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Monitoring symptom change in palliative care patients. A Bruyère Rapid Review

REPORT AUTHORS

Elizabeth Ghogomu
Vivian Welch
Cecilia Li
Shirley Bush
Christopher Barnes
Jill Rice

INSTITUT DE RECHERCHE
Bruyère
RESEARCH INSTITUTE

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Key messages

This rapid review was undertaken to assess the evidence of the effectiveness of ESAS/ESAS-r and effective implementation strategies as well as benchmarking schedule to improve the use of ESAS/ESAS-r for monitoring symptom change in palliative care patients.

We found some evidence on the effectiveness of ESAS/ESAS-r in monitoring symptom change.

- It improved symptom screening, symptom control and patient satisfaction.
- In addition, health professionals, especially nurses, found it to be useful as it helped identify symptoms that would have been missed and it enhanced patient care.

Some challenges to the implementation of ESAS/ESAS-r tool include

- limited resources and time,
- increased workload for staff,
- perceived burden to patients and
- difficulties in patients with impaired communication and cognition.

There is limited information on optimal frequency and benchmarking for monitoring symptom change with ESAS/ESAS-r tool. Although ESAS/ESAS-r is recommended for daily use in palliative care, guidelines suggest that timing of assessments should be guided by changes in the patient's condition, needs or care plan. We found no benchmarks for ESAS/ESAS-r tool.

Executive summary

The goal of palliative care is to achieve optimal symptom management in patients with advanced, progressive illness such as cancer. Common symptoms are pain, breathlessness, nausea, anorexia, increasing fatigue, anxiety, depression, constipation, diarrhea, social and spiritual difficulties.

The Edmonton symptom assessment system (ESAS) scale or the revised version (ESAS-r) is recommended in the Ontario Palliative Care Program and the revised version is used in palliative care at Bruyère Continuing Care (BCC). However, its implementation in Ontario has been unsatisfactory and some reasons are: (i) it is burdensome and time-consuming; (ii) there is a perception from health practitioners that its results did not change the course of treatment.

The Bruyère Palliative Care team is interested in the evidence on the effects of using ESAS/ESAS-r to monitor symptoms on quality of care and patient and caregiver satisfaction, as well as evidence about the optimal frequency of using the ESAS/ESAS-r in a low complexity palliative care unit setting with low alive discharge rates.

This rapid review was undertaken to assess the evidence of the effect of ESAS/ESAS-r use and effective implementation strategies (e.g. frequency, who administers it and how) to improve its use in monitoring symptom change in palliative care patients.

The following implications are based on our findings.

Implications for practice

1) A standardized tool (such as ESAS-r) should be used for monitoring symptom change in patients because it has been shown to improve symptom control.

2) Initially, symptom assessment with ESAS should be done daily and the frequency should be guided subsequently by changes in the patient's condition, needs and care plan, as recommended by clinical guidelines.

3) Collaboration (e.g. through interdisciplinary team meetings and sharing experiences and data across regions) was proposed to improve the use of ESAS in patient care.

4) Education and training of staff and patients were proposed to improve the implementation of the ESAS/ESAS-r tool.

Implications for research

Experiences from units and centres of excellence within the province and the country at large (e.g. the Princess Margaret Hospital PCU in Toronto, the Grey Nuns Hospital PCU in Edmonton, and the St Boniface PCU in Winnipeg) should be collected and monitored to improve evidence about optimal frequency and use of ESAS/ESAS-r.

Research is needed on whether less frequent administration (e.g. day 1, day 4 and weekly) would lead to improved completion rates and acceptance without worsening symptom control or missing changes in patient status.

Research is needed on comparison of daily and less frequent administration of ESAS.

Research is needed about whether uptake and use of ESAS by patients and staff could be improved by inclusive approaches to raising awareness about its benefits.

Research is needed about how to use ESAS optimally in patients with impaired cognitive status.

Research is needed about whether setting benchmarks for symptom control using ESAS-r are useful for improving patient care.

