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Edmonton symptom assessment scale: Italian validation in two palliative care settings

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Abstract In the palliative care setting, the Edmonton Symptom Assessment Scale (ESAS) was developed for use in daily symptom assessment of palliative care patients. ESAS considers the presence and severity of nine symptoms common in cancer patients: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath plus an optional tenth symptom, which can be added by the patient. The aim of this study was to validate the Italian version of ESAS and to evaluate an easy quality of life monitoring system that uses a patient's self-rating symptom assessment in two different palliative care settings: in-patients and home patients. Eighty-three in-patients and 158 home care patients were enrolled. In the latter group, the Italian validated version of the Symptom Distress Scale (SDS) was also administered at the admission of the patients. The two groups of patients have similar median survival, demographic and clinical characteris-

tics, symptom prevalence and overall distress score at baseline. ESAS shows a good concurrent validity with respect to SDS. The correlation between the physical items of ESAS and SDS was shown to be higher than the correlation between the psychological items. The association of ESAS scores and performance status (PS) showed a trend: the higher the symptom score was, the worse was the PS level. Test-retest evaluation, applied in the in-patient group, showed good agreement for depression, well-being and overall distress and a moderate agreement for all the other items. In conclusion, ESAS can be considered a valid, reliable and feasible instrument for physical symptom assessment in routine "palliative care" clinical practice with a potentially different responsiveness in different situations or care settings.

Keywords Symptom assessment tool · ESAS · SDS · VNS · Italian validation · Quality of life

Introduction

In recent decades, the concepts regarding palliative care and quality of life (QoL) have been increasing and spreading in medicine in different countries and cultures. [1–3]. QoL may be considered a measure, a result and an efficacy indicator of a curative or palliative care intervention. The QoL assessment can be used to evaluate symptom relief, to compare treatment responses or to demonstrate the effects of specific rehabilitative approaches.

QoL should be considered as a multidimensional entity with objective components such as the stage of the disease and the different therapies carried out [1, 4, 5] but, above all, with subjective components because they describe the patient's own perceptions, expectancies, living, culture and beliefs [4–13].

In the palliative care setting, the patient population is often frail, has deteriorating health and has multiple symptoms. All these factors affect the ability to collect data, and so a QoL instrument should be easy to administer to max-

imise the patients' compliance. A QoL assessment tool should have internal validity, thus measuring what is meant to be measured; moreover, it must be sufficiently sensitive to detect any change over time [14].

Symptom control, functional activity and emotional and social functions seem to be the most important components in the quality of life of terminally ill people [1–5].

Many assessment tools have been developed to measure the multidimensional features in patients with cancer both in the early or the advanced stage of their disease [14–16]. The Edmonton Symptom Assessment Scale (ESAS) was developed in the Palliative Care Unit of the Edmonton General Hospital (Canada) for use in daily symptom assessment of palliative care patients [17].

ESAS has been widely used in palliative care settings. Bruera and MacDonald compared the ESAS with the Support Team Assessment Schedule (STAS) [18] and found good agreement [19]. Philip et al. [20] compared the ESAS with the Rotterdam Symptom Checklist and the Brief Pain Inventory validated for the Australian population and found a good correlation. Rees et al. [21] found practical difficulties in assessing 71 patients admitted to a British hospice, showing that patients with a very low performance status need other tools for symptom assessment. Dudgeon et al. [22] used ESAS to audit the adequacy and speed in symptom control in a Canadian palliative care hospital. Chang et al. [23] demonstrated the good agreement between the ESAS, the Functional Assessment Cancer Therapy (FACT), the Memorial Symptom Assessment Scale (MSAS) and the Karnofsky Performance Status (KPS), showing that the ESAS is a valid instrument with a good internal consistency. Heedman et al. [24] used ESAS for symptom assessment in home care cancer patients. Finally, Stromgren et al. [25] used ESAS, the European Organisation for Research and Treatment of Cancer Quality of Life Instrument (EORTC QLQ-30) and the Hospital Anxiety and Depression Scale (HADS) for assessing symptoms in three palliative care settings: in-patients, out-patients and home care patients.

The aim of this study was to validate the Italian version of ESAS and to evaluate an easy quality of life monitoring system that uses a patient's self-rating symptom assessment in two different palliative care settings of patients with advanced cancer: home care patients and in-patients.

Methods

Patient population

The study population includes two different groups of patients enrolled in two different palliative care centres: one in northern Italy and the other in central Italy.

The first group includes consecutive in-patients no longer treated with specific anticancer therapy and admitted to a palliative care ward (of a general hospital) for symptom

control and/or terminal care. The second group includes consecutive advanced cancer patients cared for at home by a palliative care team.

