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ORIGINAL CONTRIBUTION

Quality-of-Life Measurements: Origin and Pathogenesis

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Despite extensive growth in recent years, the field of "quality-of-life" appraisal still evokes debate about basic perception of the concept and is accompanied by a plethora of indexes for measurement. One prime reason for the problems is that the measurements have been transferred from two separate sources — medical health status indexes and social-science population indexes — neither of which was designed for appraising the particular personal distinctions of the way people feel about their own quality of life.

When regulatory and commercial incentives were offered for measuring patients' quality of life, it became appraised with the indexes available from the medical and psychosocial sources, even though neither set of indexes was specifically intended for that purpose. They are not developed from the basic principle that a person's "quality of life" is a state of mind, not a state of health, which is uniquely perceived by that person, and which will not be appropriately appraised unless the most cogent personal components are allowed suitable expressions. An approach that lets patients state their own opinions directly can offer the "face validity" or "common sense" that now seems absent from the generally applied measurements.

INTRODUCTION

Although "quality of life" is now frequently discussed and measured in the medical literature, the measurements seem to be done with diverse approaches, methods, and components. Among the components used in various studies are the following: general health status, functional capacity, emotional status, level of well-being, life satisfaction, happiness, intellectual level, pain, nausea and vomiting, level of symptoms, fatigue, sexual functioning, social activity, memory level, financial status, and job status. Despite claims that the methods used to measure quality of life were "valid," many studies use only one or two of these components to represent "quality of life," even though many investigators believe this concept is usually defined more broadly [1].

These problems may arise because researchers sometimes create new instruments without a thorough search of previ-

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[c] *Abbreviations:* PULSES, Physical condition, Upper extremities, Lower extremities, Sensory components, Excretory function, and mental and emotional Status; FDA, Food and Drug Administration.

ous literature. A more likely explanation, however, is that quality of life has not been a suitably defined concept. Quality-of-life appraisal may have originated in a manner that has produced the unsatisfactory framework for current measurements.

Although the current problems in quality-of-life measurement have been recently reviewed [2-9], the history of quality-of-life measurements has not been traced to show their entrance and early evolution in medicine. By knowing how the measurements developed, it is possible to provide an explanation for the current dissatisfaction and debate surrounding their use. In this review, the origin and earliest uses of "quality of life" in the medical literature are examined. We trace the development of early functional status scales and sociological surveys that were later used in the medical literature to connote quality of life. The disparate approaches and concepts of these two sources may contribute to the current confusion of the definition and measurement of "quality of life" [10-17]. This review concludes by suggesting a proposal for the implementation of a single global rating of quality-of-life.

METHODS

A Medline search was completed using the subject heading "quality of life," including only English language articles from 1966 to 1986. The year 1986 was chosen as the end time-point because more recent reviews have documented developments in quality-of-life measurement after this time. This initial search yielded about 3,000 references.

In another pursuit, the term "quality of life" was searched as a keyword in Yale University's ORBIS database (the online library catalogue of books dating from 1977) from 1977 to 1986. Lastly, "quality of life" was searched in the card catalogue for books before 1977. Approximately 900 titles were found using this method.

Titles and abstracts were screened to determine whether established or new instruments had been used to assess quality of life. For those articles that used established instruments, the original studies that detailed the development and validation of the scales were discovered using the reference lists and bibliographies. Studies were included if they were original articles describing a scale's development or validation or if they represented a scale's first use in a clinical context. In addition, all studies in the medical literature using scales originating in the social sciences were included. Full articles were retrieved if the abstract did not reveal enough information.

RESULTS

The simultaneous development of functional status measures in the medical literature and social indicators in the social science literature were later used either solely or in combination with other measures in the rating of quality of life. The description that follows first traces the development of functional status measures, then describes the concurrent events in the social sciences that led to the development of subjective measures of well-being, and lastly shows how these two streams came together in the medical literature to produce the current quality-of-life measures.

DEVELOPMENT OF FUNCTIONAL STATUS INDEXES

Appraisal of functional status

The earliest attempts to examine nonbiologic aspects of patient's daily behavior seem to have been objective measurements of functional health status, defined as the ability to perform routine self-care and complete basic physical activities, and level of independent living.

