Original Article

The Relationship between Distressing Symptoms and Performance Status among Cancer Patients Receiving Palliative Care

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Background: Patients with advanced cancer experience distressing symptoms and progressive decline in their performance status (PS) as death approaches.
Aim: To identify the relationship between symptom burden and PS of Egyptian cancer patients receiving palliative care.
Methods: This was a prospective observational study that included 100 patients with advanced cancer. Symptom burden was assessed using the Arabic version of the revised Edmonton Symptom Assessment System (ESAS-r). Performance status was assessed using the Palliative Performance Scale (PPS).
Results: The mean total ESAS-r score was 60.1 (±10.7). The most common symptom to be reported as severe was pain (93%) followed by tiredness (74%), poor wellbeing (67%), lack of appetite (62%), anxiety (60%) and drowsiness (56%). The majority of patients (76%) had a PPS score ≤30 with an overall mean PPS score of 36.2 (±13.3). There was a statistically significant negative correlation between the total ESAS score and the PPS score (r = - 0.687, p = < 0.001).
Conclusion: The results suggest that Egyptian patients with advanced cancer experience high symptom burden and significant decline in PS. The higher the symptom burden, the poorer the PS of patients with advanced cancer.

INTRODUCTION

Cancer is a major burden disease worldwide; it is seen as a terrifying and untreatable disease leading to death. In 2012, 14.1 million new cancer patients were diagnosed and 8.2 million died of cancer worldwide [1]. Cancer is a large group of diseases that involve abnormal cell growth which attack or spread to different parts of the body [2]. Traditionally, in cancer care, patients with advanced cancer are treated by their oncologists and start palliative care (PC) late near the end-of-life (EoL). Ideally, PC is integrated early in the course of treatment at the time of diagnosis of incurable cancer and continues until the EoL [3].

Palliative care is a holistic approach of care that aims at improving the quality of life of patients with life-threatening illnesses and their families through the prevention and treatment of pain and other distressing symptoms (physical, psychological, social and spiritual) [4]. There are relationships between early PC integration and the clinical, economic, and prognostic outcomes [5]. Early PC significantly improves the quality of life, relieves pain and other symptoms, is associated with longer survival time, is more cost-effective and leads to better personal satisfaction [6].

Cancer patients near the EoL report many symptoms which may be very distressing [7, 8]. These symptoms may be caused by cancer itself or by its treatment; but regardless of the cause, symptoms can affect many aspects of daily living. If these symptoms are not addressed quickly and adequately, they may cause significant suffering for patients and their families. This is not the only negative impact of inadequately controlled symptoms as it has implications for all levels of care. For example, uncontrolled symptoms may require urgent medical attention and result in frequent avoidable emergency department visits near the EoL [8, 9].

As death approaches, the symptom burden increases among terminal cancer patients and their performance status (PS) declines [10, 11]. Hence, the assessment of symptoms and PS of patients with incurable cancer is an important initial step to provide effective PC.

The Edmonton Symptom Assessment System (ESAS), which was developed more than twenty-five years ago, is a numerical rating scale that is widely used in PC practice to assess nine common symptoms [12, 13]. The revised ESAS (ESAS-r) was developed to overcome the clarity and interpretation limitations of the original ESAS [14]. The ESAS-r is available in many languages including Arabic which was validated in Egyptian patients with advanced cancer [15].

Performance status is "*a score that estimates the patient's ability to perform certain activities of daily living without the help of others*" [16]. The measurement of PS and functional ability of cancer patients has many applications, like prognostication and planning of care [16]. The palliative performance scale (PPS) is a modification of the Karnofsky performance scale that was introduced in the 90s [17]. The PPS may be used as a prognostic indicator for death of advanced cancer patients and its

decline may be utilized to optimize the timing to start specialist PC [18, 19.]

Nursing is an integral part of interdisciplinary holistic PC [20-22]. The assessment of pain and other symptoms and determining the PS of patients with life-limiting illnesses are among the important roles played by nurses in PC [20].

The aim of this study was to describe the symptom burden among a group of Egyptian advanced cancer patients receiving PC and to correlate between the symptom burden and their PS.

METHODS

Ethical approval

The study was approved by the Ethics and Research Committee at the Faculty of Nursing, Cairo University and the Ethics Committee of Kasr AL-Ainy Center of Clinical Oncology and Nuclear Medicine. Informed consents were obtained from patients after explanation of the nature and purpose of the study.

Study design

This is a prospective descriptive exploratory study conducted on cancer patients treated at the Kasr AL-Ainy Center of Clinical Oncology and Nuclear Medicine (NEMROCK), Cairo University Hospitals and are scheduled to receive PC.

