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Cummins, Robert, Lau, Anna L.D. and Stokes, Mark 2004-08, HRQOL and subjective well-being: noncomplementary forms of outcome measurement, *Expert review of pharmacoeconomics & outcomes research*, vol. 4, no. 4, pp. 413-420.

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HRQOL and subjective well-being: noncomplementary forms of outcome measurement

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This review considers some of the broad principles that concern quality of life assessment. These are discussed in relation to health-related quality of life (HRQOL) and the measurement of subjective well-being. It is argued that there are serious logical and methodological issues concerning HRQOL measurement, to the extent that the instruments may not be regarded as valid measures of life quality as this term is generally understood. It is recommended that HRQOL measurement be abandoned in favor of three separate forms of measurement as medical symptoms, subjective well-being and specific dimensions of psychological ill-being.

Expert Rev. Pharmacoeconomics Outcomes Res. 4(4), 413–420 (2004)

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There are three basic approaches to quality of life (QOL) assessment, each separated from the others by disciplinary barriers. The oldest comes from economics – money is QOL. Economists hold this to be true at both a national level (e.g., gross domestic product) and at the level of individual wealth (utility). Whether this view is valid depends upon the definition of QOL. When defined in terms of wealth-related constructs (e.g., standard of living and educational opportunities) it functions as a self-fulfilling prophesy. However, when QOL is defined in subjective terms, concerning general feelings about the goodness of life, wealth is a very inadequate indicator.

The discipline of medicine takes a quite different approach. Here, QOL is operationalized via a construct called health-related quality of life (HRQOL). This utilizes patient-reported symptoms. Consequently, an excellent level of HRQOL represents the absence of pathology as reported by the patient.

There is another approach that has been created by a fusion of economics and medicine. The basic construct here is called quality-adjusted life years (QALYs). These are measured by asking people to choose between alternatives, none of which they would prefer. For example, 'Would you prefer to live in perfect health for only another 5 years, or would you prefer to live as a diabetic for another

20 years?' The resulting data are used to inform the economics of medical resource allocation in order to optimize population QALYs. It is the authors' view that such measures are invalid as measures of life quality since QALYs fail to correlate with the personal experience of life quality. Additionally, they are discriminatory and ethically questionable. A detailed discussion of these issues can be found in the literature [1].

Finally, there is the view from the social sciences, where the subjective component of QOL is operationalized by a construct called subjective QOL or subjective well-being (SWB). This utilizes patient-reported satisfaction with either their life as a whole or the compartments of their life (domains). Here, an excellent level of SWB represents a highly positive state of mind and satisfaction with life in general.

The two views that will be analyzed in this review are HRQOL and SWB. Both rely on self-reports and would represent congruent views of the QOL construct if a lack of pathology was proxy for SWB, but it is not. No matter whether the pathology is subjective (e.g., perceived stress) or objective (e.g., degree of physical disability), pathology does not have a simple linear relationship to SWB [2,3].

In order to understand the limitations of HRQOL measurement, the construct of SWB homeostasis will be introduced.

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KEYWORDS:

disability, health-related quality of life, illness, quality of life, subjective well-being

Subjective well-being homeostasis

Early systematic research into the use of subjective indicators was heralded by two independent and major reports in the USA [4,5]. Both had used subjective indices of well-being with large population surveys, and both provided a detailed and insightful analysis of the resulting data. Numerous such surveys followed. In 1995, 16 estimates of population life satisfaction were assembled from surveys conducted in Western nations, and it was reported that they averaged 75% of the scale maximum (SM) score with a standard deviation of just 2.5% SM [6]. The percentage SM is a standardized conversion of Likert scale data projected on to a 0–100 scale. In other words, the mean value from population surveys of subjective QOL conducted in Western nations, can be predicted to lie within the narrow range of 70–80% SM. This result has been replicated on several occasions and appears to be reliable [7,8].

In order to explain this narrow, positive range of values, a Theory of Subjective Wellbeing Homeostasis has been proposed [8–10]. This theory suggests that, in a manner analogous to the homeostatic maintenance of blood pressure or temperature, subjective QOL is actively controlled and maintained by a set of psychological devices that function under the influence of personality (see [9] for an extended description). The operation of these devices is most evident at the level of general, personal well-being. That is, homeostasis operates at a nonspecific, abstract level, as exemplified by the classic survey question, 'How satisfied are you with your life as a whole?' As this question is so general, the response that people give reflects core affect which, it is proposed, is precisely the level at which the homeostatic system operates [11].

