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EDUCATIONAL PAPER

Quality of life is a primary end-point in clinical settings

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Summary The objective of this review is to present and discuss the quality of life (QOL) construct, more specifically the QOL in the field of health and disease also designated as health-related quality of life (HRQOL). QOL is an everyday language concept with a relatively short history in the health field. It became a principal end-point in health care as a consequence of the development of patients' rights movements. It is important for clinical, economic and political decisions. There is no gold standard way to measure QOL and the existence of a huge number of measures and related QOL concepts makes it difficult to discuss QOL. This means that many times we are using the same expression "QOL" but we are not talking about the same thing. So we submit that it is important to keep looking for the good construct and the good measure. The reason why we decide to evaluate QOL influences the measures we choose. In general, QOL measures are based on questionnaires that must be short and easy to answer. The interest in these kind of soft measures (in opposition to the traditional hard physiologically or biochemically oriented measures) is growing fast.

Introduction

Quality of life (QOL) is a popular concept used in everyday language: In advertisements about domestic appliances, cars, holidays, in politics, and so on. People talk about QOL when addressing emotional feelings, personal relationships, or professional events.

Efforts to measure QOL began with the report from President Eisenhower's Commission on National Goals, intended to develop the QOL of the American People. The report, published in 1960, included a variety of social and environmental factors such as, education, concern for the individual, economic growth, health and welfare, and the defence of free world. In 1964, the American President Lyndon Johnston declared that "... goals cannot be measured by the size of our bank balance. They can only be measured by the quality of the lives our people lead...".[1]

In one of the first large studies in this field[2] entitled, Quality of Life of American People, the authors wrote that "the relationships between objective conditions and psychological states is very imperfect and that in order to know the quality of life experience it will be necessary to go directly to the individual himself for his description of how his life feels to him". In their study, they focused on "the experience of life rather than the conditions of life".

QOL becomes a very important subject in social sciences, from sociology to economy, from political science to psychology. Some landmarks can be considered in the history of QOL. Recently, Sen[3]

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(Nobel prize of economy in the late 1990s) published a book named ''Quality of Life''. The first studies[2,4] focus primarily on the individual's perceptions of well-being rather than objective indicators, emphasising general or global measures of well-being. Liu's[5] study concludes that QOL includes two components: the subjective one (or psychological) and the objective one (or social, economic, political and environmental). The subjective component is more qualitative in nature, and generally depends on the individual and is not measurable, while objective components are more quantitative, and likely to be measurable.

Evolution of health and QOL concepts

We went through a period in the mid-1960s during which the validity of a patient rating a generic health concept was questioned when it did not agree with what was in the record or with what the health provider said. The logic of validity has since been turned around. We are now entering an era in which the same findings are accepted as evidence due to the need to include patient assessments as part of the evaluation process, explains Ware.[6]

Historically, health concepts changed during the second half of the 20th-century. Large studies helped to change the importance of positive (or healthy) perspectives on health. From the negative health measures like the ''five D's'' — death, disease, disability, discomfort, and dissatisfaction —research on health has shifted towards the assessment of more positive dimensions. The new wave of health concepts developed new and more positive health measures with the purpose of evaluating health and not disease. These new health measures influenced the QOL measures.

The large Alameda County Study[7], defined physical health in terms of energy levels, symptoms, chronic conditions, impairments, disability, and general health perception. The Health Insurance Experiment or the RAND Health Insurance Study (HIE or HIS) defined four major health status dimensions:[8] physical health, mental health, social health, and general health perceptions. The Medical Outcomes Study (MOS) (a study of variations in physicians' practice styles and their impact on patient's outcomes) adopts five categories of indicators of physical and mental health:[9] clinical status, physical functioning and well-being, mental functioning and well-being, social/role functioning and well-being, and general health perceptions. These kinds of studies express and impact ideology about health and disease concepts with impact on QOL field and QOL evaluations.

