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A brief history of the Quality of Life: its use in medicine and in philosophy

M. Pennacchini[1], M. Bertolaso[1], M.M. Elvira[2], M.G. De Marinis[3]

[1]Institute of Philosophy of Scientific and Technological Activity, and [3]Department of Nursing, University Campus Bio-Medico of Rome, Italy; [2]IESE Business School, Spain and Lexington College, Chicago USA

Abstract

The term Quality of Life (QoL) has been increasingly used in medical and philosophical literatures for the past four decades. The purpose of this article is to analyze how QoL is being used in medicine and in philosophy to understand its current status.

In the 1960s and 1970s new technologies raised new questions for clinicians, so they used QoL as a parameter for making decisions in health issues. Consequently, researchers focused their interest on the construction and testing of instruments designed to measure health and QoL. However, all these instruments showed some conceptual and methodological problems that made the use of QoL in medicine difficult. While some researchers considered QoL an "idiosyncratic mystery", others believed that QoL was useful in implementing the patient's point of view into clinical practice and they suggested improving QoL's definition and methodology. In the 1980s, some consequentialist philosophers used QoL to formulate moral judgment, in particular they justified infanticide for some severely handicapped infants, and both euthanasia and suspension of life-sustaining treatment using QoL. In the 1990s, welfarist philosophers opened a new debate about QoL and they associated it with health and happiness. These philosophers developed QoL and those other concepts as subjectivist notions; consequently their definition and their measurements pose challenges. Afterwards researchers' interest in theoretical issues regarding QoL has fallen; nevertheless, physicians have continued to use QoL in clinical practice. ***Clin Ter 2011; 162(3):e99-103***

Key words: *epistemology, medical decision, moral judgment, quality of life, philosophy of medicine*

Introduction

Since the early 1970s, interest in the quality of life (QoL) concept has increased significantly in clinical practice and research. QoL has been of paramount importance for evaluating the quality and the outcomes of health care. Despite its importance, there is still no consensus on the definition or proper measurement of QoL. The purpose of this article is to analyze how QoL is being used in medicine and in philosophy to understand its current status.

The use of QoL in medicine

The term QoL began to be used in the early 1960s following changes in the health and the demographic profiles of "late modern" societies. Traditionally, public health has been concerned, not to say preoccupied, with mortality. Public health frameworks in the first half of XX century were developed and articulated to help cope with the complex patterns of "premature" mortality, and, to a lesser extent, the incidence and prevalence of morbidity. In other words, medicine focused its attention on quantity of life. In the 1960s there emerged another issue: quality of life (1).

QoL was first mentioned in medical field by Elkington (2) in 1966. In an editorial titled "Medicine and Quality of Life", he pointed out that new technologies, particularly the procedure of chronic dialysis and transplantation, raised new questions for clinicians, e.g. how does a physician protect the proper quality of life of an individual patient? How can the quality of life be improved in other patients in the future without jeopardizing that of the particular patient through whom this new knowledge is gained? Into which programs of preventive and therapeutic medicine should the resources of society be put to achieve most in health and quality of life for all members of that society?

In the 1970s the term QoL started to be used in medicine as noted by Sharon Wood-Dauphinee (3); in 1977 QoL became a keyword in the Medical Subject Headings of the US National Library of Medicine MEDLINE Computer Search System. When QoL was introduced (Year introduced: 1977 (1975)) among the MeSH (Medicines Subject Headings), it was defined as "a generic concept reflecting concern with the modification and enhancement of life attributes, e.g., physical, political, moral and social environment; the overall condition of a human life" (4).

During the 1970s physicians used QoL for making decisions in health issues. Medical practice has always involved dilemmas, tragic or painful choices. In fact, innovative (5) and aggressive therapy/treatments (6) have successfully extended length of life (7), thus generating increased demand for the evaluation of the *quality* of the time that has resulted

Correspondence: M. Pennacchini, FAST - Istituto di Filosofia dell'Agire Scientifico e Tecnologico, Università Campus Bio-Medico di Roma, Via Alvaro del Portillo, 21, 00128 Roma. E-mail: m.pennacchini@unicampus.it

from increased life expectancy (8). The sacrifices required for increased length of life (9) and the side effects associated with some therapeutic procedures (10) have highlighted the need to consider not only survival, but also the QoL (11) of a human being after innovative surgery procedures (12).

In addition, with the introduction of innovative tests such as prenatal diagnosis (13), physicians used QoL to assess which fetuses to abort (14).

In the 1980s, QoL began to be considered as a means of guiding decisions about whether to limit treatments (15) and select from patients both adults (16) and children (17); simultaneously, as health care resources were allocated (18), QoL issues took on additional importance (19). In those years the impact of an expanding range of treatments to many different groups of patients required more systematic evaluation, in terms of efficiency and effectiveness. Health care had become both more extensive and expensive. Attempts were made to consider the outcomes of care based on broader definitions of health status (other than merely recovery or survival) and QoL (20).

