

Health care providers' use and knowledge of the Edmonton Symptom Assessment System (ESAS): is there a need to improve information and training?

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Abstract

Objectives The ESAS is a clinical symptom assessment tool developed for patients receiving palliative care for pain and symptom control. Recent studies have indicated that patients have difficulty understanding terminology and correct use of the ESAS, and that they appreciate the presence of a health care provider (HCP) to assist with ESAS completion. As appropriate assessment translates into effective treatment, it is important that HCPs have a good understanding of the tool. The purpose of this study was to assess HCPs' use, knowledge, and training needs of the ESAS.

Methods One hundred ninety-three HCPs in palliative care and chronic pain, who used the ESAS, were invited to participate in a survey.

Results The response rate was 43 % ($n=83$), with 62 % nurses, 26 % physicians, and 12 % other specialties. Most participants were palliative care specialists (79 %). The majority (77 %) had a good understanding of the ESAS terms. Knowledge problems included distinguishing tiredness and drowsiness (25 %), interpreting shortness of breath as a combination of subjective and objective symptoms (19 %), not

indicating current symptom level (14 %), and reverse scoring of well-being (13 %) and appetite (9 %). Reported challenges were misinterpretation of some ESAS terms, assessing patients with impaired communication, and lack of time and reliability of caregiver assessments. Participants offered suggestions regarding how their knowledge and use of the ESAS could be improved.

Conclusions Suggestions for improving ESAS administration and training were to include term definitions and examples of how to ask about terms that might be challenging for patients. Furthermore, initial and ongoing training sessions might help to clarify issues with the tool.

Keywords Health care providers · Edmonton Symptom Assessment System · Training · Palliative care · Symptom management

Introduction

The ESAS is a recognized clinical screening tool used to assess nine symptoms commonly encountered by patients receiving palliative care for pain and symptom management [1, 2]. This tool provides a standard and validated method to quantify the severity of patients' symptoms throughout the trajectory of their disease and its treatment [3]. Although originally developed for use in a palliative care setting, the ESAS is now used in cardiology [4], intensive care units, nephrology [5, 6], hepatology [7], and long-term care [8]. Health care professionals familiar with this tool are able to use the ESAS to identify treatment priorities, evaluate the results of their treatment plan, and make appropriate adjustments.

To yield accurate results from the ESAS, however, HCPs need to understand the terminology and the appropriate use of the tool. Different versions of the ESAS have been used in research studies [9–12]. Recent studies have indicated that

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patients may have difficulty understanding the terminology and correct use of the ESAS [9, 13–15]. Additionally, numerous studies have demonstrated the lack of agreement between HCP assessment of symptoms and patient self-report [13, 16–19]. In one study, patients indicated that the presence of HCPs would help to clarify uncertainties and could contribute to accuracy and efficiency of the ESAS [20]. However, it is uncertain as to whether the patients difficulty understanding the ESAS and its correct usage extends to the HCPs themselves.

The ESAS was originally introduced as a routine assessment tool for clinical and administrative use in the Edmonton Zone Palliative Care Program (EZPCP) [2]. However, at the time of the study, the type of training on the ESAS varied across sites. The extent to which health care providers administering this tool were familiar with its appropriate use and the definitions of the symptoms being assessed was not clear. If HCPs do not adequately understand the tool and its appropriate use, then the information obtained from the ESAS will be less reliable.

The purpose of this study was to assess HCP use, knowledge and training needs with respect to the standardized symptom assessment tool, the ESAS, in palliative care and chronic pain settings. This study was designed to answer the following questions:

1. How do HCPs working in palliative care and chronic pain settings use the ESAS?
2. Which components of the ESAS present specific challenges when administered in clinical practice?
3. What are the HCPs' training needs for appropriate use of the ESAS in clinical practice?

Methods

Sample

A cross-sectional survey design was used for this study. Palliative care and chronic pain HCPs working in the EZPCP and University of Alberta Hospital (UAH) Chronic Pain Clinic, respectively, were invited to participate in a confidential, self-administered survey ($n = 193$). Staff members were eligible to participate if they were familiar with the ESAS and had used it at least once. The sample was limited to HCPs providing services in inpatient settings (hospital, hospice), outpatient clinics, and home consultations.