The medical model changes towards a more patient-centred medicine. Laine and Davidoff[10] define patient-centred care as health care that is closely congruent with and responsive to patients' wants, needs, and preferences. This movement is one component of the 1960s patients' rights movement. It is opposite to the provider-centred model of care. The consequences of that movement are the inclusion of more ''soft'' outcomes in parallel with the traditional ''hard'' outcomes. QOL is one of the innovative ''softer'' outcomes.

QOL is a primary end-point

Some authors[11] define the importance of primary end-points in clinical intervention explaining that ''ideally, clinicians making treatment decisions should refer to methodologically strong clinical trials examining the impact of therapy on clinically important outcomes. By clinically important outcomes we mean outcomes that are important to patients: health related quality of life, morbid endpoints such as stroke or myocardial infarction, or death''. Other scientists defend health-related quality of life (HRQOL) measures must be included in clinical trials as secondary end-points.[12]

Scanlon[13] defends that QOL suffers from an embarrassing richness of possibilities. What kind of circumstances provide good conditions under which to live? What kind of conditions make life good according to oneself? What makes a life valuable from the point of view of the universe? Each of these questions admits different interpretations and different answers. Each of these questions can be asked from different points of view (the subject, a benevolent third party like a friend or parent, a conscientious administrator or politician).

Is it necessary to have a QOL definition?

Defining QOL is important because the definition we choose influences the evaluation technique we adopt. Both are influenced by philosophic perspectives, values and principles that influence the research design. In fact, many articles addressing QOL do not define the concept.[14] Gill and Feinstein[15] examining 75 randomly chosen articles using QOL instruments found that very few had attempted to define what their study meant by QOL and to justify the QOL measure they used.

Hunt[16] explains the lack of conceptual clarity through two tendencies. The first one states that

there is a general agreement on the components and definition of QOL. In fact there is a wide disagreement about the meaning of the term ''quality of life'' and how to measure it. Different researchers or professionals prefer definitions and measures influenced by the preoccupations of their respective disciplines.

The second attitude is opposite to the first one and defends that there is no gold standard for QOL and, therefore, any one has the liberty to measure ''quality of life'' in any way whatsoever.

Philosophy of QOL evaluation

''Quality of life'' or rather the ''good quality of human life'' can be discussed in various settings (medical, social sciences, philosophy, etc.). Different settings adopt the term QOL for different purposes, each of them using different kinds of assessment.

According to Hayry,[17] there are three different philosophies behind QOL assessment. One based on sanctity of life, one on scientific efficiency, and another on respect for human autonomy. The first model assumes that human life is sacred, the measurement of QOL unethical and not important or secondary for clinical decisions. Prolonged life is always the primary outcome without considerations for QOL. The second model, views the evaluation of life quality on scientific grounds and is preferred by the economists, because it addresses aspects that emphasise the efficiency and equity of the system and facilitates decisions concerning resource allocation. As scientific it stresses the objectivity of the measures, mainly the reproducibility and measurability by external observation. The third one, respect for autonomy, stresses the viewpoint of personal self-determination. It assumes that QOL is no more and no less than what the person considers it to be. This last model is proposed by many interest groups, like the clergy, economists, politicians, medical professionals and even the pharmaceutical industry.

In another analysis, Brock[18] points out that philosophy distinguishes three broad kinds of theories that explain what is good for the individual or what is a good life. The three alternative theories of a good life are: hedonists, preference satisfaction, and idealist theories.

The hedonists consider as the ultimate good for people to be undergoing particular kinds of conscious experiences that can be characterised as pleasure, happiness, satisfaction, or enjoyment that typically accompany the successful pursuits of our desire. Preference satisfaction theories defend that a good life consists in the satisfaction of people's desires or preferences. The idealist theories defend that a good life consists of the realisation of specific, explicit normative ideals.

