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ORIGINAL ARTICLE

Feasibility and reliability of the revised Edmonton Symptom Assessment System (ESAS-r) in Egyptian patients with advanced cancer: A single institutional experience

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Abstract

Objective This study aims to test the acceptance, feasibility, and usefulness of the Arabic version of the revised Edmonton Symptom Assessment System (ESAS-r) among Egyptian patients with advanced cancer and to compare the rates of symptoms documented by patients and physicians.

Methods Between August 2014 and February 2015, a total of 140 patients at Ain Shams University Hospitals in Cairo, Egypt received the Arabic version of the ESAS-r. For each patient, the ESAS-r was completed twice, first by the treating physician (as part of the basic assessment) and a second time by the patient, with a maximum of 2 hours between the two assessments. An additional survey was included to assess patients' acceptance of the survey and their preferences.

Results Out of 140 enrolled patients in the study, 11 patients refused to complete the questionnaire, and 10 patients were excluded due to incomplete records in their medical records. Complete data was retrieved for 119 patients who were included for further analyses. The 78 (65%) patients declared that the test was clear and easy to complete. They were able to answer the test without help. Collectively, tiredness and sense of well-being were the most commonly encountered symptoms in ratings obtained by both patients and physicians. Tiredness was the only symptom showing a significant difference between the two rating methods, patient-rated scores being higher (P = 0.032). Cronbach's alpha showed that both tests completed by the physician and the patients were internally consistent: the physician-rated test had a coefficient of 0.877, and the patient-rated test had a coefficient of 0.863. All ESAS scores had good internal consistency, with a Cronbach's alpha coefficient of 0.88. The internal consistency remained high after removal of individual symptom scores, with Cronbach's alpha coefficients ranging from 0.823 to 0.902, indicating that no individual question had undue influence on the total ESAS score.

Conclusion The ESAS-r was easily understood by and applicable to patients. There was no significant discrepancy in the rates of symptoms reported by the patients and physicians, apart from tiredness. Based on this, the test could be applied on a larger scale with in-home patients. This test can be cost-effective and can decrease the number of hospital visits among advanced cancer patients in need of supportive treatment rather than active cancer therapy.

Key words: advanced cancer; palliative care; Egypt; Edmonton Symptom Assessment System (ESAS)

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While cancer rates in general are decreasing in the United States and many developed countries, they are increasing in developing and economically struggling countries [1]. Cancers in these regions are much more likely to go undetected until advanced stages and a greater proportion of patients will suffer severe symptoms than in high income countries [2].

Approximately 80% of cancer patients need palliative care and one of the priorities for global cancer research identified by the World Health Organization (WHO) is the development of effective palliative care delivery models [3]. Unfortunately, palliative care in Egypt is in an early stage of development with few palliative care activities available [4] and patients with advanced and end stage

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cancer have to attend by themselves to assess their condition and decide on further treatment. On the other hand, to effectively treat symptoms of this subset of patients, it is important to obtain their opinions directly. When these patients self-report their symptoms, the frequency and severity data for the symptoms tend to vary significantly from those identified by health care providers and from the data recorded in charts and on research forms [5].

The Edmonton Symptom Assessment System (ESAS) is a self-reporting tool of symptom intensity, initially developed for advanced cancer patients. It is designed to enable repeated quantitative measurements of symptom intensity with minimal patient burden [6]. The ESAS includes nine common symptoms of advanced cancer, namely pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath, with the option of adding a tenth patient-specific symptom not provided in the questionnaire [7]. In the original version, these nine symptoms were scored using a visual analogue scale (VAS), ranging from 0 to 100 mm with higher scores indicating greater symptom severity and this version has been validated in an outpatient oncology setting [7–8].

The VAS format has since been replaced by a numerical rating scale (NRS) scored between 0 and 10. Ideally, the ESAS is completed by patients. However, if the patient has limitations in completing the questionnaire, then it is completed with the assistance of a caregiver (a family member, friend, or health professional closely involved in the patient's care), with the exception of the more subjective symptoms of fatigue, depression, anxiety, and well-being [9]. The ESAS had been tested and validated after translation into a number of languages, including Spanish, Turkish, Italian, and Arabic [10–13].

