

QUALITY OF LIFE: Objectives and Methods

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INTRODUCTION

The quality of the dialogue between health authorities and health professionals is altered by the incompatibility of the arguments proposed. For example, health authorities very often emphasize the lack of correlation between the rate of increase of medical expenditure and the progress obtained in terms of life expectancy, while health professionals rightly emphasize the fact that the objectives of modern medicine now consist in reducing the consequences of disease and improving quality of life. The impossibility of demonstrating a positive action of health systems is due to the use of inappropriate measuring instruments. New instruments must therefore be developed to measure the subjective health status and its course, based on elements other than physiological parameters. Quality of life studies are essential complements to medical evaluation.

1. The quality of what ?

“The first step of any quality of life study consists of defining the universe which will constitute the subject of analysis. Once this universe has been defined, it must be categorized, i.e. the dimensions to be quantified must be defined. Measurement of the content of these dimensions requires the definition of a certain number of criteria or indicators reflecting these dimensions and the definition of adequate calibration rules”.

Quality of life is such a vast unifying concept that almost any parameters could be included: environmental factors, income levels, habits and lifestyles. We will limit the field by confining our study to evaluation of the repercussions of the disease and its treatment on the patient's quality of life. However, in general, life cannot be evaluated; the best we can do is establish a judgment on its various aspects. This approach has a double value:

- 1) it forces us to adopt a multifaceted approach, which is not a disadvantage in view of the abstract nature of the concept,
- 2) it obliges us to define, right from the outset, the various dimensions which will be investigated. Categorization is a difficult step, and in some cases is only performed retrospectively as a function of the respective positioning of the dimensions of quality of life in relation to the indicators used by the patients to evaluate them. For convenience, we will start by defining health in terms of the most frequently used WHO definition: “health is not only the absence of disease or infirmity, but a complete state of physical, mental and social well-being”. The well-being dimension, covering all of the previous dimensions, will be considered to be a dimension in its own right. Good quality of life is therefore characterized by a feeling of well-being, a balanced emotional life, satisfactory social integration and a good physical state.

At the present time, these four dimensions are only concepts, i.e. subjective impressions. Measurement of these dimensions must be based on observable material criteria. Subjective or objective variables must therefore be defined for each of them, and these will be used as intermediates between the abstracts characteristics which we are trying to define and the measurement of the descriptors on which they are based (Table 1).

Table 1: Generic quality of life indicators; distribution of items per dimension

	N =	Questionnaires			
		SF-36 ²	HUI ^{3, 4}	NHP ⁵	SIP ⁶
		36	31	38	136
Dimensions					
Positive health variables		19%	3%	0	0
Physical variables		31%	90%	55%	44%
Psychological variables		14%	7%	32%	21%
Social variables		25%	0	13%	35%
Overall perception of the health state		11%	0	0	0
Positive health variables: Feeling of good health, vitality/energy, physical strength, mental stability					
Physical variables: Vision, hearing, speech, mobility, arm movements, dexterity, sleep, pain					
Psychological variables: Mood changes, fatigue, anxiety/distress, intellectual efficiency					

The nature of the observations collected depends on the approach adopted to assess health problems. For some authors, health, without being reduced to actual morbidity, is limited to the very similar concept of a laboratory or clinical abnormality, while other authors distinguish between diseases labeled by professionals and sickness expressed in terms of behaviour. A number of definitions stress the patient's perception of illness, i.e., they are based on the patient's satisfaction or lack of satisfaction with his well-being.

These various types of approaches correspond to different information collection systems, which must be applied simultaneously in order to study each dimension of quality of life from each of its various angles. Three types of indicators are defined: biomedical, behavioral, and perceptual.

2. Quality for whom ?

Quality of life evaluation supposes that we are able to describe the hardships experienced and establish a judgment concerning the relative repercussions of the adverse effects of treatment. It inevitably includes a descriptive aspect: the intensity of the complaints experiences, and a normative aspect: the subject's assessment of his own experience. The essential difficulty is then to define the subject who makes this assessment. Who should decide what is qualitatively acceptable: the physician, the patient, or the informed citizen ?

