



## The concept of quality of life in oncology

David Osoba

University of British Columbia, Vancouver, Canada;  
Address correspondence to: David Osoba, MD, QOL  
Consulting, Retired Professor of Medicine, University of  
British Columbia, Vancouver, BC, Canada, 4939 Edendale  
Court, West Vancouver, BC, Canada, V7W 3H7, E-mail:  
david\_osoba@telus.net; The manuscript was received:  
15.08.2004, Accepted for publication: 15.09.2004

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**KEY WORDS:** *Quality of life; Medical Oncology; Quality-Adjusted Life Years*

In oncology, as in other medical specialties and health care professions, it is now generally accepted that quantity of life (survival), while extremely important, is an insufficient way of describing the total outcome of health care interventions. The development of reliable and valid instruments (usually in the form of self-report questionnaires) to describe the quality of patients' lives gives clinicians the ability to use this equally important outcome in addition to survival. Thus, it is this technological advance that is responsible for the burgeoning of health-related quality of life (HRQOL) assessment in health care. It is now common, particularly in oncology, to measure both survival and HRQOL.

The term "HRQOL" was first used in the 1970's, but became common only about 10 years ago. Initially, single dimensions of life, such as performance status or depression, were used either alone or as a battery of tests that were administered by trained assistants or by clinicians themselves. The next important step was to develop brief (30-40 items) self-administered multidimensional questionnaires that asked patients to rate their own assessment of functioning in at least the physical, emotional, and social domains of life. Some questionnaires added other items pertaining to domains such as cognitive functioning and to symptoms. It is now accepted that multidimensional, self-rating instruments are the best way to measure HRQOL.

The clinical settings in which HRQOL assessment is used are very varied, extending from primary prevention and screening, through to active treatment for cure or for prolonging life, to symptom control and palliative care. Assessment of HRQOL is well accepted in studies of symptom control, but some have questioned its use in active treatment to cure or even in palliative care.

Treatment designed to cure or to prolong life is definitively tested in randomized, controlled clinical trials and is usually judged by its effect on survival and its toxicity as compared to a standard treatment. However, many new chemotherapy agents do not turn out to meaningfully improve survival as compared to the standard treatment. It is in these situations that HRQOL often tips the balance in favour of either the new or the old treatment. Furthermore, significant toxicity, as judged by the trial personnel, is sometimes not the same as the side effects of treatment reported by the patients in HRQOL questionnaires.

In palliative care, some have questioned the need for HRQOL assessment, since it would

seem obvious that the control of bothersome symptoms should be sufficient. However, in this setting, symptoms still need to be fully reported. The control of one major symptom, e.g., pain either may be accompanied by side effects, or may unmask the presence of another symptom that was less evident, e.g., fatigue. HRQOL assessment, particularly in clinical trials in palliative care, should provide comprehensive information about the patients' responses to treatment or other interventions.

Recent advances in assessing HRQOL include the reporting of domain or symptom scores during and after treatment as a change from the pretreatment (baseline) scores, and the use of the subjectively significant difference (minimally important difference) as a means of determining the proportions of patients who improve and deteriorate after treatment.

The use of change scores produces a dynamic picture of how HRQOL domains are affected during treatment. If only group mean scores are presented, then the results often reflect a "survivor" effect, because of the dropout over time of patients who are relatively unwell and the selective survival of patients who are in better health. However, change scores take into account variation in individual patients' baseline scores. Baseline scores vary from individual to individual because of the varying extent and effects of the disease, and subsequent changes in the trajectory of the illness are often reflected by baseline scores and need to be taken into account. Unless a treatment is highly effective, patients with low baseline scores are more likely to succumb to their disease than are those with high baseline scores. Since the latter patients are more likely to survive longer, the mean group scores over time will artificially rise. The use of change scores partially corrects this difficulty.

The subjectively significant difference (SSD) is a way of interpreting the clinical meaning of changes in scores for an individual patient. In studies of the SSD and the minimally important difference (MID) in a variety of cancers and other diseases, it was found that patients could perceive a change of about 6-7% in a score as being a change over time. It has been suggested that a 10% change in the SSD is a safe cut-off to use in clinical trials when planning to determine the proportions of patients whose HRQOL scores have either improved or deteriorated. Subsequently, it has been suggested that approximately 0.5 of a standard deviation of the scale score is a reasonable statistical cut point for determining significant change. A major area of continuing research is how to deal with missing data. This is a

common problem in oncology where patients drop out because of the progression of disease or because of treatment toxicity. This kind of missingness is unavoidable and statistical techniques are one way of dealing with it. However, some missing data is avoidable, i.e., it is caused by failure to have patients complete questionnaires even when they are still able to do so.

Today, the "hottest" area of research is the development of large item banks that can be accessed by patients using computer adaptive testing (CAT) based on Item Response Theory. This procedure is designed to have an individual answer the fewest number of items that will correctly place the individual's score on a continuum ranging from 0-100 in each domain. However, until such time as CAT is available for a very broad range of conditions and diseases, most of us will have to rely on the pencil and paper method or, perhaps, the use of touch sensitive computer screens for our patients to complete HRQOL questionnaires. Even when CAT is widely available, the clinical meaning of changes in scores will still need to be addressed.

Utility measurement is also a way of assessing HRQOL. Its primary use has been to provide a single score, which when combined with length of survival, will result in a single number, such as quality-adjusted life years (QALY). This can be combined with economic analyses for purposes of health policy decision-making.

HRQOL assessment is not yet a part of routine day-to-day practice, although it has been shown to be feasible and useful in the hospital clinic setting. The questionnaire can be given to patients at the time of their clinic visit and completed on computers or hand held devices equipped with touch sensitive screens. The data is then analyzed immediately and given to the patient's doctor and nurse. Patients feel that communication is improved when their doctor has HRQOL results from the clinic visit to review at the time of the interview.

#### SUGGESTED LITERATURE

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