The ESAS has some drawbacks that may be related to the cultural background of patients, their care givers and the medical staff. The test may be not easy for some patients to understand and others can be confused or unable to understand terms such as "well-being," "tiredness," and "drowsiness" [14–15]. Another drawback is the discrepancy in the rating of symptoms between the patient and the treating staff (physician or nurse) [8].

Many patients with advanced stage cancer at Department of Clinical Oncology, Ain Shams University Hospitals, Egypt, come from remote areas and the majority of them have economic and logistic problems in transportation. There is no dedicated palliative care unit at our hospital and patients with advanced cancer and in need for palliation are managed in the outpatient clinics. The ESAS can be a useful tool to follow these patients at home and decrease their visits to hospital.

Based on this, we initiated this study to test the reliability of the ESAS-r in regard to inter-rater reliability (physician and patient both completing ESAS at the same time, independently) and internal consistency. Also, we would like to test the acceptance, feasibility, and usefulness of ESAS among Egyptian patients with advanced cancer, and to compare the patient and proxy (physician) assessments, as this is the first time that our patients have completed this questionnaire by themselves.

Patients and methods

Patients

This study was approved by the ethical committee of Ain Shams Faculty of Medicine with exemption from informed consent. Patients with advanced stage cancer receiving treatment at Department of Clinical Oncology, Ain Shams University Hospitals in Cairo, Egypt, between August 2014 and February 2015 were enrolled in this cross-sectional study. Eligibility criteria included patients with metastatic, refractory, or relapsed cancer beyond curative treatment, age ≥ 18 years and intact cognitive function as assessed by the Arabic version of the Mini-Mental State Examination (MMSE) [16]. Patients under palliative radiotherapy or palliative chemotherapy were eligible. Patients were excluded if they had delirium, dementia, uncontrolled psychiatric disease, or symptomatic brain metastases.

Study design

Between August 2014 and February 2015, a total of 140 patients at Ain Shams University Hospitals in Cairo, Egypt received the Arabic version of the revised Edmonton Symptom Assessment System (ESAS-r) [13], which is freely available for use online. For each patient, the ESAS-r was completed twice, first by the treating physician after discussion with the patient (as part of the basic routine assessment) and a second time by the patient, with a maximum of 2 hours between the two assessments to test the inter-rater agreement. In order to examine the acceptance, feasibility, and usefulness, an additional survey was completed by the patients after answering the ESAS-r. It included the following questions. (1) Do you find this test useful for you? (2) Were the questions clear for you? (3) Were you able to answer all the questions without help? (4) Do you prefer to take the test with the help of medical staff or a relative? Patients' demographic data was retrieved from their medical records and ECOG performance status was assessed for each patient by the physician.

Statistical methods

We aimed to test the inter-rater reliability of the test as well as the internal consistency. Inter-rater reliability is the degree of agreement among raters/observers (in our study, the physician and the patient). It was evaluated using a *T*-test. On the other hand, internal consistency

Table 1 Demographic characteristics of the studied patients

Patient characteristics	Number	%
Age (year)		
≤ 55	64	53.8
> 55	55	46.2
Sex		
Male	48	40.3
Female	71	59.7
Primary tumors		
Breast	34	28.6
Female genitourinary	10	8.4
Gastrointestinal tract (GIT)	23	19.3
Lung	21	17.6
Male genitourinary	12	10.1
Carcinoma of unknown primary	19	16.0
Number of metastatic sites		
Single	82	69.0
Two	25	21.0
Three or more	12	10.0
Metastatic site		
Bone	50	42.0
Brain	27	22.7
Liver	29	24.4
Lung	39	32.8
Local recurrence (Breast)	17	14.3
ECOG PS		
≤ 2	69	58.0
> 2	50	42.0

is used to measure the homogeneity of the items of the tested scale and whether the items are highly correlated with each other. Cronbach's alpha test for internal consistency was evaluated for both the patient-rated and physician-rated tests. Standard descriptive statistics, including mean, median, standard deviation, range, proportion, and frequency, together with 95% confidence intervals, were calculated using IBM SPSS Statistics (V. 21.0, IBM Corp., USA, 2012).

Results

Out of 140 enrolled patients in the study; 11 patients refused to complete the questionnaire. Main causes for refusal were frustration and thinking their condition was hopeless. Some patients were unable to wait 2 hours to retake the test, being dependent on other relatives / care providers to take them home, an understandable issue considering the serious mobility limiting factors in such patients. Ten cases were excluded due to incomplete data in their medical records. Complete data was retrieved from 119 patients who were included for further analyses. A total of 90 patients were interviewed in the outpatient clinic, and 29 patients were interviewed in the inpatient unit.

