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Title: Evaluation of health-related quality of life

Authors: Tol Azar, PhD Student, Medical University of Isfahan
Shojaeezade Davood, PhD, Tehran University of Medical Sciences
Sharifirad Golamreza, PhD, Medical University of Isfahan

Abstract: Introduction

Quality of life has an inherent meaning to most people. It is comprised of broad concepts that affect global life satisfaction, including good health, adequate housing, employment, personal and family safety, education, and leisure pursuits. For matters related to health care, quality of life has been applied specifically to those life concerns that are most affected by health or illness, hence the term "health-related quality of life" (HRQL).

DEFINING HRQL — HRQL can be formally defined as: "The extents to which one's usual or expected physical, emotional and social well-being are affected by a medical condition or its treatment". This definition incorporates the two widely accepted aspects of quality of life: subjectivity and multidimensionality.

HRQL represents a subjective appraisal of the impact of illness or its treatment; individual patients with the same objective health status can report dissimilar HRQL due to unique differences in expectations and coping abilities. As a result, HRQL must be measured from the individual's viewpoint rather than that of outside observers (ie, caregivers or healthcare professionals). Multidimensionality is the other important component of HRQL. The multidimensionality of HRQL is reflected in the work of the Patient Reported Outcomes Measurement Information System (PROMIS) Cooperative Group, an NIH-funded national effort that has produced a comprehensive, conceptual framework of self-reported health.

MEASURING HRQL — A vast array of validated and reliable questionnaires are available for assessment of HRQL. They include generic health status instruments, generic illness instruments, and disease-specific instruments.

Generic health status — Generic health status questionnaires are applicable to all populations and can be completed by individuals both with and without medical illness. These instruments provide benchmarks for comparison across diverse groups, such as healthy and ill populations, or different age groups. Examples include the Nottingham Health Profile (NHP) and the Short Form-36 (SF-36) from the Medical Outcomes Study.

Generic illness — Generic illness instruments are applicable to populations with any medical illness or condition, and can be used to compare different illnesses, levels of disease severity, or types of interventions. Such cross-disease comparisons are increasingly important in the allocation of limited healthcare resources. In addition to measuring general health status, these instruments typically assess the individual's perception of the functional impact of the illness or disability. Examples include the Sickness Impact Profile (SIP) and the Functional Assessment of Chronic Illness Therapy (FACIT).

Disease-specific — Disease-specific measures are designed to assess the QOL of individuals with specific illnesses (eg, cancer, diabetes), specific types of treatment (eg, chemotherapy, lung transplant), or specific symptoms (eg, nausea, urinary incontinence). Compared to other types of instruments, these measures provide a more detailed assessment for specific diseases and are also likely to be more sensitive to specific treatment-related changes in HRQL.

Conclusion

Combined instruments for patient-reported outcomes

PROMIS — The Patient-Reported Outcomes Measurement Information System (PROMIS), presents a new set of multidimensional HRQL instruments that combine features of the three categories above. Normed on the general United States population, PROMIS instruments are applicable across chronic illness populations in addition to having cancer-specific scales.

Neuro-QOL — The Quality of Life in Neurological Disorders (Neuro-QOL project) is a similar effort to PROMIS, funded by the National Institute of Neurological Disorders and Stroke, to develop and test HRQL instruments that are applicable across the many neurological conditions. Utilizing a methodology similar to PROMIS, these instruments are currently being tested in five adult and two pediatric diseases (stroke, amyotrophic lateral sclerosis [ALS or Lou Gehrig's disease], multiple sclerosis, Parkinson's disease, adult and pediatric epilepsy, and the muscular dystrophies). It is hoped that the resulting HRQL tools will be used to facilitate the comparison of results from clinical trials and other clinical research across conditions.

Evaluation, Health-related quality of life, Measurement

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