Background

The issue

The goal of palliative care is to achieve optimal symptom management in patients with advanced, progressive illness such as cancer [1]. Common symptoms are pain, breathlessness, nausea, anorexia, increasing fatigue, anxiety, depression, constipation, diarrhea, social and spiritual difficulties [2-4]. Several validated instruments have been developed for symptom assessment and monitoring in palliative care [5, 6] and include: Edmonton Symptom Assessment Scale (ESAS/ESAS-r), Palliative Care Outcome Scale (POS/POS-S), Memorial Symptom Assessment Scale (MSAS), Symptom Assessment Scale (SAS), Palliative Care Problem Severity Score (PCPSS), Palliative Performance Scale (PPS). The choice of instrument depends on the purpose (clinical care, audit or research) and setting (appropriateness and accessibility e.g. who will fill in the outcome measure? How long does it take to measure the outcome? How often will the outcome measure be used?) [5, 6].

The context

The Edmonton symptom assessment system (ESAS) scale or the revised version (ESAS-r) is recommended in the Ontario Palliative Care Program [7]. It has 10 items and could be completed in approximately 5 minutes [5, 6]. However, the completion rate reduced with advanced disease, less than 50% by critically ill patients and less than 5% by those close to death [5, 6]. There are two formats, paper-based and web-based, and the web-based format is typically administered through a touch-screen kiosk or the internet. The revised version is used in palliative care at Bruyère Continuing Care (BCC). Its implementation in Ontario has been unsatisfactory [8-10] and some reasons are: (i) it is burdensome and time-consuming; (ii) its results did not change the course of treatment. The Bruyère Palliative Care team is interested in the evidence on the effects of ESAS/ESAS-r on patient care and satisfaction as well as effective implementation strategies and benchmarking schedule to improve its use in monitoring symptom change in palliative care patients.

Objectives

To assess the evidence of the effects of ESAS/ESAS-r on patient care and satisfaction as well as effective implementation strategies and benchmarking schedule to improve its use in monitoring symptom change in palliative care patients.

Methods

We defined the question in consultation with the EBH Palliative Care team.

A focus group was held with four PCU physicians to define the question. Physicians asked whether there was evidence about effects of regular symptom monitoring in order to avoid missing changes in patient status and whether benchmarks were used for setting goals for symptom management and care. They described concerns with barriers to using the ESAS such as patient and provider perceptions of usefulness and burden of filling out the paper form as well as patients' cognitive impairment. They asked about evidence on optimal frequency and whether frequency could be reduced in their setting with low alive discharge rates. Discussion with the nurse reiterated the barriers due to patient cognitive impairment.

We planned to search for systematic reviews and guidelines related to monitoring symptom change in palliative care patients to assess the evidence on the effect of ESAS/ESAS-r on patient care and satisfaction as well as implementation strategies and benchmarking schedule to improve the use of ESAS/ESAS-r.

Eligibility and selection criteria

Population: palliative care patients 18 years or older (excluding children)

Intervention: implementation strategies for monitoring symptom change with the ESAS/ESAS-r

Comparison: usual or other implementation strategies for monitoring symptom change or no intervention

Outcomes: improved quality of care, symptom burden, and user satisfaction (patient/care giver or staff)

Literature search

We searched for relevant systematic reviews and guidelines in PubMed, Trip Database, and National Guideline Clearinghouse database. We also screened references of relevant articles. See Appendix 1 for full search strategy in PubMed. Due to paucity of systematic reviews, we considered including relevant studies, without limiting based on the study design. We invited the palliative care team to provide articles of relevance.

Relevance assessment

We identified five guidelines and 10 studies that met our inclusion criteria. We excluded studies in children, or in the community or residential setting (at home or long-term care facility).

Evidence review

Description of included guidelines

Three of the five guidelines were on palliative care in general [11-13]and two were specific for cancer care [7, 14]. Two are from the UK [11, 14] and one each from Australia [12], Canada [7]and USA [13]. All five guidelines recommended assessment of palliative care needs. Three guidelines recommended specific tools for assessment [7, 12, 13] and the two UK guidelines did not [11, 14].

Two tools were recommended for monitoring symptom change: ESAS by two guidelines [7, 13], and the Symptom Assessment Scale (SAS) by one guideline [12]. ESAS is designed for the assessment of nine symptoms (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing, and shortness of breath) and SAS assesses seven symptoms (pain, fatigue, nausea, bowel problems, breathing problems, difficulty sleeping, and appetite problems).

Two tools were recommended for the assessment of other palliative care needs: the Palliative Performance Scale (PPS) [7], and the Palliative Care Problem Severity Score (PCPSS) [12]. See Table 1.