QoL measures moved from being research issues for economists and others, to being explored by managers and the new specialists in public health medicine as potential considerations to guide health policy. Instead of providing more resources to meet needs, a better quality of services could be aimed at, within properly managed budgets. Instead of clinicians rationing by restricting treatment to individuals, or groups such as the elderly, new priorities could now be set (at least theoretically) with QALY-type measures helping to define "best buys" (21). Discussion of the Quality Adjusted Life Year (QALY) had been utmost extensive (22). The debate about QALYs (23), and their possible use (24), was part of the second wave of managerialism that developed from the mid 1980s onwards.

Consequently, researchers focused their interests on the construction (25) and testing of instruments (26) designed to measure health and QoL (27). Medical social scientists faced major methodological challenges in developing a measure of QoL. The investigators had achieved a consensus on the relevant factors of QoL among physicians, nurses, patients, family and others who were concerned about the patient. The academic study of the patient's QoL received considerable attention, but it generated a controversy about the relevance and feasibility of such investigations (28).

Advocates of QoL research pointed out that it would be the final common pathway of the health care effort, and that some refocusing of the goals for health care delivery away from assessment of laboratory results and toward functional outcomes in patients was necessary, if society's health was to be maintained.

The development of new measures continued through the 1990s. During these two decades methodological rigor improved in the development of psychometric properties' measurement (29). First, scientists developed generic and multidimensional questionnaires to acquire broad information on large groups of patients. Then, they developed disease-specific questionnaires aimed at evaluating the functional abilities of patients (30).

At the same time, these questionnaires showed still some conceptual and methodological problems that made it difficult to use QoL in medicine. In fact, despite such increasing interest in QoL, consensus on its definition remained absent. Researchers did not build a conceptual model or a theory as a foundation for the construct of QoL that would allow explaining relationships among its components. The field had been severely criticized for the lack of science in QoL research, which obscured the understanding of what was being measured and what it meant (31).

In 1994, Albrecht (32) wrote that theoretical work has lagged behind instrument development and validation because QoL research has largely developed inductively. So, in the mid-1990s there was a renewed attempt to define QoL with greater precision.

It must be noted that changes in the concept of health, which had occurred during the second half of the 20th century had deeply affected and modified the idea of QoL: the concept of health had undergone major changes, passing from negative health measures such as the "five D's" - death, disease, disability, discomfort, and dissatisfaction -, towards more positive domain and features (33). World Health Organization (WHO) definitions of health and QoL are positively-oriented: health is considered "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (34). And from this new perspective on health have stemmed more positive measures aimed at assessing health and disease. These new health measures have, in turn, affected the concept of QoL, which was defined by WHO in 1995 as individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations and standards and concerns. It is a broad-ranging concept affected in a complex way by person's physical health, psychological state, level of independence, social relationship, and their relationships to salient features of their environment.

Despite these wide-ranging definitions provided by the WHO, there was no generally agreed definition of QoL (35).

Moreover, in the same years, researchers thought over the QoL theme (36) and questioned whether it could be measured at al. (37). Some believed that variability across cultures, between patients, and in the same patient over time made efforts to define the term QoL impossible. They considered QoL as an "idiosyncratic mystery", so they thought that physicians and economists should avoid QoL assessment (38).

Instead, other researchers believed that QoL was useful in introducing the patient's viewpoint into clinical practice and decision processes (39) and others proposed a new method for generic measuring of global QoL (40). The idea that the patient's perspective is as valid as that of the clinician when it comes to evaluating outcomes had a great deal of legitimacy and should certainly not be abandoned. QoL represents a valid attempt to get over merely quantifiable issues to look more attentively into the needs of each person. Therefore, these scientists believed that future efforts should aim to improve QoL definition and methodology and diffuse it into clinical settings.

The use of QoL in philosophy

Consequentialist philosophers introduced the term QoL into the philosophical debate in the 1980s (41). However,

according to Fagot-Largeault (42) "only two types of consequentialism are interested of QOL: the hedonism and the welfarism, since they have also considered questions about health and well-being of human being and of animals, the other approaches have considered questions of political philosophy". Helga Kuhse, a hedonist philosopher, opened this debate arguing against the doctrine of "the sanctity of life" (43), against the application of acts and omissions doctrine in medical practice, and against the common assumption that there is a crucial moral difference between intentionally discontinuing ordinary medical treatment and intentionally discontinuing extra-ordinary medical treatment (44). She argued that intentional acts or omissions which shorten life are in practice, and must in theory be justified or rejected on the basis of QoL. Such QoL distinctions are needed in practice but they are logically incompatible with the doctrine of the sanctity of life; and the ordinary/extraordinary means distinction does not circumvent this incompatibility (45).