Assessment tools and data collection

Background questionnaire sheet which was developed by the investigator and consists of two parts. The first part included demographic data (age, gender, marital status, education, occupation and income). The second part included medical data (primary cancer, site of distant metastases and anti-cancer treatment). Nine common symptoms were assessed using the Arabic version of the ESAS-r which is available freely for use from Cancer Care Ontario [23]. The symptoms assessed include: pain, fatigue, nausea, depression, anxiety, drowsiness, shortness of breath, anorexia, and wellbeing. The ESAS-r assesses these nine symptoms on a numerical scale from 0 (none, best) to 10 (most terrible). Performance status was measured using the PPS version 2 (PPSv2) [14, 24] which replaces the original PPS [17]. In the PPSv2, physical performance is measured in 10% decremental levels from completely mobile (100%) to death (0%). These levels are determined by five discernible parameters that incorporate ambulation, activity and evidence of disease, self-care, intake and conscious level. The PPSv2 was rated according to the guidelines published by Victoria Hospice Society [14].

Procedure

Study participants were interviewed individually (by investigator FH) to explain the nature and purpose of current study. The investigator obtained informed consent from patients who agreed to participate in the study. Data collection was performed by the investigator through face to face semi-structured interview. Educated patients self-completed the ESAS-r. For illiterate patients, one of the family caregiver or the investigator

helped in completing ESAS-r. Data was tabulated and subjected to statistical analysis to answer the formulated research questions.

Statistical Analysis

Data were statistically described in terms of mean ± standard deviation (± SD), median and range, or frequencies (number of cases) and percentages when appropriate. Correlation between normally-distributed continuous variables was tested using Pearson's correlation. P value less than 0.05 was considered statistically significant. Statistical analysis was completed using SPSS software, version 14 (SPSS Inc, Chicago, Ill)

RESULTS

A total of 100 patients were recruited in the period between December 2016 and March 2017. Characteristics of the study participants are shown in Table 1.

Table 1: Patients' characteristics (n=100)

	No.	%
Age category		
Early adulthood (18-40 years)	30	30
Middle adulthood (41-60 years)	50	50
Late adulthood (> 60 years)	20	20
Gender		
Male	50	50
Female	50	50
Marital status		
Married	92	92
Single	3	3
Widowed	3	3
Divorced	2	2
Level of education		
Illiterate	49	49
< high school	36	36
High school	13	13
University	2	2
Working		
No	91	91
Yes	9	9
Income		
Enough	8	8
Not enough	92	92
1ry cancer site		
Breast	21	21
Hematological	15	15
Lung	12	12
Colorectal	11	11
Sarcomas	11	11
Others	30	30
Common metastases sites		
Bone	26	26
Liver	9	9
Lung	8	8
Brain	4	4

Table 2: ESAS items' scores severity of study participants (n=100)

ESAS item	Severity			Mean score ± SD
	Mild (from 1 to 3)	Moderate (from 4 to 7)	Severe (from 8 to 10)	
Pain	0	7	93	8.01 ± 1.43
Tiredness	0	26	74	7.52 ± 1.38
Drowsiness	4	40	56	6.54 ± 1.68
Nausea	14	44	42	6 ± 1.98
Lack of appetite	4	34	62	6.74 ± 1.76
Shortness of breath	26	34	40	5.47 ± 2.28
Depression	8	45	47	6.27 ± 1.69
Anxiety	4	36	60	6.57 ± 1.51
Poor wellbeing	0	33	67	6.97 ± 1.15

The majority (70%) of patients were in middle/late adulthood. Males and females were equally represented and 92% of patients were married. Almost half of patients were illiterate and more than 90% were not employed.

The mean total ESAS score was 60.1 (±10.7) and the median was 61.5 (range: 29 – 81). Table 2 shows the severity scores of ESAS items. Pain was the most common (93%) symptom to be severe (8 to 10 on the numerical scale) followed by tiredness (74%), poor wellbeing (67%), lack of appetite (62%), anxiety (60%) and drowsiness (56%).

Other symptoms reported by patients were constipation in 33 (33%) patients, cough in 6 (6%), headache in 5 (5%), diarrhea in 3 (3%), insomnia in 1 (1%).

The PPS scores of the study participants are summarized in Figure 1. Seventy-six percent of patients had a PPS score ≤30. The average PPS score was 36.2 (±13.3) and the median was 30 (range: 20-80).
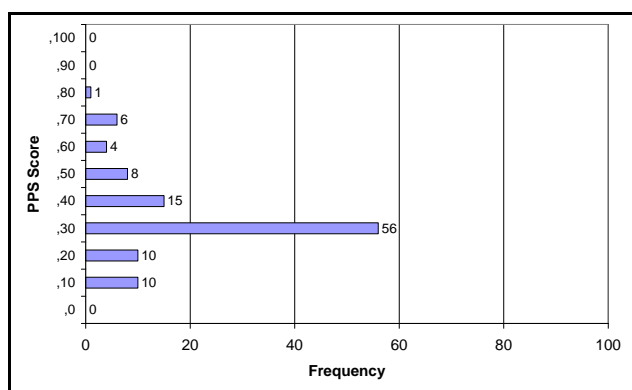

Figure 1: Frequency and distribution of patients according to the PPS Score (n=100)

The relation between the total ESAS score and the PPS score is illustrated in Figure 2. There was a statistically significant negative correlation between the two measures (r = - 0.687, p = < 0.001).