At the time of the study, the ESAS was used routinely as a standard clinical assessment tool in all EZPCP settings and in the outpatient chronic pain clinic at the UAH. Palliative care HCPs were recruited from the following sites in the EZPCP, using a stratified sampling approach: a 20-bed Tertiary Palliative Care Unit, three Hospice Palliative Care Units, a Community Consultation Team, and three Acute Care Hospital

Palliative Consultation Teams. HCPs working in chronic pain were recruited from the Chronic Pain Clinic, UAH.

Ethics approval was obtained from the Health Ethics Review Board at the University of Alberta and the Alberta Cancer Research Ethics Committee. Administrative approval was also received from the appropriate clinical sites prior to study initiation. Consent was implied if participants returned completed surveys.

Survey design

The ESAS was designed to assess nine common symptoms in advanced cancer patients—pain, nausea, tiredness, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath—with the option of adding a tenth patient-specific symptom. It can be used to screen for the patient's estimation of symptom severity over time, resulting in a longitudinal clinical symptom profile. Ideally, patients complete the ESAS form by themselves. For patients who do not speak or write English, translations into other languages are available. For cognitively or otherwise impaired patients, family or professional caregivers can complete the tool on behalf of the patient. In the EZPCP, an administration manual has been developed to assist caregivers in using the tool in clinical practice [1].

We developed a unique survey for this study, focusing on HCP use, knowledge, and training needs of the ESAS. To develop the questionnaire, we reviewed the literature and obtained feedback from HCPs in the EZPCP to identify reported challenges with using the ESAS. We also considered concerns that were identified by patients in a think aloud study of the ESAS, in which they reported difficulties in interpretation of six of the nine symptoms [20]. The survey consisted of five sections:

- (a) Part 1: Participant background information (4 questions)
- (b) Part 2: ESAS use (4 questions)
- (c) Part 3: ESAS knowledge: interpretation of ESAS terms and ratings (13 questions)
- (d) Part 4: ESAS training needs (3 questions)
- (e) Part 5: General comments (3 questions)

To assess HCP knowledge of the ESAS (Part 3), we examined the following three areas, which had previously been identified as problematic by patients [9, 20]:

1. How did HCPs interpret the potentially problematic ESAS terminology for six symptoms (i.e., tiredness, drowsiness, depression, anxiety, well-being, shortness of breath) in relation to the ESAS administration guidelines?
2. How did HCPs, themselves, score these problematic items?
3. What terms did HCPs use to explain the extreme anchor (“worst possible”) for pain and nausea to patients?

The approximate time to complete the survey was 15 min. A complete copy of the survey is available in the [Appendix](#).

Data collection

Participant recruitment and data collection occurred over a 3-month time period from September to November 2010. Palliative care HCPs were contacted in person and/or via email, using the EZPCP email distribution list. Participants working in chronic pain were contacted in person through the Multi-disciplinary Pain Centre (UAH). The study investigators contacted the unit managers at specific sites to inform them about the study and to ask for their assistance with the survey distribution to their staff. Staff members were also informed about the study through information posters at the work site and site visits by one of the study investigators, who explained the study to staff in person. Staff members who agreed to participate were given either a hard copy or web link of the survey to complete. Paper and pencil surveys were returned by mail to one of the study investigators. A reminder note was sent by e-mail two weeks after the initial survey distribution.

Data analysis

Data were analyzed using descriptive statistics (frequency, means, central tendencies). Open-ended responses were summarized using thematic analysis.

Results

A total of 193 surveys (179 paper and 14 web-based formats) were distributed to staff. Of these, 83 completed surveys were returned, resulting in a response rate of 43 %. A summary of the participant demographics appears in Table 1.

The most frequently reported uses of the tool were to screen for and quantify patient symptoms, direct treatment, and assess treatment success (58 %). Other reported uses included helping to open communication (3.5 %) and for teaching purposes (2 %). More than one third of participants assisted patients with completion of the tool (36 %). Physicians and nurses used the tool most often to direct and assess treatment,

Table 1 Summary of participant characteristics ($n=83$)