Table 1: Characteristics of included guidelines

Guideline	Recommendation	Assessment frequency	Examples of Tools
ICSI guidelines - Palliative care for adults (Institute for Clinical Systems Improvement, USA)	Clinicians should use a validated assessment tool to assess palliative care needs. Among the available assessment tools, it was the decision of this work group to recommend the Edmonton Symptom Assessment System (ESAS) because it is thorough yet simple in clinical application; it has a robust evidence-based foundation for validation in various clinical settings, and is readily available via the Internet.	Not specified	ESAS
PCOC clinical manual (Palliative Care Outcomes Collaboration, Australia)	systematically assess individual patient experiences using validated clinical assessment tools: Palliative Care Problem Severity Score (PCPSS): pain, other symptoms, psychological/spiritual, family/carer. Symptom Assessment Scale (SAS): pain, fatigue, nausea, bowel problems, breathing problems, difficulty sleeping, appetite problems.	-On admission (commencement of episode of palliative care). -A minimum of daily in palliative care inpatient settings. -At each contact in community and in-hospital consultation / liaison service settings. -At change in care plan or patient / family needs. -At discharge	SAS PCPSS
CCO guidelines (Cancer Care Ontario, Canada)	Common screening, assessment tools and guides to practice should be implemented in all levels of care in each region (e.g., ESAS, Palliative Performance Scale, Collaborative Care Plans and Symptom Management Guides to Practice)	Not specified	ESAS PPS

Guideline	Recommendation	Assessment frequency	Examples of Tools
NHS - End of life care for adults (National Institute for Health and Care Excellence, UK)	People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.	Assessment should be an ongoing and proactive process that is both planned and responsive. Timing of assessments should take into account changes in the person's condition or circumstances as well as specific requests from the person approaching the end of life and their families and carers.	Not specified
NHS Guidance on cancer services - Improving supportive and palliative care for adults with cancer (National Institute for Health and Care Excellence, UK)	Assessment and discussion of patients' needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as at diagnosis; at commencement, during, and at the end of treatment; at relapse; and when death is approaching). Cancer Networks should ensure that a unified approach to assessing and recording patients' needs is adopted, and that professionals carry out assessments in partnership with patients and carers.	While assessment should be an ongoing process throughout the course of a patient's illness, structured assessments should, as a minimum, be undertaken at each of the following key points: •around the time of diagnosis •commencement of treatment •completion of the primary treatment plan •disease recurrence •the point of recognition of incurability •the point at which dying is diagnosed •at any other time the patient requests it.	Not specified

Description of included studies

All 10 included studies are observational studies with a mixed method design (qualitative and quantitative). All except one was based in Canada. Different participants were involved (health professionals, patients and caregivers) and varied outcomes were assessed across the studies. Three of the nine studies assessed the effectiveness of ESAS as a tool for monitoring symptom change [15-17] and eight assessed the effectiveness of implementation strategies of ESAS/ ESAS-r [8-10, 16, 18-21]. One of the studies was reported in two publications and assessed both effectiveness of ESAS as a tool for monitoring symptom change and effectiveness of implementation strategies [16, 22]. See Table 2.

Table 2: Characteristics of included studies

Study ID	Country and setting	Study design/ method	Population	Intervention	Outcomes
Bainbridge 2011	Canada; Juravinski Cancer Centre (JCC) in Hamilton, Ontario	Self-completed surveys administered online at a regional cancer center	All clinical teams (physicians, nurses, and allied health professionals) (N=239)	ESAS implementation at every patient visit	Perceived value of the ESAS. The extent to which the providers use the ESAS and reasons why they might not use it; the process of how they use the ESAS, if they do; perceptions of the ESAS's usefulness to their clinical practice; and suggestions for improving the utility of ESAS in the clinical setting
Beddard-Huber 2015	Canada; Vancouver General Hospital palliative care unit	Pre-survey and post-survey questionnaires before/ after ESAS-r tool administration	Nurses (N=25) and Physicians (N=7); Patients (N=92)	ESAS-r tool administration on day 1 (n=35, 38 percent), on day 4 (n=20, 21 percent), and weekly	Prepilot: Confidence in Clinical Assessment. The Attitudes of Staff toward Introducing the ESAS-r Scale. Postpilot: Staff Perceptions of the ESAS-r Tool on workload and burden to patients. Palliative Care Unit Staff Recommendations
Carli Buttenschoen 2014	Canada; Edmonton Zone Palliative Care Program (EZPCP) and University of Alberta Hospital (UAH)	Self-administered survey	Health Care Providers working in the EZPCP and UAH Chronic Pain Clinic (N=83; 62 % nurses, 26 % physicians, and 12 % other specialties)	Use of ESAS at least once	Health Care Providers' use, knowledge, and training needs of the ESAS.
Chasen 2015	Canada; an Ontario Cancer Center in Ottawa	Interviews to complete a four-part questionnaire	Oncologists (N=40)	ESAS is used for symptom assessment	Oncologists' attitudes to palliative and palliative care services in general; and attitudes to standardized symptom assessment and the ESAS.
Dudgeon 1999	Canada; Palliative care unit at St Boniface General Hospital in Winnipeg	Chart audits	188 charts	ESAS is used twice a day (at 10:00 am and 6:00 pm) and completed by the patient, nurse or both.	Adequacy and speed of symptom control

