (days)
Urogenital system	53	45
Breast	40	13
Respiratory system	19	46
Gastrointestinal system	19	38
Other	24	34

4. Results

The patients with a diagnosis of metastatic cancer, except for those with testis tumors, lymphoma, thyroid cancer, and hematological malignancy (except those patients in whom stem cell transplantation was planned), were included as the patient group that did not have a chance for curative therapy. A total of 157 patients without a chance for curative therapy were admitted to hospital 247 times.

The patients' mean age was 55 years and 50% of the patients were female. 53% (n = 83) is foreign and 47% (n = 74) is Turkish patients Table 1. The patients' distribution according to their cancer diagnosis was as follows: 38% had gastrointestinal system cancer; 22% had respiratory system cancer; 16% had cancer of the urogenital system; 9% had breast cancer; 9% had bone, connective or soft tissue cancers; and 11% had other cancer types. The mean number of patient admissions was 3 (range: 1–9).

The patients' PPS values were not significantly different between diagnostic groups ($p < 0.05$).

4.1. Deaths

Due to the nature of the disease, 45 (28%) of the patients died during follow-up and 30 (67%) died in our unit; 7 (15%) died in intensive care and 8 (18%) died at home during home care. The PPS values were assessed as 10% (n = 4), 20% (n = 10), 30% (n = 12) and 40% (n = 19) in deceased patients. Low PPS values indicate that the patient is close to death. Low PPS values also mean shorter life duration. The 45 patients who died during the follow up period is depicted according to their PPS scores in the Graphic 1. Also the average lifetimes of the deceased patients according to their diagnosis are listed in Table 2.

5. Discussion

Our institution has been providing palliative care to patients of various cultures and nations since 2005. Multiculturalism leads to different expectations and approaches regarding end-of-life care. While planning and implementing end-of-life care, care providers should allow the patients and their family members to participate in making relevant decisions. We suggest that using tools such as the ELNAF enhances the effectiveness of planned care and therapy.

Lau et al. have reported in their study that the PPS is an important tool in the assessment of end-of-life care.[14] Head et al. revealed in their study that PPS scores are correlated with the duration of hospital stay.[8] In our study, following the ELNAF assessment, it was found that the patients remained alive for an average of over 1 month, except for those patients with breast cancer. PPS values over 30% may be a tip-off when predicting the expected amount of time that the patients will remain alive following the ELNAF assessment.

When the PPS criteria were evaluated, it was observed by Anderson et al. that lower PPS values were indicative of the fact that the patients were dependent on others regarding “ambulation, oral intake, self-care and performing normal activities”.[15] Thus, to be informed about the probable prognosis of the disease is important when supporting, informing and following up with family members in the early stages of bereavement. As has been shown in our study, some of the patients died in their homes. From this perspective, supporting caregivers during the early stages of palliative care may provide a more comfortable end-of-life process for the patient. It is also suggested that informing a patient about his or her prognosis may help guide psychologists' routine interviews with patients and caregivers.

Guidelines for predicting patient prognosis near the end of life are not intended to be used in a dogmatic fashion, and should not be converted into a scored checklist with same magic number of items required to consider a patient ready for hospice or palliative care. When the assessment is completed, the information obtained should be combined with other clinical and psychosocial information. The making of the decision to recommend that a patient receive end of-life care is one of clinical judgment, based on the needs of that specific patient.[12]

6. Conclusion

In Turkey, studies on planning end-of-life care using the Palliative Performance Scale are lacking. This study showed that when the PPS was assessed along with the patients' clinical and laboratory results, the End of Life Needs Assessment Form may be used as a robust tool in predicting prognosis and survival. More clinical studies with larger samples are needed to prove the effectiveness of the support given to patients and their caregivers after considering the PPS values.

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Conflicts of interest

There is no conflict of interest to declare for this manuscript.

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Appendix 1. End of life assessment form

Patient name and surname	Protocol number
Birth date	Sex Female Male
Admission date/hour	Department/room number:

Diagnosis of the patient:
End of life assessment criteria:

Diagnosis of the patient:

End of Life Assessment Criteria:

1. The patient has a diagnosis of a severe and progressed life-threatening disease. (If cancer: prominently invasive, metastatic, or cancer with a large primary tumor) =Yes =No

If the answer is “no”, put this form into the patient’s file after signing and without further procedure.

2. Is there a plan for future curative therapy? (If there is no known treatment method for the condition, if available options are exhausted, or if the patient rejects therapy, the patient is not suitable.)

If the answer is “yes”, put this form into the patient’s file after signing and without further procedure.

3. Have there been recent symptoms showing progression of the condition? =Yes =No

If “Yes”, choose the appropriate option:

a. Hospitalization, visit to the emergency room, or an increase in the utilization of health services.

b. Worsening symptoms and physical exam findings of the condition.

c. Worsening of the condition, as per laboratory results.

d. Worsening of the condition, as per studies and imaging.

4. Being dependent in at least 3 of following normal daily activities =Yes =No

(choose the activities that the patient cannot perform alone)

=bathing =eating own meals =urine and stool continence

=grooming =transfer =going to the bathroom

5. Palliative performance scale 60% or lower =Yes =No

Current level:_____

PPS level	Ambulation	Self-care	Oral intake	Level of consciousness	Activity	Symptom of disease
60%	Decreased	Occasional assistance	Normal or decreased	Full consciousness or confusion	Not able to perform hobbies of home chores	Prominent disease

50%	Mainly sitting	Considerable assistance	Normal or decreased	Full consciousness or confusion	Not able to do any work	Widespread disease
40%	Mainly in bed	Mainly assistance	Normal or decreased	Full consciousness, drowsiness, or confusion	Not able to do any work	Widespread disease
30%	Bedridden	Total care	Decreased	Full consciousness, drowsiness, or	Not able to do any work	Widespread disease
				confusion		
20%	Bedridden	Total care	Small morsels	Full consciousness, drowsiness, or confusion	Not able to do any work	Widespread disease
10%	Bedridden	Total care	Only oral hygiene	Drowsiness or coma	Not able to do any work	Widespread disease

6. Nutritional condition is bad, sometimes not able to take adequate fluid/calories =Yes =No

Previous weight of the patient (if available):_____ Current weight of the patient:_____

=In the previous 6 months, >10% weight loss =In the previous 3 months, >7.5% weight loss

=Serum albumin level <2.5 g/dL (_____)

=Inability to perform a proper assessment due to excessive edema and ascites

7. Patient/patient's relative is aware that the condition may lead to death =Yes =No

8. Patient/patient's relative prefers to only receive comforting interventions =Yes =No

9. Indications of intensive care was discussed with the patient and/or the patient's relative =Yes =No

Note: This form is used for the patients' end-of-life needs assessment and to provide information to the treatment team. It cannot be used alone for treatment decisions.

Assessor Name Surname Signature Date

(***continued***).

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