The past five decades saw an exponential increase in the number of articles involving quality of life in medical sciences. Until the beginning of the 1960s, the impact of a disease and its treatment was mainly expressed in measures of morbidity and mortality. The need to know the consequences of intrusive interventions such as kidney dialysis, transplantation, and aggressive cancer treatments (Elkinton, 1966) led to the expanding development of quality-of-life-related measures. Nowadays, almost each disease and treatment evaluation includes a quality-of-life instrument. Parallel with this development, it became clear that the quality of life of a patient should be judged by the patient and not, like his or her physical condition, by the physician. This was put into words powerfully by one of the pioneers of quality-of-life research, Neil Aaronson: “Given its inherently subjective nature, consensus was quickly reached that quality of life ratings should, whenever possible, be elicited directly from patients themselves” (Aaronson, Cull, Kaasa, & Sprangers, 1996, p. 180). This brings quality of life directly within the domain of the discipline of psychology, as the self-report of the patient is a behavior and is thus influenced by emotions, cognitions, abilities, and personality.

So far, most quality-of-life measurement has been carried out in research. In clinical practice, formal quality-of-life measures are rarely implemented, although one could argue that the self-reported health states as used in mental health care could be seen as an operational clinical quality-of-life assessment. In somatic clinical practice, formal quality-of-life assessment has not yet found a clear position, but there are signs that this will change. The use of quality-of-life assessment and, more generally, that of patient-reported outcomes (PROs) in routine outcome monitoring has now been established in order to test the performance of medical departments and complete hospitals (Revicki et al., 2009). Several studies and reviews have already been published about the effect of presenting quality-of-life data to the treating physicians and/or patients on patient care, satisfaction, and treatment outcome (Gutteling et al., 2008; Haverman et al., 2013; Engelen et al., 2012).

Definitions

Like the concept of intelligence, “quality of life” (QoL) can be defined in many ways, and, also like the concept of intelli-
gence, it is “operationally defined”: It is the specific operationalization of this concept that defines its meaning. For instance, it is often said that “intelligence is what an intelligence test measures.” In that line of reasoning, QoL is what “a quality-of-life questionnaire or interview measures.” One could argue that this is a rather loose, non-scientific way of defining a concept in the absence of a clear definition. On the other hand, although readers of this chapter may not use a common definition of the concept “time,” they nevertheless will not question the status of the clock as a scientific instrument. Through consensus about the instrument, we are able to reproduce experimental results. If we are able to reproduce results, the subject of the research becomes independent of the researcher and thus becomes “objective.” By introducing formalized QoL measures, the “subjective evaluation of the quality of life by the patient” becomes independent of the observation skills and of the researcher and brings QoL into the scientific domain. Because the concept of QoL leans so heavily on its operationalization, we spend a considerable part of this chapter focusing on the applications of the QoL measurement. As this measurement is performed in different fields of the health sciences, clinical, epidemiology, and health economics, we also introduce the different “perspectives” of QoL measurements.

One difference in perspectives is between that on life in general and that on “just health.” The first perspective is often referred to as “happiness research” (Veenhoven, n.d.). For instance, the World Health Organization Quality of Life (WHOQoL) research group defined QoL as a concept that encompasses and summarizes the satisfaction of individuals with all aspects of life (World Health Organization, 1993). The latter perspective focuses more on health and is referred to as “health-related QoL” or “health status” (Davis et al., 2006). Because this volume is concerned with clinical health psychology, we describe QoL from the “health” perspective.

