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## Preface

The purpose of this book is to define and measure quality, in general, and quality-of-life, in particular. I illustrate the issues involved in this task by examining the quality-of-life of the medically ill person, but I could have addressed these same issues by focusing on the quality of working life, the quality of the environment, or even the quality of an object or meal. I believe that how a qualitative<sup>1</sup> judgment is made is the same independent of the content being judged, and because of this, any qualitative assessment needs to simulate how such a judgment is made. I am not saying that the quality of a car is the same as the quality of a life; content does make a difference. What remains true, however, is that the cognitive processes involved in how different content is made into a qualitative statement is the same. As I will explain, the cognitive components of qualitative judgment involves: *description*, *evaluation* and *valuations*.<sup>2</sup>

In this book, I describe the fundamentals of this approach and then apply it to common indicators of the quality-of-life of the medically ill person. In Part I (Chaps. 1–3), I review the principles of language usage and describe various cognitive processes, while in Part II (Chaps. 4–6) I discuss the purpose (e.g., establishing invariant principles), content (objective or subjective indicators), and unit of analysis (categories or domains) of a qualitative judgment. In Part III (Chaps. 7–11), I apply the analytical approach and principles I have described to the specific content ordinarily included in a health-related qualitative judgment. In Chap. 12, the final chapter, I restate and review support for my working hypothesis, and in the Epilog I discuss future research that needs to be done.

I will address a number of specific issues in this book. For example, what is the best model<sup>3</sup> to use to conceptualize and how to obtain information about *quality*? The current standard relies on linear modeling systems and characteristic of psychometric methods (analysis of variance, regression analysis, and so on), but I will encourage the use of alternative analytic methods and schemes such as nonlinear models, neural networks, and complexity-based evolving cognitive systems. I will argue, for example, that a complexity-based self-organizing system characteristic of the central nervous system underlies how the constant stream of experiences I encounter (i.e., my phenomenology) is transformed into entities that can be processed by the brain. This occurs because of the adaptive capacity of the central nervous system, and it is this characteristic that makes this type of model particularly relevant to any assessment of quality, in general, and quality-of-life, in particular. However, once cognitive entities are formed, they can be linearly or nonlinearly combined. In addition, it is also possible to use linear models to assess outcomes generated by nonlinear means. I feel that it is necessary to expand the available models since the current domination of linear-based psychometric assessment models essentially ignores *how* the responses to a quality assessment occurs, and this creates issues concerning the validity of a qualitative assessment. In addition, psychometric

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<sup>1</sup> The term “qualitative” has a distinct meaning in the behavioral and social sciences, being applied to set of procedures that differ from psychometric methods. I will be using the term in a more restricted manner to refer to different types of quality assessments that may be assessed by either “qualitative” (e.g., grounded field theory) or psychometric methods.

<sup>2</sup> I use the term “valuation” to refer to such procedures as value elicitation, preference determination, and utility estimation (e.g., standard gamble).

<sup>3</sup> One of the primary objectives of this book is to offer an alternative to the current model that evolved from educational psychology. This new model involves the cognitive sciences and pragmatic aspects of language usage.

assessments are usually dependent on an intact language system for their input,<sup>4</sup> whereas nonlinear and complexity-based models can manage a broader array of analytical models. This will give me the opportunity to discuss alternative, nonverbal dependent models for use when dealing with the compromised person.

A reader will notice a number of distinct characteristics to my approach. For example, I use the term “assessment” almost exclusively, as opposed to the term “measurement” when characterizing quality. I also very often talk about “objectification” as opposed to “objective.” In both instances I want to emphasize that the science underlying what I am talking about is something that a person creates, it is a process, not a state or entity that exists. Thus, I avoid the terms “measurement” or “objective” since both imply something mechanical that can exist independent of me. The scientific study of quality, however, starts from something that is fundamentally subjective, and as such, is based on data that has to be assessed and transformed into something objective (i.e., the objectification process). I believe quality data can be made as objective as any other type of data, and like other forms of scientific data, can assume the characteristics of invariant statements. This, however, will require the recognition of neurobiological determinism and its influence on how I think and reason. Thus, although I see my scientific objectives as being the same as a physicist, I differ by acknowledging that I start with subjective information. I will discuss this and related issues in Chap. 12.

A second characteristic of my approach is that I follow Bridgman’s (1959) recommendation of making sure that I understand the process of understanding so that I continually try to separate what an investigator does from what a respondent does. For example, I make a distinction between categories and domains, where a “cognitive category” is a summary statement that a person generates, while “domain” refers to what an investigator does to summarize or collect information (e.g., as when using a factor analysis to identify a list of items to label). I try to avoid using the terms interchangeably, even though an investigator also generates categories, it is just that the categories an investigator cognitively creates (e.g., an item) maybe very different from what a respondent may do with the same information. The intent here, of course, is to have the investigator avoid confusing their views of existence with the respondent’s. At the same time, it recognizes that the investigator is as much a participant in the scientific study of quality as the respondent. Thus, I see the investigator and the respondent as inextricably interwoven in the process of assessing quality, and a complete picture requires separating and identifying the role of each.