Study ID	Country and setting	Study design/ method	Population	Intervention	Outcomes
Dudgeon 2008	Canada; Kingston, Frontenac, Lennox & Addington Community Care Access Centre, the Queen's Palliative Care Medicine Program, and the St. Mary's of the Lake Complex Continuing Care Palliative Care Unit, Kingston General Hospital	Chart audits and questionnaires	Adult palliative oncology patients (N=102) and primary caregivers (N=75)	ESAS tool administration	the impact on symptom management, caregiver burden and satisfaction with care delivery
Dudgeon 2009	Canada; cancer or palliative care units in the Kingston, Frontenac, Lennox & Addington (KFL&A) counties in Ontario	Self-Administered Surveys and focus groups of frontline health professionals	Health care professionals (N=30)	Full implementation of the Palliative Care Integration Project (PCIP) including ESAS tool administration	Assessment of the processes of implementation and usefulness of ESAS
Gilbert 2012 [Dudgeon 2012]	Canada; 14 regional cancer centers in Ontario	Chart audits and a User Satisfaction Survey administered to measure patient satisfaction. Semi-structured interviews and focus groups to obtain qualitative insight regarding participants' perceptions of the PPCIP.	Cancer clinic and palliative care patients as well as all patients receiving CCAC palliative home services in the community who had been introduced to ESAS either in paper form or via the kiosk technology. (N=407). Healthcare professionals (clinical and administrative team members; N=44)	Implementation of the Provincial Palliative Care Integration Project (PPCIP) including ESAS tool administration	Improvements in symptom screening, and symptom control; patient satisfaction. Challenges and components for success to implementation and uptake of screening
Lucey 2012	Ireland; Specialist palliative care unit of Milford Hospice in Limerick	A questionnaire and a focus group after introduction of ESAS tool in the hospice	Nursing staff (N=20 for survey and N=8 for focus group)	Completion of ESAS tool on admission in the hospice and thereafter by nursing staff once daily	Nursing staff perceptions of the ESAS, its implementation process and education, and effect on patient burden

Study ID	Country and setting	Study design/ method	Population	Intervention	Outcomes
Pereira 2016	Canada; 14 Regional Cancer Centres across Ontario	An anonymous, self-administered electronic questionnaire distributed to cancer care professionals	Cancer care professionals from four major provider groups: physicians, nurses, radiotherapists, and psychosocial oncology (PSO) staff (N=960)		Provider attitudes toward general symptom screening, assessment, and management; Attitudes toward the ESAS; and ESAS usage.

Synthesis of findings

Two guidelines [7, 13] recommended ESAS specifically for monitoring symptom change and one of them, the ICSI guidelines for palliative care [13], because it is thorough and simple to apply; it has been validated in various clinical settings, and is readily available via the Internet.

Effectiveness of ESAS or ESAS-r

Three studies [15-17] assessed the effectiveness of implementing the ESAS tool on symptom screening, symptom control and patient satisfaction.

Symptom screening

Two studies found that implementing ESAS improved symptom screening (from 14.6% to 54% for any symptom in all lung cancer patients within 10 months [16] and from 24.5% to 74.6% for pain in all cancer patients within 2 years [15], respectively).