The first functional classification scale for adults [18], published in 1937, was a joint project of New York's City Research Bureau of the Welfare Council, City Department of Public Welfare, and State Department of Social Welfare. Intended to examine the medical needs of elderly people receiving public assistance in New York City, the study analyzed differences "between those who are ... incapacitated in various ways for normal living and those whose capacity for normal living is not seriously impaired." Patients were classified in four categories: I, no obvious disability; II, up and able to get about; III, homebound; and IV, bedridden.

Two years later, in 1939, the New York Heart Association Classification [19] was published by a committee evaluating the functional capacity of patients with heart disease. They were categorized in four classes: I, no restrictions on activity; II, slight limitations; III, marked limitation; and IV, inability to complete any physical activity without discomfort, and possibly angina at rest. Similar categories of limitation were used in the late 1940's by the Visick Scale for post-gastrectomy patients [20] and by the American Rheumatism Association Classification [21].

In 1947, Zeman [22] published a classification that contained categories for both functional capacity and occupational skill in patients over the age of 60 years, living in an old-age home. Functional capacity was listed in five categories: Class A, unlimited and unsupervised activity; Class B, moderate activity with minimal assistance; Class C, limited capabilities and practically homebound; Class D, confined to bed; and Class E, blind or severely visually impaired. Level of skill was cited in three categories: 1, specialized; 2, ordinary; and 3, unskilled or handicapped. Thus, an active carpenter or trained cook would be classified A1, whereas a partially restricted person with no specific skills would be B3.

In 1948, David Karnofsky, evaluating the performance status of cancer patients, published a single numerical scale [23] that gave scores from 0 to 100 for a combination of three factors: the ability to carry out normal activities, including work; the need for custodial care; and the need for medical care. An improved rating on the Karnofsky scale was one of the attributes used to determine the clinical effectiveness of nitrogen mustards in palliative treatment [24].

In 1957, Moskowitz and McCann [25] published the PULSES^c profile. It was derived from the PULHEMS Profile developed by the Canadian army [26] and the later PULHES Profile used by the US Army [27] to examine the functional levels of new soldiers in World War II. PULSES — an acronym for Physical condition, Upper extremities, Lower extremities, Sensory components, Excretory function, and mental and emotional Status — was a tandem profile index in which each of the six domains received a score of 1 to 4. The PULSES profile was probably the first functional status index to include mental and emotional status.

In 1958 and 1959, Katz and colleagues at a facility for chronic care in Cleveland reported the *Index of Independence of Activities of Daily Living* [28, 29]. Originally used to evaluate functional deterioration in patients with hip fractures, the items in the index included such activities as employment, participation in social groups, preparation of own meals, bathing, transferring to bed, and walking up stairs. The index was subsequently [30] applied to other patients with chronic diseases such as stroke, multiple sclerosis, and arthritis. The authors initially chose the component items from previous experience plus a review of the literature, but the items were later [29] reduced to six: bathing, dressing, going to the toilet, transferring into and out of bed, continence, and feeding. The ratings of A to G

depended on the number of activities patients could not complete.

The Barthel Index [31], from two chronic disease hospitals in Maryland, was first published in 1958. Originally developed to assess rehabilitation potential in patients with musculoskeletal or neuromuscular disorders, the index rated patients' independence according to the amount of assistance required in 10 activities. Different weightings were used for the original 10 items, which included feeding, transferring from wheelchair to bed, coming to a sitting position, personal toilet (e.g. brushing teeth, shaving, washing face), going to the toilet, walking on level surface, managing stairs, dressing, bowel continence, and urinary continence. A patient who required no help received full credit for the activity while lower scores were given for increasing amounts of assistance. In this index, continence was weighted heavily (both for transferring to the toilet and for maintaining urinary and bowel continence) because of its social consequences and the amount of time required to attend to an incontinent patient. The Barthel index, which could be used repeatedly to assess patients' changes, was later [32] amended to add "bathing" and remove "coming to a sitting position."

Chronologically, the next pertinent index appeared in 1960 when Zubrod and colleagues from the Eastern Cooperative Cancer Chemotherapy Group reported a particularly simple measurement of patient performance according to the amount of time spent in bed [33]. Scores ranged from zero for normal activity to four for bed restriction.