As one consequence of homeostasis, the level of general life satisfaction is remarkably stable. While unusually good or bad events will cause the SWB of individuals to change in the short-term, over a period of time the homeostatic system will return this abstract satisfaction with life to its previous level [12–14]. At the level of populations, the degree of stability is extraordinary. This has been most clearly demonstrated by the application of the Australian Unity Wellbeing Index [15]. Commencing in April 2001, quarterly surveys have been conducted with 2000 Australians, randomly chosen for each survey. Despite the occurrence of tumultuous international events during the intervening period, the population SWB over the nine surveys conducted to the end of 2003, varied from 73.2 to 75.9% SM, a range of just 2.7% SM [3]. Moreover, with the exception of the survey conducted immediately following 11 September, the population SWB has varied by less than 1% between adjacent surveys. Such stability is surely comparable with any measure of objective health status averaged across the population over a 3-year period.

While this generalized sense of well-being is held positive with remarkable tenacity, it is not immutable. A sufficiently adverse environment can defeat the homeostatic system and, when this occurs, the level of SWB falls below its homeostatic range. This is evident in people with severe arthritis (63.8% SM), home-based caregivers of disabled family

members (54.5% SM), and people suffering chronic unemployment (50.4% SM) [16–18]. Such groups can experience marked upward shifts in SWB if the circumstances of their lives improve, allowing homeostasis to be restored. However, for people who are already maintaining a normally functioning homeostatic system, their levels of SWB will show little relation to variations in their chronic circumstances of living. This is why the relationship between objective and subjective QOL is normally nonsignificant.

Abstract versus specific well-being

The homeostatic system has the role of maintaining a positive sense of well-being that is both nonspecific and highly personalized. It is concerned only with the perceived well-being of the individual who is making this assessment and only in the most general sense. As one effect of this influence, people generally feel they are superior to other people, or better than average [13,19,20]. They believe they are luckier, happier and more moral [4]. This is all part of the general positive bias that is value added by the brain to such thought processes and which leads, under the normal circumstances of living, to a generalized positive self-view [21,22].

While the classic 'satisfaction with life as a whole' question is useful as an estimate of the homeostatic set point, due to its high level of abstraction it cannot provide information about the components of life that also contribute, positively or negatively, to this sense of well-being. In order to acquire such information, questions need to be directed at satisfaction with life domains. There is converging agreement within the literature on the identification of the minimal set of domains that form the first-level deconstruction of personal well-being. One such approximation is offered by the Personal Well-being Index which identifies seven domains [15]. Theoretically, such a set should be sufficient to describe the entire construct of 'life as a whole', and this case has been argued [23]. Moreover, the mean satisfaction score derived from the seven domains should approximate satisfaction with life as a whole, and this too has been verified [15]. The domains' mean score and the life as a whole score are not expected to be identical due to the differing levels of abstraction in each.

While satisfaction with life as a whole is proposed to approximate the homeostatic set point, this is not so for the domains. Questions at this level (e.g., how satisfied are you with your health?) are directed at broad but identifiable aspects of life. Thus, more specific information processing and affect linkage can be brought to bear on such evaluations. Consequently, the homeostatic influence on the satisfaction response will be diluted and the level of satisfaction will be allowed to vary either above or below the set-point. Because of this, when issues of ill health arise, the domain of health will be more affected than the other domains due to the congruence of the information being processed. Moreover, due to its specificity, the domain of health will be more sensitive to such influence than will satisfaction with life as a whole or the aggregate SWB derived from the combined domains.

In summary, SWB is a stable sense of feeling positive about one's self and one's life. The normative values are well described and the operation of the attendant homeostatic management system is beginning to be understood. All of this greatly contrasts with HRQOL as will now be described.

HRQOL scales

There are two kinds of HRQOL scales, generic and specific. The most widely used generic scale is the Short Form (SF)-36, which is designed to measure HRQOL for diverse medical groups [24]. A disadvantage of such a scale is that its broad cover makes it insensitive to specific change. For example, an intervention may increase lung capacity, yet have little impact as judged through change in a generic HRQOL scale. Thus, condition-specific scales have been developed, which concentrate on symptoms relating to the body part or system in question.

The construction of HRQOL instruments has been guided by a consensus statement resulting from a 1992 meeting of an International Board of Advisors [25]. Their deliberations form a special issue of *Quality of Life Research (Volume 2)* and includes the recommendation that:

four fundamental dimensions are essential to any HRQL (sic) measure. These include physical, mental/psychological, and social health, as well as global perceptions of function and well-being.