		Frequency	Percent
Discipline	Staff physician	11	13.2
	Fellows, residents, students	11	13.2
	Nurses	51	61.4
	Other ^a	10	12.0
Area of specialization	Palliative medicine/palliative care	66	79.2
	Family medicine	5	6.2
	Oncology	4	4.8
	Internal medicine	1	1.2
	Subacute care	2	2.4
	Anaesthesia and pain medicine	3	3.6
	No specialization in palliative care	2	2.4
	Unknown	3	3.75
Experience in palliative care	<1 month	7	8.75
	1 month–1 year	3	3.75
	>1–5 years	30	37.5
	6–10 years	13	16.25
	11–20 years	24	30.0
	Unknown	3	3.75
Time of ESAS use	<2 weeks	6	7.3
	2 weeks up to 1 month	1	1.2
	>1 month up to 6 months	4	4.9
	>6 months	71	86.6
Frequency of ESAS use	Once	4	5.0
	Once a month	8	10.0
	Once a week	14	17.0
	2–3 times a week	23	28.5
	Every day	32	39.5
English knowledge	English as first language	64	77.0

Note: Frequencies by settings: TPCU ($n=21$), UAH ($n=5$), RAH ($n=6$), CCI ($n=14$), regional ($n=10$), hospices ($n=24$), and pain clinic ($n=3$)

^a Others include dietitians, occupational therapists, pharmacists, physiotherapists, respiratory therapists, and spiritual care

whereas nursing attendants and other HCPs assisted patients with the ESAS completion.

ESAS knowledge

To assess HCP knowledge, participants responded to questions relating to three themes: (a) interpretation of problematic terms, (b) symptom scoring, and (c) anchor interpretation. The following describes the key findings related to these themes.

Interpretation of problematic terms

First, we looked at how many different interpretations participants suggested for each term. Depression had the highest number of different interpretations ($n=7$), followed by tiredness ($n=5$), anxiety ($n=4$), shortness of breath ($n=3$), well-being ($n=3$), and drowsiness ($n=2$).

Of the four possible descriptions for depression in the survey, the most frequent response was “sad” (46 %), followed by “feeling blue” (34 %), “exhaustion” (8 %), and “restless” (4 %). Participants also suggested the following additional terms to describe depression: low mood, helplessness, hopelessness, lack of interest, withdrawal, feeling depressed, and weepiness.

As tiredness and drowsiness can potentially be confusing terms, we considered them together. Most participants interpreted these terms according to the ESAS administration guidelines. Some participants (27 %), however, selected sleepy and drowsy for tiredness, and 15 % chose tiredness and exhaustion as descriptions for drowsiness. Participants offered additional descriptions for tiredness, such as fatigue, lethargy, weakness, lack of interest, and low physical activity. For drowsiness, they provided descriptions such as “being unable to keep eyes open” and “being unable to concentrate.”

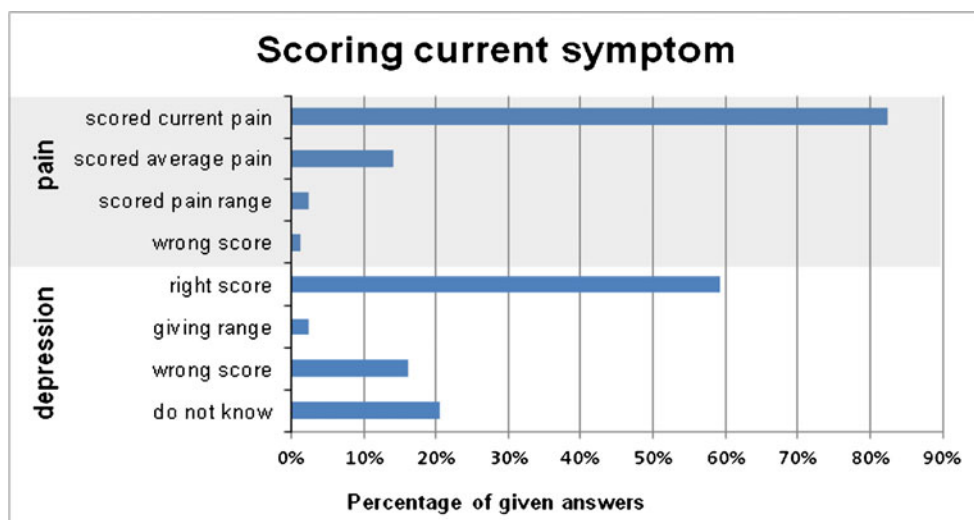
The term, anxiety, was mostly interpreted as restlessness (33 %) and worry (52 %); additional descriptions were nervousness, being unable to concentrate or unable to relax. The term well-being was well understood as overall physical and mental comfort (46 %) and as an honest answer to the question “How are you?” (26 %). In the case of shortness of breath, most participants (81 %) checked inability to catch one’s breath as the correct interpretation. On review, however, some participants (19 %) used it in combination with one of the other objective responses, such as low oxygen saturation, a respiration rate greater than 20 or pain with deep inspiration.

