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Edmonton Symptom Assessment System – Revised (ESAS-r)

Administration Manual

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1. Introduction

The Edmonton Symptom Assessment System – Revised (ESAS-r) Administration Manual was developed to provide a guiding framework for the use of the ESAS-r. Through further refinement, we hope that this manual will ultimately facilitate the consistent and psychometrically sound use of this instrument. This manual consists of three key sections: (1) Background, (2) Edmonton Symptom Assessment System – Revised, and (3) Frequently Asked Questions (FAQs). The first section provides foundational information for the development of the original Edmonton Symptom



Assessment System. The second section describes the subsequent development of the Edmonton Symptom Assessment System – Revised (ESAS-r) and process for completing the instrument. The final section consists of examples of frequently asked questions to further clarify the administration and use of the ESAS-r.

2. Background Information

2.1 Development of the Edmonton Symptom Assessment System

One out of every four Canadians will die from cancer, with an estimated 80,800 cancer deaths occurring in Canada in 2017 [1]. Prior to death, many advanced cancer patients experience significant symptom burden. Patients within three months of death are two to four times more likely to report moderate to severe symptoms than patients earlier in the cancer trajectory [2]. Approximately 60% to 80% of patients will experience pain before death [3]. Other debilitating symptoms, including anorexia, nausea, asthenia, dyspnea and delirium, occur with similar or higher frequencies [4-6]. Psychological distress, such as depression or anxiety, is often associated with these debilitating symptoms [7-12]. Up to 30% of patients will experience an adjustment disorder [11], while 10% to 20% will develop a major depressive episode [9]. Despite this substantive symptom burden, advanced cancer patients' quality of life may be enhanced through appropriate symptom assessment and management [13].

The need for routine symptom assessments in advanced cancer was well recognized over twenty-five years ago, when Bruera and colleagues [14] developed the Edmonton Symptom Assessment System (ESAS). Although there are many cancer symptom assessment tools [15], the ESAS continues to dominate the symptom assessment field in advanced cancer and palliative care. It is brief, comprehensive and practical; relevant to palliative care; and entails minimum patient burden, which is particularly important for patients at end of life. The ESAS is used in palliative care and oncology programs throughout Canada [16, 17]. As of April 2017, cancer centres in eight out of ten provinces have implemented the ESAS-r for routine screening of symptom distress; in Ontario and Quebec, the ESAS-r is collected electronically by direct patient entry; in other provinces, the information is collected on paper only, or on paper with subsequent electronic entry. In a bibliometric analysis of the ESAS [20], 311 unique documents, published between 1991 and 2006, directly cited or made an uncited reference to the original paper. Since its inception, it is used extensively for clinical, research and administrative purposes [16, 21-25].

The substantive symptom burden in advanced cancer, with escalating symptom frequency and severity as patients approach death, challenges the palliative care community to develop systematic symptom assessment approaches as the first critical step to appropriate symptom management. Although this is a well-recognized need [26,

27], there is no universally accepted symptom assessment tool in advanced cancer and palliative care. The multidimensionality of symptoms; fluctuating, unpredictable course; subjective nature of the symptom experience; and frailty associated with advancing disease create significant challenges [26, 28]. To address these unique challenges of this vulnerable population, a symptom assessment tool needs to be comprehensive, dynamic, able to capture patients' subjective experiences and psychometrically sound, while still being practical and brief, with minimal patient burden.

The complexities of symptom assessment are reflected in the diversity of symptom assessment tools. In a systematic review of cancer symptom assessment instruments, Kirkova et al. [15] identified 21 instruments, with 15 of the 21 assessing multiple (five or more) symptoms. These 15 measures varied in terms of content (ranging from 9 to 65 items), scale format (numerical, categorical, visual analog), symptom dimensions (prevalence, severity, distress, frequency, interference), time frame (ranging from “at present time” to “weeks”) and assessor (patient, caregiver, family member). A conceptual overlap between symptom assessment and quality of life, particularly health-related quality of life [29], adds to this diversity. In a systematic review of quality of life measures in palliative care, Albers et al. [30] evaluated 29 instruments. Six instruments, including the ESAS, were included in this study, as well as Kirkova et al.'s [15] systematic review. In both studies, the authors could not recommend an “ideal” or single specific instrument (see Appendix A, Table A-1 for comparison of measures).

Although there may not be an ideal instrument, there are some pivotal reasons as to why the ESAS has had such a significant widespread uptake [20]. The ESAS [14] is a comprehensive, yet brief and practical self-reporting tool of symptom severity (intensity) for 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. The original version used visual analog scales, ranging from 0 (no symptom) to 100 mm (worst possible symptom), which have subsequently been changed to 11-point numerical rating scales, with higher scores representing worse symptom intensity [31]. A unique feature of the ESAS, which is not a component of other symptom assessment tools, is the ability to capture the fluctuation of symptoms over time, through the use of a graphing system (see Appendix A, Figure A-1.). Unlike some instruments that were developed in different contexts and then applied to palliative care (e.g. Symptom Distress Scale), the original ESAS was expert-derived and based on clinical experiences of caring for advanced cancer and palliative care patients.

No single tool will ever be able to capture the extensive complexities of symptom assessment in advanced cancer and palliative care patients [15, 32]. There will always be a trade-off between comprehensiveness and practicality. The ESAS was developed as a symptom screening tool, which ideally needs to be integrated within an in-depth clinical interview process. Its focus on a single dimension of symptom assessment (i.e. severity) with nine common symptoms is a compelling feature, in comparison with other more burdensome tools that are longer and combine different symptom assessment dimensions, such as intensity, distress and frequency. Kirkova et al. [28] recommend starting with a single dimension, such as severity or distress, which provides decision making information and can subsequently lead into a more in-depth assessment. They also suggest that the concomitant use of similar but separate scales (for severity and distress) can be confusing and an increased burden for patients. Health care providers value the ESAS for its brevity, practicality for identifying patient care issues, engagement of patients in symptom assessment and use as a teaching tool [24]. In a recent review of clinical instruments for hospice and palliative care [33], out of 129 instruments, the ESAS scored above the 75th percentile, receiving one of the highest scores (16/19) in terms of psychometric soundness and potential application in clinical quality measurement.

