

Quality of Life as a Construct in Health and Disability Research

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Abstract

Definitional issues that affect the measurement of quality of life (QOL) in health care research are discussed. In reviewing a broad sample of health- and disability-related QOL studies, the authors note several characteristics in which respective approaches to measurement differ: (a) In various measurement tools, QOL has been located either within the insider's (i.e., the person being measured) judgment of the "goodness" of his or her life or outside this judgment. (b) The insider's and/or outsider's values may hold sway in deciding the elements of life that are relevant to QOL within the measurement process, and in rating the degree of "goodness" of these life domains. (c) QOL models incorporate domains of items varying in breadth and specificity; and they take either a negative or neutral view of functioning. (d) QOL models vary in their complexity, type of linkage between components, and inclusion (or not) of both the insider's judgment and external predictors of QOL. These distinctions are used by the authors in recommending approaches to QOL measurement suitable for health care research aimed at outcome assessment and description of populations. **Key words:** Quality of life, disability, chronic illness, research methodology.

IN THE UNITED STATES, studies of quality of life (QOL) first came to the fore in the mid-1970s with the exploring of perceptions of subjective well-being within the general population (1, 2), as well as the use of more objective, community-focused "social indicators" (3, 4). More recently, interest in assessing health-related quality of life (HRQOL) has increased within health care research (5–8), particularly in studying outcomes of medical interventions and in tying increases in

life quality to costs associated with medical care. Numerous QOL studies have also focused on documenting the well-being and conditions of living of those with chronic medical conditions and disabilities (9–21). This forward momentum within the health care arena has been deterred little by criticism and warnings about the uses and misuses of QOL data (22).

In the geometrically expanding quality-of-life literature, it is often noted that researchers cannot agree upon what "quality of life" means, or how it ought to be measured (6, 23, 24). Indeed, quality of life appears to have as many definitions (implicit or explicit) as the number of publications that have incorporated this construct. This uncontrolled growth in definitions parallels the development of a profusion of QOL measurement tools, which have been regularly catalogued and appraised (25, 26). The QOL tools developed or adopted for use with individuals with disabilities and recipients of medical services include the SF-36 Health Survey (27), the Sickness Impact Profile (28), the Reintegration to Normal Living Index (29), the Community Integration Questionnaire

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(30, 31), the Barthel Index (32), plus hundreds of others (25). As will be discussed below, these tools vary not only in terms of their definitions of QOL (i.e., what the “yardstick” looks like), but also in terms of how and where the “yardstick” is used (i.e., the data source relied upon in assessing QOL). Complexity is added to this definitional and operational chaos by those who see quality of life as unquantifiable and better approached through qualitative study (33).

Thus, as a focus of measurement within health care, QOL remains unfocused, which has resulted in a largely failed mission: We have instances of excellent studies describing QOL within specific groups of people in defined situations, but a cumulative picture of how the well-being of medical recipients is affected by treatment is not being developed. Nor have we developed compelling and coherent profiles of QOL within populations of individuals with varying chronic conditions and disabilities. We have instead a ragged patchwork of results. Although researchers who desire to explore the wider implications of medical interventions by including measures of QOL are to be applauded, inadequate attention to definitional issues has resulted in these authors “talking past each other.”

Within this “Tower of Babel,” many problems have converged. First, as noted, little agreement has been reached on the definition of QOL. Second, many studies are carried out with no thought given to the definitional distinctions incorporated into the QOL tools adopted or for their implications for the research questions being pursued. And, third, a variety of methodological (rather than definitional) problems weaken the applicability and generalizability of results. For example, too many researchers under-identify the respective samples studied, so that in the end we have very little understanding of whose life quality is being delineated. These methodological issues are beyond the scope of this paper. Instead, our goal is to clarify the definitional choices that affect measurement of QOL within medical research. How do the characteristics of measurement tools we adopt affect our results? Each tool carries with it a specific focus, intrinsic values, level of sensitivity, breadth of view and range of utility. The implicit concepts and models underlying measurement approaches need to be clearly explicated prior to adoption of any particular yardstick.

