Measurement Issues in Quality-of-Life Assessments

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Purpose/Objectives: To describe issues to be considered when measuring the quality of life (QOL) of patients with cancer.

Data Sources: Published articles and books, conference proceedings, and abstracts.

Data Synthesis: A review of the existing literature reveals an emerging field of research and considerable discussion of measurement issues. Consensus is growing about measurement approaches to this subjective concept; however, agreement differs regarding specific aspects of measurement approaches and interpretation of data.

Conclusions: The purpose of the QOL assessment and how the data will be analyzed are the main determinants of the choice of assessment and measurement approaches. Differences regarding how QOL is measured may be encountered based on a clinical or research purpose.

Implications for Nursing: QOL assessments may be used as part of data collection to address a specific research question or may be used to guide clinical practice. Research findings used to guide clinical practice should be evaluated for validity, reliability, and fit of the sample before being incorporated into clinical practice. QOL assessment in clinical practice may be used as an exploratory tool to identify potential problems or may be used to evaluate the effectiveness of a targeted intervention.

Key Points . . .

- ➤ Significant advances have occurred since the mid-1990s in the assessment and measurement of cancer-related quality of life.
- ➤ The science of quality-of-life assessment is evolving; however, no gold standard currently exists for measurement methodology.
- ➤ The purpose of an assessment will determine the appropriate methods to be used.

Quality-of-life (QOL) measurement very often is included in overall assessments as clinicians and researchers, especially in cancer care, strive to better patient outcomes when improvement in disease state may be limited with current therapies or the risk of untoward effects of experimental therapies may be high. To contribute to improved patient outcomes, QOL assessments for research or clinical purposes must be based on sound methods, use reliable and valid approaches, and have findings that are valid and consistent with the measurement approach. This article will discuss the methodologic components that contribute to valid and useful QOL assessment.

QOL assessment has become a central concept in clinical trials and clinical practice. In 2000, a survey of Oncology Nursing Society members identified QOL as the second most important research priority for the organization (Ropka et al., 2002). In a more recent survey to determine the Society's research priorities for 2005–2008, QOL was the most important priority (Berger et al., 2005). In 1995, the Oncology Nursing Society convened a State-of-the-Knowledge Conference to address QOL issues from theoretical, research, clinical, and educational perspectives (King et al., 1997). The group identified definitional and methodologic issues that must be considered and resolved before QOL assessments could be included among the standard assessments that lead to clinical decisions. Other groups have examined the measurement issues related to QOL assessments that are barriers to the adoption of QOL assessment as a standard of care (Mayo Clinic, 2002). Some of the identified barriers are gaps in language and communication between the research literature and clinicians, the absence of unified guidelines for the interpretation of QOL assessments, the availability of numerous instruments without consensus regarding which to use, the addition of a QOL measure to patient assessments without attention to scientific methods, and the perception of QOL assessment as an added burden without added value.

The measurement issues related to QOL assessments are associated with the complexity of the concept. Less agreement exists regarding the exact definition of what constitutes QOL for an individual (Chauhan, Eppard, & Perroti, 2004; Ware, 2003) (see Figure 1). The lack of consensus may be because QOL is an evolving phenomenon. As experts have learned more about QOL, its concepts and descriptors have changed. Additionally, QOL must be considered in the context of the healthcare experience (e.g., disease, treatment). The World Health Organization (1993) defined QOL as a state of complete physical, mental, and social well-being, not merely the absence of disease and infirmity. Five dimensions or domains of the concept generally have been agreed on in the literature: physical functioning or well-being, psychological well-being, social role functioning or well-being, disease- and treatment-related symptoms, and spiritual well-being (Ferrans, 1990a, 1990b; Haberman &

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