One study assessed the frequency of symptom screening with twice daily completion of the ESAS tool and there was no change between the morning and evening scores. Therefore, it was recommended to complete the ESAS tool only once a day [17].

Symptom control

Symptom control improved in all three studies after implementing ESAS. In one study, all mean symptom and total scores, except depression, were less in the 2003 patient sample (with the ESAS) than in 2002 (before implementation of the ESAS) (P-values ranging from 0.121 to 0.914) [15].

In the study by Gilbert et al [16], the measurement of symptom reduction was heavily dependent on daily screening with the ESAS tool as well as timely data entry. Pain scores reduced from 7 or more to 6 or less within 72 hours in 69% of 170 instances when a patient had a pain score of 7 or more; and dyspnoea scores reduced from 7 or more to 6 or less within 72 hours in 31% of 124 instances when a patient had a dyspnoea score of 7 or more measured on a visual analogue scale (VAS) from 0-10 cm. A comprehensive assessment and/or referral to psychosocial resources were provided to 47% of patients with a depression score of 5 or more.

In the third study [17], where patients were monitored daily with ESAS from admission until seven days post-admission, there were variations of symptom intensity over time. There was reduction in the intensity of symptoms measured with a visual analogue scale (VAS) of 0-100 mm from scores of 50 or more to scores of 50 or less within 24 hours of admission for pain, nausea, depression and anxiety and within 48 hours for dyspnoea. Daily monitoring with ESAS detected that depression and drowsiness worsened after day 4; and asthenia and anorexia did not improve much over seven days post-admission. For patients with scores less than 50 on admission, there was little to no improvement on pain, depression, well-being, or shortness of breath, but a steady deterioration of scores for activity, nausea, anxiety, drowsiness, and appetite over time.

Patient satisfaction

Only one study [16, 22] assessed patient satisfaction in terms of patients' perception of symptom screening and whether they perceived that practitioners incorporated their scores in care planning and selection of interventions for symptom management.

85% of patients considered ESAS to be important as it helped providers know how they were feeling;

68% said that their health care providers asked them about their symptoms and the severity;

62% indicated that their pain and other symptoms were controlled to a comfortable level; and

61% agreed that their health care team took their ESAS symptom ratings into consideration in developing a plan or taking action to manage their symptoms.

In addition, 70% of patients preferred the web-based tool to the paper-based tool and only 15% preferred the paper based tool.

Implementation strategies of ESAS or ESAS-r

Seven studies assessed ESAS [8, 9, 16, 18-21] and one assessed ESAS-r [10]. We used thematic analysis to summarize the qualitative evidence from interviews, surveys/questionnaires and focus groups. There were two main categories of evidence: staff perceptions and patient perceptions. We identified two themes: perceptions about the acceptance of the ESAS/ESAS-r tool and perceptions about the implementation process of the tool across both categories.

In addition, one study assessed components for success to implementation of the Provincial Palliative Care Integration Project (PPCIP) that included ESAS tool administration [16, 22].

STAFF PERCEPTIONS

Perceptions about the acceptance of the ESAS/ ESAS-r tool:

Although there was agreement for the need of a standardized tool for symptom screening [9, 10, 16, 19], there was lack of consensus on the chosen tool among different health professionals. Nurses and allied health professionals were more in favour of the ESAS/ ESAS-r tool than physicians. In one study [9] 93% allied health professionals and 81% nurses agreed that ESAS should be considered best practice compared to 66% physicians. In another study [10] 74% of nurses were in favour of recommending the ESAS-r tool whereas physicians' choices varied – 50% of physicians did not recommend its use as part of standard care and 50% were neutral. Sixty-four percent of medical oncologists and 88% of general practitioners in oncology agreed with using ESAS at every visit while only 6% of radiation oncologists agreed [18].

History taking was thought to be sufficient for symptom screening in one study by 51% of nurses and 39% of physicians [9].

Perceptions about the implementation process of the ESAS/ESAS-r tool:

Usefulness: in three studies [8, 9, 18], ESAS was perceived by approximately 50 to 75% of health providers to help patients report their symptoms, more so by nurses and allied health professionals than physicians [8, 9]. Two studies reported that health care professionals (especially nurses) thought ESAS/ESAS-r helped identify symptoms that could have been missed if they were not screened [10, 16]. Most health care professionals agreed that ESAS enhanced patient care [8, 16, 18, 21] and was useful in the follow-up of patients [8, 9, 16, 18]. About 50% of health care professionals agreed that ESAS improved efficiency of meeting with patients [9, 18]. Most health care professionals agreed that ESAS enhanced clinicians' assessment of symptom severity [18, 21]. Health care professionals also found ESAS beneficial as a communication tool to understand symptom system and for administrative purposes [16, 21].

