Original Article

A Multicenter Study Comparing Two Numerical Versions of the Edmonton Symptom Assessment System in Palliative Care Patients

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Abstract

Context. The Edmonton Symptom Assessment System (ESAS) is a widely used, self-report symptom intensity tool for assessing nine common symptoms in palliative care, with ratings ranging from 0 (none, best) to 10 (worst). Based on a "thinkaloud" study of 20 advanced cancer patients, the ESAS was revised (ESAS-r).

Objectives. To compare the consistency of patients' symptom ratings and obtain patient perspectives regarding ease of understanding and completion between the ESAS and ESAS-r.

Methods. Cognitively intact patients (n=160) were recruited from eight palliative care sites in Canada and Switzerland, using cross-sectional sampling (20 per site). Consenting patients completed the ESAS, ESAS-r, and a structured interview. Intraclass correlation coefficients (ICCs) were calculated to assess rating consistency.

Results. In total, 1046 patients were screened. One hundred sixty were enrolled and evaluable (female 51%, median age 61 [range 34–92], lung cancer 26%, gastrointestinal cancer 22%). Mean ESAS scores ranged from 1.2 (nausea, standard deviation [SD] 2.1) to 4.3 (appetite, SD 3.3). ICCs ranged from 0.65 to 0.83, with lowest scores (<0.8) for drowsiness, appetite, and well-being. Although most patients rated both versions as very easy or easy to understand and complete, the ESAS-r was significantly easier to understand than the ESAS (P=0.008). Significantly, more patients preferred the ESAS-r (39%) than the ESAS (14%, P<0.001) because of its definitions, clarity, and format.

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Conclusion. The ESAS-r retains core elements of the ESAS, with improved interpretation and clarity of symptom intensity assessment. It represents the next generation of ESAS development, with further validation recommended for drowsiness, appetite, and well-being. J Pain Symptom Manage 2011;41:456–468. © 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Symptom assessment, advanced cancer, instrument development, intrarater reliability

Introduction

The Edmonton Symptom Assessment System (ESAS)¹ is a self-report tool of symptom intensity, initially developed for advanced cancer patients. It includes nine common symptoms of advanced cancer (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing, shortness of breath), with the option of adding a tenth patient-specific symptom. It is designed to capture multidimensional symptom profiles over time by obtaining repeated quantitative measurements of symptom intensity with minimal patient burden. The original ESAS used visual analogue scales to rate symptom intensity. In a subsequent version, they have been replaced with 11-point numerical rating scales.²

Since its original inception by Bruera and colleagues in 1991,¹ the ESAS has been adopted in diverse palliative care programs and countries. A recent bibliometric analysis of the ESAS highlights a rapid and multinational uptake of the tool over the past 15 years,³ where it is used for clinical, research, and administrative purposes.^{4–7} A series of validation studies have complemented the rapid clinical uptake of the ESAS, providing further evidence for its psychometric properties and clinical utility.^{8,9}

Although the ESAS was designed for self-reporting, some concerns have been raised about patient comprehension of the tool¹⁰ and potential patient errors in symptom ratings.¹¹ In a recent prospective "think-aloud" study of 20 advanced cancer patients,¹² patients described difficulties in distinguishing between the symptoms of drowsiness and tiredness, rating depression and anxiety, and understanding the term well-being. Also, they often reversed the scale for the symptom appetite (i.e., 0 = worst, 10 = best as opposed to 0 = best, 10 = worst). Some patients suggested that the

time frame for rating the symptoms ("now") should be emphasized. Constipation was frequently cited as an additional patient-specific symptom.

Based on concerns raised in the literature ^{10,11} and the findings of the think-aloud study, ¹² a revised version of the ESAS, the ESAS-r, was created. The ESAS-r retains the core elements of the ESAS (nine common symptoms, option of adding a tenth symptom, 11-point numerical rating scales), with key revisions focusing on symptom assessment time frame, terminology, item order, and format (see Methods for detailed description).

The hypothesis of the present study was that the ESAS-r would be easier for patients to understand and complete than the current version (ESAS). The two primary objectives for this study were as follows:

- 1. To compare the consistency of patients' symptom ratings between the two numerical rating scale versions of the ESAS and ESAS-r, using intrarater reliability estimates; if patients' interpretations of the same symptom were different between the two versions, then it was hypothesized that intrarater reliability estimates would be lower, particularly for problematic items (e.g., drowsiness, tiredness, depression, anxiety, well-being, appetite).
- 2. To obtain patients' opinions regarding ease of understanding and completion of the ESAS and ESAS-r.