We considered just the assessments rated only by the patients themselves because proxy assessments of symptom intensity was shown to be lower than that of patient assessments for three of the nine symptoms [26].

Basic demographic and clinical data have been assessed equally in both centres excepting the performance status, which was evaluated by means of the Karnofsky Performance Status score in the in-patient group and by means of the Eastern Cooperative Oncology Group (ECOG) Performance Status score in home care patients. All patients gave verbal informed consent before participating in this study.

QoL measurement

ESAS is a tool designed to assist in the daily monitoring of nine common symptoms affecting patients with cancer in their terminal phase of life. It consists of nine 0–10 visual numerical scales (VNS) for pain, activity, nausea, depression, anxiety, drowsiness, appetite, sense of well-being and shortness of breath. There is an optional tenth symptom, which can be added by the patient.

In Bruera's original paper [17], ESAS consisted of nine 10-cm visual analogue scales (VAS). In view of the fact that both Rees et al. [21] and Chang et al. [23] observed that this is upsetting for older patients and because a numeric rating scale has been shown to be similar to VAS for pain [28] and quality of life [29, 30], we adopted the VNS.

The individual scores for each separate symptom were registered and the total score as a sum of all the individual patient symptom scores were calculated. As regards our study groups, all the in-patients (first group) were assessed with ESAS twice daily (in the morning and in the afternoon) from admission to discharge or death, whereas home care patients were assessed once weekly from admission to the home care program till death.

In the latter group of patients, the Italian-validated version of the Symptom Distress Scale (SDS) was also administered at the admission of the patients. The SDS, developed by McCorkle and Young [27], analyzes the distress level of patients with advanced cancer, as well as those suffering from other pathologies, linked to 13 symptoms (namely, intensity and frequency of nausea, appetite, insomnia, bowel pattern, respiration, coughing, fatigue, concentration, appearance and mood) using 1 to 5 scores, Likert-type scales. The total score (ranging from a minimum of 13 to a maximum of 65) is subdivided into five subscales: (1) pain (frequency and intensity); (2) nausea (frequency and intensity); (3) functional aspect, bowel pattern, respiration, coughing and fatigue; (4) psychological aspects, mood plus insomnia and (5) social aspects, con-

centration plus appearance. An Italian version of SDS has been validated [31].

Translation

The first step of the translation involved forward translation of the original American ESAS into Italian by two native Italians of the two different palliative care centres who speak English fluently. After producing the individual translations, the translators met to agree to a common pilot version. The preliminary forward translation was given to a mother tongue translator, who translated the questionnaire back into English. The back-translation was compared with the original ESAS; where the back-translated and the original did not agree, the choice of words was discussed between the Italian and English translators until a final version was reconciled.

Statistical analysis

The aggregation of the nine symptoms evaluated in ESAS is based on clinical grounds (to obtain a sensitive summary score), rather than on classical psychometric theory. The heterogeneity of the nine items and their causal nature (one on its own may suffice to change QoL; however, it is not necessary that a patient suffers from all of the symptoms to have a poor QoL) [32] render correlation-based methods like internal consistency (usually measured by Cronbach alpha) and convergent–discriminant validity (usually examined by multi-trait, multi-method analysis) inappropriate for this type of scale validation. On the other hand, basic properties such as test–retest reliability, predictive and concurrent validity, sensitivity and responsiveness assume a particular relevance, and these are the properties we have examined in the present paper.

A description of the performance of the questionnaire at item level (frequency distribution, percentage of missing) will be presented along with an analysis of the pattern of missing data (only in the in-patient group). As the length of stay in hospital is different among the in-patients, to evaluate their compliance to ESAS we calculated for each patient the percentage of completed questionnaire with respect to the number of expected completed questionnaire (two daily evaluations multiplied by the number of days of hospitalization) and the percentage of days where at least one evaluation was completed with respect to the number of days of hospital stay. The means of these two indices regarding all the in-patients will be given.

Test–retest reliability This was examined by intraclass correlation coefficient (ICC) between morning ESAS evaluation in days 2 and 3 of admission (in-patient group). The first-day data were not considered because many of the

patients missed the morning evaluation (because of admission), making the sample size for calculations too low.

Concurrent validity Agreement with a well-established instrument was evaluated by the Pearson correlation coefficient between each baseline ESAS item and the corresponding item of SDS (home care patients). The average value of intensity and frequency as measured by SDS was used for pain and nausea.

Sensitivity Sensitivity, which indicates the ability to detect differences between the study groups, was evaluated by testing the difference of each ESAS item and the global score among patients with different performance status scores by ANOVA.