Lawton and Brody's *Instrumental Activities of Daily Living Scale* [34], in 1969, appraised patients' abilities in such daily tasks as shopping, food preparation, housekeeping, laundry, use of telephone, mode of transportation, responsibility for medications, and ability to handle finances. The scale was devised with the practical goals of making assessments, planning treatment, assisting casework, aiding the teaching/training process, and helping determine the heed for facilities and services.

All of these early functional status indexes were developed under medical auspices. Many of the indexes are either still used today or became a basis for later alterations [17]. In a 1969 review, Bruett and Overs [35] noted many unpublished indexes as well as 12 activities of daily living scales dating from before 1969; we have found 24 more indexes [36-59].

DEVELOPMENT OF SOCIAL SCIENCE INDEXES

Government activities

In 1948, after the World Health Organization [60] defined health as "not only the absence of infirmity and disease but also a state of complete physical, mental, and social well being," physicians were reminded that a patient's health was more than just a corporeal state and could be affected by environmental and social factors.

The subsequent appraisal of social and environmental factors, however, was prompted not by medical researchers, but by major changes in government activities. A National Health Survey [61], created in 1957, was intended to measure the quality of health of the American people, not just longevity, and to determine "the positive elements of good health rather than merely the absence of disease and infirmity." To provide information for government officials and public health experts, the survey was designed to examine the social aspects of health, the personal impact of illness, the steps taken to prevent illness, and the relation of medical care to other demographic variables.

In 1960, the President's Commission on National Goals — comprising academicians, public servants, and leaders of industry — reported on the state of the nation[62] and proposed an outline of national policies and goals for improvement. Since only 48 of the stipulated 82 goals were measurable at that time [63], a new set of measures was needed. During President Johnson's administration (1963 to 1969), public agencies were urged and supported to develop more quantifiable new measurements to evaluate domestic social programs and to stimulate change in those deemed ineffective [64].

Development of social indicators

At about this time, the Social Indicators movement, led by psychologists and sociologists, began [65] to advocate "monitoring change in such areas of public life as education, health, employment, crime victimization, political participation, and population growth and measurement". These ideas were first broadly disseminated in 1966 in a collection of essays [63] that referred to measuring various aspects of society and comparing them with goals of the nation. One of the essayists [66] complained that the widely available economic data, usually reported through government agencies, could not be used to analyze social systems.

When the Department of Health, Education, and Welfare published *Toward a Social Report* [67] three years later, the authors advocated a change in focus: "We have measures of death and illness, but no measures of physical vigor or mental health. We have measures of the level and distribution of income, but no measures of the satisfaction that income brings." The staff director of the study later [68] lamented not only the emphasis on objective measurements, but also the paucity of available non-income statistics. (Income statistics were probably a main focus of social indicators because economists were the main source of the measures.)

A 1972 bibliography [69], showed that more than half of the approximately 1,000 articles related to Social Indicators had been published between 1970 to 1972. In 1974, a new journal, *Social Indicators Research*, dedicated to scholarship and research on the "quality of life," began to include articles on pertinent philosophical concepts, design and testing of new instruments, and studies using those instruments.

Subjective measures of well-being

The 1976 publications of Campbell, Converse, and Rogers [70] and Andrews and Withey [71] were highly influential in expanding the scope of social science measurements. Although most previous data had referred almost exclusively to objective phenomena, these new studies showed that subjective indicators could be measured, thus enabling examination of the "soft data" for "quality of life." The ideas were based on the work of Cantril's self-anchoring scale [72], Bradburn's *Scale of Affect Balance* [73], and Campbell and Converse's *The Human Meaning of Social Change* [74].

To Hadley Cantril [72], well-being was conceived as satisfaction with life, and regarded as a cognitive process in which a person's perceptions of life were compared with his aspirations — the difference between the two being regarded as his perceived well-being. In persons from 13 different nations, Cantril found that the greatest well-being and satisfaction with life occurred when perceptions of life were closest to aspirations.