Workload: health professionals in three studies (35%, 56% and 14%, respectively) found ESAS/ESAS-r to be time consuming [9, 10, 21] . In one study [19] staff found they did not have enough time to explain the form to patients and the tool was an 'add on' to existing nursing assessment protocols. There was the concern of limited resources to meet the growing workload and demand of care when ESAS was introduced in palliative cancer care [16].

Burden to patients: most nurses [10, 19, 20] and other health professionals including physicians [10, 19] perceived that ESAS/ESAS-r was burdensome to patients as some were too ill to complete the form.

Usage: the majority of nurses (89%), physicians (55%) and other providers (57%) referred to the ESAS scores in clinic either always or most of the time [8]. Similar findings were reported in two other studies [9, 18]. Most oncologists prefer to review the ESAS scores before visit rather than during visit [18]. Most (60%) health professionals indicated they always talked to their patients about their ESAS scores and 52% reported they always or often incorporated the ESAS into their care plan [9].

It was perceived that patients misinterpreted the ESAS scores in two studies [8, 18] and 50% health care professionals misinterpreted ESAS terms in one study [21].

Only 2% of health care professionals in one study found it easy to use the ESAS tool and 27% had difficulties using it in patients with impaired communication and cognition resulting in poor proxy symptom assessment [21].

Resources: assessment tools were not readily available in one study [19] and other organizational commitments trumped over the implementation of ESAS in another study [20]. With improved symptom screening and assessment, changes in infrastructure were necessary to meet the newly expressed needs of patients for symptom management and palliative care in general [16, 22] for example more time and resources would be needed to address high scores of anxiety or depression [22]. Data had to be entered manually into the electronic records after ESAS was completed as the paper based form or web-based version because there was no electronic interface between ISSAC (the web-based version of ESAS) and the electronic health records [22].

PATIENT PERCEPTIONS

Only two studies considered patients' perceptions; one with 20 participants looked at perceptions about the ESAS-r tool [10] and the other with 407 participants, perceptions about the ESAS tool [16, 22].

Perceptions about the acceptance of the ESAS-r tool:

Almost half (45%) of the patients agreed that ESAS-r was easy to understand.

Perceptions about the implementation process of the ESAS/ESAS-r tool:

Usefulness: 85% of patients considered ESAS to be important as it helped providers know how they were feeling; and 62% of patients indicated that their pain and other symptoms were controlled to a comfortable level.

Burden to patients: 60% of patients agreed that ESAS-r was not burdensome to complete.

Usage: 68% of respondents said that their health care providers asked them about their symptoms and the severity; and only 1% agreed that their health care team took their ESAS symptom ratings into consideration in developing a plan or taking action to manage their symptoms.

COMPONENTS FOR SUCCESS

Strategies for successful implementation included having clinical champions who encouraged improvement through commitment and collaboration; having provincial support that encouraged sharing experiences across regions; monthly regional data reporting and analysis; volunteer involvement; providing education and support to patients completing ESAS.

Benchmarking schedule to improve the use of ESAS/ESAS-r

The ESAS/ESAS-r tool is recommended to be completed by the patient with guidance from a health care professional, especially on the first occasion; and it was designed to be used in different settings with varying schedules [23]. In palliative home care it is recommended to use ESAS-r during each telephone or personal contact and if symptoms are in good control it should be completed once weekly. In hospice and tertiary palliative care units, the ESAS-r should be completed daily. In other settings, it should be used during the initial assessment and at each follow-up visit. If the patient cannot complete the form independently or refuses to do so, it can be completed with the assistance of a caregiver (a family member, friend or health professional closely involved in the patient’s care) or by the caregiver alone.

One of the included studies assessed the frequency and found no difference between twice daily ratings of symptoms and concluded ESAS should be used once daily [17]. They also found that there were significant changes during the first 3 days of admission in all symptom scores of 5 or more at the initial assessment.