Patients and Methods

Participants

Using a cross-sectional sampling approach, a convenience sample of 160 patients was recruited from eight palliative care sites in Canada and Switzerland: Edmonton (five sites,

 $n\!=\!100$), Calgary $(n\!=\!20)$, Toronto $(n\!=\!20)$, St. Gallen $(n\!=\!20)$. These sites were purposefully selected, being limited to programs offering specialist palliative care services, including tertiary palliative care units, inpatient hospices, acute care hospital consultation services, and outpatient consultation clinics.

Cognitively intact patients who had been referred to the participating palliative care programs were eligible. Approval was obtained from the research ethics board for each site.

Measures

ESAS. The ESAS¹ is a self-report symptom assessment measure, consisting of nine symptoms, with the option of adding a tenth patient-specific symptom. Patients rate the intensity of each of these symptoms, using an 11-point numerical rating scale, ranging from 0 (symptom absent or best) to 10 (worst possible). Each symptom rating is interpreted independently, although it is also possible to calculate a total symptom distress score. However, previous research has demonstrated that the analysis of individual symptom ratings provides a more meaningful representation of the symptom experience than a total symptom distress score. 13 ESAS validation studies have focused on gathering reliability estimates, 11,13–19 content validity evidence, 20 concurrent validity evidence, 14,17–19,21 predictive validity evidence,²² and sensitivity and/or specificity. 11,17,23 A copy of the tool appears in Appendix A.

ESAS-r. The ESAS-r is a modified version of the ESAS. The time frame for symptom ratings is specified as "now." Brief definitions have been added for the following potentially confusing symptoms: tiredness (lack of energy), drowsiness (feeling sleepy), depression (feeling sad), anxiety (feeling nervous), and well-being (how you feel overall). "Appetite" has been changed to "lack of appetite" to express the concept as a symptom. The order of symptoms has changed: related symptoms (e.g., tiredness and drowsiness; nausea and appetite; depression and anxiety) are grouped together, and "well-being" is now the ninth symptom at the end of the instrument. The example of "constipation" has been added to the tenth item, "other problem." The horizontal lines over the numbers have been removed. Every second

scale is shaded in gray to improve readability. A copy of the tool appears in Appendix B.

Three research team members (SMW, CN, CB) developed a draft version of the ESAS-r, which was subsequently reviewed by other members of the research team. All team members had extensive clinical and research experience in symptom assessment and in using the ESAS in advanced cancer and palliative populations. Definitions were inserted for problematic items previously identified by participants in the think-aloud study, using specific wording generated by patients from this study. ¹² Feedback was also obtained from an interdisciplinary group of palliative care clinicians and researchers (Edmonton), who routinely use the ESAS in their daily practice.

ESAS and ESAS-r (German). For the German-speaking Swiss subsample of patients (n=20), a professional translator developed German versions of the ESAS and ESAS-r, in close collaboration with the research team members in St. Gallen. Using a standard translation protocol, a forward and backward translation was used, in which the tool was translated from English to German, back to English, and then finalized in German.

Palliative Performance Scale. The Palliative Performance Scale (PPS)²⁴ is a measure of performance status in palliative care patients, based on ambulation, activity, evidence of disease, self-care, intake, and level of consciousness. Ratings are in 10% increments, ranging from 0% (death) to 100% (fully functional). The PPS is used to routinely assess patients' functional status as a part of standard clinical practice.

Folstein Mini-Mental State Examination.²⁵ The Mini-Mental State Examination (MMSE) is a screening tool for assessing five domains of cognitive functioning: orientation, memory, attention and calculation, recall and language. Scores range from 0 (total impairment) to 30 (fully intact), with adjustments for age and education.²⁶ The MMSE is used to routinely assess patients' cognitive status as a part of standard clinical practice. The MMSE obtained closest to the time of study participation was recorded. In some instances, the MMSE score was below the expected normal value, but the

site investigator deemed that cognitive function had normalized clinically.

Edmonton Classification System for Cancer Pain. ²⁷ The Edmonton Classification System for Cancer Pain (ECS-CP) classifies cancer pain according to five features: pain mechanism, incident pain, psychological distress, addictive behavior, and cognitive function. The ECS-CP was included in this study to describe the pain features of this sample.