Responsiveness In each of the two populations, paired *t* test was applied to test the differences between days 1 and 7 for both item score and total score to evaluate the ability of ESAS to detect changes within the patients.

Results

Eighty-three in-patients and 158 home care patients were enrolled in the two centres. The median survival was 35 days for the first vs 33.5 days for the latter. The hospital admission ended in the discharge of 80% of the in-patients (Table 1). Both populations were similar for demographic and clinical characteristics and mainly included patients with a low performance status (Table 1).

Missing data pattern In the hospital setting, the mean percentage of completed questionnaires in respect to the expected is 53.32%, whereas the mean percentage of days of hospitalization in which at least one evaluation was completed is 73.19%.

Item performance on admission Mean symptom scores and percentages of floor and ceiling answers and of missing data on admission are presented in Table 2. It shows that appetite, activity, well-being, drowsiness and pain are the most distressing symptoms (mean greater than 5) for patients on admission in the palliative care ward. A similar pattern of symptoms with a higher prevalence of depression is present in the home care patients. The highest percentage of ceiling answers are for appetite (18 vs 19%), well-being (14 vs 12%) and activity (12 vs 18%) and thus document a generally good performance of the items. On the contrary, both samples show a high floor effect for nausea and shortness of breath, respectively 61 and 49% for the in-patients and 49 and 45% for the home patients. As regards missing data on admission, the percentage of patients not filling the questionnaire is similar.

Table 1 Basic demographic and clinical characteristics of the study samples

	In-patients		Home patients	
	N	(%)	N	(%)
Gender				
Male	54	65	74	47
Female	29	35	84	53
Age, mean (SE)	66.5 (10)		66.5 (10)	
Primary tumor				
Gastrointestinal tract	14	17	72	45
Breast	10	12	13	8
Genitourinary	11	13	28	18
Head-neck	0	10	9	6
Lung	20	24	17	11
Haematological	–	–	2	1
Other/unknown	20	24	17	11
Performance status				
Karnofsky				
50–100	19	23		
30–40	48	58		
0–20	14	17		
Missing	2	2		
ECOG				
0–1			7	4
2			50	32
3			78	49
4–5			23	15
Survival, median (Q1–Q3)	35	(17–65)	33.5	(13–75)
Length of stay in hospital, median (Q1–Q3)	15	(8–21)	–	–

Test-retest reliability The ICCs between morning ESAS evaluation on days 2 and 3 (Table 3) show a good agreement as regards depression, well-being and overall distress

Table 2 Means, SDs and percentages of ceiling and floor effect and of missing data for each item

ESAS items	In-patients			Home patients						
	Mean	SD	% at floor	% at ceiling	% of missing	Mean	SD	% at floor	% at ceiling	% of missing
Pain	5.0	3.4	12	11	17	5.3	3.2	13	11	25
Activity	6.1	2.9	7	12	18	6.8	2.6	2	18	25
Nausea	1.2	2.5	61	1	18	3.0	3.6	48	9	25
Depression	4.1	3.6	27	6	20	5.3	3.2	11	11	25
Anxiety	3.3	3.4	30	7	19	4.2	3.3	18	9	25
Drowsiness	5.5	3.2	13	7	19	4.5	3.3	18	10	25
Appetite	6.1	3.2	9	18	19	5.1	3.8	21	19	26
Well-being	5.5	3.3	11	14	20	5.9	3.0	8	12	26
Shortness of breath	1.8	2.7	49	1	19	2.7	3.1	45	3	26
Overall distress	4.3	1.7	1	1	18	4.8	1.8	0	0	25

Table 3 Questionnaire reliability: intraclass correlation coefficient between morning ESAS evaluation on day 2 and day 3

ESAS items	% Agreement ^a	ICC	95% CI
Pain	70	0.56	0.39–0.73
Activity	66	0.46	0.26–0.66
Nausea	81	0.46	0.27–0.66
Depression	71	0.65	0.50–0.79
Anxiety	67	0.53	0.35–0.71
Drowsiness	72	0.47	0.72–0.66
Appetite	66	0.45	0.26–0.65
Well-being	78	0.61	0.44–0.78
Shortness of breath	77	0.59	0.42–0.75
Overall distress	80	0.61	0.45–0.76

In-patients, N=60

^aAgreement was defined as a difference between day 2 and day 3 equal to or lower than 2 points

(ICC ranging from 0.61 to 0.80) and a moderate agreement (ICC ranging from 0.41 to 0.60) for all the other scales.

