Volume 7 • Supplement 1 • 2004
VALUE IN HEALTH

# The Needs-Based Approach to Quality of Life Assessment

Stephen P. McKenna, PhD, Lynda C. Doward, BSc

Galen Research, Manchester, UK

The question of how life gains its quality has been raised by philosophers throughout history. As early as the fourth century B.C., Socrates declared that there were some things he feared more than death and that it is not life itself but the quality of that life that counts most. For Socrates, facing the death sentence at the Athenian court, it was moral merit that gave "quality" to his life [1]. Other eminent philosophers, including Aristotle, Bentham, More, and Royce [2–5] have debated whether there are "universal goods" that improve the life of all people and on who should be the judge of such improvements [1].

The last quarter of the 20th century has seen a dramatic increase in interest in quality of life (QoL). It is now difficult to identify a sphere of life or area of academic study where the term is not used. For many western societies QoL has become an accepted colloquialism used in everyday language [6]. In academia, questions of definition, methodology, and motives for its measurement have been heatedly debated from the perspectives of a variety of disciplines. Aiken [7] observes that the popularity of QoL in contemporary debates has crossed diverse areas such as medical ethics, environmental ethics, and moral issues in law and social justice. Häyre [8] and Bubolz [9] report on the divergent interests in QoL of social scientists, psychologists, economists, moral philosophers, environmentalists, and political scientists. In particular, Häyre reports that social scientists and psychologists are predominately interested in definitions and methods, while moral philosophers have concentrated on the motives for defining and measuring human QoL and on the ethical questions that arise from such measurement.

Advances in medical technology and improvements in public health have eradicated, or reduced the significance of, many life-threatening infectious diseases in the developed world. Western health and social care systems are now increasingly concerned with the treatment of chronic, disabling conditions associated with an aging population. In addition, patients' perceptions of the impact of treatment are being given greater emphasis, as it is recognized that they have ultimate responsibility for major decisions taken in connection with their own health. Where medical interventions and health care programs are designed to make life more comfortable rather than to cure, interest now focuses on QoL outcomes.

The first clinical publications incorporating the term QoL appeared in the 1960s. Wider acceptance was gained in the 1970s when QoL was introduced as a heading on MEDLINE in 1975 and accepted as a concept by Index Medicus in 1977. The number of MEDLINE publications using QoL as a keyword has grown exponentially since then. Between 1965 and 1974 only 64 MEDLINE publications used the term. This rose to 5083 publications between 1981 and 1990, with 8136 published between 1991 and 1996 and over 10,000 in 2002.

This vast interest in QoL belies the fact that the construct is still beset by theoretical disagreement. Definitions of QoL, methods of assessment, and the quality of investigation vary widely. In many cases, the term is applied inappropriately, without theoretical foundation. This has led some authors to conclude that current disagreements on the meaning of QoL are indicative of a lack of direction rather than of a healthy diversity of opinion [6].

The purpose of the current issue is to describe and illustrate one of the most widely implemented approaches to quality of life assessment—needs-based QoL. Despite this approach being widely used and published in the QoL and medical literature no document has previously attempted to bring together the body of research that has been undertaken over the last dozen years. During this time 20 disease-specific QoL instruments have been developed using this approach, many of which are now the instrument of choice for clinical trials. These measures have been carefully adapted for use in up to 30 languages. As will be seen in the following chapters and attached reference lists, the instruments developed have excellent psychometric properties. While indications are that they are highly

*Address correspondence to:* Stephen McKenna, Director of Research, Galen Research, Enterprise House, Manchester Science Park, Lloyd Street North, Manchester M15 6SE, UK. E-mail: smckenna@galen-research.com

 1098-3015/04/$15.00/S1 S1–S3

sensitive to changes associated with effective interventions further evidence of responsiveness is required and will be gained with their use in clinical studies.

Despite the relatively recent operationalization of this approach to QoL assessment the concept is not new. One of the early advocates of the importance of needs to QoL was Thomas More [4] who argued that human life quality is dependent on the satisfaction of certain basic needs. In the 19th century the radical utilitarianist and socialist reformers supported the liberal view that equality of freedom was a prerequisite for an acceptable QoL. However, they also argued that liberty alone was not sufficient, stressing that an acceptable QoL could only be achieved if members of a society received the basic goods required to satisfy their physical needs.