Helga Kuhse and Peter Singer examined the debate over infanticide for some severely handicapped infants (46) and asserted that on QoL grounds it is sometimes justifiable to end their lives (47). To ignore QoL considerations is to ignore the practical realities of caring for infants with serious impairments, devalues the importance of compassion in medical decision-making and reduces the doctor's role to that of technician seduced by modern treatment imperatives and uncaring about the possible adverse consequences for infant and family (48). The consequence of this view for the medical profession is that doctors have generally adopted the position that they have a primary duty to act in their patients' best interest (not in their patients, good) (49). Therefore, from this perspective, there are *some* lives so impoverished or filled with pain and suffering that it would be rational, and in a patient's best interests, to choose death (50).

In the mid-1980s a liberal thinker, Hugo Tristram Engelhardt jr., get interested in QoL (51). Liberalism emphasizes individual rights and equality of opportunity, so Engelhardt considered QoL as a tool of this liberty: for example, it allows to evaluate whether to give birth to a baby or to stop the use of critical care units. Engelhardt aimed to define an algorithm to help appraise in an "objective" way the secular duties of beneficence toward individuals who need care.

In the 1990s hedonists used these arguments and QoL to justify not only infanticide for severely handicapped infants, but also euthanasia (52). Because a growing proportion of persons die in hospitals, in hospices or in homes for the elderly, the management of dying was becoming less of a private matter. Powerful technological means for delaying death were introduced even in cases of patients who were very old and/or very ill (e.g., suffering from metastatic cancer or Alzheimer's disease). Thus, doctors and nurses wondered to what extent such persons could be denied the benefit of medical interventions.

When hedonists discussed QoL considerations and the QALYs to justify decisions on whether to provide or to forego life-sustaining treatment, they focused on criteria to determine which human being will live and which human being will die. Put in terms of an approach that attempts to locate the right - or wrong - making such treatment decisions in the person's best interests, this entails that a non-treatment decision is right when it is in the person's best interests, and wrong when it is not (53). In other words, in cases where a decision is made to allow a human being to die, it must be the case that death, and not continued life, is in the person's best interests (54). It does not mean a calculation of the probable economic costs of long-term care to the family or State, as Enghlhardt proposed (55). Doctor and relatives debating the treatment options for a person are primarily concerned with the kind of future life they want for him/her in the person's own interests (56).

In the 1990s, physician's renewed interest in QoL - its definition, and its applications for purposes of assessment and measurement in social and medical contexts - opened a new debate among welfarist thinkers in northern Europe. These philosophers associated QoL with the concept of health and happiness, so talking about QoL, as about health, is often equivalent to talking about happiness. Specifically, Nordenfelt (57) considers happiness conceptually connected with the attainment of the agent's purposes. QoL coincides with the individual's ability to pursue vital purposes in normal circumstances, necessary and enough purposes to reach a minimum of happiness. People have a good QoL when he/she gets what he/she wants. If the concept of happiness is directly connected to that of health, a person would be completely healthy if, and only if, he/she has the ability, given standard circumstances, to reach all his/her vital goals.

Then, in 1994, Nordenfelt (58) suggested a characterization of a concept of QoL which could, potentially, serve as a conceptual basis for the construction and evaluation of instruments designed for the measurement of QoL. It is a subjectivist concept, in fact identified with happiness-with-life. However, he notes that happiness, and therefore QoL thus understood, are subjectivist notions, whose measurement is very difficult, if not impossible.

Conclusions

During the last four decades, QoL has been increasingly used in biomedical and nursing research, although there is no consensus yet on its definition and measurement.

Physicians and nurses used QoL as a critical notion for making decisions in health issues, so many QoL instruments have been developed, but they are based upon different conceptual interpretations.

Philosophers also used QoL to formulate moral judgment: in particular, they justified infanticide for some severely handicapped infants during the 1980s, and both euthanasia and the suspension of life-sustaining treatment during the 1990s, based on QoL.

In the 1990s QoL instruments showed some conceptual and methodological problems that made it difficult to apply in medicine, so some researchers doubted that QoL could be measured. On the other hand, others believed that QoL was necessary to implement the patient's perspective into clinical practice and, consequently, suggested to improve QoL's definition and methodology.

Later, welfarist philosophers opened a new debate on QoL, associating it with health and happiness. They developed QoL and other concepts as subjectivist notions, and consequently, their definition and their measurements are challenging.

Due perhaps to these challenges, researchers' interest in theoretical issues concerning QoL, throughout the 1980s and 1990s, has fallen during this first decade of the new millennium. To date, there does not seem to exist a conceptual model or a theory for QoL (59), and there are still difficulties in measuring it (60). Yet physicians continue to use QoL in clinical practice.

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