

## Commentary

# Quality of life assessments and levels of decision making: differentiating objectives

H. J. Sutherland,\* and J. E. Till

Division of Epidemiology and Statistics, Ontario Cancer Institute/Princess Margaret Hospital, 500 Sherbourne Street, Toronto, Ontario M4X 1K9, Canada. Centre for Bioethics (H. J. Sutherland and J. E. Till), Department of Medical Biophysics (J. E. Till), University of Toronto, Toronto, Canada

**The purpose of this paper is to examine uses of quality of life (QOL) measurements at different levels of decision making within the health care system, ranging from the micro (clinical) level, through the meso (agency, institutional or regional) level to the macro and meta (governmental) levels. We use individualized, group and population-based QOL and preference assessments as illustrative examples of ways in which QOL information and decision making level interact. We conclude that the meso and macro levels pose particularly challenging problems, and suggest that, if the primary emphasis is placed on applications of QOL assessments at the micro (clinical) level of decision making, a research agenda that is much too limited may be adopted.**

*Key words:* Decision making, preferences, health profiles, utility measurement, quality of life.

## Introduction

It is increasingly recognized that rational decision making about treatments for chronic life-threatening diseases (such as cancer) should be based on theory and empirical data with respect to several end-points, including, in addition to survival, impact on quality of life (QOL), costs, and, wherever possible, patients' preferences.<sup>1,2</sup> Consequently, there has been much interest in the evaluation of health-related QOL. Some researchers have focused their efforts on developing individualized measures of QOL<sup>3–5</sup> while others have sought to produce more standardized

measurement instruments (for a review, see Osoba *et al.*<sup>6</sup>). Concurrently, methods for assessing preferences for particular aspects of health status and for various states of health (each of which reflects a particular QOL) have evolved.<sup>7</sup> We believe that both QOL and preference assessments are relevant to decision making in the health care system, regardless of whether those decisions concern individuals, groups or populations.

It is important to appreciate that two major contrasting approaches to QOL assessment can be described which are applicable to any level of decision making; the 'health profile' approach and the 'utility measurement' approach.<sup>6–9</sup> In the health profile approach, multidimensional measures may be used to obtain information about several aspects of health-related QOL, such as the nature and severity of effects of a disease or its treatment on the physical, emotional and social functioning of individuals (or groups, or populations). No preferences (or values, or weights) are necessarily obtained for the components when this 'disaggregation, no valuation' approach<sup>10</sup> is used, although such values can be elicited using other methods. In the utility or valuation measurement approach, preferences among a variety of health states are measured, usually on a unidimensional scale ranging from zero (dead) to one (perfect health). Utility assessment approaches (such as the 'standard gamble') involve decision making under conditions of uncertainty, while other valuation approaches may not (see, for example, Froberg and Kane<sup>7</sup>). Utility measures can provide a quantitative insight into which health states are preferred over others. They can also readily be combined with economic evaluation measures to assess the costs and benefits of health care.<sup>8</sup> Health profiles,

---

Supported by a grant from the National Cancer Institute of Canada with funds from the Canadian Cancer Society.

\* To whom correspondence should be addressed.

in the absence of a preference valuation component, usually cannot. However, unidimensional utility measurements do not provide detailed information about which aspects of QOL have been affected by the disease and its treatment. Thus, they can provide little insight into the underlying causes of deficiencies in QOL.

The primary objective of this paper is to examine the uses of QOL information in decision making at different levels within the health care system. We will attempt to provide illustrations for our view that QOL assessments have different purposes at these different levels of decision making. If the uses of QOL assessments differ at each level, it follows that the priorities for QOL research should differ, depending on which level of decision making provides the main context for the research.

### Levels of decision making

In a hypothetical health care system where all decisions could be made at the micro level, the purposes of QOL assessments would only need to be considered at this level, if it is assumed that every person would have unlimited access to health care. Unfortunately, in the real world, such an idealised health care system is available only to a very few privileged people. Instead, in many instances, decisions have already been made by others about which health services will be available and who will have access to them. These decisions may be made at a 'meso' or even 'macro' level of government (Table 1). For example, at the 'meso' level of decision making (such as an agency, institution, or regional network), priorities among various conventional or experimental treatment regimens for various categories of patients would be determined (for example, by the development and implementation of clinical practice guidelines).<sup>11</sup> At the 'macro' level of governmental decision making, priorities for support of different aspects of health care would be determined (such as, for example, the priority of programmes concerned with health promotion or disease preven-

tion, relative to the priority of all other aspects of health care). There is a further 'meta' level of governmental decision making, at which priorities for support of health care would be determined, relative to priorities for all other governmentally supported programs (such as education, justice, defence, etc.). Although this meta level of decision making may have a major impact on other levels of decision making, its influence extends well beyond health care, and will not be considered further here.

The proposed multi-level framework for decision making illustrated in Table 1 is not particularly novel. For example, economists make a distinction between microeconomics, an analysis of individual units in the national economy, and macroeconomics, the study of larger aggregates in the economy.<sup>12</sup> Three inter-related levels of decision making about the allocation of health care resources have been described, and termed the individual, intermediate and aggregate levels,<sup>13</sup> or the patient-centred, medical and political levels.<sup>14</sup> Analogous frameworks have also been proposed by others.<sup>15,16</sup> What does seem to be novel is the application of an explicit multi-level framework to issues relevant to QOL research.<sup>17</sup>

#### Micro-level decision making

The micro level of decision making about health services is easily defined, since the objective of the decision making is individual patient benefit. Decision making involves individual patients and health care professionals; it is concerned with individual encounters between patients and health care professionals (such as, in oncology, individual treatment decisions, either conventional or experimental, about curative, palliative or preventive care). As mentioned above, preferences of individual patients and health care professionals for particular QOL states and survival should be taken into account at this level of decision making.

Ideally, at the micro level, the individual patient should identify those aspects of QOL which are most relevant and important to him or her, and

**Table 1.** Levels of decision making within the health care system

Level	Target	Purpose of assessment	Locale
1. Micro	Individuals	Individual benefit	Bedside/clinic/office/health centre
2. Meso	Groups/small communities	Group benefit	Agency/institution/regional network
3. Macro	Large communities/populations	Population benefit	Government (e.g. Health Ministry)