Symptom scoring

Figures 1 and 2 summarize the participants’ scoring for the problematic items of pain, depression, appetite and well-being. The intent of the first question was to determine whether participants were aware that the current pain score should be documented on the ESAS. Most participants (82 %) scored in the intended manner, while 14 % recorded the average pain score and 4 % selected other responses (see Fig. 1). The next two questions focused on whether or not the participants identified the reverse scoring for appetite and well-being. Ninety-one percent of participants selected the correct response of “10” for no appetite and 88 % chose “0” for best feeling of well-being (see Fig. 2).

For the last question, participants were asked to translate an imprecise description of the severity of depression (i.e., “being pretty bad but has been much worse in the past”) into a score from 0 to 10. Participants selected responses of 2, 6, and 9, with 6 and 9 being two possible right answers: most participants (59 %) chose the lower score (i.e., 6), while fewer participants (16 %) chose the higher score (i.e., 9). About 20 % could not decide what to do: 10 % answered “do not know,” and 10 % relied on the patient to come up with a

Fig. 1 Frequencies (%) of scoring for current symptoms, pain and depression



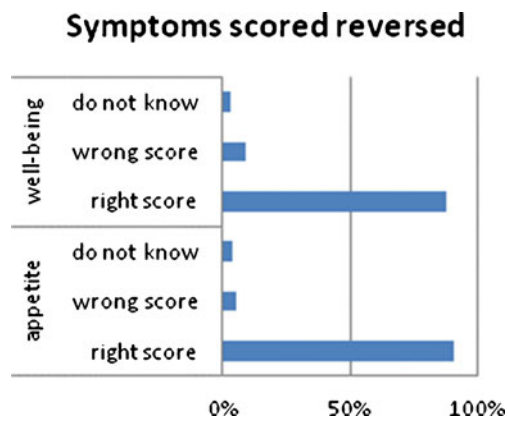


Fig. 2 Frequencies (%) of identification of reverse scoring for well-being and appetite

number. One participant (1 %) offered the range between the two possible scores (i.e., 6 and 9).

Anchor interpretation

Table 2 displays participants' responses to the two questions about how to give explanations about the extreme end-point ("worst possible) for pain and nausea. The highest frequency was for "the worst [symptom] you could imagine" (pain, 66 %; nausea, 48 %).

Challenges and benefits in clinical practice

Participants identified five key benefits in using the ESAS: monitoring symptom severity (62 %), communication tool (26 %), ease of use (2 %), administrative purposes (1 %), and assistance with patient placement for care (1 %). In

Table 2 Frequencies of participants' explanations of extreme anchors for pain and nausea

	Frequency	Percent
Worst possible pain		
The worst pain you could imagine	61	66
Not able to concentrate because of pain	15	16
The worst pain you had in the past	11	12
Do not give specific explanation	3	3
Excruciating amount of pain that would affect whole sense of being	1	1
Brings you to tears	1	1
Horrible	1	1
Worst possible nausea		
The worst nausea you can imagine	41	48
Even the thought of food makes one want throwing up	33	39
Can't keep any food down	12	15
Feeling sick to stomach	2	2
Feeling like throwing up	2	2

addition to the reported gaps in ESAS knowledge, participants reported four key challenges in using the ESAS: misinterpretation of ESAS terms (50 %), difficulties in patients with impaired communication (27 %), lack of time (14 %), and difficulties in rating current symptom level (13 %). Misinterpretation of ESAS terms included difficulties distinguishing between tiredness and drowsiness, reverse scoring of well-being and appetite, and problems translating symptom severity into numbers. In addition to these knowledge issues, other reported challenges were associated with poor reliability of caregiver assessments and lack of understanding regarding the timeframe of assessments (i.e. symptom intensity at time of assessment) (Table 3).

Additionally, participants offered suggestions on how to improve the tool by changing the item order and assisting with the interpretation of numbers. One idea was to change the order of items, by grouping related symptoms: (a) depression, anxiety and well-being, (b) appetite and nausea, and (c) tiredness and drowsiness. For patients having difficulties selecting numbers for their symptoms, one participant suggested asking the patient whether the symptom was mild moderate or severe. Eight participants (9 %) stated that even HCPs might interpret the scores differently.