Structured Interview. The structured interview consisted of seven questions focusing on patients' familiarity with the ESAS, as well as ease of understanding, ease of completion, assessment of differences and preferences between the two versions. Patient opinions were elicited using quantitative ratings (5-point Likert scales) and qualitative comments. The interview questions were developed by the research team, using parallel questions to those used in the previous think-aloud validation study. ¹²

Procedure

A research nurse or assistant screened current and new admissions to each palliative care service for study eligibility. Patients' cognitive status was assessed, based on the most recently documented MMSE score on the patient's chart and the clinical opinion of the attending physician, which mirrors clinical practice.

Before data collection, a research nurse or assistant informed eligible patients about the study and obtained written consent. All consenting patients independently completed the ESAS and then the ESAS-r, in the presence of the research nurse or assistant. The instruments were not completed in random order, as patients were expected to have been already exposed to the ESAS during the course of care by the palliative care service, thereby diminishing the value of randomization. Thereafter, the research nurse or assistant administered the structured questionnaire to elicit patients' opinions regarding the two versions.

The following information was obtained from the patients' medical records: age, gender, primary cancer diagnosis, current cancer treatment, education level, PPS, MMSE, and ECS-CP scores.

Data Analysis

Data from the eight sites were pooled and analyzed aggregately because of the small sample size at each site. Quantitative data were analyzed using descriptive statistics. Independent and paired samples t-tests, as well as the Pearson Chi-squared test, were used for group comparisons. Significance levels were set at 0.05. Intraclass correlation coefficients (ICCs) were calculated to obtain intrarater reliability estimates. For the purposes of this study, a reliability estimate of 0.8 or higher was considered a reasonable estimate.²⁸ Using conservative assumptions, if the ICC is about 0.80, a sample size of 160 would yield a 90% confidence interval of about 0.75-0.85. Qualitative comments were analyzed using content analysis to identify common themes.

Results

Participant Description

In total, 1046 patients were screened between June 12, 2008 and March 31, 2009. Three hundred twenty eligible patients were approached regarding their willingness to participate in the study. One hundred sixty patients consented and completed the study. Participant characteristics are described in Table 1. Most were inpatients (84%), with a median age of 61 years and an equal distribution of men and women. The two most common cancer diagnoses were lung (26%) and gastrointestinal (22%). Sixty-two percent of patients had previously completed the ESAS. Average scores for the ESAS and ESAS-r are summarized in Table 2. Mean scores ranged from 1.2 for nausea (ESAS, standard deviation [SD] 2.1) to 4.3 for appetite (ESAS, SD 3.3).

Most patients rated both versions as *very easy or easy to understand* (ESAS, 78%; ESAS-r, 83%) *and complete* (ESAS, 87%; ESAS-r, 89%). However, as shown in Table 3, the ESAS-r was significantly easier to understand than the ESAS (P= 0.008). There were no significant differences in ease of completion between the two forms. Sixty-two patients (39%) preferred the ESAS-r, which was significantly more than those who preferred the ESAS (n= 22, 14%, P< 0.001). Less than half (n= 76, 47%) reported no preference for either form. Based on qualitative comments, the most frequent reason for ESAS-r preference was the inclusion of

Table 1 Patient Characteristics (n = 160)

Gender Female Primary cancer diagnosis ^a Lung Gastrointestinal Genitourinary Breast Other cancer Noncancer	82 (51) 41 (26) 35 (22) 29 (18) 21 (13) 31 (19) 5 (3)
Primary cancer diagnosis ^a Lung Gastrointestinal Genitourinary Breast Other cancer Noncancer	41 (26) 35 (22) 29 (18) 21 (13) 31 (19)
Lung Gastrointestinal Genitourinary Breast Other cancer Noncancer	35 (22) 29 (18) 21 (13) 31 (19)
Lung Gastrointestinal Genitourinary Breast Other cancer Noncancer	35 (22) 29 (18) 21 (13) 31 (19)
Gastrointestinal Genitourinary Breast Other cancer Noncancer	35 (22) 29 (18) 21 (13) 31 (19)
Breast Other cancer Noncancer	29 (18) 21 (13) 31 (19)
Breast Other cancer Noncancer	21 (13) 31 (19)
Noncancer	31 (19)
	5 (3)
Current cancer treatment ^b	
None	106 (66)
Systemic therapy	31 (20)
Radiotherapy	13 (8)
Systemic and radiotherapy	2(1)
Únknown	8 (5)
Education level (years)	
0-4	4 (3)
5-8	10 (6)
9-12	85 (53)
Greater than 12	59 (37)
Unknown	2 (1)
Pain classification	
Neuropathic pain	44 (28)
Incident pain	69 (43)
Psychological distress	36 (23)
Addictive behavior	14 (9)
Cognitive status impaired	6 (4)
Previously filled out ESAS ^b	
Yes	99 (62)
No	58 (36)
Unknown	3 (2)
	~ (-)
Patient setting	194 (94)
Inpatient Outpatient	134 (84) 26 (16)
Outpatient	20 (10)
	Median (range)
Age (years)	61 (34-92)
Folstein MMSE $(0-30)^b$	29 (0-30)
Palliative performance scale	50 (20-90)
(0%-100%)	, ,