For the physician, the objective of quality of life assessment is to go beyond a strictly biological approach, useful in the emergency situation, but which only plays a secondary role once survival has been ensured. In addition to organic defects, it is also important to assess the individual as a whole, but all value judgments must be excluded as being contrary to a rigorous scientific approach. The patient is able to describe his complaints in the context of predefined questionnaires, but he is not allowed to classify them in order of importance. The items are equally weighted (FLIC⁸, QL-

Index⁹, MOS SF-36², QLQ-C30¹⁰). No global score is calculated (MOS SF-36, QLQ – C30). Inasmuch as the patient is asked to tick empty spaces in order to participate in a strange form of conversation, without giving him the right to attribute a significance to the various facts, this approach more closely corresponds to assessment of health indicators rather than quality of life indicators. The patient relates his problems and the physician collates them. The synthesis and interpretation of the data are left to clinical judgment (Table 2).

Table 2: Mode of insertion of value judgments in quality of life indicators

	No value judgment	Patient's value judgment	Healthy subject's value judgment	
No global score	MOS SF-36 QLQ-C30	Individual perception PQVS ¹³	NHP Taxpayer's preferences	Implicit global judgment ↓
Calculation of global score	FLIC, QL-Index, LASA scales ^{11, 12}	Decisional analysis Q-TWIST ¹⁴	QWB ^{15, 16} HUI ^{3, 4}	
	Implicit weighting	→		Physician's view Medical value judgment

Patients do not need to describe their complaints or disabilities totally; what is essential is that they can express their different expectations depending on the respective importance which they attribute to different aspects of their life. Only the patient can perform this task. According to A. Dazord and P. Gerin¹⁷, the patient is “the only possible expert ... the exclusive reference”. The phenomena or statuses assessed by the various items must be selected by the patient himself, but, all too frequently, they are defined by external observers or selected with reference to the average behaviour of the population.

Finally, the community seeks a coherence code to elucidate its decisions. A group of individuals considered to be representative of the general interest is asked to classify health statuses in order of severity. The severity of the impairment is revealed by the patient, but the attention which must be granted to this impairment is left to the judgment of informed citizens. Regardless of the approach adopted, quality of life profile (SIP⁶, NHP⁵) or multifactorial utility function (QWB^{15, 16}, HUI^{3, 4}), the assessment based on the importance of the items, the relative desirability of health statuses or

the partial usefulness, is determined by external observers.

3. How should quality be measured ?

The measurement of physiological or functional attributes does not raise any problem when it is performed directly on the basis of physical indicators. This is not the case when the assessment concerns the emotional repercussions for the patient. In order to infer a property from measurements performed on a perceptual indicator, the nature of the measuring instrument used and its conditions of use must be clearly specified so that the procedure can be repeated and its results can be verified. Calibration, i.e., all the rules governing attribution of numbers to the various positions of the indicator, constitutes a major aspect of standardization of the measuring instrument. It determines the empirical interpretation that can be given to the instrument and also largely determines the parametric or nonparametric nature of the subsequent statistical analysis.

- 1) The number can be used exclusively for identification purposes. For example, 1 = female, 2 = male, or vice versa, can be used in a questionnaire. This constitutes a simple labeling procedure, which allows subsequent counts. No mathematical operations can be performed with these numbers.
- 2) The number can also be used as a ranking instrument. It allows the values of an indicator to be arranged on an ordinal scale. For example: you suffer, 1 = very little, 2 = slightly, 3 = moderately, 4 = severely. However, as the scale is not calibrated by means of a constant measurement, this classification does not provide any information about the distance between the various categories. Any series of numbers which preserves the order relation is just as acceptable as the series of numbers initially established. Most clinical quality of life scales are of this type. They therefore cannot be used in cost-effectiveness studies. For the same reasons, the practice consisting of calibrating weighted indices on the basis of ordinal data is also unfounded.
- 3) Once the scale has been calibrated by means of a single unit of measurement, which remains constant over its entire range, differences of level can be compared between a control group and a treated group, for example, even if the relationships between levels do not have any meaning. This type of scale, called an equal interval or weak cardinal scale, can therefore be used to compare differences between the entities measured, but is unable to confirm that one value is a multiple of another when the origin of the scale is arbitrary. This is the case, for example, of Celsius and Fahrenheit temperature scales, which have different origins.
- 4) When a natural zero, which characterizes the origin, and the distance between two levels of the scale can be simultaneously defined for all of the modalities of an indicator, the number possesses its usual arithmetic properties. The differences and the ratio between two levels can be established. This essential property of the magnitude scale, also called ratio scale or strong cardinal scale, can be used to confirm that one health status is twice as severe as another, which was not possible previously. Another image is that of an earthquake registered as force 4 on the Richter scale which induces seismic waves twice as intense as those induced by a force 2 earthquake.