QoL can be conceived as a multidimensional or as a unidimensional concept. Another differentiation can be made between “generic” and “disease-specific.” As a multidimensional concept, QoL is often conceived as consisting of three dimensions (physical, psychological, and social), reflected in one or more scores for each. The unidimensional conception of QoL tries to capture the concept in just one value. A generic perspective of QoL assessment tries to capture all aspects relevant in (health-related) QoL, whereas, when viewed as a disease-specific concept, QoL focuses on the specific life problems that are associated with a specific disease. Generic instruments make it possible to compare the outcomes over different diseases, whereas disease-specific measures hold the promise of being sensitive to the specific illness. A third difference in perspective concerns the distinction between the societal perspective, the group (of patients) perspective, and the perspective of the individual patient. In the next section we elaborate on the relevance of the societal, group, and individual perspectives on the measurement of health-related QoL.

**Social, Group, and Individual Perspectives**

The societal perspective of QoL concerns the measurement and comparison of differences in QoL between groups of patients in the populations. Its purpose is usually to set priorities between these groups of patients, for instance, in health policy. An example of such a question is, Should we, as a government, invest in the prevention of lung cancer, home care for the elderly, or cholesterol medication?

Typically, in the answer to that question, QoL is made dependent upon the number of patients involved and the duration of the losses in QoL. For instance, a relevant research question here is, Which patient category has the highest needs: migraine—with its high prevalence—or Huntington’s disease, with its high burden but relatively lower prevalence? This idea of measurement is adopted by the World Health Organization in their Burden of Disease studies.
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which integrate mortality and morbidity in disability-adjusted life years (DALYs; U.S. Burden of Disease Collaborators, 2013). When the costs of cure are related to the increase in QoL, QoL becomes an outcome in cost-effectiveness, usually in the form of quality-adjusted life years (QALYs; discussed further later in the chapter), often referred to as cost-utility analysis. As the name suggests, DALYs and QALYs are related, as they are each other’s complement (see Figure 11.1).

The perspective of the patient group concerns the interest of a patient group with a specific disease or illness, irrespective of other patient groups. Its focus is on the impact of this disease on the life of the patients in the relevant category only. Another application is the evaluation of the effect of the different treatment options on QoL within the same group of patients, to see which treatment improves the QoL of these patients most. The research question here can be, Is treatment A more effective than treatment B in bringing the patients with a myocardial infarction back to a normal quality of life, also as related to different expressions of myocardial infarction? Understandably, in most effectiveness studies, measures of mortality and morbidity in terms of physical dysfunctions are taken as the primary outcome (here, for instance, the number of patients who die or who will have a reinfarction) and the effect on QoL are weighted as secondary outcome. However, when no cure can be expected, such as in the case of palliative treatment of patients in the final phase of their disease, the purpose can be to maintain the QoL of the patient at the highest level. Here QoL becomes a primary outcome variable, as it is the primary objective of treatment.

The individual patient perspective concerns the QoL of the individual patient. Its measurement has a function in, for instance, the decision on the best treatment for this particular patient. The answer to the question, Will the life of Mrs. Jones be more improved by chemotherapy than by radiotherapy? is not just dependent on the life expectancy associated with each of these treatments, given her age and physical condition. It is also important to consider how she estimates her QoL for the period during and after each of these treatments, knowing the consequences of each and the problems she will have to face. Decision analysis is an important tool to translate a person’s estimations into the optimal policy for a patient like Mrs. Jones, and individual weighted QoL assessment tools provide helpful reflections.

So, each perspective has its own associated set of questions, and each question requires its own specific outcome measure. These outcomes are elucidated in the next section.

**Perspective and QoL Measures**

As we discuss, most but not all QoL instruments are self-report questionnaires that have to be completed by the patient. These instruments can take different forms, because the instruments may approach QoL from different perspectives. Next we describe these differences, following the same classi-
fication of division of perspectives as above: societal, group, and individual. This division translates into generic, disease-specific, and individual weighted measures.

**Generic Measures**

Suppose that a cardiologist is interested in the effect of open-heart surgery on the lives of her patients with myocardial infarction. She wants to know which aspects of the patients’ lives show most improvement and which the least. In addition, she wants to know how good or bad the QoL of her patients is in comparison with that of the healthy population.

