

What do symptom scores mean: Observations on discrepancies when defining symptoms using words and numbers

Prepared by: Dale Wiebe, June 24, 2010 at Tertiary Palliative Care Unit, Grey Nuns Hospital

Reference: (Palliative Care Consult Team, Sunnybrook Health Sciences Centre, Toronto, ON) Gill, A., et al., What do symptom scores mean: Observations on discrepancies when defining symptoms using words and numbers, *European Journal of Oncology Nursing* (2010), doi:10.1016/j.ejon.2010.04.002

Abstract: The Edmonton Symptom Assessment System (ESAS) has become a more frequently used tool for symptom screening in oncology and palliative care settings in Ontario. The process patients use to select symptom scores however is poorly understood. Purpose: The purpose of this paper is to consider what patients mean when assigning numbers or words to symptoms, and the implications for healthcare providers who interpret these responses.

Methods and sample: A previously conducted study in our organization asked four hundred inpatient and ambulatory oncology patients to rank ESAS symptoms with the usual numerical responses (0-10) and then with word phrases of 'none', 'mild', 'moderate', or 'severe' to examine the relationship between chosen numbers and words.

Key results: Although results showed a strong positive correlation between number and word rankings for each ESAS symptom, closer examination revealed that for some patients there were discrepancies between chosen numbers and words, with broad numerical ranges, particularly for the words 'mild' and 'moderate'. Through a secondary analysis, these discrepant responses are explored and relevant literature is presented that highlights the importance of understanding patients as they communicate their symptoms.

Conclusions: Health care providers need to be aware of the potential for discrepancies when reviewing patient self-reported data. Numbers and words may not fully capture a patient's symptom burden; further exploration is required to gain a more comprehensive understanding of a patient's current state of being.

Strengths: This is a prospective study of, english speaking, adult palliative care patients in both inpatient and outpatient settings. The wide range of patient symptom responses is well described by comparing two similar scoring systems. The relative strengths of numerical and verbal symptom scoring systems are highlighted with statistically equivalent preferences for each, identifying a need for fitting the tool to the patient experience rather than the reverse.

Weaknesses: They failed to explain a standard process by which the numerical and verbal ESAS scoring systems were explained to patients, which could lead to greater variability in score correlation. The numerical scoring system was always used before the verbal score but not the reverse. The study was limited to cancer patients at a single centre. Particular reasons for choice of scores were not further explored. That information could help evaluate specific characteristics of the patients and the symptoms that would help explain the variation in reported symptom scores.

Relevance to palliative care: Symptom assessment is at least the bread, if not also the butter, of palliative care. Validating simple and accurate scoring systems is the key to health care provider communication. Nuances of symptom scoring have been discussed as complicating factors during morning rounds for the past two days.

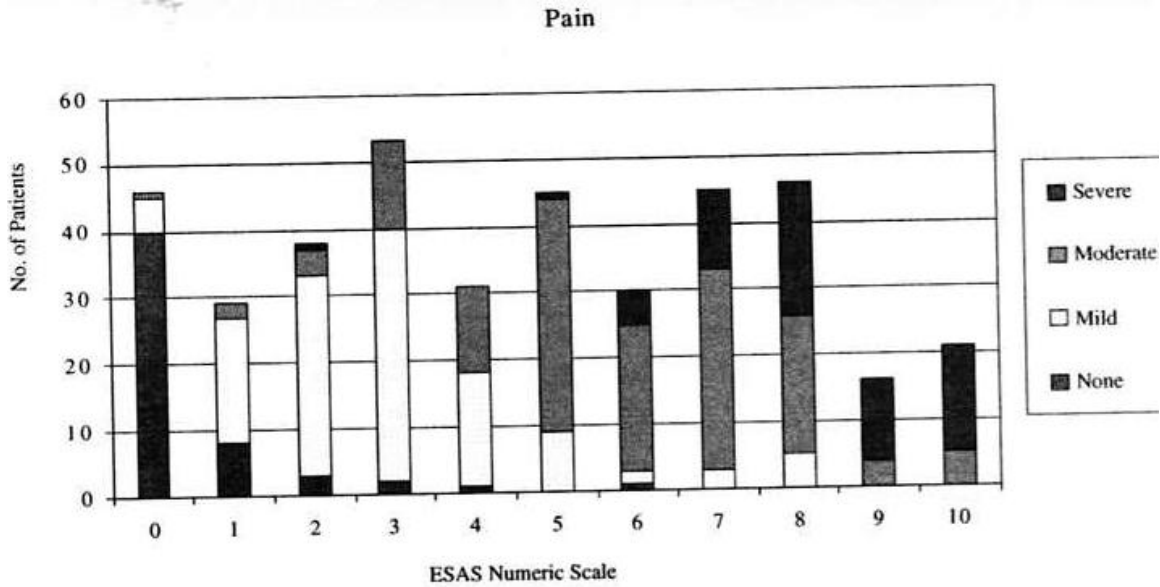


Fig. 1. Summary of responses for symptom category of 'Pain'.

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Table 1

Number–word correlation for each of the 9 symptoms.

Symptom	Spearman correlation	p-Value
Pain	0.81	<0.0001
Tiredness	0.72	<0.0001
Nausea	0.78	<0.0001
Depression	0.83	<0.0001
Anxiety	0.79	<0.0001
Drowsiness	0.77	<0.0001
Loss of appetite	0.79	<0.0001
Well-being	0.69	<0.0001
Shortness of breath	0.83	<0.0001

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Table 2

Range of responses.

	None	Mild	Moderate	SEVERE
Pain	0–3	0–8	1–10	6–10
Tired	0–3	0–8	3–10	6–10
Nausea	0–4	0–7	1–8	7–9
Depression	0–5	0–7	2–10	5–10
Anxiety	0–5	0–8	1–10	5–10
Drowsiness	0–6	0–9	0–10	5–10
Appetite	0–6	0–10	1–9	5–10
Wellbeing	0–8	0–8	1–9	5–10
Shortness of Breath	0–4	0–8	2–9	6–10

At least 2 participants needed to select a word/number combination to be included in the range. For example, only one respondent ranked their pain as 'none' and circled 6 so this was not included in the range for 'none'.