^aPercentages do not total 100 because of one participant having more than one primary cancer diagnosis.

definitions (n=30). Other reasons, in descending order, included clarity (n=19), format (n=16), and inclusion of an example for the tenth patient-specific symptom (n=7). There were no significant demographic differences in age, gender, education level, or PPS between patients who preferred the ESAS-r and those who either preferred the ESAS or had no preference. The groups also did not differ significantly in terms of prior ESAS use.

When asked how different their responses were between the ESAS and ESAS-r, about one in four

participants (28%) reported no difference in their responses, with most ratings (99%) ranging from 1 to 3, on a 5-point Likert scale (1 = no difference, 5 = very different). Only two participants rated the difference in their responses as either a 4 (n=1) or a 5 (n=1). Fig. 1 illustrates a similar pattern of distribution, when responses were grouped according to participants' expressed form preference (i.e., ESAS, ESAS-r, no preference).

When asked how important the differences were between the two forms, 41% of participants reported that the differences were not important (rating = 1). The remaining participants (59%) reported varying levels of importance, with 26 patients (16%) rating the differences between the two forms as important to very important. Fig. 2 illustrates this similar pattern of distribution, when responses were grouped according to participants' expressed form preference (i.e., ESAS, ESAS-r, no preference).

ICCs ranged from 0.65 (well-being) to 0.83 (depression, tiredness, pain), with scores of less than 0.8 for drowsiness (ICC = 0.79), appetite (ICC = 0.74), and well-being (ICC = 0.65) (Table 2). Figs. 3–5 illustrate the variability in responses for these three symptoms, using box plots. Box plots provide a visual representation of distributions by summarizing the median, quartiles (box), 95% interval (whiskers), and extreme values (highest and lowest). For each symptom, box plots were created by comparing participants' ESAS-r scores (X-axis) with their corresponding ESAS scores (Y-axis). If there were a perfect correlation between ESAS and ESAS-r scores, then it would be expected to see a single point for each numerical rating from 0 to 10, which would align in a straight line. As shown in these figures, there was considerable variability in scores, and in some cases, reversal of scores between the two versions. For example, some participants who rated their appetite and well-being as a 10 on the ESAS reversed their score to 0 on the ESAS-r (Figs. 4 and 5).

Discussion

In this prospective multicenter study conducted in a variety of palliative care settings, patients' perceived ease of understanding and completion of both forms of the symptom

^bScores on admission and/or most recent chart documentation; for some patients, cognitive status had significantly improved by the time of recruitment.

Table 2 ICCs for Symptom Ratings Using ESAS and ESAS-r (n=160) and Average Symptom Ratings for ESAS and ESAS-r (n=160)

Symptom			Mean (SD)			
	ICC	Confidence Interval (95%)	ESAS	ESAS-r		
Depression	0.83	0.78-0.88	1.8 (2.2)	2.1 (2.3)		
Tiredness	0.83	0.78 - 0.87	4.1 (2.7)	3.9 (2.8)		
Pain	0.83	0.77 - 0.87	2.9 (2.5)	3.0 (2.7)		
Shortness of breath	0.82	0.76 - 0.87	2.2 (2.7)	2.2 (2.7)		
Anxiety	0.81	0.75 - 0.86	2.2 (2.4)	2.2 (2.4)		
Nausea	0.80	0.74 - 0.85	1.2 (2.1)	1.3 (2.4)		
Drowsiness	0.79	0.72 - 0.84	3.3 (2.7)	3.6 (2.9)		
Appetite	0.74	0.66 - 0.81	4.3 (3.3)	3.6 (3.3)		
Well-being	0.65	0.55 - 0.73	4.0 (2.6)	3.6 (2.8)		

intensity tool were high. However, the ESAS-r was significantly easier to understand (P= 0.008), with significantly more patients preferring the ESAS-r to the ESAS (P< 0.001). Although most patients did not perceive their responses to be different between the two versions, the moderate ICCs, particularly for drowsiness, appetite, and well-being, suggest that there was considerable variability in responses between forms. These findings suggest that the ESAS-r can replace the ESAS. However, ongoing prospective validation evidence for drowsiness, appetite, and well-being, for example, with comparable quantitative measures, are needed.