The authors then recommend a list of additional HRQOL domains considered important but not always necessary and place responsibility for inclusion or omission on the individual investigator. This list is pain, energy/vitality, sleep, appetite, and symptoms relevant to the intervention and natural history of the disease or condition.

It is notable that the four fundamental dimensions bear a very strong resemblance to the 1947 World Health Organization definition of health as a 'state of complete physical, emotional and social well-being' [26]. The original term 'emotional' has become 'mental/psychological' and the 'state of complete' has become operationalized as 'global perceptions of function and well-being'. It appears clear that the guidelines for the construction of HRQOL scales have been modeled on the 1947 definition of health.

Defining HRQOL in this way has led to major problems of scale construction and the generation of data that are most uncertain in their interpretation. Perhaps not surprisingly, they have also been severely criticized [27,28]. Some of the contentious issues are as follows:

- The consensus statement adopted by test developers combines global perceptions of well-being with more specific concerns (e.g., physical functioning). This has caused the creation of scales that combine the scores from global items with the scores from items that represent some of their components. (see Incontinence Quality of Life Instrument [29]). This makes no logical sense.
- It has been highlighted that even if the World Health Organization's definition of health as a hypothetical construct composed of physical, psychological and social elements is to be

accepted, this does not imply that QOL is also composed of these dimensions [27] – 'judgements about physical capacities and abilities have only relative objectivity. Thus, the observation that person A cannot walk as far as person B is merely a statement of fact, but if we extrapolate from this that person A has a poorer QOL – this is a reinforcement of stereotypes that underlie discriminatory practices'.

- The term 'emotional functioning' presumably is intended to represent the affective component of subjective QOL. It is widely agreed that subjective life quality comprises an interactive state of emotion and cognition. How, then, is such emotional functioning to be measured? The answer should refer to the circumplex model of affect, which, for over 10 years, has dominated the operationalization of affect [30]. This model depicts the affects on the circumference of a circle divided into quadrants by the axes of pleasant–unpleasant and activated–deactivated. Modified programs of structural modeling are used to position the specific affects with respect to one another in a highly predictable way, with the affective antonyms lying opposite one another. This model has been found sufficiently robust to seriously advance the understanding of affect, and especially its measurement. However, the HRQOL scales evidence no understanding of this important advance. Affects such as anxiety or stress are apparently selected at random to represent emotional functioning. They are inadequate to perform this role.
- The constructs of physical and social functioning were probably selected due to their connection to health and the important human need to feel connected to other people. However, this choice disenfranchises other important areas which have just as much relevance for the human sense of well-being. These include such constructs as being productive, having high self-esteem, feeling in control and having a sense of optimism. A good perspective onto this disenfranchisement is provided by data from 11 surveys conducted in Canada [28]. These surveys included between them, 16 items of satisfaction that were used to predict happiness. Various combinations of items were included in different surveys, but all included satisfaction with health. Multiple regression analyses revealed that the top four predictors of happiness were self-esteem (maximum $\beta = 0.38$), satisfaction with partner ($\beta = 0.30$), satisfaction with friendship ($\beta = 0.23$) and financial security ($\beta = 0.21$). Satisfaction with health was never the strongest predictor. Its maximum β was 0.18 and, in five out of 11 of the surveys, its contribution was too low to enter into the regression equation.
- There is also the issue of conceptual breadth. A recent reviewer states, 'HRQOL narrows the QOL concept to aspects of life affected by a person's health condition and its treatment' [31]. In confirmation of this view, another contemporary reviewer describes generic HRQOL instruments as providing a summary health profile while specialist instruments focus on specific problems associated with a disease or area of functioning [32]. It is evident from such perspectives

that the developed view of HRQOL is far more limited than the original intention of the consensus to include perceptions of overall life quality [25].

- A crucial distinction in QOL measurement is that between objective and subjective variables. Such different forms of measurement (e.g., physical health and satisfaction with health) do not form reliable linear relationships with one another due to SWB homeostasis [2]. Thus, objective measures of health cannot be reliably used to predict subjective health states, and neither can objective and subjective variables be validly combined into scales of measurement. Unfortunately, this is common practice for HRQOL scales (e.g., World Health Organization Quality of Life-100) [33]. For a critique of this scale see [34].