Reported barriers to implementing the ESAS extend beyond the features of the tool, itself, to concerns regarding implementation and relevancy in clinical practice. These include, but are not limited to, the lack of understanding regarding frequency of assessments, interpretation of the numerical rating scales and incorporation of patient preferences for symptom relief [24, 34]. In one study [24], participants reported concerns about high symptom ratings being interpreted as poor quality of care, as opposed to patients' preferences or expected changes associated with advancing disease. Attitudinal issues, such as viewing routine assessments as "unnatural" [24] or preferences to use own symptom assessments [34], reflect the limited knowledge translation activities associated with the ESAS dissemination. In our ESAS survey of palliative care and pain specialists [35], participants identified the need for better initial training and follow-up educational activities, to ensure its proper use in practice. This concern is being addressed in one of our group's studies, through the development of knowledge translation strategies.

Despite this substantive endorsement of the ESAS, there are inherent problems associated with how the tool is currently being used. 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. Based on this work, we have identified three key challenges with the rapid widespread uptake and current clinical use of the ESAS: (1) Extensive modifications made to the ESAS with little if any validity evidence to support these changes; (2) Problematic items that could lead to misinterpretation; and (3) Potential perception of the ESAS as a well validated tool with no further need to do validation studies.

Since its inception, the ESAS has undergone a variety of modifications, with little, if any, validity evidence to support these changes. Based on our literature review [36], we identified 13 validation studies published between 1991 and 2006. An update of this review (1991-2010), with seven additional psychometric studies published since 2007, appears in Table A-2 (see Appendix A). Sixteen studies used an English version, while four studies used a French [37], Italian [38], Spanish [39] or Turkish [40] translation. Of the 16 English studies, we identified eight different versions of the ESAS. Sources of variability included scale format, number of items, scale anchors, types of symptoms assessed and symptom order. In one study, symptoms were assessed over a 24 hour time period, as opposed to time of assessment, as originally intended [41]. Some studies collapsed continuous responses into categorical variables. A number of studies used a total symptom distress score as a measure of overall symptom burden, while other studies focused on independent symptoms. In some cases, modifications were made without direct reference in the text, resulting in potential misinterpretation of findings and inability to make cross study comparisons. There is no other tool that we are aware of that has undergone such profound changes without any supportive validity evidence.

Although the ESAS was designed for self-reporting, concerns have been raised about the potential for symptom reporting errors. In a nursing survey in the Edmonton Zone Palliative Care Program (EZPCP), only 14 of 48 staff (29%) agreed with the statement “The ESAS is easy for patients to understand” [42]. The two most frequent comments were patients’ difficulty in understanding the term, wellbeing, and confusion of tiredness and drowsiness. Garyali et al. identified potential errors in patient self-reports using the ESAS, including reverse scoring for sleep and appetite, inconsistent time frames for pain ratings and low specificities for fatigue, drowsiness, appetite and sleep [41]. In our think aloud study with 20 advanced cancer patients [43], problematic characteristics included confusing terminology (drowsiness vs. tiredness, depression, anxiety, wellbeing), reverse scoring for wellbeing and appetite, lack of coherent item order,

unclear time frame and need to include additional symptoms. Many of these concerns were confirmed in a replication think aloud study involving 11 Norwegian advanced cancer inpatients [44], as well as a survey of 84 health care providers working in palliative care and chronic pain [35].

Validity evidence has lagged behind the rapid, widespread uptake of the ESAS. In our initial literature review of validation studies (1991-2006) [36], 10 of the 13 identified studies were published eight or more years after the initial ESAS publication in 1991. Table A-3 summarizes the psychometric evidence for the ESAS, based on our literature review [36], plus seven additional psychometric studies published between 2007 and 2010 (see Appendix A). None of the earlier studies published between 1991 and 2006 addressed any of these concerns about problematic items, yet these references are often cited in the literature as supporting the ESAS as being a well-validated tool. Although this earlier work was foundational, a standardized version that addresses these concerns needs to be validated further, using more heterogeneous advanced cancer patients in both inpatient and outpatient settings.

3. Edmonton Symptom Assessment System – Revised

3.1 Development of the Edmonton Symptom Assessment System – Revised

Based on the concerns raised in the literature [41], the findings of our think aloud study [43] and our literature review of validation studies [36], a revised version of the ESAS, the ESAS-r (see section 3.3, page 9), was created. The ESAS-r retains the core elements of the ESAS, with key revisions as follows:

- The timeframe for symptom ratings is specified as “now”.
- Brief definitions have been added for the following symptoms: tiredness (lack of energy), drowsiness (feeling sleepy), depression (feeling sad), anxiety (feeling nervous) and wellbeing (how you feel overall). “Appetite” has been changed to “lack of appetite”.
- Related symptoms (e.g. tiredness and drowsiness; nausea and appetite; depression and anxiety) are grouped together, and “wellbeing” is now the ninth symptom at the end of the instrument.
- The example of “constipation” has been added to the tenth scale, “other symptom.”

In our multicentre study comparing the ESAS and ESAS-r in 160 palliative care patients [31], the ESAS-r was significantly easier to understand ($p=.008$) and preferred

($p < 0.001$) than the ESAS. Further validity evidence supports the adoption of the ESAS-r (see Appendix B).

3.2 Guidelines for Completion of the ESAS-r

(see Appendix C for ESAS-r Clinical Assessment Guide)

What is the ESAS-r?

The ESAS-r helps to assess nine common symptoms in palliative care patients. The ESAS-r is one valuable part of a holistic clinical assessment. It is not a complete assessment in itself.

Why?

The goal of this tool is to retrieve the patient's perspective of symptoms. It helps to direct treatment and to assess for treatment effects.

How?