To answer questions on these different aspects, she needs a QoL instrument that consists of different subscales, each covering an important dimension of the life of the patient. Such an instrument measures QoL in a multidimensional way, generally by a questionnaire. Most of these questionnaires include at least the following three dimensions: physical, psychological, and social functioning/well-being. As she also wants to know what the lives of her patients with myocardial infarction are like in comparison with those of a group of healthy people, this questionnaire should be generic. For both research questions, the cardiologist is in need of a generic instrument, measuring a broad spectrum of QoL dimensions relevant for both patients with myocardial infarction and the general public. Examples of such generic items might be “Due to my health, I feel depressed” or “My health impedes my functioning at work.” Well-known generic multidimensional QoL instruments and their dimensions include the Short Form–36 (SF-36; www.sf-36.org; Ware & Gandek, 1998) and the Nottingham Health Profile (NHP; McKenna, Hunt, & Tennant, 1993).

Our cardiologist might be interested, however, in just one of these dimensions. She may want to know in particular the effect of open-heart surgery on the emotional well-being of the patients. Or she might be interested in a specific domain within the emotional dimension, such as negative emotions. Emotional well-being as measured by one of the generic questionnaires is relatively global, and the number of items devoted to each dimension is, due to space restrictions, limited to a few. It is better, therefore, for her to use a domain-specific questionnaire. This is a generic questionnaire, but it focuses only on the relevant dimension of interest and provides more detail and is more reliable due to the larger number of items. In her case, she might use a questionnaire that measures the negative emotions she is interested in, such as the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983).

**Disease-Specific Measures**

Suppose our cardiologist is not so much interested in comparing the QoL of her patients with that of other groups. Rather, she wants to know how the treatment influences the specific problems that her patients experience because of their cardiac disease. Has the patient less fear of a heart attack? Has the patient resumed sports? The cardiologist needs a questionnaire that homes in on such specific problems. This questionnaire belongs to the family of disease-specific questionnaires, which act like a magnifying glass and have a good resolution for detecting the differences between the problems of patients with the same disease and the changes in such disease-related problems. Note the subtle difference with domain-specific questionnaires: These questionnaires also home in on a specific aspect, but that aspect is not necessarily related to a specific disease, such as anxiety. Disease-specific questionnaires are therefore more sensitive for detecting changes (have a higher response sensitivity) than generic questionnaires. Like generic questionnaires, disease-specific questionnaires are usually multidimensional. Whereas the number of generic questionnaires is relatively small, the number of disease-specific questionnaires is very high; for almost every common disease a disease-specific questionnaire has been constructed. A well-known disease-specific questionnaire is the QoL measure for cancer patients developed by the European Organization for Research and Treatment of Cancer (EORTC). The EORTC QLQ-30, which has been translated into more than 80 languages, can be supplemented by modules specifically for patients with breast cancer.

2 These types of measures are commonly used in clinical health psychology.
lung cancer, esophageal cancer, and many others (Cull et al., 2001).

**Individual Weighted Measures**

The inherent value of QoL varies considerably between patients: QoL is called “subjective” for good reason. There are specific instruments that measure this variance at an individual level. The patient is not only asked to indicate any problems in specific domains of QoL but is also asked to indicate how important that domain of QoL is from his or her perspective. An important example of such an instrument is the Schedule for the Evaluation of Individual Quality of Life (SEIQoL). When using the SEIQoL—mostly in an interview format—the individual starts by naming the five most important areas of his or her life. Next, the person rates the importance of each one and finally rates his or her own current position with respect to each of these areas. These ratings thus correspond with how good or poor the person’s life is in these personal aspects3 (O’Boyle, 1994). The applicability of patient-generated outcome measures in a clinical trial setting is not obvious, as there is not yet a clear consensus about summation of the different weightings of the individual patients. Nevertheless, patient-generated outcome measures are promising in guiding individual patient treatment decisions (Patel, Veenstra, & Patrick, 2003).