Approximately 40% of patients preferred the revised version of the ESAS to the original version, with the most common reason being the definitions. In some clinical settings, the ESAS is completed by patients with guidance from a health care professional. In this situation, the inclusion of definitions may not be as critical, as the health care professional is available to provide clarification. However, these definitions can be helpful for training new staff in administering the ESAS, as well

as for ensuring reasonable consistency across clinicians in terms of their explanations of symptoms, particularly for abstract concepts such as well-being. Furthermore, the use of electronic kiosks or the Internet for self-reporting ESAS scores for the purpose of screening for symptom distress has been described. As patients do not have immediate access to a health care professional while completing the ESAS using these modalities, the inclusion of definitions would be helpful to assist with interpretation of potentially confusing terms.

Substantive differences in symptom intensity ratings between the ESAS and ESAS-r were observed for three of the defined symptoms, drowsiness, appetite, and well-being, with ICCs below 0.8 for these three symptoms. Although the ICCs were above 0.8 for the remaining symptoms, the highest ICC was 0.83 with moderately wide confidence intervals, suggesting considerable variability in responses between the two forms. These response differences may have been because of differences in interpretation of the terminology, potentially suggesting an improvement in scores when definitions were

Table 3

Comparison of ESAS and ESAS-r in Terms of Ease of Understanding, Ease of Completion, and Patient Preference (n = 160)

		/		
	ESAS	ESAS-r		
Survey Question	Mean (SD)	Mean (SD)	No Preference	<i>P</i> -value ^b
Q1. How easy was it to understand each form? ^a Q2. How easy was it to fill out each form? ^a	1.81 (1.2) 1.48 (1.0)	1.66 (1.0) 1.41 (0.9)		$0.008 \\ 0.149$
	n (%)	n (%)	n (%)	
Q3. Overall, which form do you prefer?	22 (14)	62 (39)	76 (47)	< 0.001

 $^{{}^{}a}$ Scale = 1 (very easy) to 5 (very hard).

^bPaired sample t-test for Q1 and Q2, one sample Chi-squared test for Q3.

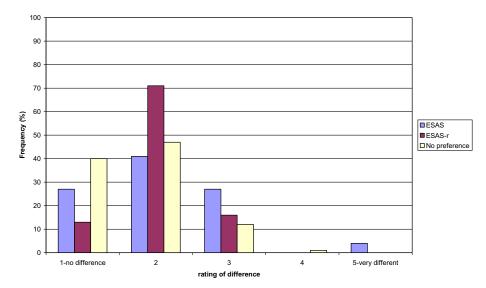


Fig. 1. Overall, how different were your responses between Form A (ESAS) and Form B (ESAS-r)? (n=160).

used for clarification. This is supported, in part, by the finding that the ESAS-r was significantly easier to understand than the ESAS and participants' qualitative comments regarding the usefulness of definitions. Noguera et al. ³⁰ recently demonstrated that using different words to express anxiety and depression in the Spanish version of the ESAS affected the screening performance of the scales, when compared with the Hospital Anxiety Depression Scale as a gold standard.

The symptom of drowsiness has previously been identified as being confusing, particularly when compared with tiredness.¹² The inclusion of definitions for both these symptoms, in the ESAS-r, provides greater clarity regarding their differences. By grouping them together, patients may compare their responses more readily and make adjustments to their ratings if necessary, if they have difficulty distinguishing between the two symptoms. The presence of a health care professional during tool administration, particularly for patients who are not familiar with the ESAS, could further help patients clarify these two symptoms to ensure consistency in interpretation of symptoms.

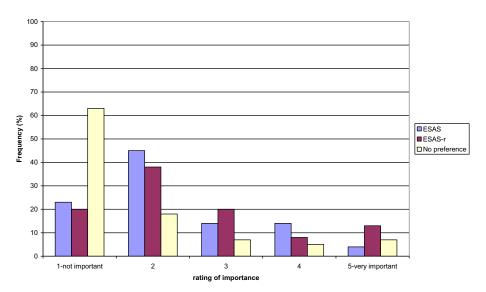


Fig. 2. Overall, how important is the difference between Form A (ESAS) and Form B (ESAS-r)? (n = 158).