ESAS training needs

Although most participants reported that they had received adequate training in using the ESAS, some participants ($n = 17$, 20 %) did not believe their training had been sufficient. Training experiences varied, including informal one-on-one training ($n = 54$, 65 %), group training ($n = 32$, 38 %), and written materials ($n = 32$, 38 %). Two participants received training at conferences, while another two acquired personal knowledge through a handbook or observation. A small percentage ($n = 3$, 2 %) reported not receiving any training. Participants offered suggestions for improving their training experiences, including the development of written materials (including information about definitions, examples of how to ask questions, timing of assessments) and the provision of refresher training programs at regularly scheduled intervals, such as yearly.

Discussion

Most HCPs in this study demonstrated an adequate knowledge and appropriate use of the ESAS in clinical practice. Some participants, however, lacked sufficient knowledge in the interpretation of certain symptoms, particularly tiredness, drowsiness, shortness of breath, well-being, and appetite. Reported benefits of the tool mainly related to direct patient care (symptom monitoring, treatment planning, communication); however, the tool was also useful for administrative and

Table 3 Frequencies of benefits and challenges of using the ESAS in clinical practice

Benefits	n	%	Challenges	n	%
Shows changes of perceived symptom severity	78	62%	Misinterpretation of ESAS terms	45	50%
Monitors effects of treatment			Confusion with tiredness and drowsiness		
Points out treatment priorities			Reverse scoring of appetite and wellbeing		
Helps not to miss a symptom			Translating severity of symptom into numbers		
Good tool of communication	33	26%	Difficult in patients with impaired communication	24	27%
Helps to understand symptom system			In delirium, dementia or sedated patients		
			Patients with ALS or tracheotomy		
			Language barrier		
			Lack of reliability of proxy assessments	18	20%
Quick and easy	3	2%	Lack of time to do the ESAS	13	14%
			Difficulty to engage staff to do ESAS when time consuming		
Administrative purposes	1	1%	Rating the current symptom level	11	13%
Helps with patient placement	1	1%			

placement purposes. Reported clinical challenges focused on patient-related factors (patients' misinterpretation of ESAS items, impaired communication) and staff-related factors (time constraints, poor reliability of caregiver assessments; misunderstanding of the timeframe of assessments).

These findings suggest that the interpretation of symptoms is potentially problematic, not only for patients, as previously reported in the literature [9, 20, 21, 23, 24], but also for HCPs. Study participants provided many valid descriptions for explaining symptoms to patients, illustrating the complex multidimensional nature of most symptoms [22]. However, similar to patients' experiences [20], some participants appeared to have more difficulty differentiating between potentially confusing terms, such as tiredness and drowsiness. Although shortness of breath was well understood as a subjective symptom by most participants, about one in five participants interpreted it as a combination of subjective symptoms and objective signs. These findings further validate the need to clarify these terms in the ESAS.

Barriers to implementing the ESAS extend beyond the features of the tool, itself, to staff-related concerns [27–29].

Previously reported concerns from HCPs have focused on four key areas: (a) clinical relevancy [28], (b) misunderstandings regarding appropriate use [15, 29], (c) misinterpretation of high symptom ratings as poor quality of care [15], and (d) attitudinal barriers [15, 28]. Some HCPs have suggested that the tool lacks clinical relevancy if other team members do not refer to the tool when deciding about treatment options [28]. Others have highlighted concerns regarding the lack of understanding regarding the tool's use, particularly with respect to frequency of assessments and the misinterpretation of numerical rating scales [15, 29]. In one study [15], participants reported concerns about high symptom ratings being interpreted as poor quality of care. They did not, however, consider other possible explanations for these high ratings, such as expected changes associated with advancing disease or patient preferences. In some cases, patients may rate their symptoms high, yet also view this as being a preferred or acceptable level of symptom control [25]. Attitudinal issues included viewing routine assessments as "unnatural" or burdensome for patients [15, 28], or preferences to use one's own symptom assessments [29]. These concerns reinforce the need for targeted knowledge translation activities and

educational programs for staff to enhance the uptake and ensure the appropriate use of the ESAS in clinical practice [28].