Not only are such variable combinations psychometrically invalid but they also confuse outcome with causation. This problem has been articulated by Fayers and colleagues who distinguish between indicator and causal variables [35]. Indicator variables (the perception of health quality) constitute a measured end state. Causal variables are the patient perceived symptoms (e.g., activity limitations and high urination frequency) that cause the end state (perceived life quality) to change (FIGURE 1).

The sequence of events is as follows:

- A physical medical symptom (e.g., performance limitation) enters the conscious awareness of the patient. Note: unless this occurs, the medical symptom is irrelevant to either perceived health or any general sense of well-being.
- This perception of the symptom may become a causal variable. It has the potential to influence perceived health and well-being. The strength of this influence can be measured by asking the patient to register their level of concern regarding the symptom.
- This level of concern then has the potential to influence the patient's view of their general state of health. However, this is only a potential influence. It may, in fact, cause no actual change in perceived health quality because:
 - The level of concern is too low
 - Other positive perceptions of health, such as fitness, negate the concern
 - Perceived health quality is one component of SWB, and these are reciprocally related. Thus, perceived health is

under the influence of SWB homeostasis, which acts to resist change

- Due to these interactions, there is no necessary or linear relationship between a physical medical symptom and the domain-level indicator variable of perceived health. Whether such an influence can be detected will depend on the strength of concern generated by the symptom and the balance of the other forces that have been described. This means that perceived health quality is relatively insensitive to physical medical symptoms.
- Due to the reciprocal connection with SWB, perceived health quality may also decrease in the absence of physical medical symptoms. If SWB decreases, it will exert pressure on all of the life domains, such as perceived health, to decrease in sympathy. Thus, a person who is depressed will express low satisfaction with their health.
- Perceived health has the potential to decrease the global indicator variable of SWB. However, such an influence will be strongly resisted, not only by the compensatory influences of other life domains, but also directly by the homeostatic system. This is the heartland of perceived well-being, and influences delivered via any one domain, such as perceived health, will only defeat the management system if their onset is sudden and/or intense. Thus, SWB is the most insensitive indicator variable. It is also the most important since, when it does fall below its normative range, this loss of perceived well-being is experienced as depression [36]. From this scheme it becomes clear that if symptoms are used as indicator variables, they become synonymous with perceived health or even SWB. This is analogous to the use of wealth to define QOL by economists, and is self-fulfilling. In order to escape such circularity, symptoms and their psychological consequences must be separately measured. Yet, this principle is violated by all HRQOL scales. For example, the SF-36, which is the most widely used generic HRQOL scale, combines limitations in ability to walk 100 m, with a rating of current health, from excellent to poor [24]. It is unfortunate that this crucial distinction is not obvious from the normal analytic procedures researchers apply to their data. This is especially an issue in medical contexts where the symptoms are often severe enough to cause perceived health quality, and even

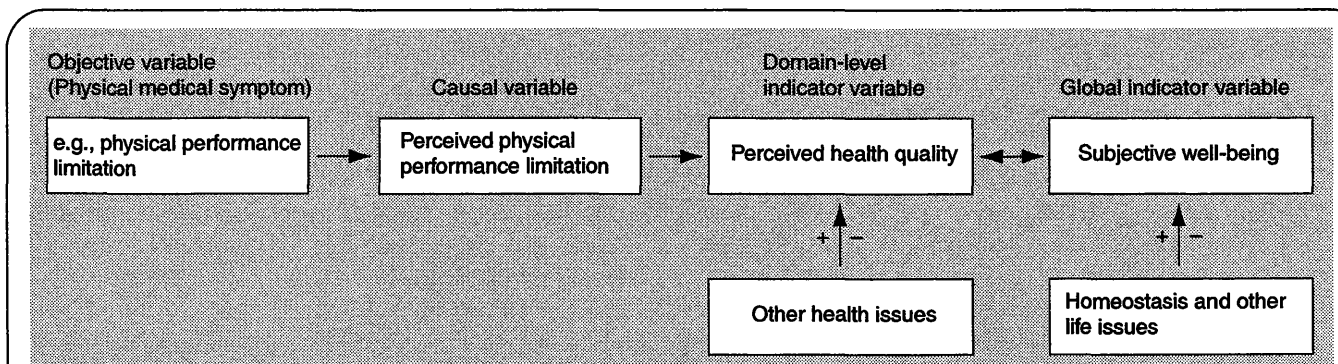


Figure 1. The causal chain of well-being.