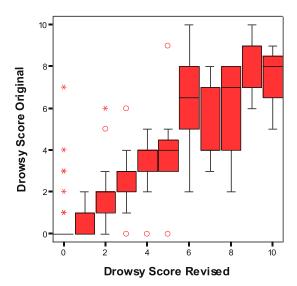


Fig. 3. Distribution of drowsiness scores (ESAS vs. ESAS-r).

One item that had been previously identified as problematic was "appetite," the ratings for which were often reversed. 11,12 In the ESAS-r, the term was changed to "lack of appetite" to convert it to a symptom, in keeping with the other items in the tool. Qualitative comments from patients suggested that the use of a double negative ("no lack of appetite") was confusing. The moderate ICC for appetite (r= 0.74) further reinforces this inconsistency in responses between the two forms, which may have been related to difficulties in item interpretation.

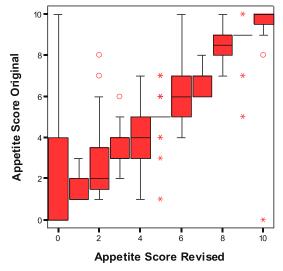


Fig. 4. Distribution of appetite scores (ESAS vs. ESAS-r).

The symptom of well-being can be difficult for patients to comprehend, as suggested by previous research.¹² The inclusion of the definition in the ESAS-r, "how you feel overall," encourages patients to consider this symptom as an overall assessment of their health, in view of their other symptoms. The placement of this symptom at the end of the instrument further reinforces its use as an overall summary of their symptoms.

The inclusion of the example of "constipation" at the bottom of the "other problem" scale in the ESAS-r may have introduced bias by prompting patients to report constipation as opposed to other problems. However, while reporting of constipation increased with the ESAS-r compared with the ESAS (39 patients vs. 12 patients, respectively), reporting of problems other than constipation was not substantially decreased (34 vs. 37 patients, respectively).

In the previous think-aloud study, patients suggested clarifying the time frame for rating symptoms. 12 In the ESAS-r, the time frame was specified as "now" because this was how the tool was originally designed. However, this is not explicitly written on the original ESAS, although it is described in the guidelines for administration.² This may have contributed to some of the variability in responses between the two forms. Some authors have reported using a time frame of 24 hours for the ESAS.¹¹ In a study of 1147 cancer outpatients, Shi et al.³¹ have reported that ratings for worst pain in the past week correlate more closely with pain interference than ratings for current pain.

If the ESAS is completed in the presence of a health care professional, then the range of symptom intensity over time can be explored, in which clinicians can compare the patient's current symptom ratings with past symptom experiences (e.g., over the past week, worst, best, average). However, if the tool is being completed without an opportunity to elaborate on the scores, then it would be important to choose the most relevant time frame. This may differ based on the palliative care setting, patient needs, fluctuation of symptoms over time, and frequency of symptom assessments.

There are several limitations of this study. For patients who were naïve to the ESAS, the ESAS-r was consistently presented after the ESAS, which could have affected perception

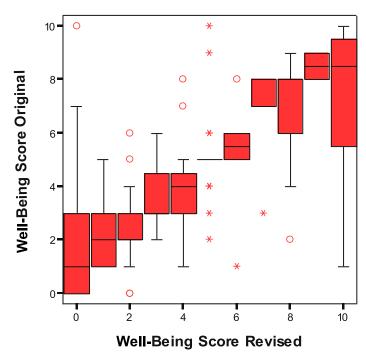


Fig. 5. Distribution of well-being scores (ESAS vs. ESAS-r).

of the revised instrument. However, this was a relatively small proportion of the entire sample (n = 58, 36%). In addition, there were no significant differences, in terms of preference for the ESAS-r vs. the ESAS, between participants who had previously completed the ESAS and those who were not familiar with it. The presence of a research nurse or assistant may have influenced patient responses, as opposed to having patients complete the ESAS without someone present. It is also uncertain if the German versions of the ESAS and ESAS-r were interpreted in the same way as the English versions; gathering validity evidence for the German versions of the ESAS was beyond the scope of this study, a focus for future research. However, results for the subgroup of patients in St. Gallen did not differ significantly from results for the entire study group. A fourth limitation relates to reliance on clinical impression of recovery of cognitive function in patients who had an abnormal MMSE before study entry. However, this is in keeping with clinical practice. Also, patients with mild cognitive impairments are able to complete the ESAS, sometimes with the assistance of a health care provider. A further limitation is that most participants were

inpatients, reflecting referral patterns of the participating programs, and therefore the results may not be generalizable to outpatients.

