

The Unanswered Challenges in Measuring Quality of Life

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The measurement of health status and quality of life is a major challenge facing health researchers. The task is to locate individuals within life space and show how health-related events impact on their life space. The specific quest is for measures sensitive to changes in health status/quality of life that can be attributed to health problems and interventions. Pharmaceutical companies must demonstrate, to the agencies responsible for approving drugs, the impact of their products on the quantity and quality of life. Researchers need responsive, sensible instruments for assessing the efficacy and effectiveness of interventions in randomized controlled trials and clinical studies. Providers, managers, and policy-makers need to know the cost-effectiveness of interventions and programs. Outcomes information systems are introducing measures into managed care in the United States, for purposes of both management and marketing. National organizations in the United States, such as the National Council for Quality Assurance and the Foundation of Accountability, are requiring report cards for managing care that include assessments of outcome.

The creation, adaptation, and testing of measures has been a growth industry in Europe and North America over the past 20 years, as evidenced in publications, presentations at conferences, peer-reviewed grants, industry funding, graduate theses, seminars, workshops, consulting activities, and the commercialization of specific products. International collaborations and networks of providers are being formed to create new measures. Researchers and commercial enterprises compete for their share of the academic and private markets.

One might wonder about the state of the quest for measures. There is general agreement that health should be conceptualized in terms of physical, mental, and social well-being, rather than just the absence of disease (World Health Organization, 1958). There is further agreement that quality-of-life assessments should include measures of general health status, disease-specific measures, and measures of patient pref-

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erences. Spilker's (1996) edited work covers 215 measures. Bowling (1995, 1997) and McDowell and Newell (1996) offer thoughtful guides to the use of the more established measures. An entire journal, *Quality of Life Research*, is dedicated to the subject and several major journals have published special issues on it. My bookshelves hold more than 30 volumes related to the measurement of health status and quality of life, and my holdings are by no means exhaustive.

The range of measures reflects four basic strategies in creating them: psychometric methods, clinimetric methods, deriving utilities, and Rasch modelling. In the absence of objective criteria for health status/quality of life, researchers have adapted items from existing measures and created items to reflect theoretical domains and concepts of interest. Psychometric methods are used for reducing the number of items, identifying the factors or facets of the underlying structure of the responses, and testing the internal consistency of the responses. The measures are correlated with pre-existing measures to establish construct validity. Clinimetricians select items based on occurrences of symptoms and problems reported as important by providers and patients, or in other studies. The items are specific to the disease and interventions of interest, and they are gauged on clinical criteria. The selection and weighting of the final items are based in part on the declarations of importance. Validity is determined by how well the measures predict clinical outcomes. Researchers, working from concepts of economics and decision theory, derive utilities for given health states based on patient preferences. Typically, the methods produce a single value for each health state, ranging between 0.0 for death and 1.0 for perfect health. The standard gamble is the "cardinal method," as it is theoretically tied to the axiomatic theory of Von Neuman and Morgenstern (Drummond, O'Brien, Stoddart, & Torrance, 1997). Other measures are based on time-tradeoff methods, multi-attribute theory, and rating scales. Researchers employing the Rasch model for item-response theory focus on the scoring of responses of items, so the items can be weighted to reflect degree of health and quality and the respondents can be rated and scored on the underlying dimension of interest.

Brock (1995) summarizes the current state of the quest as follows: "While that literature provides little in the way of well-developed, philosophical accounts of the quality of life or of a good life, it is a rich body of analysis, data, and experience on which philosophical accounts of a good life can draw." While there is reference to the World Health Organization dimensions, researchers focus on the physical and mental dimensions of health, giving nominal attention to social dimensions.

There are attempts to broaden the definition and domains or attributes, such as the WHO Quality of Life Instrument (Szabo, 1996), and to recast the items accordingly, but this is a fledgling international collaboration. If we knew the dimensions of life, we could begin to focus on the precision with which location and motion might be measured.

Random error in the measurement of key endpoints increases the size and costs of studies (Fleiss, 1986) and the difficulty in using the results to make key decisions in clinical policy and management of individuals (Nunnally, 1978). While authors have defined the uses of the measures and have set stringent standards for the reliability and validity of responsiveness, most researchers ignore these and cite instead the standards of 25 years ago, for the initial development of measures (Kane & Kane, 1981; McDowell & Jenkinson, 1996; McHorney & Tarlov, 1995; Williams & Naylor, 1992; Wright & Feinstein, 1992).

Responsiveness is the Achilles' heel of measurement. A measure is responsive if it mirrors the status of individuals over time, whether it changes or not. It is difficult to identify true change and no change from random fluctuations in scores. I think this is so for two reasons. First, we drift in life; our points of view change subtly as we move through our experiences. Summary assessments of functioning, activities, moods, and feelings over the previous week or month may well shift from one time to another without assessment being either "wrong" or "unreliable." Second, as we encounter significant health events, our perspective or frame of reference may well shift. Even though a hip or knee may not work as well after total joint replacement as the normal joint, an individual can alter expectations for performance and redefine health status and quality of life accordingly. Qualitative researchers may have to provide quantitative researchers with directions as to how to reconstruct their concepts and methods (Kessler & Mroczek, 1996).

A reformulation of the theory and concepts of health status and quality of life is required, and the theory and concepts should stem from an idea of the good life. The advance of strategies and tools is contingent upon new ideas being in place rather than the constant production of new tools for old concepts. This is what the quest for quality of life should be about.

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