

Journal Watch

Are the Most Distressing Concerns of Patients With Inoperable Lung Cancer Adequately Assessed? A Mixed-Methods Analysis

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J Clin Oncol 2010; 28:1942-1949.

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Reviewed: Tertiary Palliative Care Unit 43, Grey Nuns Community Hospital
December 1, 2010

ABSTRACT

Purpose: Standardized questionnaires for patient-reported outcomes are generally composed of specified predetermined items, although other areas may also cause patients distress. We therefore studied reports of what was most distressing for 343 patients with inoperable lung cancer (LC) at six time points during the first year postdiagnosis and how these concerns were assessed by three quality-of-life and symptom questionnaires.

Patients and Methods: Qualitative analysis of patients' responses to the question "What do you find most distressing at present?" generated 20 categories, with 17 under the dimensions of "bodily distress," "life situation with LC," and "iatrogenic distress." Descriptive and inferential statistical analyses were conducted.

Results: The majority of statements reported as most distressing related to somatic and psychosocial problems, with 26% of patients reporting an overarching form of distress instead of specific problems at some time point. Twenty-seven percent reported some facet of their contact with the health care system as causing them most distress. While 55% to 59% of concerns reported as most distressing were clearly assessed by the European Organisation for Research and Treatment for Cancer Quality of Life Questionnaire Core-30 and Lung Cancer Module instruments, the Memorial Symptom Assessment Scale, and the modified Distress Screening Tool, iatrogenic distress is not specifically targeted by any of the three instruments examined.

Conclusion: Using this approach, several distressing issues were found to be commonly reported by this patient group but were not assessed by standardized questionnaires. This highlights the need to carefully consider choice of instrument in relation to study objectives and characteristics of the sample investigated and to consider complementary means of assessment in clinical practice.

Strengths:

- Large sample size (n=343) with repeated measures (six time points)
- Use of a qualitative approach (i.e. open-ended question) to assess patients' most distressing concerns

Weaknesses:

- Limited generalizability (sample limited to patients with inoperable lung cancer)
- Potential sample selection bias (recruitment from university hospital outpatient settings; sample was younger and survived longer than cancer registry population)
- Drop out rate not reported

Relevance to Palliative Care:

Palliative care patients may not always disclose all of their distressing symptoms if they are not asked directly about them. In addition, some concerns may not be directly addressed using standard symptom assessment measures, such as the Edmonton Symptom Assessment System (ESAS), which focuses on symptom intensity as opposed to symptom distress. This study provides support for asking a general open-ended question regarding distressing concerns (i.e. "What do you perceive as most distressing at present?").