The patient should be instructed to rate the severity of each symptom on a 0 to 10 scale, where 0 represents absence (or best possible intensity) of the symptom and 10 represents the worst possible severity. The number should be circled on the scale. The circled numbers can be transcribed onto the ESAS-r graph. The patient should be instructed to rate each symptom according to how s/he feels now. The health care professional may choose to ask additional questions about the severity of symptoms at other time points (e.g. symptom severity at best and at worst over the past 24 hours).

When?

The ESAS-r captures the pattern of symptom severity at a point in time. Repeating the assessment will track the changes over time. It is a good practice to do the ESAS-r at an initial encounter with the patient and during each follow-up telephone or personal contact.

Who?

It is preferable that the patient provides self-ratings of symptom severity. If the patient cannot complete the tool independently but can still provide input, then the ESAS-r is completed with the assistance of a caregiver (a family member, friend, health care professional).

Where?

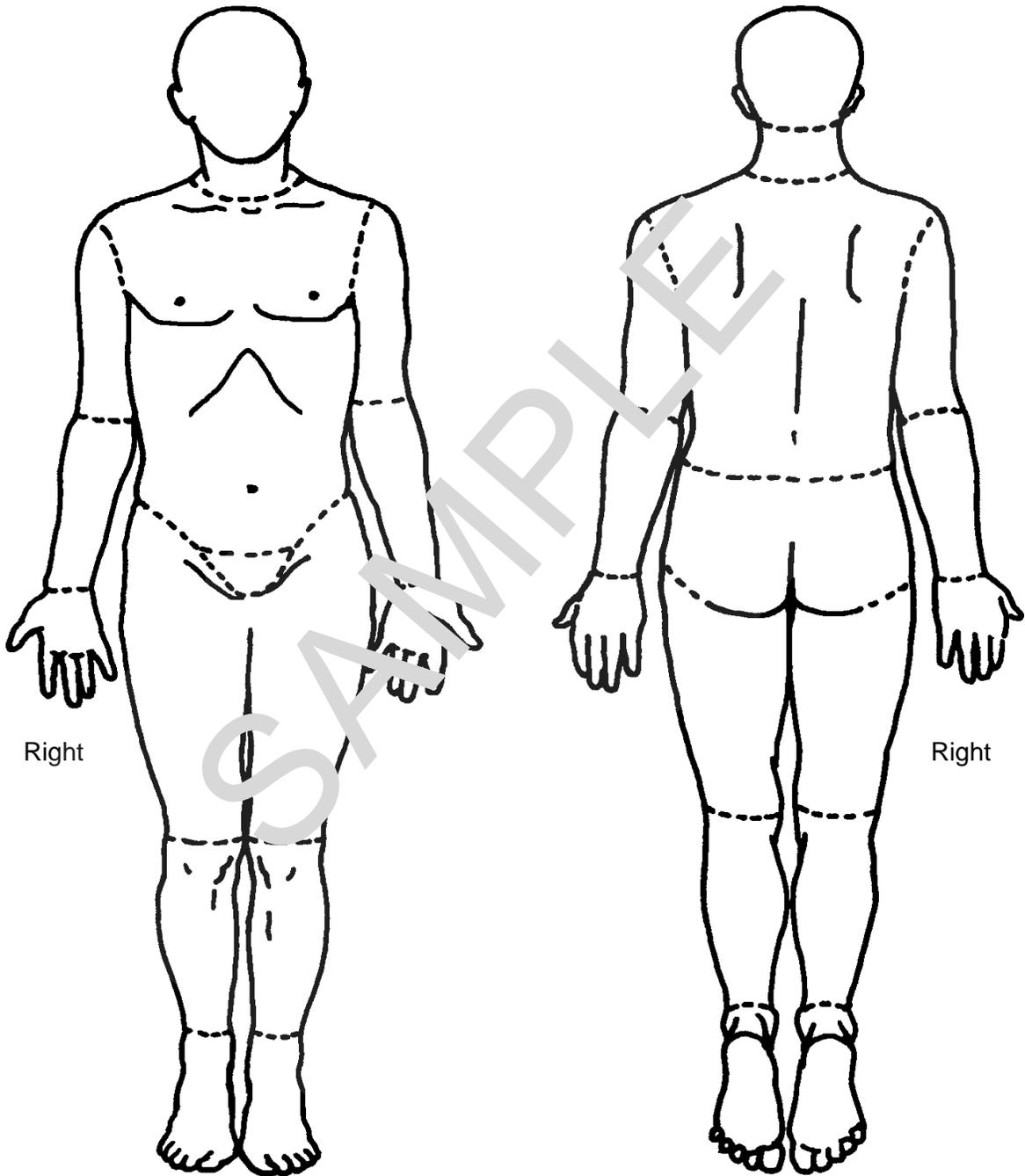
The ESAS-r is used in any setting where palliative care patients are assessed and cared for.

3.3 Sample of the ESAS-r (front and back sides)

A copy of the tool for use can be found at: <https://www.albertahealthservices.ca/frm-07903.pdf>

 	
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 <i>(Tiredness = lack of energy)</i>	0 1 2 3 4 5 6 7 8 9 10 Worst Possible Tiredness
No Drowsiness <i>(Drowsiness = feeling sleepy)</i>	0 1 2 3 4 5 6 7 8 9 10 Worst Possible Drowsiness
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 <i>(Depression = feeling down)</i>	0 1 2 3 4 5 6 7 8 9 10 Worst Possible Depression
No Anxiety <i>(Anxiety = feeling nervous)</i>	0 1 2 3 4 5 6 7 8 9 10 Worst Possible Anxiety
Best Wellbeing <i>(Wellbeing = how you feel overall)</i>	0 1 2 3 4 5 6 7 8 9 10 Worst Possible Wellbeing
No _____ Other Problem <i>(for example constipation)</i>	0 1 2 3 4 5 6 7 8 9 10 Worst Possible _____
Patient's Name _____ Date _____ Time _____	Completed by (check one): <input type="checkbox"/> Patient <input type="checkbox"/> Family caregiver <input type="checkbox"/> Health care professional caregiver <input type="checkbox"/> Caregiver-assisted
ESAS-r Revised: November 2010	
BODY DIAGRAM ON REVERSE SIDE	

Please mark on these pictures where it is that you hurt:



4. Frequently Asked Questions (FAQ)

4.1 Should there be a set time to do the ESAS-r (AM/PM)? Should there be a set frequency for completing the ESAS-r (daily/weekly)?

