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Concepts and Measurement of Quality of Life in Health Care

Edited by Lennart Nordenfelt

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EDITOR'S PREFACE

Questions concerning the notion of quality of life, its definition, and its applications for purposes of assessment and measurement in social and medical contexts, have been widely discussed in Scandinavia during the last ten years. To a great extent this discussion mirrors the international development in the area. Several methods for the assessment and measurement of quality of life have been borrowed from the UK and the US and then further developed in northern Europe. But there has also been an internal development. This holds in particular for the social arena, where Scandinavia has had a special tradition both in theory and practice.

In this volume an attempt is made to illustrate some aspects of the philosophical, and in general theoretical, discussion concerning quality of life in Scandinavia. In addition, some prominent scholars from other parts of Europe, i.e., France, the Netherlands, the UK and Italy, have been invited to contribute. The volume is divided into three sections. The first contains philosophical analyses of the general notion of quality of life and proposes a number of different explications. The second section considers various applications of the notion of quality of life in health care. The papers serve to disentangle some intellectual and ethical problems that stem from these applications. The third section is more practical and focuses on methods of measuring quality of life in medicine and health care.

A few of the authors represented here presented their essays at a symposium on Quality of Life in Linköping, Sweden, in April 1991. The others were invited after that date to write original contributions for this volume.

As the editor of this volume, I wish to express my gratitude to a number of persons for their help in preparing the book. I wish particularly to thank Professor Stuart Spicker and Mr. Malcolm Forbes for their hard work in transforming the papers into a publishable form. I also wish to thank my colleague, Henk ten Have for his good advice and for his willingness to accept this manuscript in the European subseries for studies in Philosophy of

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Linköping, January 1994

Lennart Nordenfelt

LENNART NORDENFELT

INTRODUCTION

QUALITY OF LIFE AS A NEW GOAL FOR MEDICINE AND HEALTH CARE

There is a growing concern among members of the health care system, as well as among the public, that the ultimate goal of medicine and health care cannot be simply the cure of disease and the forestalling of death. Several factors in the development of medicine, as well as in the panorama of health problems, have contributed to this concern.

A particularly important factor is the technological progress within medicine. The technology in, for instance, intensive care units has made it possible to save or at least to prolong many lives which would previously have terminated. But the life that has been prolonged can, as in many cases of severe cancer, be a life of great pain and disability. Or it can, as in the case of late stages of Alzheimer's disease, be a life which is devoid of human dignity.

Another factor has to do with the changing nature of the disease panorama. The dominant diseases are now not acute, in general treatable, infectious diseases but instead chronic diseases and chronic impairments for which there is at present no chance of effective cure. In these cases health care must aim at a goal which is distinct from the elimination of disease. It must aim at improving the life of the patient in other respects; it must support, encourage, and in general provide patients with the means to cope with a life that involves a serious long-term health problem.

A third factor is more theoretical and ideological. I have in mind the criticism of the so-called machine model of the human being. This is the model which is supposed to form the basis of much scientific medicine in its concentration on the human being as a biological organism, and its lack of interest in the human being as a social agent. Really effective and humane medicine, the critic emphasizes, must understand and care about a person as an integrated, feeling, and active being. It is the quality of such an integrated person's life that we should care about, not primarily the person as a biological organism.

As a result of these developments, there is now in medicine an extensive literature dealing with quality-of-life (QoL) issues. In some of the clinical specialities, such as cancer care, cardiovascular care and psychiatric care, attempts have been made, at least partially, to define therapeutic success in

terms of the patient's QoL. For this purpose a number of instruments or scales, mainly of a questionnaire type, have been devised. Some of these scales have been frequently used and are known under such names as *The Nottingham Health Profile* and *The Sickness Impact Profile* [13].

But the crucial question now is: what do these instruments in fact measure? What is in fact defined as an important goal of medicine by these instruments? What concept of QoL do they presuppose? And how is this notion related to health, in particular when the latter is not just taken to be identical with the absence of disease? These are some of the questions to be dealt with in this volume. In this introductory essay I shall in particular highlight the first, most basic question. I shall discuss various platforms for analyzing and defining the notion of QoL. I shall try to show that the various possible definitions will have profoundly different implications for the procedure of applying the notion in the context of health care.

TOWARDS A CONCEPTUAL ANALYSIS

The notation "QoL" is composed of two terms: "quality" and "life." Both are in need of analysis. Notwithstanding the increasingly rich literature on QoL, the basic notion of life has been almost completely neglected in this context. (For an outstanding exception see [20].) Though I shall not here attempt a full-length analysis, some conceptual observations are necessary for the present purpose.