Concurrent validity A high correlation ($P=0.77$) emerged between the ESAS summary distress measure and the SDS summary score (Table 4). Correlation between the correspondent specific items of the two questionnaires was high and also significantly different from zero, thus confirming a good concurrent validity.

Sensitivity Table 5 shows the differences of each ESAS item and of the global score between groups of patients with different PS levels.

Although no statistically significant different scores emerged among the three groups of PS, in both groups of patients under study it can be observed that the higher the PS level, the lower is the mean score for all items and for the overall score. Only the in-patient population, which was admitted to the palliative care ward mainly for symp-

Table 4 Concurrent validity: correlation coefficients between ESAS items and SDS items

ESAS items	N	Pearson correlation coefficient
Pain	103	0.80
Activity	105	0.79
Nausea	101	0.88
Depression	104	0.64
Anxiety	–	
Drowsiness	–	
Appetite	103	0.74
Well-being	–	
Shortness of breath	103	0.84
Overall distress	105	0.77

All $P < 0.001$

Only for home care group

tom control, shows higher pain scores associated with higher level of PS.

Responsiveness We compared each item score and total score between days 1 and 7 in both populations (Table 6). In the in-patient group, data were available for 29 patients out of 83. Only anxiety showed a significant improvement. However, pain, activity, nausea, depression and drowsiness scores also decreased on the seventh day, although the difference was not statistically significant.

In the home patient group ($n=107$), pain, nausea, well-being and overall distress scores on day 7 were significantly lower than on day 1.

Discussion

ESAS is a simple scale for symptom assessment first described for palliative care patients. Its easy administra-

Table 6 Responsiveness: mean scores of each item at admission and 1 week after

ESAS items	In-patients (N=29)		Home patients (N=107)	
	Delta ^a	P	Delta ^a	P
Pain	1.2	NS	2.6	<0.001
Activity	0.4	NS	0.8	0.003
Nausea	0.6	NS	1.2	<0.001
Depression	0.9	NS	0.7	0.014
Anxiety	1.2	0.043	0.4	NS
Drowsiness	0.6	NS	-0.2	NS
Appetite	-0.1	NS	0.4	NS
Well-being	-0.1	NS	1.6	<0.001
Shortness of breath	0.7	NS	0.6	0.014
Overall distress	0.5	NS	0.9	<0.001

^aPositive variations indicate any improvement, negative variations indicate worsening

tion makes it a widely applied scale for symptom assessment also in other care settings [23].

In this study, we have evaluated the psychometric properties and the applicability of the Italian version of ESAS in patients with advanced cancer cared for in two different palliative care settings: the home care and the in-patient care. These two populations, quite different in number, have similar median survival and demographic and clinical characteristics. In addition, symptom prevalence and the overall distress score at baseline are similar between home patients and in-patients. In particular, both samples show a low percentage of patients reporting shortness of breath, a symptom that is often related to a short survival.

The ESAS clearly showed a good concurrent validity with respect to validated SDS. However, the correlation between the physical items of the two questionnaires (ESAS and SDS) was shown to be higher than the correlation between the psychological ones. This data would confirm a greater variance of the VNS instrument in the

Table 5 Sensibility (known group comparison): mean scores of each item by PS level

ESAS items	KPS				ECOG			
	10–20 (N=14)	30–40 (N=48)	≥50 (N=19)		4–5 (N=8)	3 (N=60)	0–2 (N=51)	
Pain	3.7	5.1	6.3	NS	7.4	4.8	5.5	NS
Activity	7.3	6.0	5.4	NS	8.2	6.8	6.5	NS
Nausea	2.0	0.6	2.4	0.043	2.5	3.0	3.0	NS
Depression	5.0	4.2	3.4	NS	6.7	5.3	5.2	NS
Anxiety	5.2	3.0	2.8	NS	3.8	4.3	4.1	NS
Drowsiness	6.7	5.7	4.1	NS	5.6	5.0	3.9	NS
Appetite	6.3	6.3	5.2	NS	6.7	5.0	4.8	NS
Well-being	5.2	5.6	5.4	NS	7.2	6.2	5.3	NS
Shortness of breath	2.4	2.10	0.6	NS	2.5	3.0	2.3	NS
Overall distress	4.8	4.3	3.9	NS	5.6	4.9	4.5	NS

NS Not significant

assessment of psychological symptoms [23] and the basic difficulty in selecting an effective instrument for measuring the psychological changes of terminal cancer patients [31, 34] using only a quantitative method.

Although not statistically significant, the association of ESAS scores and PS scores (KPS and ECOG scales) shows a trend: the higher the symptom score, the worse the performance status level. A further insight into these data reveals a difference in pain score in the in-patient group, e.g. the presence of higher pain scores when KPS is greater than 50. This underlines that pain management control was the main reason for hospitalisation of these patients.