Norman Bradburn [73] viewed subjective well-being as the balance between positive and negative affects. The greater the ratio of positive affect to negative affect, the higher the sense of well-being. Bradburn's scale used 10 questions that each began with "During the past few

weeks did you ever feel..." and were answered with "often," "sometimes," or "never." Five questions aimed at positive affect (e.g., being particularly excited or interested in something), and five at negative affect (e.g., being very lonely or remote from other people). Bradburn's scale has subsequently been used extensively, particularly in a 1981 national study of 33,000 Canadians [75].

In *The Human Meaning of Social Change* [74] — which dealt with issues surrounding measurement of "aspirations, expectations, and satisfactions" — Campbell and Converse in 1972 laid the theoretical groundwork for later publications. Their work was extended in 1976 in *The Quality of American Life* [70], using data from interviews completed during 1971 to 1972 in which a representative sample of U.S. citizens described their lives. The investigators asked four separate types of questions: a global question about life satisfaction; ten life characterizations expressed in terms such as enjoyable/miserable and rewarding/disappointing; more directed questions regarding satisfaction in such domains as employment and housing; and further specifications of satisfaction within those domains. The responses were then combined in various ways to yield the *Overall Scale of Life Satisfaction*, *Index of Well-being*, *Index of General Affect*, and *Index of Perceived Stress*.

Using some of Campbell, Converse and Rodgers's theoretical arguments [70], Andrews and Withey [71, 76] began to develop measures of life quality for interviews conducted in 1972. The conceptual model also included affective components of people's lives, rather than just their physical or social conditions. Respondents were asked questions such as, "How do you feel about your life as a whole?" and "How do you feel about what you are accomplishing in your life?" The 123 items in the questionnaire were grouped into 12 common "life domains," which were then assumed to represent quality of life.

MEDICINE AND THE SOCIAL SCIENCES

Early clinical attention to quality of survival and life

Although the clinical measurements of functional status were often used for elderly people, little attention was given by clinicians and researchers to the early publications in the non-clinical literature of surveys that had been done by psychologists using indexes to appraise happiness and psychological well-being. One study [77], in 1953, used objective measures: good health, financial security, hobbies and interests, friends, living with one's spouse, age, and sex. Another study [78], in 1961, used subjective measures, expressed as a life satisfaction scale and two smaller life satisfaction indexes.

In what seems to be the first measure of the quality of survival in a clinical trial, breast cancer patients in 1966 were studied after radical mastectomy or limited surgery [79]. The post-operative questionnaire contained objective measures such as lymphedema and activity status, but also an evaluation of the patient's attitude. Activity status was determined from the patient's ability to return to the same level as before the operation. Attitude — rated as "good," "fair," or "poor" — was based on the patient's number of complaints. Although the authors did not clearly state how the results of the questionnaire were translated into the measures of attitude, this study seems to have been a pioneering effort to include patients' subjective opinions in comparing the effects of treatment. In another study in 1968, functional status and attitude were replaced by a battery of neurologic, psychiatric, and psychometric tests to denote quality of survival after

surgery for anterior cerebral artery aneurysms [80].

Despite these early advances, the standard approach for judging efficacy of cancer therapeutic agents continued to be quantity of survival. After noting that cancer patients were often distressed by the adverse (but unmeasured) symptomatic effects of radiotherapy and chemotherapy, Feinstein et al. [81] in 1969 called for better methods that would measure quality of survival, at least according to a patient's pain, distress, or suffering. Over the next several years, however, only a few studies [82-92], by examining functional status or attitude toward life, claimed to measure quality of survival.

As a specific concept, the term "quality of life" (rather than quality of survival) seems to have entered the medical literature in a 1966 article [93] about medically-indigent patients receiving hemodialysis. After noting that the post-dialysis medical problems included sepsis and cannula clotting, the authors concluded that, "while an effective degree of life prolongation was obtained for some of these patients, for most the *quality of life* was unacceptable" (italics added). Quality of life seems to have been judged from such events as difficulties finding a job, becoming too weak to care for children, and withdrawal from spouse and children. The authors also acknowledged that the problems, which had made all the patients contemplate suicide, might have been improved with more suitable attention.

In a subsequent editorial, "Medicine and the Quality of Life" [94], J.R. Elkinton borrowed Francis Bacon's definition that quality of life is "the harmony within a man, and between a man and world." In view of all the technical and ethical problems at that time, Elkinton questioned whether chronic dialysis provided an acceptable quality of life and called for physicians to participate more actively in helping to make these decisions for society and for individual patients.