Future research priorities include gathering further validity evidence for the ESAS-r, focusing on optimal definitions and time frames for symptom assessments. In particular, further research is needed to better understand the variability in responses for the symptoms drowsiness, appetite, and well-being. It is possible that this variability represents an improvement in ratings with the ESAS-r in comparison with the ESAS. This needs to be explored in more detail. Based on participants' feedback, the wording for the definition for appetite continues to be potentially confusing and requires further validation. Most patients in this study were familiar with the ESAS, which provided important perspectives of people who were knowledgeable about this tool. Additional testing with patients who are not familiar with the ESAS, alone and in the presence of a health care provider, is warranted. As an extension of the qualitative think-aloud ESAS study, ¹² further qualitative research focusing on patients' and health care professionals' interpretations of item scales, particularly problematic items, would be useful. Finally, gathering further validity evidence for using the ESAS in non-English-speaking countries and languages other than English is warranted.

Disclosures and Acknowledgments

This work was supported by a Canadian Institutes for Health Research New Emerging Team grant. The authors declare no conflicts of interest.

The authors wish to thank the patients, their families, and the following collaborators: Christina Dunn, RN, Carla Stiles, RN, Pablo Amigo, MD, Sarah Burton-Macleod, MD, Ingrid deKock, MD, Joan Faily, MD, Robin Fainsinger, MD, Mehrnoush Mirhosseini, MD, Doreen Oneschuk, MD, Yoko Tarumi, MD, Vincent Thai, MD, Gary Wolch, MD, David Blum, MD, Hanspeter Häne, MD-student, Susanne Linder, RN, Rolf Oberholzer, MD, Susanne Ott-Jaworski, MD-student, and the palliative care program staff in Edmonton, Calgary, Toronto and St. Gallen.

References

- 1. Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. J Palliat Care 1991;7:6—9.
- 2. Regional Palliative Care Program in Edmonton Alberta. Guidelines for using the Edmonton Symptom Assessment System. Available from http://www.palliative.org. Accessed September 1, 2010.
- 3. Cummings G, Biondo P, Hagen N, Fainsinger R, Stiles C. Bibilometric review: Edmonton Symptom Assessment Scale (ESAS). Palliat Med 2008;22: 552–553.
- 4. Heedman PA, Strang P. Symptom assessment in advanced palliative home care for cancer patients using the ESAS: clinical aspects. Anticancer Res 2001;21:4077–4082.
- 5. Chow E, Davis L, Holden L, Tsao M, Danjoux C. Prospective assessment of patient-rated symptoms following whole brain radiotherapy for brain metastases. J Pain Symptom Manage 2005;30:18–23.
- 6. Dudgeon DJ, Harlos M, Clinch JJ. The Edmonton Symptom Assessment Scale (ESAS) as an audit tool. J Palliat Care 1999;15:14—19.
- 7. Porzio G, Ricevuto E, Aielli F, et al. The Supportive Care Task Force at the University of L'Aquila: 2-years experience. Support Care Cancer 2005;13:351–355.

- 8. Nekolaichuk C, Watanabe S, Beaumont C. The Edmonton Symptom Assessment System: a 15-year retrospective review of validation studies (1991-2006). Palliat Med 2008;22:111—122.
- 9. Richardson LA, Jones GW. A review of the reliability and validity of the Edmonton Symptom Assessment System. Curr Oncol 2009;16:53–64.
- 10. Watanabe S, McKinnon S, Macmillan K, Hanson J. Palliative care nurses' perception of the Edmonton Symptom Assessment Scale: a pilot survey. Int J Palliat Nurs 2006;12:111—114.
- 11. Garyali A, Palmer JL, Yennurajalingam S, et al. Errors in symptom intensity self-assessment by patients receiving outpatient palliative care. J Palliat Med 2006;9:1059–1065.
- 12. Watanabe S, Nekolaichuk C, Beaumont C, Mawani A. The Edmonton Symptom Assessment System: what do patients think? Support Care Cancer 2009;17:675–683.
- 13. Nekolaichuk CL, Maguire TO, Suarez-Almazor M, Rogers WT, Bruera E. Assessing the reliability of patient, nurse, and family caregiver symptom ratings in hospitalized advanced cancer patients. J Clin Oncol 1999;17:3621–3630.
- 14. Bruera E, MacDonald S. Audit methods: the Edmonton Symptom Assessment System. In: Higginson I, ed. Clinical audit in palliative care. Oxford, UK: Radcliffe Medical Press, 1993: 61–77.
- 15. Nekolaichuk CL, Bruera E, Spachynski K, et al. A comparison of patient and proxy symptom assessments in advanced cancer patients. Palliat Med 1999;13:311–323.
- 16. Pautex S, Berger A, Chatelain C, Herrmann F, Zulian GB. Symptom assessment in elderly cancer patients receiving palliative care. Crit Rev Oncol Hematol 2003;47:281–286.
- 17. Moro C, Brunelli C, Miccinesi G, et al. Edmonton Symptom Assessment Scale: Italian validation in two palliative care settings. Support Care Cancer 2006;14:30–37.
- 18. Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. Cancer 2000;88:2164—2171.
- 19. Davison SN, Jhangri GS, Johnson JA. Cross-sectional validity of a modified Edmonton Symptom Assessment System in dialysis patients: a simple assessment of symptom burden. Kidney Int 2006;69: 1621–1625.
- 20. Stromgren AS, Groenvold M, Pedersen L, Olsen AK, Sjogren P. Symptomatology of cancer patients in palliative care: content validation of self-assessment questionnaires against medical records. Eur J Cancer 2002;38:788–794.
- 21. Philip J, Smith WB, Craft P, Lickiss N. Concurrent validity of the modified Edmonton Symptom Assessment System with the Rotterdam Symptom Checklist and the Brief Pain Inventory. Support Care Cancer 1998;6:539–541.

