

# Palliative Care Patients' Perspectives of a French Translation of the Edmonton Symptom Assessment System Revised (ESAS-r)

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## Aims:

The Edmonton Symptom Assessment System Revised (ESAS-r) is a nine-item self-report symptom intensity tool developed for palliative care patients, with the option of adding a 10th patient-specific symptom. Each symptom is rated on a scale from 0 (none or best possible) to 10 (worst possible). Due to growing international uptake, the ESAS-r has been translated into different languages. However, there has not been any agreement regarding a single standard process for translation into multiple languages, which also includes patients' perspectives. The purpose of this study was to obtain palliative care patients' perspectives regarding a French translation of the ESAS-r.

## Methods:

We developed a French version of the ESAS-r (see Figure 1), using a standard translation method, involving both professional translators and bilingual palliative care experts (see Figure 3). Fifteen francophone-speaking palliative care patients were recruited from acute care, cancer care and tertiary palliative care sites in Ottawa and Edmonton. Participants completed the ESAS-r and then reviewed the tool to identify any problems associated with the translation, in the presence of a trained interviewer. Descriptive statistics and thematic analysis were used to analyze the quantitative and qualitative data, respectively.

## Results:

Most participants were cancer patients (n=14, 93%), with a median age of 72 years. The two highest rated symptoms were tiredness (Mean=4.8, SD 2.3) and well-being (Mean=4.2, SD 2.8). Based on participants' concerns, translations for four of the nine symptoms were revised: drowsiness, nausea, lack of appetite and shortness of breath. Concerns expressed for three additional symptoms (depression, anxiety, well-being) were related to overall difficulty rating these symptoms, not specific to the translation. There were no concerns expressed for pain and tiredness.

Figure 1. ESAS-r Tool in English and Validated French Translation

Figure 2. Study sites in Ottawa & Edmonton



Figure 3. Flow Chart of Step Wise Approach

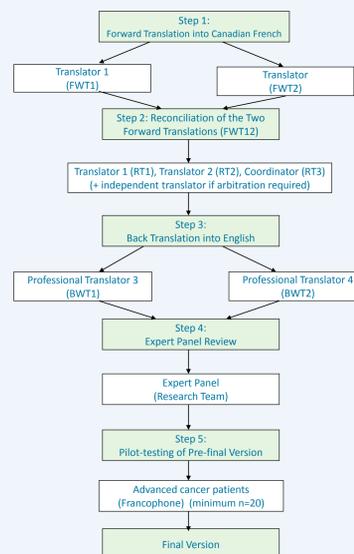


Table 1. Patient Demographics

Characteristic	Freq, n (%)	Characteristic	Freq, n (%)
Gender		Education Level (years)	
Male	10 (67)	5-8	1 (7)
Female	5 (33)	9-12	2 (13)
Marital Status		Greater than 12	6 (40)
Married/Common Law	10 (67)	Unknown	6 (40)
Widowed	2 (13)	Location of Recruitment	
Single	2 (13)	Ottawa	11 (73)
Divorced	1 (7)	Edmonton	4 (27)
Primary Cancer Diagnosis		Previous Exposure to ESAS (Ottawa)	
Gastrointestinal	5 (33)	Yes	3 (20)
Genitourinary	3 (20)	No	8 (53)
Lung	2 (13)	Previous Exposure to ESAS-r (Edmonton)	
Hematology	1 (7)	Yes	4 (27)
Breast	1 (7)	No	0
Unknown Primary	1 (7)	Patient Type	
Other Cancer	1 (7)	Inpatients	13 (87)
Non-Cancer	1 (7)	Outpatients	2 (13)
Current Cancer Treatment			
None <sup>1</sup>	10 (67)	Characteristic	Median (Range)
Other	3 (20)	Age (years)	72 (34-83)
Radiotherapy	2 (13)	Palliative Performance Scale (0-100%)	60 (30-80)

<sup>1</sup> Nine participants with cancer not currently receiving cancer treatment, one participant did not have cancer diagnosis

Table 2. ESAS-r Symptom Ratings

ESAS/ESAS-r Symptom Ratings	Mean (SD)
Tiredness	4.8 (2.3)
Wellbeing	4.2 (2.8)
Drowsiness	4.0 (2.3)
Shortness of Breath	3.5 (3.0)
Appetite	3.2 (3.0)
Pain	3.1 (2.4)
Depression	3.0 (3.2)
Anxiety	2.8 (3.0)
Other Symptom	2.1 (2.3)
Nausea	0.8 (1.5)

Table 3. Qualitative Responses

Question	Summary of Patients Comments	Final Recommendations of Changes
Pain Concerns?	Question difficult, but clear.	No changes.
Tiredness Concerns?	Question difficult, subjective, varies over time, but clear	No changes.
Drowsiness Concerns?	Drowsiness because somnolence has no specific meaning for someone with grade 10 education; Explanation in brackets was helpful.	Use "somnolence" as main line with brackets: "Se sentir très éveillé" (left) "Se sentir très endormi" (right) Add additional descriptors in guidelines.
Nausea Concerns?	Abstract question because it depends on some factors (ex. The gender...); Only keeping "Envie de vomir" instead of nausea which is not commonly used and difficult to understand.	Use "envie de vomir" as main line with "envie de vomir = nausée" in brackets; Add additional descriptors in guidelines.
Lack of Appetite Concerns?	Could be replaced by: "good appetite" or "no desire to eat"; Dysphagia; Replace poor appetite by difficulty swallowing (or include "difficulty swallowing" in the item) Difficulty to swallow instead of <absence of>.	Use "Très bon appétit" instead of "Aucun manque appétit" and "Aucun appétit" instead of "Le pire manque d'appétit possible"
Shortness of Breath Concerns?	Could be replaced by: "Difficulty to breathe" or "Normal breathing"; Gaspings for air.	Add "Manque de souffle" in brackets underneath "Aucun essoufflement".
Depression Concerns?	Do not consider depression = tristesse (sad), because someone can be sad without depression; Separate depression and sadness; Depression and anxiety are two similar terms and difficult to rate separately.	No changes. Consider further descriptions in guidelines.
Anxiety Concerns?	Difficulty rating anxiety because difficult to define even with explanations in brackets. Anxiety can also mean suffocating, feeling caught "in a net/shell"; nervous is too vague and general; Depression and anxiety are two similar terms and difficult to rate separately.	No changes. Consider further descriptions in guidelines.
Well-Being Concerns?	Difficulty with well-being. Better phrase would be: how do you feel in general? No use to say "sentiment de bien-être"; Sense of well-being was upsetting because asks about something very personal.	No changes. Keep same order as original translation.
Other Symptom Concerns?	Could be replaced by: "No other problem? All is good?"	Add "Autre problème" (p.e. constipation) on first line before rating scale

## Discussion:

Literal translations of some of the symptoms were not always meaningful (e.g. drowsiness, nausea, lack of appetite, shortness of breath) Based on patients' input, the translation was adapted to include more familiar words used in everyday language. Similar to the English version, patients had difficulty rating certain symptoms (depression, anxiety, wellbeing). Adequate healthcare provider education (p.e. descriptions in ESAS-r guidelines) is needed to ensure that patients are able to appropriately express their symptom experience.

## Conclusion:

The findings from this study provide a vital step in the development of a standardized translation protocol, including patient perspectives, which can be applied to other languages.

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## Special Acknowledgements:

Dr. Pierre Allard  
 Samantha Zinkie  
 Viki Muller