Early quality-of-life indexes and social science transfers

The medical literature contained no instruments specifically aimed at measuring quality of life until two appeared in 1970: the *Vitagram Index* [95] and *Life Units* [96]. *The Vitagram Index* [95] was a two-dimensional graph with duration of life on the X-axis. Quality of life, on the Y-axis, was determined from a functional status scale that gave patients points for their ability to work and ambulate. The area under the curve, regarded as the total quality of survival, was assessed for patients who were receiving one of several treatments for lung cancer.

Similar in design, *Life Units* [96] were constructed as a sum of the products of years of life and "quality of life," as determined by "social usefulness," defined by restrictions on a patient's ability to work. In this index, which was designed for heart-valve transplant patients, the greater the number of life units, the greater the success of the surgery. Although intended both to determine efficacy and to aid decisions about whether a patient should undergo surgery, this index seems never to have been mentioned again after its first report.

The first quality-of-life measurement to become popular was Priestman and Baum's 1976 *Linear Analogue Self Assessment Scale* [97], which used a visual analogue appraisal [98-100]. On a 10-centimeter line labeled with extreme "anchors" at each end, subjects placed a mark, corresponding to their feelings at the moment. The ten questions in the index ranged from feelings of well-being, to pain, to the patient's perception of efficacy of treatment. The sum of the marks given as ratings for the 10 questions became an overall measure of quality of life.

During the next few years, instead of continuing either this technique or the early approaches based on health status, many investigators began to appraise quality of life with instruments or components taken directly from the social sciences. In 1982 Johnson et al. [101] used seven variables and the *Affect Transformation Scale* from previous social science publications [70, 73]. The research showed that patients with successful transplants had a better quality of life than hemodialysis patients for whom transplantation was not planned, awaited, or already failed. Appraising the quality-of-life results, the authors urged "continued efforts to apply social psychological research to clinical investigations ... for evaluating medical interventions of many different kinds."

In 1984, Simmons et al. [102], also appraising quality of life in patients receiving hemodialysis, used a theoretical framework that combined physical, social, and emotional well-being, including the previously developed *Index of Well-Being* [70]. The latter index as well as the *Index of Psychological Affect* and *Index of Overall Life Satisfaction* — all scales previously developed by Campbell, Converse, and Rodgers [70] — were used by a nephrology group, led by R.W. Evans, to measure quality of life in a study comparing patients receiving transplanted kidneys from living versus cadaver donors [103] and in another study of patients with end-stage renal disease [104]. The authors said they chose the three cited indexes because comparative data were available from a set of normal populational controls. In a 1983 analysis of outcomes after heart-valve surgery [105], the investigators used multiple instruments, but the subjective section of one of the questionnaires included *Bradburn's Scale for Well-being* [73].

From the social sciences, physicians also borrowed psychological tests as part of a battery of appraisals. Examples of such usages before 1986 include the following indexes: *Rorschach test* [106], *Shanan Sentence Completion Technique* [106], *Psychosocial Adjustment to Illness Scale* [107], *Mooney Problem Checklist* [108], *Minnesota Multiphasic Personality Inventory* [107], and *Profile of Mood States* [108, 109]. Other borrowed approaches included the use of sociologic guidelines for questionnaires [110, 111] and, in health services research, economic forms of utility analysis [112, 113].

NEW INCENTIVES FOR QUALITY-OF-LIFE MEASUREMENT

Two later events added further impetus for measuring of quality of life in clinical trials.

One of these events was the Food and Drug Administration's (FDA) decision to require quality-of-life data as one of the "key efficacy parameters" in clinical trials for new anticancer agents [114]. The FDA said it would be willing to approve a drug in certain cases if it only reduced pain or toxic effects. A working group from the FDA and the National Cancer Institute [115] later recommended that validated quality-of-life instruments be used for comparing either pre- and post-treatment, or treatment versus placebo groups. The stated belief was, "[R]easonable assurance that a new drug imparts comparable net patient benefit is a legitimate basis for demonstrating effectiveness." In the original statement, the FDA defined quality of life only in relation to performance status or pain, but the later recommendation allowed measurement of improvement in tumor-caused symptoms, in functional status, in body mass, and in psychological status, as well as decreased reliance on medical support.