Another included study administered ESAS-r on admission then on day 4 and weekly thereafter to patients who were cognitively capable [10]. The authors chose this frequency because the completion of the tool was found to be burdensome to staff and patients and they believed data collection on admission and day 4 would capture acute symptom changes while weekly data collection would show trends. This is in agreement with our findings from other included studies [9, 17, 19, 20].

The two guidelines [7, 13] that recommended ESAS specifically for monitoring symptom change did not indicate the optimal frequency for its use.

Three guidelines recommended that symptom assessment should be on-going and take into account changes in the patient's condition or circumstances [11, 12, 14]. Two of them recommended key points for symptom assessment. In the Australian PCOC guidelines [12], the Symptom Assessment Scale (SAS) was to be administered to patients on admission, a minimum of daily in palliative care inpatient settings, at change in care plan or patient/family needs and at discharge. In the NHS Guidance on cancer services [14], the key points for symptom assessment were: around the time of diagnosis, commencement of treatment, completion of the primary treatment plan, disease recurrence, the point of recognition of incurability, the point at which dying is diagnosed, at any other time the patient requests it.

The Australian PCOC guidelines [12] also has three patient outcome measures and associated benchmarks. These outcomes (Time from date ready for care to episode start; Time in the unstable phase; and Change in symptoms/problems) are measured with other tools (PCPSS & SAS). The unstable phase could be caused by an urgent change in the plan of care or emergency treatment is required because patient experiences a new problem that was not anticipated and/or patient experiences a rapid increase in the severity of a current problem and/or family/carers circumstances change suddenly impacting on patient care. See Table 3 for details.

Table 3: Outcome measures and benchmarks in the PCOC guidelines

Outcome measure	**Benchmark**
Time from date ready for care to episode start: reports responsiveness of palliative care services to patient needs. measures the time taken for an episode to commence following the date the patient is available and ready to receive palliative care.	90% of patients must have their episode commence on the day of, or the day after date ready for care.
Time in the unstable phase The unstable phase alerts clinical staff to the need for urgent changes to the patient's plan of care or that emergency intervention is required. Patients assessed to be in the unstable phase require intense review for a short period of time	90% of unstable phases must last for 3 days or less.
Change in symptoms/problems Change in symptoms or problems is calculated by the difference in assessment from the beginning of a phase to the end of phase, and is calculated using the measures from both the Palliative Care Problem Severity Score (PCPSS) and Symptom Assessment Scale (SAS).	Pain (PCPSS & SAS) At least 90% of patients with absent or mild PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase. At least 60% of patients with moderate or severe PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase. At least 90% of patients with absent or mild SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase. At least 60% of patients with moderate or severe SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase. Fatigue (SAS) At least 90% of patients with absent or mild fatigue at the beginning of their phase of palliative care have absent or mild fatigue at the end of the phase. At least 60% of patients with moderate or severe fatigue at the beginning of their phase of palliative care have absent or mild fatigue at the end of the phase. Breathing problems (SAS) At least 90% of patients with absent or mild breathing problems at the beginning of their phase of palliative care have absent or mild breathing problems at the end of the phase. At least 60% of patients with moderate or severe breathing problems at the beginning of their phase of palliative care have absent or mild breathing problems at the end of the phase. Family/carer problems (PCPSS) At least 90% of patients with absent or mild family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase. At least 60% of patients with moderate or severe family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase.

Discussion

Applicability of evidence/ implementation

Although ESAS/ESAS-r is recommended in the Ontario Palliative Care Program its implementation has been unsatisfactory. To improve implementation, potential challenges and strategies to overcome them should be identified and prioritized based on the likelihood of successful quality improvement and maintaining the change over time. Different challenges may be faced at different times, and at different types of palliative care units (PCUs) with varying resources for improvement strategies.

We found some evidence on the effectiveness of ESAS/ ESAS-r in monitoring symptom change. It improved symptom screening, symptom control and patient satisfaction. In addition, health professionals, especially nurses, found it to be useful as it helped identify symptoms that would have been missed and it enhanced patient care. This is in agreement with findings of other studies [24, 25]. Participants had different perceptions about the implementation of ESAS/ESAS-r tool. Health professionals found ESAS/ESAS-r to be burdensome to patients especially those who were too ill whereas some patients found ESAS-r not burdensome. Some patients preferred the web-based version of ESAS to the paper-based version. Health professionals and patients misinterpreted the ESAS terms or scores. On the other hand, patients found ESAS-r was easy to understand.