Major advances in needs theory in the 1940s and 1950s resulted from investigations into human motivation. Researchers in this field proposed that individuals are driven or motivated by their needs [10,11]. The relation between needs and QoL continued to be explored within the social indicators movement [12].

The needs-based approach to QoL measurement draws on these theories. Its application to QoL measurement has developed in Europe and has been adopted by researchers in the USA [13]. The approach resulted from the development of a QoL instrument specific to depression (the QLDS [14]). Recognizing the importance of deriving the content of an instrument directly from relevant patients, the researchers began by interviewing patients about the impact of depression on their lives. Analyzing the interview transcripts they noticed that the respondents described their experiences in terms of needs that were, or were not, being met—rather than in functional terms. Patients who had recovered from their illness referred to needs that they had become able to satisfy again as their health improved.

Proponents of the needs-based approach postulate that life gains its quality from the ability and capacity of the individual to satisfy their needs, either inborn or learned during socialization processes [14,15]. Functions such as employment, hobbies and socializing are important only insofar as they provide the means by which these needs can be fulfillled. It is taken as axiomatic that QoL is high when most human needs are fulfilled and low when few needs are being satisfied.

Unlike the approach taken by proponents of health-related quality of life (HRQL), needs-based QoL is viewed as a distinct construct from function and health status. Gill and Feinstein [16] suggest that QoL, rather than being a description of a patient's health status, is a reflection of the way in which patients perceive and react to their health status and to other nonmedical aspects of their lives. Similarly, Koch [17] argues that where ". . . questionnaires begin with the assumption of 'disease burden' and a medical model of life quality, the assumptions of these positions—not the individual's state—is often what is typically measured." Two other assumptions of the HRQL approach are also not made by the needs-based approach; that health is the most important influence on QoL and that health does not interact with other influences on QoL. It is the interaction of all potential influences that determine life quality [18].

These are exciting times for QoL research. Advances in measurement techniques are rapid, leading to the development of more sensitive and responsive tools. Among these, this new generation of needs-based QoL instruments will help improve the precision with which the outcomes of clinical interventions can be assessed.

## References


1 Cohen C. On the quality of life: some philosophical reflections. Circulation 1982;66 (Suppl III); III–29–III-33.
2 Aristotle. Nicomachean ethics. Ostwald M, trans. New York: Bobbs Merrill, 1962. Cited in Aiken W. The quality of life. Appl Philos 1982;1:26–36.
3 Bentham J. Deontology: Together with a Table on the Springs of Action and Article on Utilitarianism. Goldworth A, ed. Oxford: Clarendon Press, 1834/1983.
4 More T. Utopia. London: Chatto & Windus Publishers, 1516/1908.
5 Royce J. The Philosophy of Loyalty, Lecture IV, Section 4. New York: Macmillan, 1908.
6 Draper P. Quality of life as quality of being: an alternative to the subject–object dichotomy. J Adv Nurs 1992;1:965–70.
7 Aiken W. The quality of life. Appl Philos 1982;1:26–36.
8 Häyry M. Measuring the QoL: why, how and what? Theor Med 1991;12:97–116.
9 Bubolz M, Eicher JB, Evers SJ, Sontag MS. A human ecological approach to QoL: conceptual framework and results of a preliminary study. Soc Indicators Res 1980;7:103–36.
10 Maslow AH. Motivation and Personality. New York: Harper & Row, 1954.
11 McCelland DC. Personality. New York: William Sloane, 1951.

12 McCall S. Quality of life. Soc Indicators Res 1975;2:229–48.
13 Edwards TC, Huebner CE, Connell FA, Patrick DL. Adolescent quality of life, part I: conceptual and measurement framework. J Adolesc 2002; 25:275–86.
14 Hunt SM, McKenna SP. The QLDS: a scale for the measurement of quality of life in depression. Health Policy 1992;22:307–19.
15 Hörnquist JO. The concept of quality of life. Scand J Soc Med 1982;10:57–61.
16 Gill TM, Feinstein AR. A critical appraisal of the quality of quality of life measurements. JAMA 1994;272:619–25.
17 Koch T. Life quality vs the "quality of life": assumptions underlying prospective quality of life instruments in health care planning. Soc Sci Med 2000;51:419–27.
18 McKenna SP, Whalley D, Doward LC. Which outcomes are important in schizophrenia? Int J Meth Psychiatr Res 2000;9(Suppl):S58–67.