**The Application of QoL in Decision Making**

Suppose that an oncologist has the choice between two interventions for patients with prostate cancer, the first being surgery and the second being chemotherapy. The first treatment is associated with a remaining life expectancy of 15 years, the second with a life expectancy of 10 years. On the basis of that information only, a surgery treatment should be preferred. However, this surgery can have side effects, such as impotence. When making a decision about the best option, not only the duration of the patient’s remaining life but also its quality is important. It is, therefore, important to know the QoL of the patients who have received these interventions and the perception of the patient who is confronted with the decision about the QoL of each group. For this, there are several *valuation* procedures or methods for quantifying the QoL associated with the remaining estimated life duration. A simple method is to give the patient information about the conditions that can be expected for his or her life during and after each treatment option. Next, he or she is asked to rate this expectation on a visual analogue scale (VAS). The VAS is usually a line of about 10 centimeters with the extremes (often) defined as “perfect health” (100) or “dead” (0). Suppose that the patient gives a rating of 60 to the remaining life associated with the intervention surgery and 70 to that associated with the intervention chemotherapy. This results in a QoL corrected survival of $0.6 \times 15 = 9$ QALYs for surgery and $0.7 \times 10 = 7$ QALYs for chemotherapy. It will be clear that on basis of this calculation, surgery treatment is still to be preferred to chemotherapy.4

There are a number of other valuation methods apart from the VAS, for which we refer to the specialized literature (Green, Brazier, & Deverill, 2000). Some multidimensional generic instruments come with specific scoring algorithms that provide unidimensional values on the basis of former validation research. Most notable are the EuroQoL EQ-5D (www.euroqol.org), the Health Utility Index (HUI; http://fhs.mcmaster.ca/hug/) and the SF-6D (Brazier, Roberts, Tsuchiya, & Busschbach, 2004). The latter reference also provides a comparison between the sensitivity of the EQ-5D and the SF-6D: The EQ-5D is more sensitive than the SF-6D when used with patients who are severely ill, whereas the SF-6D seems to perform better in patients who have mild complaints.

**Health Economics and the Societal Perspective**

A specific feature of QoL research in health economics is that the general public deter-

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3 Although the areas often differ between individuals and render a comparison difficult, the overall SEIQoL Index across areas can be grouped, thus enabling the calculation of group averages as well.

4 Because the real figures change across time, we have presented imaginary figures here.
mines the value of a health state, not the patient. As health economics almost always relates to health insurance, the measurement is accomplished from an insurance perspective. When using the insurance perspective, one has to judge at the outset what is valuable and what is not. For instance, when someone's house is on fire, it has no meaning to ask the person to express how he values fire insurance. From this insurance perspective, the general public is seen as the potential patients, who are anticipating that they themselves might one day be those patients. Noneconomists, such as psychologists and physicians, are often reluctant to accept this societal perspective. Moreover, the psychometrics of the questionnaire are different from standard psychometrics as applied to standard questionnaires, such as IQ and attitude tests in psychology. For instance, a key feature of a validated IQ test is a known distribution of scores in the general population. This key feature in “normal” validity is hardly relevant in health economics: A validated test is a test that can determine health state in patients, and for which the societal values of these health states are known, irrespective of the distribution of these health states. Much of the debate about the validity of health economic tests and the related QALY concept arises from a misunderstanding of the societal perspective of health economics. It is of the utmost importance for noneconomists to first familiarize themselves with this societal perspective before judgments about validity are made, as normal psychometrics can be misleading (Green et al., 2000; Wit, Busschbach, & Charro, 2000).

