

FAST FACTS AND CONCEPTS #52 QUALITY OF LIFE

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Introduction 'Quality of life' is a term commonly used by health professionals when trying to help patients and families make decisions concerning care near the end of life. Formal studies using quality of life instruments are increasingly common in clinical trials, typically used as an outcome measurement before and after treatment. Implicit is the notion that if quantity of the time left cannot be increased, then quality of life should be maximized. But what does 'quality of life' (QOL) mean, and how should clinicians use this information in decision making?

Aspects of QOL There are two key concepts about QOL: it is multi-dimensional and most appropriately determined by the patient. Although family members, physicians and other health professionals can make significant observations about QOL, studies consistently document important variances between patient and surrogate defined QOL.

A quality of life assessment can be considered *a review of systems of the patient's world*. The multi-dimensional aspects of QOL can be assessed by asking questions in the following key domains: physical, functional, emotional, social, and spiritual/existential. The sum of these questions can be a "snapshot" of the patient's world and give the clinician an idea of what is important to a patient, what limits them, and what goals of care may be meaningful. Medical interventions usually affect physical and functional well-being.

Measures of QOL Many instruments specifically designed for palliative care patients are available to measure what QOL means for patients nearing the end of life. Unfortunately, most of these instruments have not been adequately validated. A systematic review showed that the Missoula VITAS-QOL, the QUAL-E, and QODD had the best ratings. While QOL instruments (questionnaires) have been developed for many conditions, a few basic open ended questions can be helpful in talking to patients:

- *How has your disease interfered with your daily activities?* (Functional domain)
- *Have you been getting along with family and friends as a result of your illness?* (Social)
- *Have you been feeling worried or sad about your illness?* (Emotional)
- *Have you been feeling sick or bedridden because of your illness?* (Physical)
- *How much or which symptoms bother you the most?* (Physical)
- *How have your religious beliefs been affected by your illness?* (Spiritual/existential)
- *Do you find yourself wondering what is the meaning of all this?* (Spiritual/existential)

Final words Patients almost always appreciate having the chance to discuss these issues with their doctor. For one thing, asking these questions tells patients that the physician has an interest in their well being that goes beyond the actual disease. Physicians who have a better understanding of the totality of the disease-experience for the patient (which is another way of reframing the meaning of QOL), will be better prepared to care for patients near the end-of-life.

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