

Poor correlation between physician and patient assessment of quality of life in palliative care

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Wide variations found between quality of life assessments made by patients and by physicians indicate that patient symptom expression is a complex multidimensional construct.

In a recent study (see opposite), Petersen et al. observed a poor level of agreement between patient and physician assessments of patients' health-related quality of life (HRQOL) on first contact, with no significant improvement during follow-up encounters. My research group made a similar observation in 49 patients admitted to an acute palliative care unit,¹ with a tendency for physicians to underrate most symptoms, particularly sedation, shortness of breath, and pain. Other authors have observed both underrating and overrating by health-care professionals.² These findings emphasise the need for routine patient-based symptom assessment in the clinical setting. Unfortunately, except for pain evaluation, such assessments are infrequent in clinical practice, even within palliative care centres. Even for pain evaluations, the accuracy of these assessments when conducted within regular clinical care has been questioned.³

Why does this discrepancy occur? It is possible that physicians do not appro-

priately assess the intensity of some symptoms, because of limited time, or insufficient focus on emotional distress when debilitating physical symptoms are present. Another possible interpretation is that palliative care physicians make consistent errors in symptom assessment. An approach that considers the patient's numerical report regarding their symptoms as the 'gold standard' would reach this conclusion. The patient's self-rating of symptom intensity needs to be interpreted as a multidimensional construct, however.^{4,5} It is not possible to measure the actual production of nociceptive input from a painful bone metastasis, the production of afferent dyspnoea by 'J' receptors in the lung or respiratory muscles, or the afferent nausea stimulus emerging from the gastric wall to produce numerical representations of the primary pathophysiological mechanisms. The perception of these stimuli within the somatosensory cortex also cannot be measured. A number of inhibitory and

facilitating pathways are capable of altering the intensity of symptom perception. Finally, the numerical rating reflects the individual's expression of symptom perception, which may be significantly affected by their belief about the nature of the symptoms, their understanding of the assessment tool, and cultural and social factors.

The impact of this numerical rating on the treatment of the patient's symptoms has to be taken in context. For example, a pain intensity score of 8/10 in a patient whose pain had been consistently scored at 2 or 3, and who has experienced considerable tumour growth, is likely to overwhelmingly reflect increased nociceptive input and require specific analgesic therapy. On the other hand, a pain intensity score of 8/10 in a patient who has been consistently expressing similar intensity for several months and who has a history of heavy chemical dependence is much less likely to reflect nociceptive input and will, therefore, require less analgesia and more psy-

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chosocial interventions. Symptoms such as fatigue, nausea, or dyspnoea are subject to similar levels of variability.

Patients and palliative care physicians could be interpreted as contributing complementary rather than opposing information from different perspectives. Using generalisability theory, it might be possible to reach a better understanding of the multidimensional construct included in each of the different symptoms reported by patients.⁵ Future research should focus on the influence of mood, delirium, chemical coping, and so on.⁶ In addition, qualitative studies should be conducted to

better characterise how palliative care physicians make decisions when noticeable differences are observed between their interpretation of a symptom and that symptom as reported by the patient.

References

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Synopsis

MA Petersen, H Larsen, L Pedersen, et al. (2006) **Assessing health-related quality of life in palliative care: comparing patient and physician assessments.** *Eur J Cancer* 42:1159–1166

Background. Assessment of the efficacy of palliative care measures is subject to a number of biases, linked to difficulty in patient recruitment and the severe attrition that must be expected because of deterioration in patient condition or early death. Although patients' assessment of their own quality of life must be considered the 'gold standard', the use of 'proxy' assessments (e.g. from nurses, clinicians or family) could improve the range and applicability of studies in palliative care. It is important for accuracy, however, that these proxy assessments concur with patients' own ratings.

Objective. To determine the reliability of physician assessments of patients' health-related quality of life (HRQOL) in palliative care compared with patient assessments.

Design. This was a longitudinal study in adult palliative care patients with breast, colorectal, gynaecological, head and neck, lung or other cancers, seen at a single centre and being managed as inpatients, outpatients, or with home care.

Intervention. Between June 1998 and August 2003, patients and physicians completed questionnaires including items from the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ)-C30, at their first contact, and then weekly for 13 weeks or for as long as the patients wished or were able to continue.

Outcome measure. The outcome measure for this study was the degree of agreement between patients' and physicians' assessment of HRQOL at first contact and for the following 13 weeks of care.

Results. At the first assessment, 115 patients met the inclusion criteria. A high number of patients were not able to complete 13 full weeks of the study (only around 25% of patients were still alive 13 weeks after referral); therefore, the authors focused primarily on the initial questionnaire and used data from the further time points (weeks 1–13) to verify their findings. Agreement between patients and physicians was poor overall. Patient and physician assessments were significantly different for all HRQOL domains assessed ($P < 0.01$ for all). Generally, physicians judged that patients had fewer symptoms and better functioning than did their patients, the exceptions being physical and social functioning. The smallest absolute differences (indicating better reliability) between physician and patient assessments were seen for physical functioning, nausea/vomiting and constipation, and the largest absolute differences were seen for insomnia and two psychosocial scales: emotional and social functioning. The overall agreement between patient and clinician for the period of time following admission was no better than at the admission consultation.

Conclusion. The authors conclude that, despite their experience, physicians working in palliative care have very different perceptions of patients' HRQOL than do their patients themselves. The use of physician assessments in palliative care studies may bias findings and should not be considered a viable alternative to patient self-assessment.

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