Each site should decide what time of day is best to administer the ESAS-r. Factors that need to be considered include the following: frequency of clinic appointments, time of day of patients' arrival, patient's cognition and stamina/energy level throughout the day. The frequency with which the ESAS-r should be completed depends on what type of site is administering it. For example, in the Edmonton Zone Palliative Care Program (EZPCP), the Tertiary Palliative Care Unit administers the ESAS-r every day, since the patients have been admitted for intensive symptom management. On the other hand, the University of Alberta Hospital consultation team administers the tool at initial consult with the physicians/nurse consultants, and thereafter when a re-assessment is needed. If symptoms are under good control, then it can be done weekly instead of daily to decrease patient burden. Please see Table A-4 (Appendix A) for a summary of administration processes across the EZPCP sites.

4.2 What are some of the benefits associated with using the ESAS/ESAS-r?

There are many benefits associated with using the ESAS-r:

- ✓ Health care professionals may view the trends of symptoms over time.
- ✓ Health care professionals can obtain a number that reflects how a patient is feeling at the time of the assessment and determine how to best help the patient.
- ✓ The standardized use of the ESAS-r creates consistency among staff members.
- ✓ The ESAS [24]/ESAS-r is brief and easy to use.
- ✓ The ESAS [24]/ESAS-r engages patients in their overall care.
- ✓ The routine use of a symptom assessment tool helps staff care for their patients and their patients benefit from its use [ESAS, 42]

4.3 What are some of the challenges associated with using the ESAS/ESAS-r?

There are some challenges associated with using the ESAS/ESAS-r:

- Some patients decline or are unable to give a specific numerical rating [ESAS, 42].
- There are translation or language issues [ESAS, 24].
- For some staff, it may be "unnatural to use pen and paper," as these assessments are usually done informally [ESAS, 24].

4.4 What kind of training would be best for your site?

There are many ways that staff may learn about the ESAS-r. Some approaches suggested by the EZPCP staff include:

- Group sessions
- One on one sessions
- Webinars
- Shadowing staff who are skilled in using the tool
- Written information distributed in staff mail boxes
- Case scenarios (e.g on website)
- Online module (e.g. My Learning Link in Alberta Health Services)

4.5 What is the best way to teach the ESAS-r?

In the EZPCP, one way to educate staff about the ESAS-r would be through a health care professional from each site who receives extensive training and returns to his/her home site to train other staff members. Other methods could be a designated trainer (such as a Clinical Nurse Educator/Nurse Practitioner) who travels to each site to teach.

4.6 Who should be completing the ESAS-r?

Ideally, the patient should fill out the ESAS-r on his/her own to reflect his/her experience. When the patient is unable to complete the tool independently, a health care professional may score the ESAS-r, but it should be noted on the form that it was completed by a healthcare professional, rather than the patient.

4.7 What other information of interest could be added to the assessment?

Additional information of interest could include:

- Noting if rating is before or after an intervention
- Noting the best rating and worst rating in the past 24 hours
- Noting if the symptom only occurs with certain triggers

4.8 Which staff member should be in charge of administering the ESAS-r?

This question is site specific. In the EZPCP hospices, the health care aides mainly administer the form, while on the Royal Alexandra Hospital consultation team and the Community Consult Team, the physician and nursing staff administer the ESAS-r. Please refer to Table A-4 for more information on each site.

4.9 How can health care professionals get the most meaningful rating when patients are not able to fill out the ESAS-r on their own (caregivers such as family members or health care professionals rate for the patient)?

Family and health care professionals can each complete the ESAS-r and their corresponding answers can be compared.

4.10 What protocol can be taken to complete the ESAS-r if the patient is in isolation?

The Alberta Health Services (AHS) isolation policy does not address precautions for the use of paper specifically, but in principle, items should not be transferred from the patient room to other care areas.

4.11 What do you do when a patient provides more than one score for a single symptom on the ESAS-r?

If a patient gives more than one score while rating a symptom, then try to get clarification first. If the patient is still not able to provide a single number, the general rule is to take the score that is the worst. That score can then be graphed and compared over time.

4.12 What can you do when a patient is unable to give a numerical rating on the ESAS-r?

If you are completing the tool by pen and paper, then explain to the patient that it is very important that you get a numerical rating. This information is used to compare the trend of the numbers over a period of time. This can help with symptom interventions that ensure patients receive optimal care. It is a good idea to ask them if they need any clarification of the symptoms so that they can give a numerical rating. You may also ask them how a rating from the day in question would compare to an earlier day for which the patients actually gave a rating.

4.13 What rating should we record when a patient and family member disagree on a score given on the ESAS-r?

The patient and family member may disagree on a symptom rating. They may decide to discuss it and come to an answer together that they can report to you. If this is not possible, then the rating should be taken from the patient. If the patient has been filling out the form on a regular basis and there is some trending that could be shown, then the patient can be asked if the symptom was better or worse relative to each time point. Ideally, it would be interesting to report both ratings to better understand the reasons for the disagreement. This may not be practical with the current system, but would be of interest as part of the clinical assessment.

4.14 How can I ask about sensitive symptoms (depression, anxiety, wellbeing)?

It is best to ask the more sensitive questions later on in an interview so a patient does not close off the conversation. All the psychosocial symptoms have been grouped together at the end of the tool to assist with this.

4.15 How can I explain the importance of doing the ESAS-r to patients?

It is important to explain the significance of repeatedly completing the ESAS-r to patients. The main reason is that the tracking of symptoms provides a readily accessible visual representation of the patient's symptom profile over time.

We endeavor to provide the best patient care in a timely manner by capturing symptoms as they arise and avoiding a symptom crisis.