An important distinction is one between a *complete life* and a *partial life*. Moreover, there are at least two dimensions along which the degree of completeness can be measured. One dimension has to do with *time*; another has to do with the totality of *aspects of life*. A complete life in the former sense is composed of the continuous series of life-events that a particular person goes through during his or her existence from birth to death. A complete life in the latter sense is the sum total of all the aspects of his or her existence at a certain moment or during a certain period of time. A *maximally complete* life is, then, the sum total of all the aspects of a person's existence during his or her entire life-time.

The idea of an *aspect of life* is very essential. Since it is easily seen that apart from God no one is going to study every aspect of a person's life, we must make some selection, and preferably a well-motivated one. The selection should be guided by the particular purpose that an assessment or measurement of life-quality has.

At least the following main aspects of life could be considered.

a. The experiential aspect of life; the sum total of a person's sensations, perceptions, cognitions, emotions, and moods.
b. The activities in life; the sum total of a person's actions.
c. The achievements in life; the sum total of the results of a person's actions.
d. Events in a person's life, those that the subject is aware of or which are for other reasons ascribed to him or her, or both.
e. Circumstances surrounding a person, either those that the subject is aware of or which are for other reasons ascribed to him or her, or both.

Moreover, these five categories can be mixed into combinations so that we receive a great, if not infinite, number of interpretations of the notion of life. One interpretation is the maximal one. A maximal life contains all the mentioned elements, i.e., it is the sum total of a person's experiences, activities, and achievements, as well as all events and circumstances ascribable to him or her.

It is evident, as illustrated by the essays in this volume, that different theories of life-quality have focused on different aspects of *life* in the full sense of the word. This partly has to do with what aspect the theorist judges to be an important aspect, one that is worthwhile considering for his or her particular purpose. Unfortunately, however, the choice of aspects is not always clearly motivated. (For a discussion of some cases, see my analysis in [18].)

It is very important to draw the distinction between, on the one hand, aspects of a person's life which could be objectively (or at least intersubjectively) ascribed to him or her, and, on the other hand, such aspects as the subject perceives or by which he or she is causally influenced. This is one of three senses in which we can talk about *objective* quality of life and *subjective* quality of life.

A person can be placed in a set of circumstances, or he or she may have a set of personal properties, which for one reason or another have a high value. But it may be the case that the person is not aware of them. And it may even be the case, although this is more unlikely, that the circumstances or the personal properties do not causally influence the person's conscious life. Let me illustrate from the field of welfare and well-being. A man may have a great sum of money in his bank account of which he is not aware. In some sense, the "objective" sense, this man is a wealthy man and can receive a high score on some welfare scale. On the other hand, if the man is

not aware of the money, he cannot make use of it for any purpose. The subjective well-being is not affected.

Similarly, we can imagine that a person receiving some medical treatment has obtained bodily and mental resources that could be used for many good purposes. On an ability and energy scale this person scores high. On the other hand, if the person is not aware of this fact, and it does not influence his or her life, then this does not affect his or her subjective well-being.

As a corollary to this we can note the following interpretations of the term 'welfare'. On the one hand, it may signify a state of affairs generally taken to be advantageous to anyone in such a situation. On the other hand, it can signify a state which is perceived and appreciated by a particular person, or the person's conscious life may be causally influenced by it. In the latter sense, then, 'welfare' becomes a completely relational term.

A second distinction marked by the terms 'objective' and 'subjective' is the one between non-mental states of affairs and mental ones. A state of affairs, or an event external to a person's experiential life, is often called "objective" (because it is accessible to other people than the subject him- or herself), whereas a mental event, be it perceptive, cognitive, or emotional, is called "subjective", according to this interpretation. (These distinctions are well elaborated in Musschenga's essay [15].)

What, then, about the notion of *quality*? In ordinary and philosophical discourse the term 'quality' may be used in both a neutral and a normative sense. In the former case 'quality' is simply coextensive with 'property', as in the locution: "What qualities does this substance have?" In the QoL discourse, however, 'quality' is almost exclusively used in the second, normative sense, indicating some kind of *evaluation* of a phenomenon, a ranking of the phenomenon along an evaluative scale. It is essential in the QoL-context to be able to say that a person's life-quality is high or low or, even clearer, that the quality is good or bad.

We are then faced with two difficult issues in need of exploration. The first concerns finding an evaluative dimension along which to rank life; the second concerns who should evaluate a person's life?

(1) Which is (or which are) the evaluative dimension(s) along which a person's life (or certain aspects of this person's life) should be assessed or measured?