SWB, to fall. In this situation, items specifying both indicator and causal variables will correlate with one another, giving the impression that their combination forms a coherent scale. However, if the items are responded to by people in a non-pathological situation, their normal state of independence will be evident.

- Finally, there is the problem of combining medical symptoms to form scales of measurement. In their traditional context, symptoms are diagnostic of specific disorders. An increased production of lymphocytes is diagnostic of infection but not of diabetes. Moreover, the level of lymphocytes is normally unrelated to the control of glucose metabolism, so it is inconceivable that someone would produce a scale of blood quality that combined the average levels of lymphocytes and insulin into a single index. Clearly, each objective measure has its own diagnostic utility, and this utility is obliterated by their combination. This logic also holds for the broadest picture of objective life quality. Consider, for example, the person who is extremely wealthy, yet in poor health and chronic pain, who has many excellent friends yet lives in prison. The combination of such variables cannot be interpreted. Thus, each objective domain of life must be evaluated on its own separate merits. There is no global construct of objective life quality.

This principle of independence also holds at the level of functional systems. Consider urinary incontinence. There are several symptoms that may pertain to this condition, such as signs of infection, loss of local muscular tone and frequency of urination. A person who has incontinence may, or may not, have each of these symptoms, but once again, their diagnostic utility rests on their separate evaluation, not on some numerical average of their values. Yet typically HRQOL scales comprise such symptom combinations. So what is it, exactly, that HRQOL scales measure?

What is the quality in HRQOL?

All HRQOL scales require that the patient self-reports on their medical status. The development of this technology is a fairly natural extension of normal medical diagnostic procedure, in which the patient is asked to describe the symptoms they experience. In a traditional diagnostic process, patient-reported shortness of breath or urinary incontinence sets the stage for further diagnostic interrogation aimed at discovering the severity and cause of the condition. The HRQOL technology extends the interpretation of perceived symptoms from medical pathology to imply life quality. In doing this, the technology confounds two quite different constructs.

Quality is usually defined along the lines of degree of excellence, as being of high quality or of a high standard [37,101,102]. Implicit, is that when the term 'quality' is applied to some entity it implies better than average or better than normal. Thus, a quality life is a better than an average life. So the basic terminology of HRQOL is inconsistent with common usage. It defines the normal state, which is the absence of perceived medical symptoms, as excellent quality.

This is not a trivial issue of semantics. It is entirely misleading as evidenced from most journal articles on this topic which use HRQOL and QOL as synonyms.

In fact, HRQOL does not even equate to excellent health. A definition of excellent physical and mental health would invoke at least a high level of physical fitness, perceived good health, an absence of pathology existing below conscious awareness (e.g., high blood pressure), and a positive attitude to life. Therefore, excellent HRQOL is quite different from excellent physical and mental health. Excellent HRQOL is, simply, the absence of medical symptoms as perceived by the patient.

How should the absence of medical symptoms be interpreted?

The measurement of HRQOL comprises an inverse index of perceived badness from the patient's point of view, such that the absence of perceived badness equates to HRQOL excellence. Thus, these scales concern just one half of the perceptual universe of positive and negative states. They only concern ill-being.

Therefore, an obvious question is what advantage HRQOL scales have over other traditional measures of perceived ill-being, such as scales of depression, anxiety or stress. Scales to measure these constructs have become highly refined over many decades of development. The end-states that they measure are not only psychometrically and conceptually separable, but they have different treatment implications [38]. HRQOL scales lack such refinement. They share variance with these traditional measures of ill-being but neither offer new insights into ill-being nor define some novel state of ill-being.

However, such scales are not normally interpreted in terms of ill-being. Researchers and clinicians almost always interpret HRQOL data as though the quality they measure equates to a high life quality generally. This is certainly not the case. If someone has a very poor HRQOL then the symptoms are likely to be strong enough to cause homeostatic failure and SWB will decrease as a consequence. However, someone can be medically symptom free yet have a very low SWB due to disasters in other aspects of their life, as has been argued. Thus, a high HRQOL does not equate with high life quality as a general experience.

It also does not correspond with excellent health since it will not record the influence of disease symptoms that lie below the level of conscious awareness. How, then, should HRQOL data be interpreted? HRQOL scales produce data that are a mish-mash of perceived medical ill health and general negative affect. In this they lack the diagnostic utility of individual medical symptoms and specific psychological measures of ill-being. Combined with the other problems of scale construction that have been described it is clear that they cannot be recommended. The authors recommend that HRQOL be abandoned in favor of more specific medical and psychological measures.

