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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.

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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

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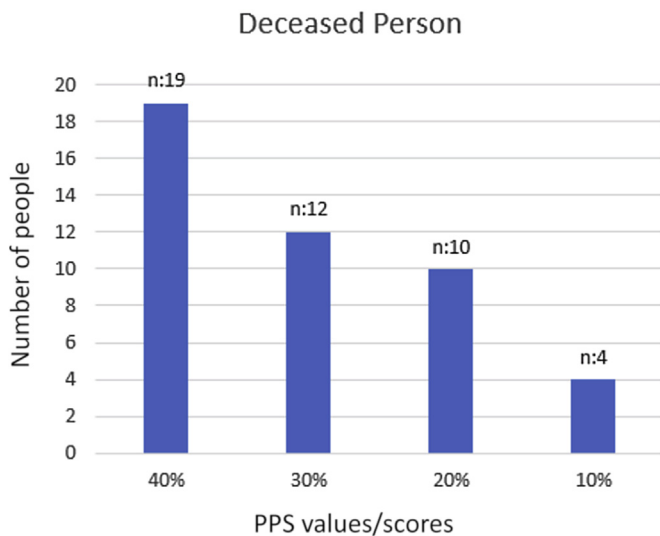
Graphic 1. The 45 patients who died during the follow up period is depicted according to their PPS scores.

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