The basic premise of this article is that measurement of QOL always incorporates value judgments. Such judgments may be implicit or explicit, made by the insider (i.e., the person

being measured) or by an outsider, but are always intrinsic to QOL measurement. For example, on the one hand, the insider may be asked explicitly to rate (i.e., place value on) his or her “satisfaction,” “well-being” or “quality of life” since Treatment X. Or, on the other hand, the researcher (an outsider) may insert his or her own value judgment and conclude that “their QOL is lower, as most study participants experienced higher levels of depression after onset of disability compared to levels in non-disabled controls.”

We suggest that the key question in QOL research is: Whose values are being tapped? We also suggest that the reason QOL is important to measure is that it is the primary means of inserting the insider’s values into measurement of health benefits. From the insider’s perspective, it is the primary means of becoming empowered within the measurement paradigm. If values other than those of the insider are incorporated into a study, the results speak to the questions of “gains,” “societal benefits” or “change,” but not QOL. Such research on the benefits of and changes associated with medical treatment are clearly important, but the point here is that they should not be mislabelled as QOL studies.

In exploring approaches to QOL measurement, we will first analyze the two questions underlying such measurement: (a) What parts or elements of life are incorporated into measurement? In the model of life that underlies measurement, what components are deemed relevant to measurement, where is QOL specifically located among them, and how do life elements outside QOL relate to QOL? (b) How is the “quality” of these elements determined? In other words, how does evaluation of life get inserted into measurement, and whose values are adopted? Based upon this analysis, we will then recommend approaches for measuring QOL, ending with a brief discussion of how such recommendations are affected by the purposes to which QOL measures are to be put.

Models Underlying QOL Measurement

Although various QOL measures differ widely, each embodies an operational definition of what QOL is. The measure includes only those aspects and domains of life viewed as relevant to and affecting QOL and excludes those which are not. Models of life underlying QOL measurement can be characterized in terms of the domains/elements included and the structural relationships between those domains. Thirdly, models differ in terms of where within these structured domains QOL is located.

QOL Models: Domains and Elements

QOL models differ, firstly, in the breadth of content areas or domains incorporated. At one end of the continuum are studies of QOL that adopt single variables as indicators of QOL, such as measures of depression or work status. Many tools measuring HRQOL focus also on a relatively narrow swath of the person's lifespace, with the effects of illness, pathology and impairment at the center of the model. The consequences of illness or impairment are highlighted, as with a narrow beam of a flashlight. Thus, measures of handicap, adhering to the long-standing International Classification of Impairments, Disability and Handicap (ICIDH) definition (34), are sometimes used as indicators of QOL. The typical ICIDH-based model states that pathology affects impairment, in turn affecting disability, and in turn handicap. Contextual elements—beyond the initiating pathological event—often are included in ICIDH-based (and other chronic-disease) models; however, their role is clearly secondary (35). As Minaire (36) suggests, these models focus on the social aspects of illness: Illness is the lens through which life is viewed. Chubon (37) argues against the use of many health- and disability-relevant QOL measures because of the narrow focus they adopt.

In measures emerging from social science traditions, a broader view of life is often taken. The impact of pathology is typically acknowledged but is not the central issue, and it is interwoven with other, more broadly defined extra- and intra-person variables. For example, Felce (38) suggests six QOL domains, with no less than five subdomains in each.

The ICIDH definitions of impairment, disability and handicap are currently being revised (39) after being in place since 1980. In the system being tested, the focus of attention is being placed on impairment, activity and participation, thus focusing more fully on functioning within a broad social context. When the revisions become available, broader views of life may become more frequently incorporated into QOL studies within health care research as measures are developed and adopted to reflect the revised ICIDH view.

QOL models also differ in the assumed valence applied to the elements within the domains. In other words, life after onset of disease or trauma may be viewed within some models solely in terms of negative consequences (e.g., symptoms, problems, disability, handicap). Alternatively, a neutral stance may be taken, in which assessment focuses on functioning and assumes that dysfunc-

tion neither monopolizes life nor dominates the picture to be drawn of QOL. The difference is exemplified by the thrust of what is typically asked in assessing the person's life: Does the assessment tool ask about problems (thereby taking a negatively valenced view) or does it ask, for example, about the frequency of events such as "using transportation" (a neutral question allowing a range of responses that may indicate a problem for some individuals but a strength for others)?