Some challenges to the implementation of ESAS/ESAS-r tool include limited resources and time, increased workload for staff, perceived burden to patients and difficulties in patients with impaired communication and cognition. Disparities have been found between patient and proxy assessment of symptoms with ESAS as demonstrated in other studies [26, 27] and for other tools such as SAS [28].

One study assessed components for success to implementation of the Provincial Palliative Care Integration Project (PPCIP) that included ESAS tool administration [16, 22]. These strategies included having clinical champions who encouraged improvement through commitment and collaboration; having provincial support that encouraged sharing experiences across regions; monthly regional data reporting and analysis; volunteer involvement; providing education and support to patients completing ESAS.

Most of the studies were conducted in patients who were cognitively capable and could complete the ESAS/ESAS-r tool by themselves but some settings included cognitively impaired patients who were excluded.

There is limited information on optimal frequency and benchmarking for monitoring symptom change with ESAS/ESAS-r tool. Although ESAS/ESAS-r is recommended for daily use in palliative care, guidelines suggest that timing of assessments should be guided by changes in the patient's condition, needs or care plan. We found no benchmarks for ESAS/ESAS-r tool.

Strength and limitations

Similar themes and challenges were found across included studies. Most of the included studies were small with less than 100 participants; only four studies had over 100 participants and one study had 188 charts reviewed. Many of the studies were conducted in Ontario, Canada; however, the settings differed across the studies.

There was limited research about solutions to the challenges identified.

Implications

The following implications are based on our findings.

Implications for practice

1) A standardized tool (such as ESAS-r) should be used for monitoring symptom change in patients because it has been shown to improve symptom control.

2) Initially, symptom assessment with ESAS should be done daily and the frequency should be guided subsequently by changes in the patient's condition, needs and care plan, as recommended by clinical guidelines.

3) Collaboration (e.g. through interdisciplinary team meetings and sharing experiences and data across regions) was proposed to improve the use of ESAS in patient care.

5) Education and training of staff and patients were proposed to improve the implementation of the ESAS/ESAS-r tool.

Implications for research

Experiences from units and centres of excellence within the province and the country at large (e.g. the Princess Margaret Hospital PCU in Toronto, the Grey Nuns Hospital PCU in Edmonton, and the St Boniface PCU in Winnipeg) should be collected and monitored to improve evidence about optimal frequency and use of ESAS/ESAS-r.

Research is needed on whether less frequent administration (e.g. day 1, day 4 and weekly) would lead to improved completion rates and acceptance without worsening symptom control or missing changes in patient status.

Research is needed on comparison of daily and less frequent administration of ESAS.

Research is needed about whether uptake and use of ESAS by patients and staff could be improved by inclusive approaches to raising awareness about its benefits.

Research is needed about how to use ESAS optimally in patients with impaired cognitive status.

Research is needed about whether setting benchmarks for symptom control using ESAS-r are useful for improving patient care.

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Appendix

Search strategies

PubMed

#1	palliative care[MeSH Terms]	45417
#2	palliative care	61175
#3	end of life care[MeSH Terms]	44601
#4	end of life care	68785
#5	end of life	60807
#6	terminally ill[MeSH Terms]	5872
#7	terminally ill	9636
#8	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7	151664
#9	monitoring	524528
#10	symptom change	12778
#11	#9 AND #10	467
#12	#8 and #11	21
#13	assessment	1062192
#14	system	2416142
#15	tool	351154
#16	#13 AND #14	117508
#17	#13 AND #15	57406
#18	#10 AND #16	296
#19	#10 AND #17	160
#20	#8 AND #18	44
#21	#8 AND #19	22
#22	#10 AND #13	2771
#23	#8 AND #22	214
#24	#8 AND #16	1675
#25	symptom	162272
#26	#25 AND #13	25959
#27	#8 AND #26	2274
#28	#25 AND #13 AND #15	1636
#29	#8 AND #28	245
#30	#25 AND #13 AND #14	2898
#31	#8 AND #30	403
#33	"Symptom Assessment Scale"	537
#34	#8 AND #33	238
#35	"Palliative Care Problem Severity Score"	3
#36	#8 AND #35	3
#37	"Palliative Performance Scale"	109
#38	#8 AND #37	108

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