For economists, only weak or strong cardinal scales provide a true measurement which can be related to costs.

4. Why assess quality ?

In order for scales to be efficient measuring instruments, they must be used wisely. In other words, they must only be used to measure what they are designed to measure. The choice of an instrument supposes a preliminary definition of the user's needs: identification of a problem, evaluation of individual preferences, or the search for greater coherence in the allocation of rare resources.

4.1 *Efficacy assessment*

The physician tries to achieve the best possible management, in the context of existing techniques and equipment, for his patient who entrusts him with his most precious possession, his life. The objective is to control every aspect of the disease, which explains the physician's desire to remain within an objective and multidimensional framework. This method has been used since the 19th century by psychometricians, who wanted impose the discipline of measurement and numbers to the realm of the mind. It is also the approach adopted by A. Feinstein, the ardent supporter of clinical biometry. In order to restore clinical assessment to the place which it should never have lost, it must be given a real scientific status. Only the use of numbers allows uncertain data derived from observation to be converted into solid and reliable information. In the privacy of his office, the physician does not need a questionnaire to assess the quality of life of his patient, he just needs to listen to their complaints in order to be able to remedy them. The situation is very different when evaluating a treatment. Selection of the best protocols depends on the use of reproducible measuring instruments in different patient groups. The scientific collection of clinical data leaves little place for the evaluation of individual preferences.

4.2 *Revealing value judgments*

The humanist, regardless of his specific training: psychologist, physician, economist, strives to place the patient at the heart of the specific colloquium by giving him a means of expressing his specificity. Three concepts of specific colloquiums can be distinguished. The most traditional is that of President Portès, and the most utopian is that of informed consent and between total paternalism and sovereignty of the consumer, there is a place for a proactive relationship between the physician and the patient, in which the physician either reveals or educates the patient's value judgments. Louis Portès' position is clear: "every patient is and must be considered to be a child by the physician; a child to be educated, not deceived, a child to be consoled, not abused, a child to be saved". The physician's role is therefore to take all of the decisions on behalf of the patient. This paternalistic vision is in total contradiction with the theory of informed consent, according to which the physician presents the patient with the range of technically feasible solutions and the patient chooses between these options on the basis of his own particular value judgments. However, this approach is no more realistic than the former; very often the patient refuses to defend his own interests and asks the physician to do so in his place. A third approach must be defined between these two extremes, in which the physician does not just replace the patient's value judgments with his own, but encourages the patient to express his real priorities.

The specificity of the patient's complaints is due to the fact that they can be present at various levels and that patients do not always attach the same importance to each one. Calibration helps to makes these concepts operational. A data bank of items is constituted during patient interviews. Direct definition of the dimensions by patients guarantees the choice of an appropriate set of dimensions. Two types of questions are formulated for each item: the first concerns the presence or intensity of the impairment experienced and the second concerns the importance given to this item by the patient. Authors diverge at this stage of the analysis: some only include in the final questionnaire those items with the highest product of the frequency and amplitude of the impairment in the survey

population. Only those items which reflect central values, according to which the patients orient their life, are adopted, while items of secondary importance are eliminated. The evaluation instrument implicitly integrates the patient's preferences, as these constitute the basis for its structure and for the choice of its components. However, once the questionnaire has been constructed, the items adopted are equally weighted (BCQ¹⁸, IVCMI¹⁹⁻²³). In contrast, other authors prefer to retain an indicator of the relative impairment associated with alterations in quality of life by integrating weighting coefficients for each item in the final version of the questionnaire, either to calculate a weighted global score (SEI QOL²⁴⁻²⁵) or to define a multicriteria quality of life profile measured in terms of the intensity and degree of impairment, satisfaction or dissatisfaction and the distance in relation to life objectives (PQVS¹³).