There are many values to be considered. There are, for instance, moral values, prudential values, aesthetic values, intellectual values, values of humour, values of decency, values of welfare as well as values of experiential well-being. A total life or any part of such a total life can be evaluated along all of these value-dimensions.

Furthermore, there may be an evaluation *among* the dimensions. One dimension may be considered to have a higher dignity or be preferable for some purpose than another. In talking about QoL (unqualified) one may thus mean the quality according to what one takes to be the *most important* evaluative dimension. We can here suggest an analogy with the Platonic universe of ideas. All ideas are valuable entities, but the idea of goodness is the most valuable of all.

(2) Who should be the evaluator of a particular person's life? This might then also entail: Who is to choose the dimension to be utilized in the evaluation?

A Platonic-Aristotelian answer to these two questions would run along the following lines. There are a number of dimensions of value; there is also a scale among the values, where one dimension of value can be compared to another dimension of value. These evaluations are given once and for all, in the same sense as mathematical truths are given once and for all. There is in principle no room for personal choice among values. As a result, it does not matter who exercizes an evaluation in a particular case. As long as this person has the proper insight into the realm of absolute values, then this person will also come out with *the* correct evaluation of this person's life-quality. In particular, Aristotle gave us a substantial treatment of the perfect life and he suggested that the best life, all things considered, is the life in accordance with the highest of virtues. Such a life is what he called a *eudaimonian* life. (For a detailed analysis, see Ostenfeld [22].)

There is no single contemporary view on this matter. There are contemporary views which come close to the Aristotelian one (consider, for instance, von Wright's on the good life [25] and Nussbaum's treatment of non-relative virtues [21]. But there are also contemporary views which are the direct opposite of an Aristotelian approach (see Nordenfelt's [19] and Sandøe's essays [24]. For a critical analysis of this approach see Cattorini and Mordacci [5]). Moreover, there are views which lie somewhere between (Kajandi's [10]). The anti-Aristotelian view entails the conclusion that there is no hierarchy of values given once and for all. All values are chosen by in-

dividuals and therefore every assessment of life-quality is dependent on the person who makes the evaluation.

This is the problematic starting-point for the *empirical science* of quality-of-life research. What dimensions of evaluation and what criteria should we follow? There seem to be two kinds of plausible strategies available — one more collective and paternalistic, the other more liberal and individualistic.

The former strategy, which could be realized in a variety of ways, would entail the following. A number of "experts" or politicians come together to decide what is the essence of QoL. They decide first what aspects of life are the most important for the particular purpose chosen — for instance, circumstantial aspects, activity aspects, or experiential aspects. Second, through a consensus-reasoning or through a simple majority vote they decide on the scale along which individual lives should be measured.

This could be done in a more or less *a priori* fashion. The people involved in the decision could have an Aristotelian view and attempt to work out the details of their *eudaimonia*-concept, and then try to establish this as the basis for assessment. (An example of this is, perhaps, the need-approach for the evaluation of QoL which is to be further described below.) A more *a posteriori* (or democratic) procedure would involve making an empirical investigation and obtaining an idea about how people in general evaluate their lives. This is the procedure chosen for the establishment of some measurement scales in health care; see, e.g.,[8] [23].

The *individualistic* strategy entails that there is no general instrument for the assessment of QoL, or at least there is no presupposition that such an instrument is available. The person who has the task of making the assessment, whether this is a physician or a social worker, permits the subjects themselves to make the evaluation. The subjects can thus make their life-evaluation according to their own preferences. *X's quality of life becomes identical with X's own evaluation of his or her QoL.*

We have here identified the third sense of the phrase "subjective quality of life". I.e., the person's subjective quality of life is identical with his or her own evaluation of the life.

Furthermore, the subject's own evaluation can be performed on two levels, both of which may have practical significance. The subject can provide an evaluation in a very radical sense of the word. He or she can decide what values should be considered in a particular assessment of QoL. The subject can, for instance, say the following: "I am immobile and in great pain, but I prefer this state because it makes me morally sensitive. Since my

primary goal is to be a moral person, I prefer this state of affairs to a state where I could move about freely and have less pain."

The other interpretation is the more conventional. According to this the subject is asked to provide an evaluation of his or her QoL concerning a certain well-defined sector of aspects, and within a certain realm of values.

But what, now, is the deeper meaning of the locution "X's evaluation of his or her QoL"? And how can we come to understand this evaluation? It seems as if the locution can be interpreted in two ways, one more superficial than the other, and these interpretations have methodological consequences, moreover. The most straightforward and superficial interpretation is: X's evaluation of X's QoL is identical with X's explicit answer to a question concerning X's QoL, presupposing that X has correctly understood the question and attempts to answer honestly.