The second event occurred when quality-of-life assessment was used as the primary outcome in a randomized trial published prominently in the *New England Journal of Medicine* in 1986 [116]. To

assess the quality of life for patients taking one of three anti-hypertensive medications, Croog et al. [116] examined satisfaction with life, physical state, emotional state, intellectual state, social functioning, and the *Index of Well-Being* [70]. This article has now been cited almost 1,000 times [117]. When the results showed superiority for one of the anti-hypertensive agents, pharmaceutical manufacturers realized that their products could be promoted not just for physiologic effects, but for quality of life.

With these regulatory and commercial incentives, clinical investigators and their statistical consultants began to augment their customary data with methods of measuring quality of life, and began to rely on the "accepted" approaches offered by either the "established" health status or psychosocial indexes. A search for "quality of life" as a Medline subject heading for each year from 1969 to 2000 produced the results shown in Figure 1. A relatively small but steady rise in articles occurred during 1975 to 1988, but a sharp increase began in 1989 and has continued thereafter.

This review of the entrance and early evolution of quality-of-life measurements in medicine will end here, because the subsequent developments and current status of those measurements have been abundantly described elsewhere [1, 3, 8, 17, 118-120]. The field has now grown so extensively that it is regularly discussed at symposia and large meetings; and it is the sole focus of an international journal, *Quality of Life Research.*

DISCUSSION

The current review demonstrates that the concept and measurement of "quality of life" entered medical research from two different sources, each of which led to different problems. Indexes of functional capacity and performance, originally developed for evaluating treatment of patients, were later augmented by appraisals of social, emotional, and other functions to produce indexes of health sta-

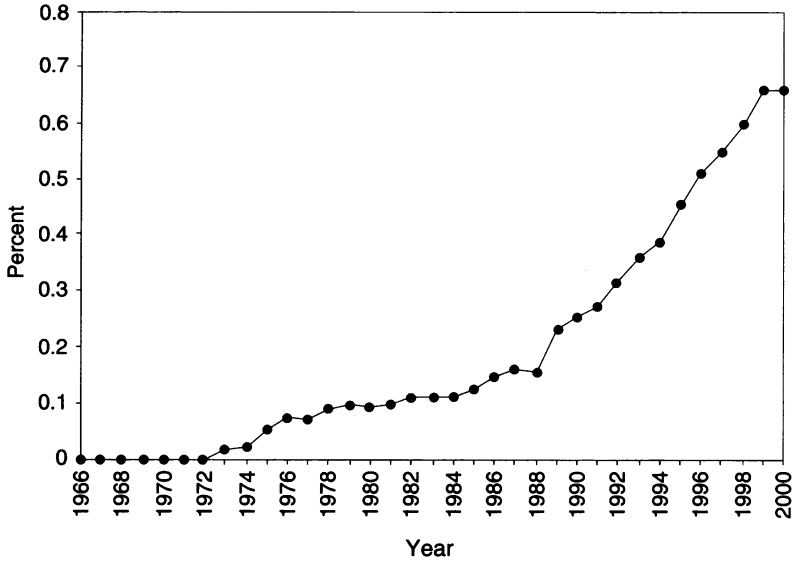

Figure 1. Articles indexed with "Quality of Life" as a Medline subject heading as a percentage of total Medline-cited articles, 1966-2000.

tus. The health-status indexes, although often adequate for assessing health status, were then used inappropriately to denote the quality of life for individual patients.

Indexes of happiness, well-being, and other "affects" had been developed by social scientists to assess populational phenomena and had been constructed with sociometric or psychometric principles of measurement. The populational results were not always suitable, however, for individual patients, whose most pertinent quality-of-life components might not have been included or suitably weighted among the multiple items of the populational instrument. A separate problem was that a person's "quality of life" might be influenced much more by non-medical than by medical phenomena. Furthermore, the multi-item populational instruments were not always effective in assessing the changes that occurred after therapeutic interventions.