In a cost-effectiveness study, the number of QALYs that accrue from a specific treatment is compared with the costs of treatment and possible savings that are lost and/or gained. For instance, when the surgery and its related costs for prostate cancer is $9,000 and the number of QALYs is three more than the option of doing nothing, its costs are $3,000 per QALY. When chemotherapy costs $1,500 and its number of QALYs is one more than doing nothing, then this implies a cost per QALY of $1,500, which indicates a more cost-effective treatment than surgery. On the basis of cost-effectiveness arguments alone, we would prefer the chemotherapy intervention, which gives us QALYs for half the price. Obviously, criteria other than economics need consideration in the decision-making process, chiefly those based on humane and political values. Nevertheless, the QALY concept has made a valuable contribution to health care decision making, as it has moved the discussions of cost-effectiveness away from “subjective value judgments” to formal and validated evaluation methods. This is also an example in which the QoL research has lifted the “subjective” aspects of QoL to a level on which observations can be made in a scientifically verifiable, objective manner.

Specific Topics and Recent Developments

Construction of QoL Questionnaires

The development of a standardized psychological instrument follows a number of well-described steps: collection of items, item reduction, and testing of reliability, validity, and (sometimes) of responsiveness to change. Broadly speaking, the construction of an instrument of QoL does not differ from that of other psychological measures. Some aspects are, however, different or deserve more emphasis. First, health-related QoL reflects the evaluation of the patient (or healthy person) on his or her health. That means that the first step in gathering items involves interviewing patients about their experience concerning the different life aspects in relation to the illness. Further, because the instrument often needs also to be answered by patients in a severe phase of a disease that is often accompanied by pain and fatigue, it has to be short. Feasibility is, therefore, an important requirement of QoL measures. Consequently, QoL measures often have only a limited number of items per domain, as reliability is a trade-off for feasibility. Moreover, before undergoing psychometric testing, the concept version of a QoL instrument first receives an extensive tryout among the patient group in order to see whether the items are understandable, applicable, and written in common wording (McKenna et al., 1993). When a lot of normative data are available and the instrument can be completed using a computer, the use of methods derived from item response theory enables the researcher/clin-
cian to obtain a reliable and valid score of the patient by using just a few items. For a specific demographic subgroup within the general population, such as older people, existing questionnaires can be tested first to see whether their psychometric properties also hold for these groups (Haywood, Garrat, & Fitzpatrick, 2005). For a group of children or their parents, specific QoL questionnaires are developed, such as the Child Health Questionnaire (CHQ; Raat, Bonsel, Essink-Bot, Landgraf, & Gemke, 2002) or the Pediatric Quality of Life Inventory (Ped-QL; Varni, Seid, & Kurtin, 2001).

**Measurement Formats**

Patients with severe and debilitating afflictions who are bedridden, as in the final stages of cardiac disease or cancer, can be too fatigued to answer a paper-and-pencil questionnaire. It is not uncommon to present these questionnaires in the form of a structured interview, though most of the available evidence about reliability and validity does not apply to this way of administration. Feasibility in this case again has priority over psychometric background and comparability with previous findings based on the (original) questionnaire format.

QoL questionnaires differ in their instructions regarding the recall time. The recall time is dependent on the research question (Is it about the past day or the past year?), the specific disease of the patients (Is it a fluctuating or a stable disease?), and the attention span of the patients (Is it for children or adults?). The recall times range from “at the moment” (as in the NHP) to the preceding 4 weeks (several items from the SF-36). As another example, the Migraine Disability Assessment Scale (MIDAS; Stewart et al., 2000) looks back across a 3-month period, whereas the Migraine-Specific Quality of Life Questionnaire (MSQoLQ; Hartmaier, Santanello, Epstein, & Silberstein, 1995) covers the 24-hour period around a migraine attack, to be used in trials of acute medication to alleviate the symptoms of separate attacks.

The necessary number of assessments depends on the stability of the condition of the patient. For cancer patients at the end of life, in whom dramatic changes can be expected in a short time, more frequent assessments are recommended, for instance every week (Tang & McCorkle, 2002). In most patients, the frequency of assessments is much lower, as QoL is a more obvious outcome in chronic diseases with a stable course than in diseases with an acute manifestation. A modern development is the use of “experience sampling” methods, by which patients answer the questions on their physical and mental states with the help of an electronic diary on a mobile phone at different times during the day. Scores on these measures are averaged into an overall score.