The predominance of negative views of life after onset of illness or disability is illustrated by Ziebland and her colleagues (40). They posit four models of disability that underlie the items comprising HRQOL assessment tools. Items which, when summed, measure the person's degree of disability, may be couched in terms of a tacit model of total disqualification (e.g., "unable to walk?"), subjective distress (e.g., "trouble bending or lifting?"), comparative limitations (e.g., "more mistakes than usual?") or dependence on other persons or devices (e.g., "need help to walk?"). They suggest that the measured disability level of any individual will vary across HRQOL instruments as a function of the tacit models used in framing items within the respective questionnaires. What "goes without saying" is that a sole focus on disability guarantees a negative view of the QOL of the person with the disability or chronic illness.

A neutrally valenced model encourages a view of the person as more than his or her disability (41), where ability and strengths can be delineated to form a more complete sense of the person's QOL. For example, for studying the QOL of older persons, Raphael and his colleagues (42) generated a measurement approach focusing on three domains: being, belonging and becoming. Further, as Rowe and Kahn (43) suggest with respect to studies of aging, where negatively valenced views are typical, shifting the emphasis from studying "usual" to studying "successful" aging encourages us to seek the factors in the person and environment that promote success.

The newly emerging ICIDH brings with it a less negatively valenced approach than in the past (39). The original version focused on the consequences of pathology in the individual, defining these solely in negative terms (impairments, disabilities and handicaps). This negatively valenced model was widely adopted after the ICIDH's introduction in 1980 (34), despite the burgeoning at that time of measures adopting multidimensional, neutral views of functioning with a disability (44, 45). Again, perhaps when the new ICIDH is introduced, QOL measures will

take a broader view of living life with a disability, and one that is less negatively valenced.

Finally, the content incorporated into QOL models differs in terms of the specificity of the items. Thus, some models adopt broadly defined constructs as items for analysis (e.g., “overall goodness of life,” “overall mood”) or combine specific items into broad, construct-oriented scores (e.g., “work handicap”). Other models are noted for their concreteness and specificity (e.g., “satisfaction with leisure activities,” “number of different people visited in the past month”). For example, in their research, based on an ICIDH-type model predicting QOL of individuals with traumatic brain injury (TBI) living in the community, Heinemann and Whiteneck (10) found that QOL was most strongly associated with the broad concepts of social and work handicaps, accounting for 13% of the variance. In contrast, Granger and colleagues (46), studying a sample of 22 young people with TBI, predicted 80% of the variance in general life satisfaction using three relatively specific variables: access to transportation, depression level and problem-solving ability.

QOL Models: Structure

Models underlying measurement of QOL also vary in the structural relationships posited between domains. In the simplest unidimensional models, QOL is located in a single “place” (e.g., “QOL is equivalent to the person’s level of depression”) and no relationships with other life elements are incorporated into the model. More often, QOL models go beyond such simplicity in one of two ways: Some posit multidimensional components that together comprise QOL (e.g., “QOL is constituted by work status, degree of social contact and health status”). Others may include a variety of factors that together predict QOL, but which themselves are considered external to and not components of QOL (47) (e.g., “QOL—however measured—is predicted by work, social contacts and health”). Often a combined approach is adopted: multidimensionally defined QOL predicted by a variety of external factors.

Multidimensional models vary in terms of the types of linkages specified between components of the model, varying along a continuum of the degree to which hypotheses about relationships between variables as well as causal links are incorporated into the model. Residing at one end of the continuum are descriptive multidimensional models. In such models, multiple domains of the individual’s lifespace are viewed as comprising QOL,

but relationships between domains and elements remain unspecified. For example, Dennis and her colleagues (23) suggest that QOL is a function of three sets of factors: those factors unique to the individual, those unique to the individual’s culture and those common to all people. These domains are posited, but neither how they interrelate nor how they “produce” QOL is specified.

At the other extreme of this continuum are models that posit specific causal, explanatory linkages between components of QOL. For example, Ormel and his colleagues (24) propose a social production function framework underlying QOL, through which they causally link health to quality of life measures. Within their view, people work to maintain their psychological well-being (i.e., QOL) by trying to optimize achievement of universal needs (i.e., physical and social well-being) via six instrumental goals (i.e., optimal level of arousal, pleasant environment, absence of physiological needs, control over scarce resources, behavioral confirmation and affection). Addressing these goals occurs within the context of the individual’s resources, instrumental activities and endowments. Ill health or impairment typically reduces the individual’s repertoire of instrumental activities, so that instrumental goals as well as physical and social well-being are threatened. The individual may shift activities and the use of resources to get his or her needs met. If substitutability is limited, QOL will decrease.