“Did you know....?”

Did you know that if you help a patient record his/her score on the ESAS-r, you should check off completed by the “patient” not “caregiver assisted”?

Did you know that it is important to bring up other symptoms of interest to rate that you may notice the patient having (e.g. coughing)?

Did you know that you do not need to have the patient complete the diagram on the back side of the ESAS-r every time you administer the form (only when a symptom location may change)?

Did you know that electronically administering the ESAS-r may speed up the process of completion?

Did you know that you may learn about the ESAS-r and how it is used in this manual, through our study staff and through the website <https://www.albertahealthservices.ca/info/Page14546.aspx> (47)?

4.16 For what disease populations can the ESAS-r be used?

Originally, the ESAS was developed to capture symptoms in advanced cancer patients. Over time, its use has expanded to patients earlier in the cancer trajectory (see Table A-5, Appendix A) and with non-cancer diagnoses, such as nephrology (ESAS-r-RD) [54,55], chronic obstructive pulmonary disease [64,65], hepatology, heart failure [64-66], dementia [63] and Parkinson's disease (ESAS-r-PD) [67]. It has also been used in non-cancer settings, such as intensive care and long term care.

4.17 What is the minimal clinically important difference (MCID) in scores for the ESAS/ESAS-r?

A difference of two points on an 11-point (0-10) numerical rating scale or a 30% decrease in pain intensity has generally been recognized as being a minimum clinically important difference (MCID) for pain [61]. In one study of 276 advanced cancer patients receiving palliative radiation therapy who completed the ESAS, the MCID for clinical improvement was 1.1 (depression) and 1.2 (pain), while the MCID for deterioration ranged from 1.1 (depression, anxiety) to 1.8 (tiredness) [62]. In an international multicenter study including 796 advanced cancer patients, the optimal cutoff was ≥ 1 point for improvement and ≤ -1 point for deterioration for all symptoms, based on receiver-operating characteristic curves (68) Since these studies were conducted using the ESAS, further studies using the ESAS-r are warranted.

4.18 Are there copyright issues with using the ESAS-r?

The ESAS-r is in the public domain and freely available for use with appropriate acknowledgement of its source
<https://www.albertahealthservices.ca/info/page14546.aspx>

There is, however, a requesters’ permission form to be completed so its use can be tracked.

4.19 Where can all the translations of the ESAS-r be found?

Other translations of the ESAS-r (and ESAS) are available on the Cancer Care Ontario website. The languages included are:

Disclaimer: These tools have not been validated by AHS, nor the principal investigators. They are also not translations of the current version found in this manual.

Albanian	Italian
Algonquin	Japanese
Arabic	Korean
Armenian	Oji Cree
Burmese	Polish
Chinese	Portuguese
Cree	Punjabi
English	Russian
Estonian	Serbo/Croatian
Farsi	Somali
Finnish	Spanish
French	Tagalog
German	Tamil
Greek	Turkish
Hindi	Ukrainian
Hungarian	Urdu
Inuktitut (Eastern Arctic Dialect)	Vietnamese

<https://www.cancercareontario.ca/en/guidelines-advice/symptom-side-effect-management/symptom-assessment-tool>) [48]

4.20 How do we indicate who completed the ESAS-r?

The ESAS-r may be completed by any of the following individuals, depending on the patient's ability to independently provide self-reported symptoms:

- Patient
- Family Caregiver
- Health Care Professional Caregiver
- Caregiver Assisted

Please tick the appropriate box at the bottom of the ESAS-r form.

5. Summary

Canadians are living longer, with more complex conditions, necessitating the need for appropriate and timely access to palliative care services [45]. With our aging population and co-existence of multiple chronic illnesses, many people at the end of life will experience increased symptom burden and would benefit from systematic palliative care assessment and management approaches.

The ESAS-r [31] is a practical and concise screening tool for assessing symptom burden. It offers distinct advantages over the ESAS, while still retaining core elements of the original tool. The inclusion of definitions, reordering of items and clarification regarding time frame will reduce potential patient errors in tool completion and for self-report distress screening programs, such as electronic kiosks or the internet [18], where patients do not have immediate access to a health care professional. These definitions can also be helpful for training new staff in administering the ESAS-r and for ensuring consistency across clinicians in terms of explanations of symptoms.

At the present time, we believe that the ESAS-r offers the best systematic approach for assessing symptoms in patients receiving palliative care. The ESAS-r enhances clinical assessment, enables physicians and the inter-disciplinary team to appropriately manage patients' symptoms, and facilitates better allocation of resources. Further, this system can enable researchers to compare results of outcome surveys and clinical trials in palliative care cancer symptom management.

Our research group has conducted a series of studies for gathering validity evidence for the ESAS and ESAS-r (see Appendix B). Gathering further validity evidence for the ESAS-r will enhance its use in clinical practice, research and administrative settings. Ultimately, these proposed changes will reduce errors in symptom reporting, improve symptom assessment and strengthen its adoption as a standardized symptom assessment and distress screening tool in cancer patients in Canada, with future developments in aging, non-cancer and non-English speaking populations.

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Appendix A: Tables and Figures

Table A-1. Comparison of Symptom Assessment Measures for Cancer and Palliative Patients

Instrument	Item No.	Scale	Dimensions					Assessor		
			Presence	Severity	Distress	Freq	Interfere	Self	Assist	Caregiver
ESAS	9	NRS (0-10)		✓				✓	✓	✓
CAMPUS-R	10	VAS	✓	✓			✓	✓	✓	
CSS	12	NRS (0-10)	✓		✓			✓		
CSAI	20	LASA (1-15)	✓		✓			✓		
MDASI	19	NRS (0-10)	✓	✓			✓	✓		
MSAS	32	4&5-pt Likert	✓	✓	✓	✓		✓		
MSAS-SF	32	4&5-pt	✓		✓	✓		✓		
CMSAS	14	4&5-pt	✓	✓	✓			✓		
OTTAT	37	5-pt Likert		✓		✓		✓		
POMS	65	5-pt adj Rating						✓		
PSAR	9	NRS	✓	✓						✓
RSCL	30	4-pt Likert		✓				✓		
Reduced E-STAS	12	5-pt Likert	✓	✓	✓	✓				✓
SDS	13	5-pt			✓			✓		
SES	14	Yes/no	✓					✓		
Symptom Monitor	10	NRS (0-10)	✓	✓	✓			✓	✓	✓