QOL assessment for people with chronic illness or disability

It is very easy to create QOL scales that discriminate against people who are disadvantaged. All that is required, is for such scales to contain items directly relevant to the specific aspects of dysfunction. For example, a scale for people with Parkinson's

disease would contain items concerning motor limitations, while scales for people with intellectual disability would enquire about ability in forward planning. These are the symptoms of the respective conditions, as has been argued, and when they are applied, two outcomes are inevitable as:

- The people concerned will score lower than the general population. As a consequence, the interpretation will be made that they have lower than normal life quality, thereby confirming prejudice. Such scales determinedly prevent such people registering a level of perceived life quality that is as high, or higher, than the general population mean.
- A high life quality is judged by the relative absence of disability. A person with Parkinson's disease who is minimally physically affected by the disorder is judged to have a high life quality. Such judgement disallows the possibility that the person's life may in other respects be in chaos, since their partner has just left them for their best friend, they have been sacked from work, and they have donated their life savings to the local casino.

There are several principles for valid QOL measurement as follows:

- Life quality must be judged against general population normative scores. Thus, the same scales and criteria for judging life quality must be applied to all people, no matter what their particular circumstances.
- Objective and subjective variables, causal and indicator variables, must be separately measured. However, there is no valid concept of objective life quality. Instead, there are a number of key variables, such as health and wealth, that may be separately measured and evaluated.
- SWB is quite different from this. Here the global construct can be captured through the single question, 'How satisfied are you with your life as a whole?' Moreover, this global item can then be deconstructed into a minimal set of first level domains which, together, comprise the global construct. For example, the seven domains of the Personal Well-being Index are defined as satisfaction with standard of living, health, achievements in life, relationships, safety, connection to community and future security [15]. These domains form a robust single factor, which explains over half of the variance in life as a whole and therefore, constitutes a useful measure of subjective QOL.
- Researchers and clinicians can use the level of indicator variable that best meets their needs. Perceived health will be a more sensitive indicator than SWB, but SWB has the ability to signal depression.

Expert opinion

We have argued that the end state called HRQOL does not represent physical and mental health as positive experiences, and nor does it represent SWB as conceived by the social sciences.

Instead it represents a construct that has, as its optimal extent, a condition of health neutrality, where no symptoms of pathology are apparent to the patient.

Even ignoring the considerable psychometric difficulties that have been described, it is not clear why it is useful to measure this particular end state, which occupies some kind of middle-ground between medical pathology and SWB. Our suggestion is that HRQOL measurement be abandoned, and that within the context of medical practice three forms of measurement are used as:

- The conventional medical symptoms of pathology. These inform the medical diagnosis of a particular medical condition
- Perceived general health and/or SWB. This informs on whether the medical symptoms are powerful enough to cause the normal positive state of well-being to be defeated. The 7-item Personal Well-being Index could be used for this purpose [15]. This scale is available at [103]

If the condition of psychological ill-being is to be examined, then we recommend the Depression, Anxiety, Stress Scale [27]. This brief 21-item scale produces a valid and reliable measure of these three separate constructs.

Five-year view

Within the next 5 years the use of HRQOL measurement will be much diminished. There will be two reasons. The first is that researchers will be unable to characterize the end-state measured by HRQOL scales as a unique and interesting construct. Instead, it will be increasingly revealed to be a generalized state of negative affect, that is more usefully measured through its component parts as perceived medical symptoms, depression, anxiety and stress.

The second reason that the popularity of HRQOL measurement will wane is increased theoretical understanding of SWB.

Key issues

- Health-related quality of life (HRQOL) is a troubled construct. This review challenges both the theory and measurement process.
- Subjective well-being is presented as a highly stable measure whose performance can be understood through homeostatic control.
- It is recommended that HRQOL measurement be abandoned.
- It is recommended that alternative and separate measurements be made as follows:
Patient-perceived symptoms: to inform medical diagnosis
Subjective well-being: as the measure of perceived life quality
Depression, anxiety and stress: as measures of psychological ill-being

New data will confirm that:

- Objective variables (e.g., physical performance) and causal variables (e.g., perceived physical performance limitations) are theoretically and empirically distinct from indicator variables (e.g., SWB) that represent the perceived state of life quality

- Each of these three variable types relate to one another in accordance with a homeostatic model of SWB

Acknowledgement

The authors would like to thank Ann-Marie James for her assistance in the production of this manuscript.

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