At the midpoint of the continuum are correlational or predictive models. These models not only posit diverse domains that “capture” QOL but also pinpoint linkages (correlational or predictive) between domains. In other words, models of this type provide more than a list of domains found in descriptive models, but less than an explanation of how domains relate to each other, which is associated with truly causal models.

It should be noted that predictive and causal models may posit non-linear relationships between elements or domains and QOL (24), including what Batterham and his colleagues refer to as threshold variables (48). Thus, for example, Lindstrom and Köhler (49), in comparing QOL of adolescents with disabilities to those without disabilities, analyzed the percent of these youths’ families achieving a set threshold on each of several variables (external conditions, interpersonal functioning and psychological well-being).

It should also be noted that through the logic of the model’s predictive or causal structure, key domains and elements of the model may play a strong role in dictating the remaining elements.

For example, medical models that underlie measures of health-related QOL (36, 50) often "begin" with pathology. They suggest that HRQOL is produced as a function of pathology interacting with a variety of elements within the individual and his or her environment. Thus, Wilson and Cleary (51) tie QOL to health within a framework of complex hierarchical effects. Health-related QOL within their model is directly affected by the individual's values and preferences, general health perceptions, and social and psychological supports, as well as by "nonmedical factors." Pathology, within this model, is the prime mover, but only directly affects QOL through general health perceptions. However, pathology dictates many of the domains of interest that are incorporated into the model and is the organizing principle within the model.

QOL Models: Location of QOL

Models vary in terms of where within the structured domains one looks to find the "life," the "quality" of which is being evaluated. Models differ at the grossest level in terms of whether QOL is located solely within the judgment of the insider or, instead, outside that judgment, or whether QOL is a combination of the insider's judgment and external variables. Thus, QOL has been conceptualized as solely the insider's judgment of the "goodness" of his or her life (whether cognitively and/or emotionally conceived) (47, 52). Within this view, the QOL judgment depends on the insider's values and how much weight is given by the person to each element of life that potentially affects "goodness." The insider may incorporate every potential domain of life in arriving at a judgment or may include very few. He or she may explicitly review life's elements or may simply provide a "gut reaction." No matter how compelling any factor may seem to an outsider (such as severe depression or a fire that destroys an individual's possessions), the insider's QOL judgment may or may not be affected by these externally defined "catastrophes," depending on the insider's valuation of them. Thus, in this approach, "life" is outside the insider's judgment, but QOL resides totally within.

In contrast, models aimed at documenting QOL at the level of the community (53) typically have focused on factors fully external to the individual (e.g., measures of housing conditions, crime, pollution, quality of schools). In other models, factors "attached" to the person, but external to his or her judgment of the goodness of

these factors, comprise QOL, including measures of the individual's emotional well-being, statuses, patterns of activity engagement and/or time (54–57) (e.g., level of depression, work status, socializing with friends). In these models, QOL is located fully outside the insider's judgment and, in fact, is located in the judgments of outsiders; this is discussed more fully below.

Some measurement systems define QOL as a combination of the individual's internal evaluation of life's "goodness" and external conditions (58). For example, Felce (38) defines QOL as a function of objective life conditions and personal satisfaction with those conditions, both of which are weighted by the individual in terms of his or her personal values and aspirations. However, all too often the model does not make the locus of QOL explicit (i.e., whether QOL resides both inside and outside the individual, or whether QOL is fully an internal judgment and the external factors included in measurement are merely predictors of QOL).

With models placing the person's internal judgment of "goodness" at the center of QOL, debate has focused on whether QOL should be assessed by seeking a single judgment of this experience or by separately evaluating several areas of the individual's view of life, such as family life, friendships and work (24, 59, 60) (i.e., is the internal judgment of QOL unidimensional or multidimensional? And, do we gain in our knowledge of QOL if we ask the insider to make the basis of his or her evaluation explicit and multidimensional?).

