Needs-Based Health-Related Quality of Life Measurement: New Wine in Old Bottles?

To the Editor—Several recent articles, including those appearing in this Value in Health supplement (Value in Health 2004; 7(S1)), advocate the adoption of a needs-based approach to the measurement of quality of life (QoL). Because this advocacy seems to in part be driven by the perceived failures of other models, it might be useful to consider its advantages over its rivals. In one sense, the needs-based approach has already demonstrated a technical superiority of sorts as many, perhaps most, measures of QoL lack an explicit, formal model at all. But, first things first. What exactly is a needs-based model (NBM)? There may be a better formulation of its components and distinguishing characteristics elsewhere, but for the purposes of this commentary we might use a recent article that adopted this model and apply forensic analysis to deduce this information. The term “quality of life” is applicable here, although in the context of the treatment of ill-health and disease the term “health-related quality of life” is more accurate and is to be preferred. The model argues that disease-related impairment and disability influence a person’s ability to meet his or her needs and that QoL [1] is defined as the extent to which needs are fulfilled. QoL assessment is intended to provide an accurate summary of the impact of disease from the perspective of the patient. It is important to note that it is not intended to determine disease severity or to aid in deciding on the most appropriate intervention for individual patients. The model is particularly useful ... (in) allowing impacts to be summarized in a single outcome measure. The concepts underpinning NBM thus appear to be the following:

1. Impairment and disability influence capacity to meet “needs”;
2. Quality of life measures the extent to “needs” are met—thereby revealing the gap between expectation and reality;
3. Patient perception constitutes the authoritative view in defining that gap.

Need here appears to be exclusively defined in terms of patient perception. Nevertheless, need is capable of definition in terms of multiple and (potentially conflicting) interpretations. Is “need” really more than the identification of an attribute, a function, a good, a service or product that is necessary in some way, but is otherwise lacking? Is it more adequately defined as simply the capacity to derive benefit? Should “need(s)” be described in terms of Maslow’s hierarchy? Beyond this, can we distinguish “needs” with higher status or rank from others of a lower order? It is this latter process that introduces the concept of preference where some needs dominate others. The difference between “needs” and “wants” is an important one too, as can be witnessed whenever a jackpot prize is announced in the UK National Lottery. Many people express the “want”—few, if any, have a real “need” for the prize.

Suppose for a moment that we have a shared understanding of what is meant by the concept of “needs”; an important next question relates to the means by which that concept is translated into a descriptive system and more importantly, by whom. The NBM approach dictates that we consult exclusively with patients in deriving candidate items. This is described as a basic requirement of QoL instruments because it ensures that the content of the final instrument is relevant to the target population and that issues considered important by patients are not omitted. The method adopted for this journey of discovery is that of unstructured qualitative interviews with patients. This is described as a basic requirement of QoL instruments because it ensures that the content of the final instrument is relevant to the target population and that issues considered important by patients are not omitted. The method adopted for this journey of discovery is that of unstructured qualitative interviews with patients. This is akin to the artist who works with so-called found objects—the rusted can or bicycle wheel has significance ascribed to them by the artist, even though the casual bystander still perceives them as the junk that they are in terms of their own reality. So it is with the transcribed dialogue derived from such unstructured interviews. The found objects of conversation form the basis for a post hoc reconstruction, albeit one that is based in part on the rigor of content analysis. The research scientist necessarily has to impose a certain discipline on the otherwise chaotic mass of evidence with which they are confronted. In so doing, they bring to bear their own value judgments about how to restructure and present those data in a form that makes them more readily available to third parties. Hence, although the source of materials used in the construction of measures of QoL might very well be patients or others with relevant first-hand knowledge of ill health, those primary data are overlaid by the research methodology that is applied to them and the research analysts...
who utilize those methods. It becomes difficult to know how this resulting hybrid can be described as exclusively representing the patients’ views.

This position can be exacerbated in subsequent item testing and selection. The choices made to include, or exclude, items are in effect the exercise of values held by the researcher about what is, or is not important or relevant—whether or not that choice is based on technical grounds arising from, say, the use of Rasch models or IRT methods in general. Rasch models are essentially probabilistic in character nature and rest on the assumed ordering of items on an underlying QoL continuum and the extent to which individuals reflect their own QoL through their responses to those items. This is in itself a perfectly sustainable approach to modeling QoL, but we should be clear about how that probabilistic model operates. Items that meet the requirements perform satisfactorily “count.” Those that fail “do not count.” Nevertheless, it is perfectly feasible to take account of patient preferences in the course of item reduction. In so doing a new set of problems emerge. Individual patients will have individual preferences as to what is important for them. How is the instrument developer to aggregate these data across the patient group as a whole without recourse to some method or other that attenuates the contribution of the individual? Does NBM represent patients’ views or patient’s views? Once those patient preferences are set aside by the researcher then that characteristic becomes redundant and a claim for the superiority of NBM is correspondingly diminished.

Where such models are used to weight items then any suggestion of proximity to patients in terms of importance and relevance becomes virtually impossible to sustain. Poorly performing items can nevertheless reflect aspects of QoL that are highly value by patients. Nevertheless, once the technical process of item reduction has kicked in there is no escaping the analytic steamroller. Furthermore, much of the process of testing reliability and performance in the finished product relies on, for example, discriminating between patients with known characteristics, for example disease severity, or convergence with other data generated by other QoL instruments. Whether or not those tests should be expected to help in establishing performance takes us back to a crucial issue that precedes the use of any single approach, NBM or otherwise.

In designing any new QoL instrument we need to be clear about the purpose for which it is intended. If as suggested earlier, QoL measurement is intended merely as a way of summarizing the patient’s perspective of their illness, then this is to deny its wider potential. If, however, we are seeking to measure QoL to determine health outcomes and where we wish to ensure that those outcomes are expressed in terms that are recognized as valuable by patients, then there is undoubted merit in ensuring that the instrument captures those aspects of the condition and/or its treatment that they value. It is this attribute of value that separates QoL measurement in general from more narrowly focused clinical or condition-specific measures. Where the values embedded in a measure arise from the researcher or the methods they choose to employ, in place of the patient then that differentiating factor is lost and with that loss goes any claim for conceptual superiority. The needs-based approach is neither new nor novel. It is simply the repackaging of ideas and techniques that have formed part and parcel of much instrument development over the past three decades. It remains benign so long as instrument developers and users do not elevate it to orthodoxy. The danger for the untutored is that needs-based becomes needs-must.—Paul Kind, MPhil, Principal Investigator, Outcomes Research Group, Center for Health Economics, Alcuin College, University of York, and Editorial Advisory Board member of Value in Health.

Reference