The approach of physicians proficient in explicit decision-making methods has different modalities, but is based on the same philosophy: adopt the best possible individual decision on each occasion, according to the patient's personality, work activity, and attitude in relation to the risk. Medical practice is consequently not a science, but an art based on science. The establishment of individual preferences, and the other person's experience of disease are not sufficient. Often, by trying to do the right thing and by trying to counteract the patient's irrational and poorly informed approach, the physician may act against the patient's preferences. McNeil²⁶ clearly demonstrated the danger of this type of behaviour. Two strategies can be envisaged to treat lung cancer: surgery and radiotherapy. The first offers a 5-year survival rate of 33%, but is not devoid of risks, as the intraoperative mortality rate can be as high as 10%. The second modality is totally safe, but has a less favorable 5-year survival rate of 22%. Patients faced with this choice tend to prefer the less dangerous solution. What right does the surgeon have to suggest that the first strategy is preferable to the second, when the patient experiences a total rejection of the risk? Patients should therefore be encouraged to directly define their preferences in relation to a range of health statuses integrating the various dimensions of impairment of quality of life²⁷. The measuring tools used to reveal their preferences can be very different: standard gamble²⁸, time trade-off, rating scale. In all three cases, a synthetic judgment is formulated, integrating the intensity of quality of life alterations without attributing specific scores to these alterations. A flowchart can then be used to select the most preferred strategy to be taken on the basis of the endpoints defined. By a sequential process of averaging out and returning along the branches of the flowchart, the clinician can make the best possible decision according to the value judgments defined by the patient.

4.3 *In search of a collective consistent code*

The method used by economists is not fundamentally different. It is inevitably global and supposes the existence of a quality of life continuum ranging from good health to death. The simplest way of introducing the concept is to imagine that the terms of the WHO definition of health can be classified according to a strictly ordered scale ranging from well-being and love of life of death, ranging from the presence of signs and symptoms, physical decrepitude, alteration of mental capacities, and social withdraw. This heuristic approach helps to explain the one-dimensional nature of the scale, but it distorts reality, as it only classifies isolated disturbances. In reality, several dysfunctions usually appear in combination. The entire range of quality of life alterations must therefore be situated on the scale by reasoning in terms of stereotypes or on the basis of health status classification systems.

Global quality of life assessment therefore consists of determining the value of the coefficients between 0 and 1, which can be attributed to each of these typical cases. These weighting factors constitute adjustment factors of the quantity of life according to its quality, hence their name of quality of life (QOL) coefficients. The product of the years or fractions of years spent in a particular health status and the corresponding quality of life coefficient transforms the time spent in poor health into equivalent fractions of years of good health. Repetition of this operation over time for

various stages of the disease provides the number of years left to live, corrected as a function of the quality of life, called QALY. The cost of treatment can then be divided by the QALY result in order to define a criterion reflecting the impact of treatment or nontreatment, or in order to compare the respective merits of two alternative treatments²⁹. The numerator and denominator are obviously discounted, as two identical health effects or two health expenditures of the same sum do not have the same value when they occur at different times during the course of the disease.

Two types of situation must be distinguished: either the technologies can be applied simultaneously and perfectly independently in distinct medical fields, or they are mutually exclusive in the case of the same indication. According to the first hypothesis, the flowchart consists of classifying the projects in order of their mean cost-performance ratio, within the limits of the available budget. According to the second hypothesis, i.e. when the technologies are incompatible, the research strategy must be divided into two successive operations. The first phase consists of defining from among all of the possible strategies, a group of efficient strategies based on the principle of dominance. During the second phase, the community selects the best strategy from among all of the efficient strategies, according to the sum which it is prepared to pay to obtain an excess cost/improved effectiveness ratio which is considered to be optimal. In view of budget limitations, arbitrages will be inevitable in the future and cannot be left entirely in the hands of administrators or physicians. A choice in the field of health is never dictated by purely scientific considerations, but is based on a certain concept of good and a list of priority of values. This implies that the patient-consumer's representatives must be involved in health decision-making at the regional and national levels. A debate concerning society's objectives is a normal part of an open, pluralist democracy, but is essential for the main parties concerned to be able to participate in this debate.

CONCLUSION

Quality of life assessment will undoubtedly undergo considerable development, regardless of the future of our social protection system. In the hypothesis of the development of an almost open market health system, into which mechanisms of prescriber and consumer sensitization to quality will be introduced, choice of treatment will be guided by evaluation of cost-effectiveness. In an administrative rationing situation, the results obtained in a given indication, in terms of life expectancy adjusted for quality, will have to be compared with the corresponding expenditure. In the 21st century, health services will very probably be structured and organized according to the quality of the service rendered to consumers.

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