The current instruments, while useful for measuring functional status, happiness, or other "affects," have been misused by researchers who claim that they represent the "quality of life" of individual patients. This and other problems in the current assessment of quality of life as well as suggestions for better measurements are considered in the discussion that follows.

Reasons for plethora of instruments

An outsider observing the current scene might readily ask why the literature contains so many quality-of-life indexes for such a diverse array of diseases.

One immediate reason is the distinction between "quality of life" and "health-related quality of life." To avoid including non-medical components — such as family problems, economic status, and religious or spiritual influences — investigators later decided to focus on medical factors, expressed as a combination of functional status and symptoms related to specific diseases. Whether this combination adequately reflects "health-related quality of life" is an arguable issue, but the many different symptoms of different diseases would obviously lead to a diversity of indexes for "health-related quality of life."

Another reason for the plethora of indexes may be that investigators do not always complete a thorough search of the literature to see if an adequate index already exists for their study. A statement by Lawton and Brody [34] more than 30 years ago is often still applicable today: "The present state of the trade seems to be one in which each investigator or practitioner feels an inner compusion [sic] to make his own scale and to cry that other existent scales cannot possibly fit his own setting."

Perhaps the most cogent reason for the many indexes, however, may be that the clinical outcomes most desired by patients receiving treatment are relief of symptoms, improvement in function, and avoidance of adverse reactions. These attributes, though, are often transferred to a different concept, called "quality of life", which is difficult to measure because a person's quality of life — even when solely "health-related" — has different components, significance, and meaning that are unique for each person.

Patient-centered versus group-centered indexes

Since physicians and family relatives may often misconstrue patients' beliefs about quality of life [105, 121, 122], investigators have included different categories of people when constructing an index. This approach is well illustrated with the *QL-Index* [123], which was developed from surveys of more than 1,000 people in Australia, who were asked what they regarded as quality of life and what domains should be included in a brief, simple scale. The respondents comprised cancer patients, their relatives, patients with other chronic diseases, relatives of

those patients, healthy people aged 20 years or more, doctors, nurses, social workers, and clergy who were seen in various settings that included the clinic, the hospital, and a terminal-care hospice. Despite admirable size and efforts in the survey, the result—a summary and consensus of the 1,000 participants — may not allow adequate expression for the way that individual patients determine their own quality of life. A pain that is tolerated by one patient might be unbearable to another. The inability to return to work might devastate a thirty-year old but hardly affect a seventy-year old. These individual differences are not easily cited in populational-consensus quality-of-life indexes that owe their derivation to populational indexes originating from the social sciences.

If patients, however, are not invited and allowed to state their own beliefs and the relative importance of those beliefs, the result is a quality-of-life assessment produced by investigators, physicians, consensus, or mathematical formulas, not by the pertinent individual patient.

Single global rating versus multi-item questionnaires

A patient's single simple global rating (such as a visual analog mark, verbal category, or numerical score) for gradations such as poor or good can eliminate the inadequacy and bias inherent in letting researchers choose and weight a set of individual domains. After patients give this simple rating for how they feel about the relative excellence of their own quality of life, a separate second rating can be given for "health-related quality of life," either directly or for the impact of health on the previous rating. If desired, the particular entities that most affect the favorable or unfavorable ratings can be discerned from the patient's further responses either to more open-ended questions or to a suitably organized checklist of possibilities.

The simple two-question approach to "quality of life" seems clinically sensible and offers unquestionable "face validity." The purpose of the results would be to provide a direct, appropriate assessment of quality of life. The new ratings would be a supplement, not a replacement, for separate pertinent indexes that appraise associated phenomena, such as changes in symptoms, functional capacity, and other components of health status.

CONCLUSION

The current problems and imperfections in quality-of-life indexes can be attributed to, and explained by, an origin in two different streams of thought, neither of which has led to a fully satisfactory approach. From the medical stream, the transfer of health status indexes was not a suitable way to denote a patient's belief about quality of life. From the psychosocial stream, the multi-item instruments, based on consensus or other populational decisions, may not allow patients to express and weight the diverse features that can affect their own feelings, and to adequately report changes in status. Since quality of life is determined uniquely by each patient, and reflects a personal reaction rather than an objective "status," a possible solution to the problems is to return to an old clinical approach, which directly asks patients to indicate what they feel.

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