The other interpretation is the following: X's evaluation of his or her life is the evaluation that X would make given that X could organize his or her value system coherently and could give a proper assessment of all relevant details of his or her life (according to this system).

This, then, is an *ideal* notion of subjective evaluation of QoL. No subject can fully accomplish this, however. Most of us lack coherent value-systems and we are unable to remember and truly grasp all relevant facts about our lives. Moreover, some individuals are particularly poor at this task. The persons may not have the intellectual qualifications. Some human beings, not only infants and the mentally retarded, do not understand the notion of a value. Moreover, they may have little possibility of grasping a broader view of their lives, let alone of organizing their value-system coherently.

Thus, to achieve the deep subjective evaluation of a life seems to be an extremely difficult task. On the other hand, the more subtle interpretation appears to be the more intellectually reasonable. A person's evaluation of his or her life cannot, strictly speaking, be identical with what he or she "honestly" says in reply to a question. If it were, there would be no room for a subject to make a mistake in assessing his or her QoL. (Questions concerning honesty and the possibility of self-deception in relation to QoL are in the focus of Siri Naess' contribution to this volume [17].)

But if nobody can achieve full insight into his or her own quality of life, even on this individualistic interpretation, what are the methodological implications? Here some theorists seem to propose a compromise among a number of methods.

First, it is said, there is good reason to believe that a normal adult is capable of providing a rough estimate of his or her QoL. The person may, however, need some help from an external assessor to more thoroughly think about all relevant areas and all relevant events. As in the case of psychotherapy, the assessor can help the subject to come to describe his or her value system, and to help the subject think about all relevant matters in order to obtain a reasonably accurate account of his or her QoL.

Some people — infants, the mentally retarded, some psychotics and the truly senile — have no or very little capacity to express orally their view about QoL. In such cases other people must assist and complete the evaluation for them. But this can still, and should (according to the individualistic philosophy) be done *from the subject's point of view*. It remains the subject's QoL that should be assessed and no-one else's. (A discussion of some of these issues is found in Kajandi's and Musschenga's essays [10] [15].)

What, then, are the methods for such an other-person evaluation? Here we should be able to rely both on common sense and scientific, i.e., psychological insights. There are, it may be argued, many ways in which we can determine if a person prefers the situation in which he or she is placed and in general likes to live. In particular, a mother can know quite well if her baby is well and happy. The baby reveals it with its body language, with cries and laughter, through other facial expressions and signs of ease and tension, etc. The other-person interpretation, in this case, remains, however, an interpretation of the subject's signs, although these signs may not be conventionally linguistic.

Let me recapitulate: The fact that another person takes part in the evaluation of a subject's QoL need not entail the abandonment of the individualistic (subjectivistic) notion of QoL. To be sure, the other-person interpretation is difficult in practice and there is a significant risk of mistakes. But this, I think, is an unavoidable state of affairs.

ON THE CONTEMPORARY DISCUSSION OF QOL

Quality of life and health

Thus far my approach has been rather abstract. I have sketched a few metaphysical platforms for making QoL-assessments. But how could this reasoning be applied to today's QoL-discussion and the actual measurements which are made in, for instance, social work and health care? Let me, in answering this, focus on the field of *health care* as do most of the other

contributions to this volume. I shall in this discussion also stress the crucial role of the *purpose* with which a particular QoL-measurement is undertaken. (A background to today's QoL-discussion in health care is given in Bury's essay [4].)

A first question concerns the scope of the notion of life in QoL-measurements in the health-care context. It is clear that the idea of an entire life in the temporal sense is excluded. The typical assessment of life-quality is supposed to serve a practical purpose; among other things it is presumed to serve *the purpose of improving one or more persons' QoL*. Thus the assessment cannot in such cases presuppose that the subject has already lived his or her whole life (i.e., has died). Moreover, the task is to assess and measure something which is *at present* the case, i.e., such relatively stable factors in life as define the person's present life-situation.

But certainly not all aspects of the present are to be considered. Today's QoL assessors tend to select very carefully among aspects, mainly concentrating on personal — bodily and mental — properties as well as the person's experiential aspects. Sometimes a set of circumstantial facts are also included. (For a discussion concerning the selection of aspects, see Björk and Roos [2].)

There is a tendency, then, in contemporary assessments of people's QoL, apart from the extreme cases of metaphysical or religious assessments, to concentrate on the present, and also to concentrate on such features of the present judged to be relatively permanent for or "surrounding" the individual. "Permanence" here essentially means that the factors judged are not likely to improve by themselves; indeed, they may be more likely to "deteriorate" by themselves.

