Chapter XLV
Health-Related Quality of Life Measures in the Information Age

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ABSTRACT

This chapter provides an introduction to a variety of essential issues concerning quality of life (QoL) as a social-scientific construct. The chapter begins with an introduction to the notion of QoL as an essentially contested concept and provides a taxonomy for classifying various instruments. The various methods of operationalizing the measurement of health-related quality of life (HRQoL) are outlined and a variety of practical examples are provided. A range of methods of determining the validity, reliability, and responsiveness of QoL measures are discussed to provide the reader with the tools necessary to critically evaluate the broad range of QoL instruments available. Finally, the scope of employment of QoL instruments is explored and several important limitations of this mode of assessment are discussed.

INTRODUCTION

One of the oldest and most fundamental assessments performed by health care providers is the medical history. The medical history can be described as a discussion concerning one's health that takes place between a health care professional and a patient. While there are many different objectives that can be accomplished through the medical history, physicians have traditionally relied upon this assessment to provide important diagnostic indicators through the collection of symptoms in order to assist in making a diagnosis, to gage the severity of a disease process, and to assess the efficacy of various treatments. Insight into the health status of an individual can be acquired through the medical history in many different ways; such as, inquiring about functional limitations, physical changes or eliciting purely qualitative descriptors of psychological distress.

In an effort to focus, quantify and standardize certain aspects of the medical history investigators have developed various "Quality of Life" questionnaires. To date, over ninety thousand peer reviewed articles are indexed on MEDLINE under the key words "Quality of Life" and this body of research stands as a testament to their importance. This chapter will provide an introduction to a variety of essential issues concerning QoL instruments. To begin, the difficulty concerning defining QoL and its conceptualization will be reviewed. The notion of QoL as an essentially contested concept will be introduced. A framework for classifying instruments will be outlined and various measurement techniques will be described. The necessary knowledge required to understand the essential methods of establishing validity, reliability and responsiveness of QoL measures will be provided. Finally, the scope of their employment in the field of health care will be introduced and several important limitations of QoL instruments will be discussed.

CONCEPTUALIZATION OF QoL

An accurate definition of a concept should strive to be both exhaustive and exclusive. That is to say, a definition should include all that is pertinent, while excluding all that is not. Clearly, meeting these criteria is often not possible, yet, it has been noted that moving toward this ideal is more difficult with some concepts than with others. Such is the case with quality of life (QoL). Put simply, there is no one definition of QoL (Hunt, 1997). Although many definitions have been proposed, each has its own limitations (Power & Kuyken, 1998). In many ways, QoL can be recognized as an "essentially contested concept" (Gallie, 1964). An essentially contested concept is one that has widespread agreement about its existence and its core "notion", but significant debate exists about both its full meaning and operationalization. Put more practically, it is not a matter of further philosophical debate or empirical research which will furnish a more "correct" definition of QoL; but rather, even in principle, it is not possible to arrive at its conclusive definition. QoL is a socially constructed concept and it can hold different and equally valid meanings for different people. This "relativity" stems from the fact that there is no objective referent object that individuals can turn to in order to decide what should and should not be included in its definition. It is a latent construct. Given the inherent instability of QoL as a concept, many have questioned its utility as a practical tool in research and decision-making. Yet, there are many essentially contested concepts that have proven to be very important to society. Few would argue that the concepts of democracy, peace and justice remain important despite their essentially contested nature. In a similar fashion, QoL is a concept that has proven to be useful in understanding both individual and collective self-perceptions. In light of these considerations, defining QoL can be described as an exercise in both stipulation and negotiation. Finding common, relevant ground for the content within QoL surveys is accomplished in a variety of ways; most often through focus groups and expert agreement. The process of stipulation can be either explicit, wherein an author states the breadth of phenomena intended to be measured; or implicit, wherein one is left to surmise the phenomena intended to be measured by the content of the questions employed. In common practice the latter is far more often encountered than the former (Gill & Feinstein, 1994). In either case, it is important to determine what a QoL instrument is intending to measure. With this in mind, the following sections will now address the practical art of measuring QoL.

CLASSIFYING QoL MEASURES

The most basic practical aspects of QoL measurement involve the specific means selected to elicit