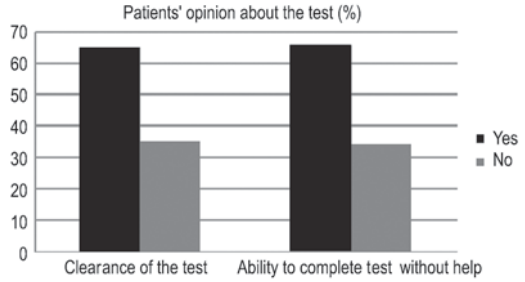

Fig. 1 Patients' opinion about the test

Patients' characteristics

Regarding the demographic data of the patients (Table 1), seventy-one (59.7%) were females, the median age was 50 years (range from 20–84 years), the most common primary tumor was breast tumor (28.6%) followed by lung tumor (19.3%). Eighty-two (69%) patients had a single site of metastasis while 25 (21%) patients had two metastatic sites and the remaining 12 (10%) patients had ≥ 3 metastatic sites. Bone represented the commonest site of metastasis. Fifty (42%) of the study population patients had ECOG performance status > 2.

Patients' opinions about the test

A total of 99 (83%) patients found the test useful for their medical condition. The majority of the patients (65%) declared that the test was clear. A total of 79 (66%) patients were able to answer the test without help; forty (34%) patients needed assistance from the researcher or a relative to finish the questionnaire, mostly due to illiteracy and their level of education (Fig. 1). The illustration part of the questionnaire was appreciated by the majority of the patients. Only nine (8%) patients reported other symptoms.

Inter-rater reliability

Collectively tiredness and sense of well-being were the most commonly encountered symptoms in ratings obtained by both patients and physicians (Table 2). Tiredness was the only symptom showing a significant difference between the two rating methods, patient-rated scores being higher ($P = 0.032$).

Internal consistency

Cronbach's alpha was then calculated (Table 3), and it was found that both tests performed by the physician and the patients were internally consistent; the physician-rated test had a coefficient of 0.877, and the patient-rated test had a coefficient of 0.863.

All ESAS-r scores had good internal consistency, with a Cronbach's alpha coefficient of 0.88. The internal consistency remained high after removal of individual symptom scores, with Cronbach's alpha coefficients ranging

Table 2 ESAS scores obtained by physician and patient ratings

	Physician		Patients		Independent *t*-test	
	Mean	SD	Mean	SD	*t*	*P*
Pain	4.34	1.68	4.72	2.15	–1.512	0.132
Tiredness	5.07	1.69	5.61	2.12	–2.163	0.032
Drowsiness	2.18	2.09	2.40	2.43	–0.772	0.441
Nausea	3.03	1.74	3.25	1.95	–0.913	0.362
Appetite	4.61	1.85	5.08	2.14	–1.818	0.070
Shortness of breath	2.76	2.24	2.91	2.38	–0.504	0.615
Depression	3.83	2.18	3.97	2.34	–0.459	0.646
Anexiety	4.24	2.17	4.33	2.24	–0.294	0.769
Well-being	5.87	2.00	5.97	2.14	–0.376	0.707
Total score	35.92	12.63	38.23	14.58	–1.302	0.194

Table 3 Cronbach's alpha after removal of individual symptom scores in the ESAS performed by the physician and the patient

ESAS	Cronbach's alpha if item deleted	
	Physician	Patient
Pain	0.850	0.881
Tiredness	0.835	0.867
Drowsiness	0.844	0.880
Nausea	0.854	0.888
Appetite	0.836	0.870
Shortness of breath	0.868	0.902
Depression	0.840	0.873
Anexiety	0.852	0.887
Well-being	0.828	0.863
Other	0.879	N/A

from 0.823 to 0.902, indicating that no individual question had an undue influence on the total ESAS score.