Unlike these previous studies, clinical relevancy and attitudinal issues were not a concern for participants in this study. Most participants recognized the clinical value of using the ESAS as a brief, easy-to-use tool for symptom monitoring and treatment planning, as well as for communication purposes, not only with patients but also with family members and other HCPs. These findings are reinforced by two previous studies in which HCPs have highlighted the benefits of using the ESAS in clinical practice. In a pilot study implementing the ESAS in hospice settings, HCPs [15] valued the ESAS for its brevity, practicality for identifying patient care issues, engagement of patients in symptom assessment and use as a teaching tool. A second study revealed that use of the ESAS led to improvements in patient care [29]. The clinical relevancy of the ESAS is further supported by a recent review of clinical instruments for hospice and palliative care [30]. Out of 129 instruments, the ESAS scored above the 75th percentile, receiving one of the highest scores in terms of psychometric soundness and potential application in clinical quality measurement. In a second review comparing fourteen cancer symptom assessment instruments, the ESAS was among the three tools nearest to an ideal assessment instrument [26].

Despite these substantive endorsements, there are inherent problems with how the ESAS has been used. To address some of the issues associated with the tool itself, our research group has undertaken a series of studies to review the current status of the ESAS, identify problematic areas associated with its use in clinical practice and develop a revised version, the ESAS-r [12, 14, 20, 31]. This revised version was based on a patient “think aloud” study, in which 20 patients were asked to provide their clinical reasoning regarding the ratings they selected while completing the ESAS, as well as their personal opinions regarding the tool [20]. A comparison study of the original ESAS and the ESAS-r, involving 160 patients, provided additional support for the proposed changes [31]. However, these changes were based on patient input only. The findings from this study provide further support for using the ESAS-r in clinical practice, by focusing on HCP perceptions. In 2011, after this study was completed, the ESAS-r was introduced into the EZPCP, in place of the ESAS. The revised form included definitions of potentially confusing terms, specified a timeframe of “now,” changed the order of the terms and added an example for “other symptom.”

The main limitation of this study was that it was conducted within a single palliative care program where the ESAS and more recently, the ESAS-r, have been well-integrated over multiple sites and years. The historical use of the ESAS in this program, spanning 20 years, may have influenced the findings. However, only 30 % of respondents had more than 10 years of palliative care experience. A second limitation is the potential selection bias of the participants, as we were

unable to assess the demographics and perceptions of non-responders.

Implications for training and education

Participants identified both process and content needs for better initial training and follow-up educational activities. To ensure appropriate use of the tool in practice, the following recommendations are being proposed:

1. The clinical relevancy of the tool, including its use as a communication tool within and across settings, needs to be emphasized and illustrated in all training activities.
2. Training programs need to be easy to access and user-friendly, with the availability of multiple educational formats and modalities, including case presentations, formal teaching rounds and web-based programs.
3. The administration manual could be further developed to include case studies, frequently asked questions and supporting research, with a companion “quick user guide.”
4. Initial introductory training should be offered for all new staff. Regular repeated training sessions need to be developed to review specific problems and address complex cases.
5. Program content should include information on symptom assessment in general, as well as the application of the tool in clinical practice. The following topics could be included:
 - a. Symptom complexity in palliative care, such as pain expression in delirium (cognitive impairment), other symptoms affecting a patient’s pain expression (e.g., depression, anxiety), language, and/or physical barriers (weakness, paralysis).
 - b. Challenges of symptom assessment: patient’s perspectives
 - i. Patients’ difficulty in transferring symptom severity perception into a specific number
 - ii. Reasons for under and over reporting of symptoms
 - c. Challenges of symptom assessment: HCPs perspective
 - d. Appropriate use of the ESAS/ESAS-r
 - i. Review of terminology
 - ii. Clarity regarding patient-reported time frame
 - iii. Specific knowledge based questions (see [Appendix](#) for examples)

The ESAS, and its successor, the ESAS-r, were developed as a symptom screening tool. Ideally, this tool needs to be

integrated within an in-depth clinical interview process that focuses on a holistic approach to support patients and their families at end of life. To successfully implement this tool in practice, it needs to be adopted at a program level, with input from clinical staff at all stages of the implementation process, supplemented by ongoing training and educational activities.

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Conflict of interest The authors have no conflict of interest to declare. The authors have full control of all primary data and agree to allow the journal to review their data if requested.

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