Adapted from Kirkova et al [15] & Albers et al [37]-Abbreviations: ESAS, Edmonton Symptom Assessment System; CAMPUS-R, Cambridge Palliative Assessment Schedule; CSS, The Canberra Symptom Score Card; CSAI, Computerized Symptom Assessment Instrument; MDASI, M. D. Anderson Symptom Assessment Inventory; MSAS, Memorial Symptom Assessment Scale; MSAS-SF, Memorial Symptom Assessment Scale-Short Form; CMSAS, Condensed Memorial Symptom Assessment Scale; OTTAT, Oncology Treatment Toxicity Assessment Tool; POMS, Profile of Mood States; PSAR, Pain and Symptom Assessment Record; RSCL, Rotterdam Symptom Checklist; Reduced E-STAS, Reduced Extended Support Team Assessment Schedule; SDS, Symptom Distress Scale; SES, The Symptom Experience Scale; NRS, numerical rating scale; VAS, visual analog scale

Table A-2. Summary of ESAS Modifications (1991-2010)

First Author	Items	Language	ESAS Modifications
Visual Analog Scale			
Bruera [14]	8	English	8-item version used for descriptive study; 9 item version (including shortness of breath) plus "empty VAS" item (other symptoms) also described
Bruera [14], Philip [48], Nekolaichuk [49,50], Chang [51]	9	English	None
Stromgren [52]	9	unspecified	Not administered to patients
Visual Analog Scale/Numerical Rating Scale			
Pautex [36]	9	French	Replaced tiredness with weakness, added pain relief question at the end
Davison [53,54]	10	English	Modified anchor (worst possible to severe), additional symptom (pruritus).
Numerical Rating Scale			
Noguera [38]	6	Spanish	6-item scale limited to two symptoms (depression and anxiety) with 3 different descriptors per symptom; included 3 other questions regarding anorexia, fatigue, difficulty sleeping
Watanabe [42], Selby [55], Gill [56]	9	English	None
Moro [37]	9	Italian	None
Yesilbalkan [39]	9	Turkish	None
Garyali [40]	10	English	Replaced tiredness with fatigue, additional item for sleep, different order (wellbeing at end), modified anchor (worst possible o worst imaginable), symptom ratings over past 24 hours (vs. "now")
Vignaroli [57]	10	English	Replaced tiredness with fatigue, wellbeing moved to end, main focus on depression & anxiety
Bush [58]	10	English	Additional item for sleep; wellbeing moved to end
Easson [59]	11	English	Additional items for abdominal discomfort/bloating and mobility (i.e. able to move normally)

Table A-3. Summary of Psychometric Evidence for the ESAS (1991-2010)

Year	First Author	Validity Evidence	Reliability
1991	Bruera [14]	Description of instrument	----
1993	Bruera [14]	Concurrent validity	Test-retest (1 hour)
1998	Philip [48]	Concurrent validity	----
1999a	Nekolaichuk [49]	----	Inter-rater
1999b	Nekolaichuk [50]	----	Inter-rater (raters by occasions)
2000	Chang [51]	Concurrent validity	Test-retest (1 day, 1 week) Internal consistency (Cronbach's α)
2002	Stromgren [52]	Content validity	----
2003	Pautex [36]	----	Inter-rater reliability
2006a	Davison [53]	Concurrent validity	Test-retest (1 week)
2006b	Davison [54]	Predictive validity	----
2006	Garyali [40]	Sensitivity & Specificity	Test-retest (same day)
2006	Moro [37]	Concurrent validity Sensitivity, Responsiveness	Test-retest (1 day)
2006	Vignaroli [57]	Concurrent validity Sensitivity & Specificity	----
2007	Easson [59]	Content validity, Responsiveness	Internal consistency (Cronbach's α) ^a
2008	Yesilbalkan [39]	Concurrent validity ^b	Internal consistency (Cronbach's α)
2009	Watanabe [42]	Construct validity	----
2009	Noguera [38]	Concurrent validity Sensitivity & Specificity	----
2010	Selby [55]	Sensitivity & Specificity	----
2010	Bush [58]	Concurrent validity	----
2010	Gill [56]	Concurrent validity	----

Table A-4. Description of EZPCP Site Usage of ESAS-r

EZPCP Site	How Often	Time of day	Who is involved	Other times used
St. Joseph's Hospice	Daily	Morning	Health Care Aids	Patient Bedside Rounds
Tertiary Palliative Care Unit	Daily	Evening	1) Physicians 2) Registered Nurses 3) Licensed Practical Nurses 4) Health Care Aids (usually)	Not reported
Royal Alexandra Hospital	1) Initial consult by physician 2) Then 2X per week by nursing staff 3) If unstable then done as needed	At time of assessment	1) Physician 2) Nursing staff	Not reported
Norwood Hospice	Daily	Alternate days and evenings	1) Health Care Aids (and patients) 2) Registered Nurses 3) Licensed Practical Nurses	Not reported
University of Alberta Hospital	1) Initial consult by physician 2) Then as needed when staff feels reassessment is needed (not often)	At time of assessment	1) Physician 2) Registered Nurses 3) Residents	Not reported
Edmonton General Hospice	Daily	End of day shift	1) Health Care Aids (only using the graph though, not the actual form) 2) Physicians (sometimes) 3) Registered Nurses and Licensed Practical Nurses on admission	Not reported
Cross Cancer Institute: Community Liaison	Initial outpatient assessment and follow-up, in person and by telephone	At time of assessment	Registered Nurses	Not reported
Cross Cancer Institute: Symptom Control	1) Outpatients: triage, initial consultation, follow up; triage and follow up may take place in person or by telephone. 2) Inpatients: initial consultation and follow up	At time of assessment	1) Registered Nurses 2) Pharmacist 3) Physician	Not reported
Community Consult	Initial visit at the beginning of the interview	At time of assessment	1) Registered Nurses 2) Physicians	Not reported
Home Care	Most time staff visit clients' homes	At time of assessment	1) Registered Nurses (majority) 2) Licensed Practical Nurses 3) Respiratory Therapists 4) Occupational Therapists 5) Social workers	Not reported
Cross Cancer Institute: Interdisciplinary Team	1) Only in Pain and Symptom Clinic 2) Can be done by telephone before clinic visit (to see trends/changes)	morning	1) Dieticians 2) Respiratory Therapists 3) Pharmacist 4) Occupational Therapists 5) Physiotherapist 6) Speech Language Pathologists 7) Supportive care council (larger scale) 8) psychosocial staff (psychologists, art therapists, spiritual care)	1) Pharmacist would like to use for inpatients as well. 2) Occupational Therapists may use rating scale for some items in other assessments