Values: Insiders vs. Outsiders

QOL measurement varies not only in the model adopted but also, and most importantly, in terms of the values that hold sway during the evaluative process that defines QOL assessment. Whose values are acknowledged: those of the insider or those of an outsider (e.g., family member, physician, researcher)? A variety of avenues are available within QOL measurement to give preferential place to the insider or to one or more outsiders; this preferential place carries with it the power of being heard. This is done, first, in assigning responsibility for assessing the "goodness" of an individual's (or group's) QOL to either the insider or outsider. Second, power also resides in the act of deciding the importance or relevance of domains of life that potentially affect QOL. Thus, for example, power is given, on the one hand, to the evaluator of the "goodness" of the insider's recreational life, and, on the other, to the person who decides if this aspect of life will

be evaluated at all (i.e., is it one of the domains included in the QOL assessment?) and if so, how important it is to the focal person (i.e., the respondent).

The issue of whose values are given sway is highly correlated with, but potentially independent of, where QOL is located. For example, if QOL is located within the insider's judgment, it would seem logical to ask the insider to evaluate his or her own QOL. However, other approaches are conceivable. For example, QOL defined as the insider's judgment might be assessed by asking family members to judge the insider's sense of well-being, especially if the insider's cognitive or emotional functioning is in question. One can also imagine the internal experience of QOL being measured "objectively," such as by using serotonin levels or other physiological measures as indicators of the insider's experience of overall well-being.

A critical point here is that various sources provide different views of the target individual's life, any one of which may be useful. The problem occurs only when these views become substitutes for and replace the insider's view. Thus, when a measurement system adopts one particular perspective, the implication is that that source has the authority of truth, because it is the evaluator's values that are incorporated into the assessment. In this vein, Minaire (36) argues that "quality of life" should only be applied to subjective assessments by insiders. He views QOL as "belonging" to the person, in effect defining or "making" the person who she or he is. Although this debate has often been couched in terms of subjective vs. objective assessment, it is really a matter of whose values holds sway: the insider's or the outsider's.

Clearly, when an outsider is the subjective evaluator of the insider's QOL, the outsider's values are given predominance. This is also the case when researchers replace the insider's values with their own assumptions about societal values. For example, if "better" QOL within a study is defined as a function of income level and education, the implicit value typically adopted is that higher levels of attainment in these areas are correlated directly with higher levels of QOL. However, for many individuals, their achieving up to a threshold in these areas contributes to their experience of QOL, but achievement beyond that point has no effect. In this case, their values are not congruent with the value assumptions of the QOL model.

Sometimes, societal values are incorporated into the QOL assessment through the use of normative data from the general population or from subgroups, such as other disability or illness

groups. For example, the QOL of a group of people with disabilities, when compared to a non-disabled group, may be judged lower by the researcher because it evidences more depression than is typical in the control group. This judgment does not flow intrinsically from these data, but instead from the societal values being adopted by the researcher.

Some have criticized insider assessment of QOL, because these measures may be less a reflection of the person's "real" QOL than the person's psychological adjustment to disability. In other words, the insider's assessment of his or her satisfaction or well-being is viewed as being an unreliable indicator of the "real" conditions, actions and events that affect or comprise QOL. So, for example, in some studies of QOL, the smaller-than-expected differences found in QOL judgments between people with disabilities and those without have been viewed as underestimates, as the individual with a disability is assumed to be denying or minimizing his or her true feelings (61). In one study, people with disabilities rated health and mobility as "less important" in their lives than did a non-disabled comparison group; the authors suggested that this resulted from a selective de-emphasis of those functions affected most by disability, due to adjustment and habituation processes (9).

The issue of subtly shifting judgments of QOL is not problematic, however, to those who view "real" QOL as residing within the insider's judgment. QOL assessments that shift to fit the person's internal dynamics and values are expected (62), even if they do not "fit" shifts in external realities, such as changes in work status, mobility or the like. Complementary subjective and objective measures—what we would call a combination of insider and outsider assessments—have been recommended to address this issue (48, 63). However, we believe that this simply sidesteps the question of whose values hold sway. We would argue instead that when the insider's assessment of QOL and objective QOL data (or an outsider's value judgment) correlate poorly, two aspects of life are being measured: true QOL and external predictors, which simply follow different rules of cause and effect.

