

Virtual Mentor

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From the Editor

Measuring the Unmeasurable? Quality of Life and Medical Decision Making

The traditional objective indicators of clinical success and effectiveness, from which the physician drew his treatment decisions in the past decades, were based on quantitative parameters like mortality rate or length of survival, biological or physiologic measures, or improvement in clinical findings. Recently, however, a paradigm shift has taken place: traditional objective measures and the judgement of the physician are being replaced by patients' evaluations of physical functioning and overall health as the main factors in the decision making process and the assessment of a treatment's success [1, 2]. This change was accompanied by a philosophical shift in health-related thinking: while previous medical thinking emphasized disease and focused on physician appraisal of health states, this new line of thought emphasizes health, functioning, and well-being that is centred around the patient's coping resources and evaluation of health [3-7]. The physicians' job, as professor M. Sullivan from the University of Washington said, is "to focus on patients' lives rather than patients' bodies" [8].

This paradigm shift arose from an awareness that neither objective medical outcome measures nor we as physicians can say unequivocally what is the best for the patient. When engaging in clinical decision making, physicians tend to value primarily information about the effect of treatments on physiological functioning and disease progression, rather than information about the impact on the patient's quality of life [9-11]. Without having some idea about how the patient values his or her quality of life at present, however, physicians cannot determine what treatment will most benefit the patient [12-13]. What we view as best for the patient must inevitably include a quality-of-life component because what we call medically indicated treatments presuppose certain values and certain standards of quality of life that may not be true for every patient. Quality-of-life considerations do not only take place in extreme medical situations such as withdrawal of treatment in severely disabled newborns or in patients in a persistent vegetative state, but are part of every treatment consideration for each physician in everyday clinical life. This issue of *Virtual Mentor* explores subtle quality-of-life considerations as well as the philosophical claims about measuring such perceptions and the practical aspects of using quality-of-life rankings when attempting to allocate resources.

Our clinical cases illustrate the importance of quality-of-life considerations at the beginning, middle, and end of life. The question of how certain health states and treatments impact our quality of life spans across the years: how should we, for example, decide about a treatment that, statistically, confers benefit but may impair the quality of our successful, busy lives as adults during our best years?

In clinical decision making, quality of life serves not only as an ethical guide but also as a valid and reliable empirical measure of health status that supplements traditional objective measures. The clinical pearl exemplifies the role that quality-of-life scores play in both clinical research and especially in the individual patient-physician relationship and in the decision-making process.

One of the major challenges for physicians when dealing with quality-of-life measures is that many patients with serious and persistent disabilities report that they experience a good or excellent quality-of-life, when to external observers these individuals seem to have a diminished quality of life. Two articles examining this disability paradox [14] are critiqued here by 3 researchers. Following those discussions, we invited an author of one of the target articles to respond to the critique.

In Oregon's attempt to cover more people on its government-funded Medicaid plan and find an ethically justifiable way of fairly distributing scarce health care resources, the concept of quality-adjusted life years (QALYs) was employed. The question of using the QALY approach as the basis of an effective and just health care allocation system is analyzed by 3 authors; from the public health and the philosophical perspectives and from the point of view of its practical use as a policy tool.

In looking over the entire issue, there seems to be a specific dilemma surrounding quality-of-life assessments: On one side, physicians implicitly use quality-of-life measures in treatment decisions and also integrate the patients' own evaluation of health status into clinical decision making. On the other side, the idea that one can measure quality of life seems to be an incoherent, or, at least, a flawed one, whose variables are very difficult for the physician to analyse, to control, and, thus, to integrate into clinical decision making.

So how do you think we should resolve this dilemma? Should we abandon quality-of-life scores as a valid and promising clinical tool, or should we continue looking for disease and population-specific measures that can help us to integrate the patient's best interest into our clinical decision making? Read this issue and make up your own mind.

Matthis Synofzik

References

1. Abbott JA, Hawe J, Garry R. Quality of life should be considered the primary outcome for measuring success of endometrial ablation. *J Am Assoc Gynecol Laparosc.* 2003;10:491-495.
2. Bombardier C. Outcome assessments in the evaluation of treatment of spinal disorders. Introduction. *Spine.* 2000;25:3097-3099.
3. Greenfield S, Nelson EC. Recent developments and future issues in the use of health status assessment measures in clinical settings. *Med Care.* 1992;30 (5 Suppl):MS23-41.
4. Hollnagel H, Malterud K. Shifting attention from objective risk factors to patients' self-assessed health resources: a clinical model for general practice. *Fam Pract.*

1995;12:423-429.

5. Nelson ND, Trail M, Van JN, Appel SH, Lai EC. Quality of life in patients with amyotrophic lateral sclerosis: perceptions, coping resources, and illness characteristics. *J Palliat Med.* 2003;6:417-424.
6. Bovier PA, Chamot E, Perneger TV. Perceived stress, internal resources, and social support as determinants of mental health among young adults. *Qual Life Res.* 2004;13:161-170.
7. Hesselink AE, Penninx BW, Schlosser MA, et al. The role of coping resources and coping style in quality of life of patients with asthma or COPD. *Qual Life Res.* 2004;13:509-518.
8. Sullivan M. The new subjective medicine: taking the patient's point of view on health care and health. *Soc Sci Med.* 2003;56:1595-1604.
9. Van der Molen T, Pieters W, Bellamy D, Taylor R. Measuring the success of treatment for chronic obstructive pulmonary disease--patient, physician and healthcare payer perspectives. *Respir Med.* 2002;96 Suppl C:S17-21.
10. Rameckers E. Using health outcomes data to inform decision-making: patient perspective. *Pharmacoeconomics.* 2001;19 Suppl 2:53-55.
11. Solomon MJ, Pager CK, Keshava A, et al. What do patients want? Patient preferences and surrogate decision making in the treatment of colorectal cancer. *Dis Colon Rectum.* 2003;46:1351-1357.
12. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *JAMA.* 1995;273:59-65.
13. Beauchamp T, Childress J. *Principles of Biomedical Ethics.* 5th ed. New York, Oxford: Oxford University Press; 2001:113-164.
14. Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med.* 1999;48:977-988.

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