Discussion

To our knowledge, this is the first study to test the ESAS on Egyptian patients with advanced cancer at out-patient oncology clinics outside of a palliative care unit. The ESAS was originally developed and applied in the palliative care setting. Few studies have evaluated the use of the ESAS outside palliative care units or long-term hospice facilities. The trials for using the tools to monitor symptoms for palliative patients in out-patient settings have shown positive results [17–19]. Follwell *et al* used the ESAS in a palliative care outpatient clinic. The administration of the ESAS at the initial assessment, one week, and one month later showed marked improvement in both symptom control and patient satisfaction with care. These results are encouraging for the use of the ESAS to provide enhanced symptom management for patients not requiring inpatient care [20].

The ESAS-r was described as generally clear by 65% of our studied patients while 34% found it confusing to express the severity of the symptoms in numbers and needed assistance. In a pilot study conducted by Baba and colleagues [21], 71% of their 24 patients felt that the ESAS was simple to fill in and there were no missing questions. In another multicenter study, 160 patients were enrolled, and 83% rated the ESAS-r as very easy or easy to understand [17]. However, about 18% of our patients were illiterate, and this could explain the lower figures reported in the current study.

Patient assessment of symptoms is considered the "gold standard" [22–23]. However, there are some situations in which proxy assessments may be helpful or necessary, for example when patients over- or under-report their symptoms, or when they are mildly to moderately disoriented [8].

There is no regular self-assessment of symptoms by patients in our department and symptom assessment is done mainly by the treating physician. Thus, it was important to study the correlation between symptom assessment by both physician and patient. In our study, we compared the results obtained from the questionnaire performed by the physician with that performed by patients in the same setting and circumstances (with a maximum of 2 h between the assessments). The results were comparable with no statistically significant difference in the total score (mean score of 35.92 ± 12.63 and 38.23 ± 14.58 for physician's and patients' completed ESAS-r respectively). Both the tests performed by the physician and the patient showed internal consistency and Cronbach's alpha score for the whole test and individual items showed that all ESAS-r scores had good internal consistency, with a Cronbach's alpha coefficient of 0.88. The internal consistency remained high after removal of individual symptom scores, with Cronbach's alpha coefficients ranging from 0.823 to 0.902, indicating that no individual question had undue influence on the total ESAS-r score. This is in contrast to Nekolaichuk and his colleagues who compared patient and proxy (physician and nurse) assessments of symptoms using ESAS in advanced cancer patients. Their sample included 49 patients with advanced cancer in an acute palliative care facility. Every patient

had three independent assessments on two separate occasions within 11 days of admission. In their study, average physician ratings of symptoms were lower than patient ratings across both occasions [8]. Other studies [24–28] were the work of Nekolaichuk and her colleagues.

In the current study, tiredness score was significantly higher in the patient-rated test; this could indicate an overestimation of tiredness in advanced cancer patients. Hence, when trying to evaluate a case without seeing the patient, the measure of tiredness should be interpreted with caution. Tiredness should not be underestimated, yet it should not be considered the sole item determining whether the patient is scheduled for an urgent visit. In the study of Nekolaichuk *et al*, the physician ratings were significantly lower ($P < 0.01$) for three of the symptoms: drowsiness, shortness of breath, and pain, but not tiredness [8].

We recognize that the use of systematic patient-reported assessment is important to improve palliative care for patients with advanced cancer. Improving symptom management of cancer patients needs training of health care professionals and regular documentation of assessment findings. These changes may be challenging for some already overburdened clinical teams. Nevertheless, it is likely that such changes can be made: our findings suggest that efforts toward incorporating symptom assessment in daily practice should be done because it was found that there was a reasonable association between patient reporting and clinical impressions of the treating physician.

Palliative care of cancer patients is a growing medical specialty in Egypt. There is a need to develop tools and methods that are convenient for Egyptian patients to assess the burden of symptoms as well as special training programs for physicians to improve the quality of health care in different cancer centers.

Conclusion

To our knowledge, this is the first study in Egypt to examine the feasibility of using the ESAS-r for reporting symptoms in patients with advanced stage cancers. The current study showed that self-rating by patients using the ESAS-r was well appreciated by patients, was reliable, and could be applied on a larger scale with in-home patients. This test can be cost-effective for deciding whether to transport patients to hospital versus reporting from home while the patient is actually in need of supportive treatment rather than active cancer therapy. However, more research is necessary to identify the necessary tools for making these assessments in the context of different symptoms and settings and to develop the training needed by health care providers to integrate these tools and the information they yield into their clinical practice.

Conflicts of interest

The authors indicated no potential conflicts of interest.

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