Understanding the process of how an investigator understands is also essential to my argument that an optimal quality-of-life or HRQOL assessment has to include a valuation, preference, or utility estimation. In its absence, a quality-of-life or HRQOL assessment will only approximate an ideal assessment. My primary evidence for this argument comes from the observation that investigators have gravitated to this type of model from the onset of the field. Thus, some of the earliest efforts in such qualitative assessments include valuations of one sort or another (e.g., the Health Utilities Index or Quality of Well-being Scale). In Chap. 12 I discuss this issue in greater detail, particularly concerning whether weighting an evaluated descriptor makes a difference. To achieve my goals, I have to provide the appropriate intellectual foundation for the issues I raise. Thus, at times, I discuss material from such diverse areas as philosophy, psychology, and neurocognition. In each case, I will make the connection to issues of quality assessment clear. Part of the justification for wielding such a broad brush is that I want to be able to describe an approach to the definition and assessment of quality that is consistent across applications (e.g., quality-of-life, quality of working life, judging a painting, judging a car, and so on). In order to do this, I have to address some fundamental issues, such as how I come to know that what I report as quality; how I can judge that my quality-of-life or HRQOL is real and true; what specific cognitive processes (such as concept formation) and brain mechanisms might be involved; and how these mechanisms mediate the formation of a quality assessment. I also want to know if a definition of quality is derivable as a mathematical proposition,

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<sup>4</sup>Of course, nonverbal behavior can also be assessed using linear modeling, but the broader issue here is that the intent of linear modeling is to establish a causal relationship, while nonlinear modeling acknowledges that the input and output of a system are best characterized as probabilistic, and requires an assessment model that acknowledges this.

whether it evolves from a social consensus, or whether it is an experience that everyone has (my operating assumption).

There has been a considerable amount of effort to define quality or quality-of-life that involves several disciplines, each of which has its own unique set of assumptions that often contradict each other. To deal with this I will initially determine the extent to which each of a representative sample of quality-of-life or HRQOL definitions uses literal or figurative language (e.g., metaphors). This will permit me to determine if part of the difficulty in finding a common definition of quality-of-life or HRQOL has to do with differences in how language is used in these definitions (Chap. 2). I will also describe various *cognitive processes* and consider their role in generating a quality-of-life or HRQOL assessment. Quality, as an abstract entity, was considered a “concept” and how they were formed and used, will be extensively discussed (Chap. 3). Both of these tactics will be used throughout this presentation.

In this book, I will make explicit how performing a qualitative assessment is an *ethical act*. Thus, it seems obvious that one of the major reasons for performing a qualitative, and particularly a quality-of-life, assessment is because I want to ensure that the events that befall a person or interventions that have been applied to them do them no harm. The politics involved in ensuring this (e.g., quality control efforts), as well as the more general issues dealing with how we live our lives (i.e., the communities we live in, the crime rate, poverty, and so on) and what impact this has on our life quality, are all relevant here. Thus, a major theme running throughout this effort will be the explication of how a quality assessment can be used to improve the ethical character of social interactions, with a particular emphasis on the relationship between the patient and clinician.

I approach my task as someone whose training as an experimental and clinical psychologist makes it natural to approach the preparation of this task from the perspective of the individual. I have, however, felt free to use and integrate the insights and principles characteristic of other disciplines (e.g., sociology, philosophy or linguistics) when necessary, even though this places me at risk of inadequately representing these disciplines. Still, this risk was worth taking, considering that the object of this inquiry, understanding the nature of a quality and quality-of-life assessment, seems to naturally encompass a broad array of issues that would be inappropriate to not consider.

My interest in the ethical and political intent of quality-of-life or HRQOL research comes, not unexpectedly, from what I have learned from patients, friends, and family members who have had to use the American healthcare system or who have experienced changes in social policies (both good and bad). I have also observed that the role bioethics currently plays is limited to that of an outside critic rather than as a intimate determinant of the character of the healthcare process. I propose, as others have, that the continued promotion and integration of quality assessment into, for example, healthcare activities increases the chances of *preventing* or reducing ethical transgressions. This, I argue, is essential if health care is to make a maximum contribution to a person’s existence.

Finally, I hope that the model I am proposing will stimulate debate and active discussion about how best to assess quality and quality-of-life. To achieve this I have adopted the tactic of being quite open about the limitations of current efforts to define and assess quality, including considering whether it should be assessed at all. I also acknowledge that there is an inherent ambiguity and complexity about this concept and the task concerning its assessment, as would be expected for such an important personal and societal indicator. I find that these complexities are balanced by the richness of the intellectual opportunities created by the concept; it is a concept worth struggling to define and assess. The length of its history alone attests to its capacity to deal with a fundamental human concern: the nature of our current existence or how one has lived one’s life. Its potential as a source for social innovations is also exciting, and remains an underdeveloped activity. The task remaining, however, is to convincingly capture the joy, pain, and suffering real people experience with the numbers that I will use to characterize their experiences.

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