Table A-5: ESAS Validation Studies in Early (Non-Palliative) Cancer Populations

First Author	Sample Size	Population	Country	Validity Evidence	Other Measures	Reliability
Chang ¹ (13)	240	inpatients (140) & outpatients (100)	USA	Concurrent	FACT, MSAS, KPS, BPI	Test-retest (2d, 1 wk)
Yesilbalkan (40)	113	inpatients & outpatients, chemotx units	Turkey	Concurrent		Internal consistency
Steinberg (69)	98	lung (new diagnosis)	Canada	Concurrent Predictive	DT	-----
Barbera (2)	23,802	outpatients (mixed)	Canada	Discriminant	PPS, gender, comorbidity, survival	-----
Granda-Cameron (70)	11	Sarcoma (new diag, on chemo)	USA	Change over intervention	FACT-G	-----
Yi (71)	97	Breast cancer survivors	USA	-----	QOL-BC	-----
Kurt (72)	50	inpatients & outpatients (chemo tx)	Turkey	Change over intervention	-----	-----
Rhondali ¹ (73)	146	outpatients	Canada	Concurrent Sensitivity Specificity	BEDS	-----
Akin (74)	119	patients on chemotx unit	Turkey	-----	-----	Inter-rater agreement
Bagha ¹ (75)	1215	outpatients (mixed)	Canada	Sensitivity Specificity	GAD-7 PHQ-9 DART	-----
Kwon(76)	200	Outpatients, Early vs. late referrals to Supportive Care	USA	Discriminant	-----	-----

Figure A-1: The Original ESAS

 **Alberta Health Services**

SYMPTOM CONTROL & PALLIATIVE CARE **PASTE PATIENT ID LABEL HERE**

INPATIENT- NEW & FOLLOW-UP

Edmonton Symptom Assessment System

Numerical Scale

Palliative Care Program

DATE: _____

Please circle the number that best describes:

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 Well-Being	0 1 2 3 4 5 6 7 8 9 10	Worst possible feeling of well-being
No Shortness of Breath	0 1 2 3 4 5 6 7 8 9 10	Worst possible Shortness of
Other	0 1 2 3 4 5 6 7 8 9 10	

Completed By:

<input type="checkbox"/> Patient	<input type="checkbox"/> Family/Caregiver
<input type="checkbox"/> Caregiver	<input type="checkbox"/> Nurse
<input type="checkbox"/> Care Assisted	<input type="checkbox"/> Staff/Physician
<input type="checkbox"/> Patient Refusal	

Appendix B

Titles of Validation Studies

1. Watanabe S, Nekolaichuk C, Beaumont C, Mawani A. The Edmonton Symptom Assessment System (ESAS): what do patients think? [abstract]. *Palliative Medicine* 2008; 22(4): 456. Support Care Cancer. 2009 Jun;17(6):675-83. doi: 10.1007/s00520-008-0522-1. [Poster No. 187, 5th Research Forum of the European Association of Palliative Care, Trondheim, Norway, May 28-31, 2008].
2. Nekolaichuk C, Watanabe S, Beaumont C. The Edmonton Symptom Assessment System: a 15-year retrospective review of validation studies (1991-2006). *Palliat Med.* 2008 Mar; 22(2):111-22. doi: 10.1177/0269216307087659.
3. Watanabe S, Nekolaichuk C, Beaumont C, Mawani A. The Edmonton Symptom Assessment System (ESAS): gathering validity evidence for symptom assessment in palliative care patients [abstract]. *Journal of Palliative Care* 2008; 24(3): 198. [Oral presentation by S. Watanabe & C. Nekolaichuk at the 17th International Congress on Palliative Care, Montreal, Canada, September 23-26, 2008].
4. Watanabe SM, Nekolaichuk C, Beaumont C, Johnson L, Myers J, Strasser F. A multi-centre comparison of two numerical versions of the Edmonton Symptom Assessment System in palliative care patients. *J Pain Symptom Manage.* 2011 Feb; 41(2):456-68. doi: 10.1016/j.jpainsymman.2010.04.020. Epub 2010 Sep 15.
5. Nekolaichuk C, Fainsinger R, Amigo P, DeKock I, Faily J, Burton-McLeod S, Mirhosseini N, Murray A, Oneschuk D, Tarumi Y, Thai V, Watanabe S, Wolch G, Hanson J. A multicentre study of advanced cancer patient's categorizations of pain intensity. *Palliative Medicine* 2010; 24(4, Suppl): S23. [Oral presentation by C. Nekolaichuk, 6th Research Forum of the European Association of Palliative Care, Glasgow, Scotland, June 10-12, 2010]. doi: 10.1177/0269216310366390