- 22. Davison SN, Jhangri GS, Johnson JA. Longitudinal validation of a modified Edmonton Symptom Assessment System (ESAS) in haemodialysis patients. Nephrol Dial Transplant 2006;21:3189—3195.
- 23. Vignaroli E, Pace EA, Willey J, et al. The Edmonton Symptom Assessment System as a screening tool for depression and anxiety. J Palliat Med 2006; 9:296–303.
- 24. Anderson F, Downing GM, Hill J, Casorso L, Lerch N. Palliative Performance Scale (PPS): a new tool. J Palliat Care 1996;12:5—11.
- 25. Folstein MF, Folstein S, McHugh PR. "Minimental state": a practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res 1975;12:189–198.
- 26. Crum RM, Anthony JC, Bassett SS, Folstein MF. Population-based norms for the Mini-Mental State Examination by age and educational level. JAMA 1993;269:2386—2391.

- 27. Fainsinger RL, Nekolaichuk CL. A "TNM" classification system for cancer pain: the Edmonton Classification System for Cancer Pain (ECS-CP). Support Care Cancer 2008;16:547–555.
- 28. Gall MD, Gall JP, Borg WR. Educational research: An introduction, 7th ed. Boston, MA: Pearson Education, 2003.
- 29. Cancer Care Ontario. Cancer system quality index: Symptom assessment. Available from http://csqi.cancercare.on.ca/cms/one.aspx?portalId=634 05&pageId=68032. Accessed September 1, 2010.
- 30. Noguera A, Centeno C, Carvajal A, et al. "Are you discouraged? Are you anxious, nervous or uneasy?": in Spanish some words could be better. J Palliat Med 2009;12:707—712.
- 31. Shi Q, Wang XS, Mendoza TR, Pandya KJ, Cleeland CS. Assessing persistent cancer pain: a comparison of current pain ratings and pain recalled from the past week. J Pain Symptom Manage 2009;37:168–174.

Appendix A

Edmonton Symptom Assessment System (current version)

Edmonton Sympton Numerical Scale Regional Palliative C				Syste	m:							
Please circle the i	num	ber th	nat be	est de	escrib	es:						
No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	
Patient's Name												omplete by (check one)
Date				Time	e							Patient Caregiver Caregiver assisted
									BOI	DY D	IAGE	RAM ON REVERSE SIDE

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Capital Health

Appendix B

Edmonton Symptom Assessment System (revised version) (ESAS-r)

Please circle the number that best describes how you feel NOW:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
No tiredness (Tiredness=lack o	0 of ene	1 ergy)	2	3	4	5	6	7	8	9	10	Worst possible tiredness
No drowsiness (Drowsiness=feel	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
(Diowsilless-leei	iriy s	ieepy)									
No nausea	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
No lack of appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible lack of appetite
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
No depression	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
(Depression=feeling sad)												
No anxiety (Anxiety=feeling I	0 nervo	1 us)	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Best well-being (Well-being=how		1 Seel o	2 veral	3	4	5	6	7	8	9	10	Worst possible well-being
(Wen being-new	your	0010	voran	,								
No	0	1	2	3	4	5	6	7	8	9	10	Worst possible
Other problem (fo	or exa	ample	, con	stipa	tion)							
Patient name:												
Date:												
Time:												