Test–retest evaluation has been applied only in the in-patient group, wherein it shows good agreement for only two symptoms and distress score over a 24-h period of time and only moderate for all the remaining items. It is our opinion that this may be because symptoms in the palliative care patients may change rapidly, so that test–retest designed to evaluate reliability is probably not easily applicable to this kind of patients.

Another finding that emerged from our study is the higher percentage of missing data in both populations at baseline, suggesting a greater difficulty in the palliative care setting for self-report questionnaires. However, the percentage of missing data completely overlaps the literature compliance rate for the terminally ill [33].

In the in-patient group, longitudinal analysis of missing data shows a rather low average percentage (53.3%) of completed vs expected questionnaires, which confirms the difficulty in applying such a strict (twice daily) QoL monitoring system in such a population; on the other hand, the mean percentage of days of assistance in which at least one evaluation was given seems to be acceptable (73.2%), which indicates that ESAS does not seem to be too burdensome for patients in a daily monitoring system.

It is interesting to observe that the measure of responsiveness is quite different in the two populations: the significant improvement for pain, nausea and overall distress in home patients has a similar but not significant trend in the in-patients, where only anxiety has a significant improvement. These data could be due to the low number of the in-patient population; moreover, these results could also be affected by a sort of prevalent response shift in the assessment process [35] in the home population due to the weekly administration of the ESAS vs the daily ESAS administration in the in-patient sample. We consider that a weekly repetition could allow a change in patients' perception (scale recalibration) more easily than a twice-daily valuation does.

Our study is different from Rees' study [21] since our data show a statistical significant improvement in symptom control (pain, activity, nausea, well-being, shortness of breath and overall distress) in home patients and a trend towards improving symptoms in in-patients. We suppose

that this is due to our patient-population characteristics, whose survival was longer than that reported by Rees (35 days in in-patients and 33 days in home patients vs 16 days). This aspect allows better symptom control before general deterioration in the final stage of the disease. Moreover, in her study, Rees applies VAS, which is more complicated for the patients to fill out especially for psychological symptoms, as the author herself reported.

In our study, we underline an improvement in pain score in our population; this allows us to affirm that ESAS is a valid tool to assess the intensity of pain in our patient population. As Heedman and Strang [36] have focused, the improvement may not be strictly related only to change in medication, since pain relief could be the result of the multidimensional approach. In any case, the aim of our study was not to describe the results of medical approach to obtain pain relief but to measure psychometric properties of an assessment tool called ESAS.

An unexpected result regards the well-being scores that worsened as opposed to the other symptom trend in the in-patient group. These conflicting data can be explained with the wide meaning of the Italian word 'well-being' for patients. It could underlay several domains (perception of terminal stage, care in hospital or at home, social difficulties, body images) which are not strictly correlated to worsening in symptom score or functional status.

As Heedman et al. [24] observed, the sensation of well-being is a 'broad' issue, and an improved sensation of well-being when the patient is close to death is not realistic, although maintaining the initial level may be a possible aim.

Moreover, the same authors concluded that a single and comprehensive item of assessment of well-being is probably a more reliable and valid outcome measure for palliative care intervention since it includes not merely physical and emotional dimensions. This aspect could explain the different trend in different care settings, given that home care patients could experience a good symptom control in a familiar environment that would improve emotional and spiritual aspects as well. This reflects the results of recent studies [38, 39] where spiritual well-being clearly affects advanced cancer patients' quality of life and therefore can be related to symptom expression and communication between clinicians and patients.

In conclusion, we consider ESAS to be a valid, reliable and feasible instrument for physical symptom assessment in routine 'palliative care' clinical practice with a potentially different responsiveness in different situations or care settings.

According to the papers of Stromgren et al. [25, 37], ESAS includes seven of the 12 most frequent symptoms reported in medical records. Even if in our study we did not compare medical records with patients' records, we consider that these data support the use of ESAS tool for

medical research, although it does not give an in-depth understanding of the individual patient's unique situation.

However, we believe that a symptom assessment tool can only supply the care giver with a general indication of the presence and intensity of patients' suffering. In the routine clinical practice, an assessment tool cannot and must not substitute for and replace the communication between the physician/nurse and the patient. Only inter-

personal communications allow thorough symptom investigation and, consequently, the possibility to assess the cause and the appropriate pharmacological and non-pharmacological treatment.

This is part of the palliative care philosophy that considers the importance of a holistic approach in assessing and treating patients with cancer in every stage of their disease.

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