6. Watanabe SM, Nekolaichuk CL, Beaumont C. Palliative care providers' opinions of the Edmonton Symptom Assessment System Revised (ESAS-r) in clinical practice. *J Pain Symptom Manage* 2012; 44:e2-3. doi: 10.1016/j.jpainsymman.2012.07.008
7. Nekolaichuk C, Watanabe S, Mawani A. What is the most appropriate time frame for assessing symptoms? A validation study of the Edmonton Symptom Assessment System-Revised (ESAS-r) in advanced cancer patients [abstract]. *European Journal of Palliative Care* (in press). [Poster No. 216, 8th World Research Congress of the European Association of Palliative Care, Lleida, Spain, June 5-7 2014 & Society of Palliative Care Physicians Annual Meeting, Toronto, ON, May 29-31, 2014]. doi: 10.1177/0269216314532748



Appendix C

Guidelines for Administration of the ESAS-r (Clinical Assessment Guide)

Purpose

The *ESAS* is a tool that was developed to assist in the assessment of nine symptoms that are common in palliative care patients: pain, tiredness, drowsiness, nausea, lack of appetite, depression, anxiety, shortness of breath, and wellbeing (1). There is also a blank scale for patient-specific symptoms.

The *ESAS* has been revised to improve ease of understanding and completion for patients (2).

The revised version of the tool is known as the *ESAS-r*. Changes include specifying a timeframe of “now”, adding definitions for potentially confusing symptoms, modifying the order of symptoms, adding an example for “other symptom”, and altering the format for improved readability.

The *ESAS-r* is intended to capture the *patient’s perspective* on symptoms. However, in some situations it may be necessary to obtain a caregiver’s perspective. The *ESAS-r* provides a profile of symptom severity *at a point in time*. Repeated assessments may help to track changes in symptom severity over time. The *ESAS-r* is *only one part of a holistic clinical assessment*. It is not a complete symptom assessment in itself.

General Information - How to administer the ESAS-r

- It is recommended that the patient complete the *ESAS-r* *with guidance from a health care professional*, especially on the first occasion.
- The patient should be instructed to rate the severity of each symptom on a *0 to 10 scale*, where 0 represents absence of the symptom and 10 represents the worst possible severity. The number should be circled on the scale.
- The patient should be instructed to rate each symptom according to how he or she feels *now*. The health care professional may choose to ask additional questions about the severity of symptoms at other time points e.g. symptom severity at best and at worst over the past 24 hours.
- **Definitions** have been added to items that have been found to be more problematic for patients to understand or rate (3); it is recommended to review these with the patient:
 - Tiredness - lack of energy
 - Drowsiness - feeling sleepy
 - Depression - feeling sad
 - Anxiety - feeling nervous
 - Wellbeing - how you feel overall
- With the previous version of the *ESAS*, patients often *reversed the scale for appetite* i.e. they considered “0” as “no appetite” and “10” as “best appetite”. The scale has now been re-labeled as “lack of appetite”. Coaching patients on the correct direction of the scale is still recommended.
- The *body diagram* on the reverse side of the *ESAS-r* can be used to indicate sites of pain.
- The circled numbers can be transcribed onto the *ESAS-r graph*.

When to do the ESAS-r

- In palliative home care, it is a good practice to complete and graph the ESAS-r during each telephone or personal contact. If symptoms are in good control, and there are no predominant psychosocial issues, then the ESAS-r can be completed weekly for patients in the home.
- In hospice and tertiary palliative care units, the ESAS-r should be completed daily.
- In other settings, palliative care consultants will utilize this tool upon initial assessment and at each follow-up visit.

Who should do the ESAS-r

- It is preferable for the patient to provide ratings of symptom severity by himself/herself.
- If the patient cannot independently provide ratings of symptom severity but can still provide input (e.g. when the patient is mildly cognitively impaired), then the ESAS-r is completed with the assistance of a caregiver (a family member, friend, or health professional closely involved in the patient's care).
- If the patient cannot participate in the symptom assessment at all, or refuses to do so, the ESAS-r is completed by the caregiver alone. The caregiver assesses the remaining symptoms as objectively as possible. The following are examples of objective indicators:

Pain – grimacing, guarding against painful maneuvers

Tiredness – increased amount of time spent resting

Drowsiness – decreased level of alertness

Nausea – retching or vomiting

Appetite – quantity of food intake

Shortness of breath – increased respiratory rate or effort that appears to be causing distress to the patient

Depression – tearfulness, flat affect, withdrawal from social interactions, irritability, decreased concentration and/or memory, disturbed sleep pattern

Anxiety – agitation, flushing, restlessness, sweating, increased heart rate (intermittent), shortness of breath

Wellbeing – how the patient appears overall

If it is not possible to rate a symptom, the caregiver may indicate “U” for “Unable to assess” on the ESAS-r and ESAS-r Graph.

The method of completion of the ESAS-r must be indicated in the space provided at the bottom of the ESAS-r and the ESAS-r Graph as follows:

Bottom of ESAS-r Numerical Scale

Completed by (*check one*):

- Patient
- Family caregiver
- Health care professional caregiver
- Caregiver-assisted

Bottom of ESAS-r Graph

Insert letter from key in date column (date indicated at the top of form)

Completed by □□□□□□

Key:

- P = Patient
- F = Family caregiver
- H = Health care professional caregiver
- A = Caregiver-assisted

Where to document the ESAS-r

- *The ESAS-r is always done on the ESAS-r numerical scale and the results later transferred to the ESAS-r Graph. Graphing symptom severity directly onto the ESAS-r Graph without the use of the numerical scale is not a valid use of the ESAS-r, nor a reliable method of symptom assessment (attention to the graphed historical trend may affect the current scores and thus undermine one of the main purposes of the ESAS, i.e. to assess the current symptom profile as accurately as possible).*

Other information about the ESAS-r

- The ESAS-r Graph contains space to add the patient's Folstein Mini-Mental State Examination score. The "normal" box refers to the cutoff for a normal score for the patient, based on age and education level (see Instructions for MMSE).
- A space for the Palliative Performance Scale (PPS) is also provided.
- The ESAS-r is available in other languages, although most translations have not been validated (4).

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<https://www.albertahealthservices.ca/info/page14546.aspx> - (Assessment approaches tab)