To this point in the discussion of how insider vs. outsider values are incorporated into QOL assessment, we have focused primarily on power that flows from being the evaluator of the "goodness" of the insider's life. Empowerment also resides in evaluating the relevance to QOL of items and domains. Typically, the domains and specific items within QOL measures are gener-

ated (by the researcher) through deductive procedures; further, all items are deemed (by the researcher) equally relevant to all respondents. However, this dominance of the researcher's values has been challenged in two ways. First, inductive approaches have been used to generate items/domains felt to be relevant by representatives of a population. Thus, using an inductive approach, Flanagan (59, 64) analyzed 6,500 critical incidents obtained from 3,000 study participants to develop his 15-scale QOL measure. Similarly, individuals have participated in focus groups, surveys and interviews to generate the items that comprise domains they view as relevant to QOL measurement (65–68). In diverse ways, inductive methods have been used to develop standard lists of items and domains that reflect the views of insiders.

A second way in which the values of the insider have been acknowledged is by asking the insiders to rate the relevance of components of a standard measure (in addition to their degree of satisfaction with respect to each element) (9, 59, 64). For example, Lankhorst and colleagues (69, 70) asked individuals with spinal cord injury and rheumatoid arthritis to rate their abilities on 39 items (primarily activities, such as climbing stairs and travel). They then asked respondents to rate the impact of each item on their lives. The final score reflected the sum of each item's ability rating weighted by its importance to the individual.

In sum, in the approaches to QOL measurement that are most empowering, individuals dictate the elements that are included, how important each is to their lives and how well they are doing with respect to each element (71, 72). We join many in the field who argue for the importance of adopting measures that fully incorporate the consumer's voice in defining how domains and elements vary in importance for each target individual (5, 6, 63, 73), and who in general urge that the insider's perspectives be sought (74).

Measurement of Quality of Life

The characteristics of QOL models and measurement that we have outlined can be applied in developing recommended approaches to measurement:

- QOL has been located either within the insider's judgment of the "goodness" of his or her life or outside this judgment.
 - The insider's and/or outsider's values may hold sway in deciding which aspects of life are relevant to QOL and the voice that will be heard in rating the degree of "goodness" of life.
 - QOL models incorporate domains of items varying in breadth and specificity; they take either a negative or neutral view of functioning.
 - QOL models vary in their complexity, type of linkage between components and their inclusion (or not) of both the insider's judgment and external predictors of QOL.
- Given these distinctions, what recommendations can be made for measurement of QOL? First, a sine qua non of QOL measurement is incorporation of the insider's values, both in terms of ratings of "goodness" and ratings of the relevance of items and domains. Thus, the essential measures within a QOL study are those that emerge from within the insider's judgment and that fully express what is relevant to his or her judgment. Secondary measures (if any) can be obtained from any other source and express the values of others; they may be used simply to supplement or complement the judgment provided by the insider or to predict the essential QOL data. The corollary is that if the essential (insider-driven) data do not exist, the study is of something other than QOL.
- Essential QOL measures can be obtained in at least three ways, reflecting unidimensional vs. multidimensional views of QOL:
- Single, standard items have been developed to tap the insider's overall rating of the "goodness" of life (1, 75). Such items assume that the insider implicitly or explicitly considers and appropriately weights each component of life relevant to him or her (e.g., work, family relationships, significant other, mood) in reaching a single judgment of the overall "goodness" of his or her life. The shortcoming of this approach is that it does not reveal the elements that the insider is considering when evaluating QOL. Researchers can analyze external predictors of this QOL judgment, but not the multidimensional value judgments that contribute to the overall judgment.
 - The researcher can ask the insider to generate an individualized list of aspects of life he or she considers relevant to the QOL judgment (65). In this approach, the insider's task is to then rate each life component both in terms of the degree of its relevance to his or her QOL and its "goodness" within his or her life. The drawback of this method is the lack of comparability of items across participants in a study.

Also, participants may vary widely in their ability to generate the full range of items that significantly affect their QOL. An individual with a toothache comes to mind: momentary pains and pleasures may take over in generating a list of “what’s important” at the time of participation in the study.

- To avoid the limitations noted above, the researcher can develop a list of life components (inductively or deductively) or adopt an existing list, such as that developed by Flanagan (59, 64). The insider’s task is then to rate each item in terms of relevance and “goodness.” In adopting such a list, the researcher also needs to include the opportunity for the insider to add one or more components not included on the standard list, to insure that all life areas relevant to the individual’s judgment of QOL are available. Using a combination of Flanagan’s list and a single-item measure of QOL, Brown and Vandergoot (75) recently explored how internal values predict the overall judgment of QOL in samples of individuals with TBI and with spinal cord injury.

