

# Patient-Reported QOL Assessment: Sufficient for Clinical Decision-Making?

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*Commentary on "Quality-of-Life Assessment for Routine Oncology Clinical Practice," by Halyard and Ferrans (page 221).*

**D**rs. Halyard and Ferrans argue for the clinical value of patient-reported quality-of-life (QOL) assessment in oncology practice settings. Similar to the work on the prognostic value of patient self-reports of functional status in understanding mortality in frail elders,<sup>1-4</sup> the authors base their argument on findings that patient-reported QOL can contribute unique information to predictions of cancer morbidity and mortality, information that is not provided by other indicators (eg, histologic findings, clinical data).

Because the authors approach QOL concepts from the perspective of clinicians and patients making decisions about oncology care, clinicians will find the paper informative, even if they are knowledgeable about QOL outcomes from clinical trials. In fact, this paper represents a welcome shift from regarding QOL as an outcome to regarding it as a process. This commentary considers how the concepts of patient preferences and

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proxy judgments of QOL might be used to enrich the Halyard and Ferrans framework and thus provide a stronger model for implementing QOL assessments in the clinical setting.

The paper presents several lines of evidence that provide a foundation for understanding the clinical value of QOL assessment—research on the contribution that QOL information makes in decisions about aggressive therapy as well as randomized controlled trials that examine the usefulness of QOL in clinical management. The authors posit that patient reports about QOL provide objective information that overcomes the biases inherent in clinician judgments. For example, clinicians may be reluctant to pursue aggressive therapy because of concerns about toxicities. In these situations, if ongoing patient-reported QOL reveals little negative impact of treatment, the clinician could recommend continuing therapy without undue concern about patient burden.

### Ways to Determine QOL

In spite of evidence for the value of patient-reported QOL, the paper does not present a clear picture of how patient-reported QOL should be incorporated into the clinical setting. Toward this end, two models in particular may be considered. In one, the clinician would base treatment recommendations upon patient-reported QOL assessments. In another, a shared decision-making model, the clinician and the patient would discuss the patient's QOL assessments and work together to make a treatment decision. A key feature of shared decision-making is that it incorporates patient preferences for QOL outcomes. Patient preferences are important when treatment alternatives differ in characteristics and expected health outcomes; thus, patients and clinicians must consider complex tradeoffs among treatment characteristics and outcomes when making clinical decisions.

Patient-reported QOL and patient preferences have been described as distinct, yet complementary, constructs.<sup>5,6</sup> Patient-reported QOL assessments provide information about patient experiences, functions, and feelings of well-being. In contrast, patient preference assessments provide information about preferred QOL outcomes as they relate to other outcomes. If QOL assessments are not accompanied by either patient-clinician discussion or formal assessment of patient preferences, then information gathered from these assessments may not be used easily in individual decision-making—this strategy only imparts information to clinicians and patients on well-being and functioning, but it offers no information on patients' preferences about future cancer care. Thus, assessment of patient preference is critical to the use of QOL assessments when deciding upon oncology treatment.

### Perspectives of QOL

The authors also make an important conceptual distinction between patient reports and proxy reports of patient QOL. They argue that the implementation of QOL assessment in clinical practice should be based upon direct patient reports.

Further, they describe several limitations of relying upon proxy reports of patient QOL. In one review of studies examining patient QOL according to the judgment of proxies,<sup>7</sup> Sprangers and Aaronson noted low correspondence between reports by patients and proxies—the proxy reports tended to underestimate patient distress and functional difficulties.

Along with others, we have argued that the value of a proxy QOL judgment may be based upon two perspectives—the proxy-patient perspective and the proxy-proxy perspective.<sup>8-10</sup> The proxy-patient perspective pertains to information that the proxy thinks would be reported by the patient, whereas the proxy-proxy perspective refers to an outside impression of the patient's QOL—which may be different from that of the patient. The proxy-proxy perspective is important, because it may supply valuable outside information about a patient's condition and experience. For example, a patient may become accustomed to a symptom, such as pain, and may become less aware of its full burden, but a proxy may provide information that has unique clinical value; in this case, a proxy may observe that a patient is not sleeping or is unable to enjoy close relationships because of pain, and this valuable information may result in adjustment of pain medication. Thus, whereas a patient's QOL self-reporting and preferences may stand as the “bottom line” when making clinical decisions, proxy information may offer a clinically meaningful and expanded view of the patient's experience.

### Shifting the Focus

Drs. Halyard and Ferrans urge that the value of patient-reported QOL be considered in the clinical oncology setting, and this viewpoint represents an important shift in cancer care. They provide a strong rationale and exemplary models for viewing QOL as a clinical process instead of as an outcome. Their paper provides a foundation for integrating QOL assessments into clinical practice and overcoming many possible barriers.

Nonetheless, the paper's emphasis on patient-reported QOL as the exclusive source of information about the patient for clinical decision-making does not acknowledge the unique role of patient preferences and proxy judgments in the clinical setting. Thus, this commentary takes the perspective that patient self-report of QOL is an important, but insufficient, component of clinical decision-making. A more comprehensive conceptual framework of QOL used in deciding between treatment options, therefore, would incorporate both patient preferences and proxy judgments of patient QOL.

### ACKNOWLEDGMENTS

Sara J. Knight is supported by a VA Health Services Research IIR award (02-142-1) and her work on this paper was supported by the resources and facilities of the Program to Improve Care for Veterans with Complex Comorbid Conditions at the San Francisco VA Medical Center.

The contents of this work are solely the responsibility of the author and do not necessarily represent the official views of the Department of Veterans Affairs.

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