In order to determine what scales of evaluation should be used, it is important to distinguish between the QoL-instruments used in psychiatry and social medicine, and those employed in somatic medicine. The former instruments tend to cover more aspects of human life. They are principally used as guides in clinical work and to improve the QoL of individual patients. The somatic ones, on the other hand, can be very limited in content and may only mirror aspects which are closely related to the subject's *health*. These instruments may be used both in the clinical context and in large-scale assessments of medical technologies, which are undertaken for a purpose like resource allocation. (For a comprehensive account of different applications of QoL-instruments, see Fitzpatrick and Albrecht's essay [7].)

As an example of an instrument from psychiatry, I mention only one that is developed by a Swedish researcher, Madis Kajandi [9], which is based on

a concept developed by Siri Naess [16]. The elements of Kajandi's instrument are the following: *external life conditions*, (which can be divided into working life, personal economy, and housing quality); *interpersonal relations* (divided into partner-relations, relations of friendship, relations to parents and relations to one's children); *inner mental states* (divided into involvement in life, energy, self-actualization, freedom, self-assuredness, self-acceptance, emotional experiences, security, and general mood).

It is evident that Kajandi's instrument ranges across a multitude of aspects of human life: the most stable circumstances in the individual's life, most of his or her personal relations and all important mental states, as well as many of his or her mental abilities. But what evaluation scale is used?

Kajandi, like most theorists in this area, says rather little about the nature of the scale. It seems, however, to be presupposed in these contexts that the scale of evaluation has to do with *the individual's welfare or well-being*. One important aspect, if not completely exclusive, is whether the *subject likes his or her life, or not*. This is not unexpected. People seek psychiatric care because they frequently have personal problems of a basic kind. They are depressed, they feel anguish, they cannot cope with their lives. Their most urgent wish is to transcend these problems and improve their well-being. There is, under these circumstances, very little room for an evaluation of their lives from a moral, aesthetic, or intellectual point of view, unless these aspects happen to have a significant influence on the subject's well-being.

In *somatic medicine* the focus is much more precise. This is so because of the often quite limited and practical purpose of the QoL-measurement. Here, for example, the purpose can be the testing of a new medical methodology, e.g., a drug which affects a very limited bodily function, or which has only a pain-relieving effect.

The question can then, of course, be raised: What are we measuring? Are we simply measuring health, or are we measuring something "between" health and QoL, e.g., subjective health? (Note that some leading textbooks refer to many of the instruments in this *somatic* area as "health-measuring instruments" [13].)

There is here conceptual unclarity which is in need of further analysis. Indeed, there are fundamental differences in our conceptions of health. Some theorists, who align themselves more closely with a bio-statistical analysis of health, represented by the work of C. Boorse [3], view health as the absence of disease, and consider diseases as virtually measurable along physiological parameters.

According to this view, the use of a questionnaire which seeks to determine how the subject feels (e.g., if he or she has any pain, or if he or she can cope with stairs), entails the measurement of something over and above somatic health. On this view, then, it is justifiable to claim that the measurement concerns QoL.

On the other hand, assume that we adopt a holistic conception of health (reflected in many contemporary texts) entailing that a person is healthy if and only if, he or she is capable of realizing certain vital goals in life [18]. A holistic concept of this kind automatically infers that the absence of pain, and the basic ability to cope with stairs, are contained in the notion of health itself. QoL for a holistic health theorist must entail something more, e.g., the person's full emotional life and his or her reactions to the course of the world, including his or her own health status. (These and other aspects of the multidimensionality of the concept of health are discussed in Fagot-Largeault's essay [6].)

Quality of life and human needs

A rather different approach to characterize the concept of quality of life involves the idea of a *human need*. Need has often been thought to be an attractive concept since it suggests an objective state of affairs. It has been favored as the anchoring concept in many social-work and health-care discussions, in particular concerning the allocation of resources. For instance, the Swedish Public Health Act maintains that the policies of the health care system should be determined only by the needs of patients.

There is a long tradition in psychology (following Abraham Maslow [12]) of attempts to characterize the basic needs of a human being. The presupposition is that there is a restricted set of universal, basic human needs. These needs can be identified and studied, it is assumed, by empirical biology and psychology, since these needs continuously manifest themselves in overt behavior.

Anton Aggernaes [1] works quite clearly within the Maslowian framework. In his essay he sets himself the task of identifying a limited set of universal human needs. As a result, he proposes a list of needs which is slightly different from and simpler than the classical Maslowian one. Aggernaes' list of basic needs is exhausted by the following four categories:

1. the elementary biological needs;
2. a need for warm interaction with other human beings;