Two additional attributes are necessary in obtaining essential measures of QOL. First, a broad range of life elements must be included in the evaluative task. Narrow measures, such as those tapping vocational outcome, mood or health status, by definition do not “capture” the intrinsic breadth of “life.” Nothing but conceptual confusion arises from (for example) operationalizing QOL as “level of depression” or any other single variable or narrow band of variables. A welcome trend is the specific labelling of health-related QOL, differentiating it from broader-based views of QOL.

Second, the evaluative task must be a neutral in considering the elements of life. Because the focus is on “life,” not on problems or consequences of pathology or the like, the “yardstick” should provide as much opportunity to reflect on what is good about life as on what is bad. The measuring tool, in other words, should be unbiased, designed to permit measurement of both negative and positive elements of life. Assessing problems, symptoms, disability, depression and the like may be important, but their summation does not reveal the quality of a person’s life.

In sum, we suggest that QOL can only be measured by tapping the insider’s values and by insuring that a broad, neutrally valenced review of life is incorporated into the rating task. Beyond this minimum, two additional qualities recommend themselves in QOL measurement:

- Adoption of a multidimensional model that causally links the external world to the insider’s judgment. In this way, QOL research can explore the factors that most strongly affect the insider’s experience of life. In addition, it is clear that models that provide explanatory linkages between elements of the model are more useful in the long run, particularly in terms of generating testable hypotheses.
- Incorporation into the model of content that has high specificity. Too often, broad constructs (e.g., “work handicap”) are achieved by summing items that respectively may have very different effects on the QOL judgment. When they are deconstructed, their contribution can be more easily revealed. However, pilot studies are needed to determine which of the hundreds of possible specific life elements correlate with QOL, and among which groups.

The Research Purposes to Which QOL Measures Are Applied

Finally, how does the purpose that the QOL instrument is to serve affect the development or adoption of one system rather than another? In addition to their use in clinical practice (71, 76, 77), which is beyond the scope of this paper, QOL data are used in research for three basic purposes.

First, much of the attention being paid to QOL measurement follows from its use to assess the effects or outcomes of health interventions, either as the sole evaluative measure or, more typically, as one component in a total package, including measures of impairment, disability and/or handicap (6, 78). When used in outcome studies, QOL assessment must be based on an underlying model that includes the most probable loci of the effects of the intervention in the target’s life. For example, if one is comparing the QOL of individuals who received Treatment X with that of individuals who received Treatment Y, the model of QOL adopted should be one that contains the domains most likely to be affected by these treatments, as well as elements/predictors expected to moderate the effects of treatments. More specifically, outcome studies benefit from the adoption of predictive or causal models of QOL, which provides a basis for linking one event (e.g., provision of services) to a subsequent event (i.e., any outcome, including QOL).

In outcome research focusing on QOL within the context of health care, with rare exception a medical model is adopted, in which the insider’s health and medical interventions play major roles.

The focus is relatively narrow: how illness affects QOL and how this can be alleviated with drugs, surgical techniques and the like. Lehman (79) argues that a broader QOL framework is more appropriate for assessing QOL in individuals with chronic or disabling conditions, as a broader view will "account not only for direct health outcomes but also for the potential social and economic effects of medical disability."

A second research purpose for which QOL data are obtained is to describe populations and subgroups (80). For example, is QOL different for people with disabilities living in rural areas compared to suburban or urban dwellers? How does HRQOL vary geographically, across states or countries? In studies of individuals with disabilities that address the question of how subgroups differ, QOL data from one group may be compared to data from groups with other types of disability or to data from groups of people without disabilities, to provide both a contextual base for broadening understanding and implicit societal values for evaluating the respective groups (11–13).

A third (related) purpose for which QOL data are obtained is to provide a basis for developing policy. If one wants to develop policy, for example, regarding the need for nursing homes, a medical model may be appropriate. If one wants to know what a subgroup living in the community needs in the broadest sense, a less health-driven approach is warranted (41). In either case, selecting a neutrally valenced, broadly focused approach, including complex predictors of QOL, encourages the documentation of areas of strength, which may provide useful insights into variables that support success.

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