What does the answer mean? A qualitative study of how palliative cancer patients interpret and respond to the Edmonton Symptom Assessment System

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Abstract
The Edmonton Symptom Assessment System (ESAS) is a well-known self-reporting tool for symptom assessment in palliative care. Research has shown that patients experience difficulties in the scoring and interpretation, which may lead to suboptimal treatment. The aims were to examine how palliative care cancer patients interpreted and responded to the ESAS. Eleven patients (3F/8M), median age 65 (34-95) with mixed diagnoses were interviewed by means of cognitive interviewing, immediately after having completed the ESAS. The highest mean scores were found with tiredness (6.3) and oral dryness (5.7). The results showed that sources of error were related to interpretation of symptoms and differences in the understanding and use of the response format. The depression and anxiety symptoms were perceived as difficult to interpret, while the appetite item was particularly prone to misunderstandings. Contextual factors, such as mood and time of day, influenced the answers. Lack of information and feedback from staff influenced the scores. Some patients stated that they scored at random because they did not understand why and how the ESAS was used. The patients’ interpretation must be considered in order to minimize errors. The ESAS should always be reviewed with the patients after completion to improve symptom management, thereby strengthening the usability of the ESAS.

Strengths
Similar results to 2009
Despite small sample, problems were noted suggesting widespread problem
Audio taped and transcribed: prevented interpretation bias
Validates tool

Weaknesses
Length of stay at the time of assessment was not included: ie day 1 or day 10
Timeframe of ESAS application was not present time(NOW) as compared to the practice on TPCU
Eliminated cognitively impaired patients
Retrospective cognitive interviewing was not clarified

Relevance to Palliative Care
Informs us about what patients are thinking
Stresses importance of nurse education