DISCUSSION

Palliative care is generally underdeveloped in Egypt with relatively few specialized PC services [25]. In this context, little is known about the needs of Egyptian terminal cancer patients [15, 26, 27]. The current study is one of the few studies that addressed the needs of PC patients in Egypt. Our results confirm the high symptom burden experienced by Egyptian patients with advanced cancer [26]. In a previous study from Egypt, patients with newly diagnosed incurable cancer had high symptom burden where the average number of symptoms per patients was 17 and 67% of patients had >5 moderate/severe symptoms [26].
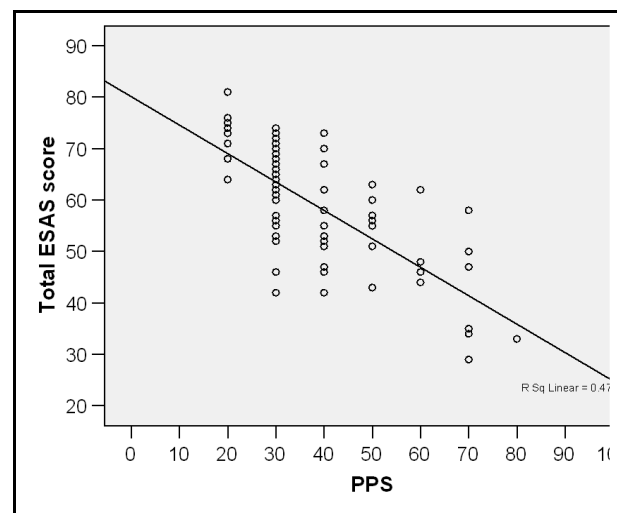

Figure 2: Correlation between the total ESAS-r score and PPS score (n=100)

The relation between the symptom burden and the functional status of patients with advanced cancer has been reported by other researchers; however, the results are not consistent among studies.

In our study there was a significant negative correlation between symptom burden on the ESAS and PS on the PPS (p = < 0.001). Congruent with our results, other researchers found a significant negative relationship between symptom burden and functional status of advanced cancer patients [27-31]. In a recent study from Egypt that included patients with metastatic cancer, the total average ESAS score differed significantly according to the Eastern Cooperative Oncology Group (ECOG) performance scale from 34 in patients with an ECOG score of 1 to 70 in patients with an ECOG score

of 4 (p<0.001) [27]. Similarly, in a study from Japan that included 292 cancer patients, the total ESAS-r score was significantly higher among patients with an ECOG score of 2-4 than those with a score of 0-1 (p<0.0001) [28]. In another study that included pancreatic cancer patients; pain, digestive symptoms, cachexia and ascites were significantly more likely to be reported by patients with an ECOG score of ≥1 [29]. In lung cancer patients, moderate/severe fatigue is associated with significantly poorer PS [30]. This was confirmed in another study where there was a strong negative relationship between Karnofsky PS and the top four symptoms (pain, fatigue, disturbed sleep and distress) in lung cancer patients [31].

Other studies found no significant correlation between symptom burden and PS of advance cancer patients [32, 33]. Fu et al studied the relationship between symptom burden (using the ESAS) and the functional status (using the Functional Independence Measure [FIM]) of cancer patients in a rehabilitation unit [32]. They found no significant relationship between the total ESAS score and the total FIM score. It should be noted that the mean ESAS score upon admission to the rehabilitation unit in the study of Fu et al was much lower than that in our study (29 vs. 60, respectively). This is because they included only patients who were able to tolerate 3 hours of therapy per day and this may have decreased the number of patients with high symptom burden in their study. Another explanation by the Fu et al, is that successful control of distressing symptoms may have contributed to this insignificance [32]. Another study by Selby et al included 58 cancer patients followed by a PC consult team [33]. They assessed the functional status using the PPS like in our study. The average PPS score in their study was much higher than that in our study (69 vs. 36, respectively). They found no significant relationship between symptom burden and PS [33]. The latter two studies included patients with less symptom burden and better PS compared to our study. This may have contributed to the non-significant correlation between symptom burden and PS reported by them.

The results illustrated above don't explain clearly the relationship between symptom burden and PS. Could it be just an association? It is clear that cancer patients near the EoL have high symptom burden and declining PS. However, there may be a causal relationship as well. Uncontrolled distressing symptoms are expected to have a negative impact on the PS of cancer patients and the reverse may be true. Further studies are required to clarify the relationship between symptom burden and PS in advanced cancer patients.

Limitations of the current study include convenience sampling, the inclusion of a relatively small sample size and being from a single institution. It is recommended to repeat the study on a representative larger sample to achieve generalizable results. Also, half of patients were illiterates and the ESAS-r was completed with the help of the investigator instead of being self-completed.

Conclusions

The results of the current study suggest that Egyptian patients with advanced cancer experience high symptom burden and significant decline in PS. The higher the symptom burden, the poorer the PS of patients with advanced cancer.

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