**From Outcome to Screener and Target**

So far, QoL measures are often found as an outcome measure of a disease or an intervention. A new development is the use of QoL measures as the target of an intervention or as a screening tool (Espallargues, Valderas, & Alonso, 2000). An example of this application is the medical procedure in which patients with liver disease complete a computerized version of the SF-36 as part of the intake procedure. The scores are presented to their physicians as background information in order to enable the physicians to adapt their policies on the basis of these outcomes in order to improve the patients’ QoL (Gutteling et al., 2008).

The discussion about the use of QoL measures in clinical practice is related to that about patient-reported outcome measures (PROs or PROMS). PROs are defined as “reports coming directly from patients about how they feel or function in relation to a health condition and its therapy without interpretation by healthcare professionals or anyone else” (Patrick, Guyatt, & Acquadvro, 2011). QoL measures form an important category within PROs.

The application of QoL measures to guide the clinician in the treatment of patients has been studied and reviewed quite a lot, in particular in patients with cancer. So far, its effect on the process of care is promising, but the effect on patient outcome is limited (Valderas et al., 2008; Luckett, Butow,
A recent review in oncology on PROs in general indicated “strong evidence that the well-implemented PRO’s improved patient-provider communication and patient satisfaction” (Chen, Ou, & Hollis, 2013). Methodological issues, for instance the limited use of the information by the doctors and the variation in contexts and interventions, prevent us from drawing too-firm conclusions. But the introduction of electronic methods for the measurement of PROs (“e-PROs”), such as computers and smart phones, has enhanced its feasibility in clinical practice enormously, and an abundance of data will be ready for giving definite answers to questions about its clinical effects.

There is also an increasing tendency for public health service agencies and health insurance companies to demand the routine collection of PROs from the institutions with which they have a cooperative agreement. For instance, the British National Health Service recommends and supports the routine collection of PROs for hip or knee replacement, groin hernia, and varicose vein surgery (U.K. Department of Health, 2008). Apart from condition-specific measures, a generic measure (the EQ-5D) is used here as well. It can be applied to evaluate the clinical quality of an institute (for benchmarks and audits).

Another example, using a domain-specific QoL instrument as both a screening device and a treatment target, lies in the treatment of patients with migraine. A common strategy in the treatment of patients with migraine is to start with common analgesics first and, if this is not successful, to continue with migraine-specific medication (“stepped care”). However, Lipton, Stewart, Stone, Lainez, and Sawyer (2000) followed another strategy. They asked the patients at intake to complete the MIDAS so they could determine the severity of their migraine-related disability. The type of medication chosen was then based on the grade of the disability (following a “stratified care” approach). Patients with more severe migraine received migraine-specific medication immediately. The authors found that this “stratified care” procedure resulted in improved migraine relief and lesser disability than the alternative stepped-care treatment.

**Response Shift**

A salient phenomenon that struck researchers at the beginning of QoL research was the normalization of QoL scores of patients with life-threatening diseases, such as cancer, or with other severe disabilities. It was noted that these patients often reported a level of QoL similar to that of healthy people (Breetvelt & Van Dam, 1991). Apart from feeling better due to the beneficial effects of treatment, this phenomenon can be explained by a change in the patient’s perception of what “health” now means for them. In most occasions this change consists of a lowering of their standards for a good QoL, and, consequently, patients start to consider a lower QoL as normal. In health-related QoL research this phenomenon is referred to as “response shift,” and it is associated with an underestimation of treatment effects. Response shift relates to cognitive dissonance reduction in cognitive psychology, to preference drift in economics, and to coping in medical or health psychology. The idea that preference drift reduces the treatment effect on QoL suggests that the patient may not be the best assessor of the “true” QoL. On the other hand, one could argue that response shift is a part of the real evaluation of QoL in patients and should therefore be viewed as a true representation of the patient’s preferences. A meta-analysis of studies on response shift indicated that its magnitude varied a lot but that it was small on average (Schwartz et al., 2006). In health economics and epidemiology research, the problem of response shift is less pronounced. In epidemiology, the value of a health state is often determined by physicians, and in health economics the general public values health states, as health economics adopts the societal perspective and not the patient perspective. As both the general public and physicians have a fixed perspective in time, preference drift is eliminated (Wit et al., 2000).

**Minimal Clinical Difference**

An important question is what size of change in QoL is needed to be considered meaningful. It is a question that is relevant for other outcome measures as well. Several methods are available to compute a minimally important change for QoL instruments. In most
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circumstances half a standard deviation is considered to be a relevant threshold for changes in QoL for chronic diseases (Norman, Sloan, & Wyewich, 2003).

Andrasik (2001) summarized in a review on QoL a number of approaches to determine clinically meaningful and significant treatment effects that were derived from Jacobson and Truax (1991). A preferred approach is one in which the patient achieves a level of functioning that, after treatment, falls within the normative range. Clinical change would be demonstrated when postintervention QoL results in the patient’s (1) falling outside the range of the dysfunctional group, defined as being 2 standard deviations away from the mean; (2) falling within the range of the functional group, defined as being less than 2 standard deviations away from the mean; or (3) being closer to the mean of the functional group than to that of the dysfunctional group. For this approach, the collection of adequate normative data is of paramount importance.

Cross-Cultural Application

QoL measures are sometimes used for comparing the QoL between different nations and to estimate the global burden of a specific disease worldwide. Also, a clinical trial may be designed multinationally and involve the outcomes from patients in several countries. Going from the different national scores to a summarizing figure across the countries can only be accomplished when each local instrument measures the same concept in the same degree. One method of obtaining this required uniformity is to use formal translation protocols to translate existing reliable and valid instruments from their original versions into other languages. These protocols are not simple procedures that can be performed with just the use of a dictionary. The process often consists of a sequence of procedures, such as forward and backward translation, use of several independent translators, or development of translated versions that are the outcome of panel meetings. Next, the translated questionnaires have to be tested in a pilot study by administering them to an appropriate number of participants (about 15–20) from the target population who are asked to comment on the content and comprehensibility of the translated instrument. When this has led to the necessary adaptations, the translated version has to be evaluated psychometrically, and its internal consistency, test–retest reliability, validity, and, if applicable, responsiveness to change need to be evaluated (Peters & Passchier, 2006).

An even more elaborate procedure to design a questionnaire that is comparable between nations or cultures was used by the World Health Organization (1993). They started the development of a QoL questionnaire from scratch by having focus groups, composed of representatives from each of the countries in question, define the life domains that were relevant for their country. After the definitions of the relevant common domains were obtained, items within each domain were determined and formulated in these focus groups. This procedure resulted in a final questionnaire of 100 items (the WHOQOL) that might be extended with modules that are relevant for a specific country (or culture) only. It is available in many language versions.

Conclusion

QoL is a concept that has “won” its position during the past 50 years in health care. Its methods of measurement vary and are dependent on the purpose of the researcher or clinician. The goals of measuring QoL are mainly to measure the impact of a disease on the patient’s life, to measure the effect of a treatment, to choose between treatments, and to screen and determine an intervention strategy. Traditional psychometric indices are applicable on most QoL measures, but feasibility merits specific attention. Validation of QoL instruments in health economics requires a nonclassical design, as norms are not determined by the distribution of scores but by the general public that values the health states. QoL measures are nowadays well accepted in research, and their application in clinical practice is slowly but steadily increasing. Recent developments include the use of computerized versions that allow a reliable and valid measurement of the QoL with a reduced number of items.

A shorter version, the WHOQoL-BREF, consisting of 26 items, is now available as well (World Health Organization, 1998).
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