QOL definition

QOL is recognised as a vague and ethereal entity, something that many people talk about, but which nobody knows very clearly what to do about . We can find many definitions. According to Farquhar,[19] QOL definitions can be classified as: global definitions, component definitions (research-specific and non-research-specific), focused definitions (explicit or implicit), combination definitions and lay definitions. As an example we chose some different definitions:

QOL is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.[20] QOL is the subjective perception of satisfaction or happiness with life in domains of importance to the individual.[21] QOL is a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her.[22] QOL is the difference between a person's expectations and actual experience.[23] QOL is an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns.[24]

The previous definitions include concepts such as well-being, satisfaction, happiness, expectancy, or functionality. We can find all these concepts in the techniques used to measure QOL. No single definition of QOL, which is appropriate for both practice and research, has become standard.

Are health and QOL the same thing?

For some researchers the answer is yes, for others no. Guyatt et al.[25] and Fries and Spitz[26] explain that health status, functional status, QOL, and patient outcome, are concepts used interchangeably to refer the same idea of health. The concept or idea of health varies from extreme to extreme, from death to happiness. Because the concept of health or QOL also depends on the level of income, poor environment, lack of freedom, and because these aspects are not important in medical contexts or for the evaluation of disease progress, we can adopt a concept of HRQOL which will focus

primarily on medical aspects. Physiological measures are important to clinicians but they mean nothing to the patients. Often physiological measures are poorly related with well-being and functional capacities. Patients with the same stage of disease vary widely in the way they feel.

Wilson and Cleary[27] used the terms health status and HRQOL interchangeably (although recognising that "the concept of QOL is distinct from health, though related to it") Ware[6] defends that QOL is a much broader concept than health status, and includes the latter. Fries and Spitz[26] explain that health status is a measure of QOL at a particular point in time.

Revicki et al.[28] describe that although functional status, perceived or subjective health status, QOL, and HRQOL are often used interchangeably, these terms have subtle but important differences with respect to dimensionality, perspective and scope. QOL has meaning beyond an individual's health.

The World Health Organization defines health as a state of physical, social and mental well-being and not merely the absence of disease or infirmity, explaining that health is a resource for everyday life, not the object of living. It is a positive concept emphasising social and personal resources as well as physical capabilities,[29] meaning that health is a basic resource for a good life or a good QOL.

General QOL is not the same as HRQOL

As we mentioned before, many people talk about functional status and well-being as if they were synonymous with QOL; however, it is recognised that QOL is a much broader concept. For example, Campbel et al.[2] in a study designed to monitor the QOL of American life with a national sample identified 12 domains of life: community, education, family life, friendships, health, housing, marriage, nation, neighbourhood, self, standard of living, and work. Flanagan[30] in a study which began in 1972, designed to identify the major factors affecting the QOL of adult Americans, used a different method he entitled "critical incident technique" and identified 15 domains: material comforts; health and personal safety; relationships with relatives; having and rearing children; close relationships with spouse or sexual partner; close friends; helping and encouraging others; participating in government and local affairs; learning, attending school, improving understanding; understanding yourself and knowing your assets and limitations; work that is interesting, rewarding, worthwhile; expressing yourself in a creative manner; socialising with others; reading, listening to music, or watching sports, other entertainment; participation in active recreation.

In both studies, health is only one of the domains of general QOL and emerged as the most important one. We can study the QOL in each of the fields described above, for example marriage-related QOL, or work-related QOL. In our setting, we are interested in HRQOL.

QOL in the field of disease

QOL related with (that depends on) disease or HRQOL, can be defined as "the subjective assessment of the impact of disease and treatment across the physical, psychological, social and somatic domains of functioning and well-being".[28]

HRQOL is a welcome addition or supplement to the traditional physiological or biological measures, because it describes and characterises what the patient has experienced as the result of medical care.

It is an important end-point because the literature strongly suggests that there is not a direct one-to-one relationship between severity of abnormalities, symptoms, functional limitations, disability and loss of QOL.[27] Health perceptions, well-being, life satisfaction are not directly proportional to symptoms and functional limitations, which in turn are not directly proportional to physiological and anatomic abnormalities. The effects flowing from biological abnormalities to QOL are mediated and modified by psychological, social and cultural factors.[31]

QOL levels

According to Spilker,[32] QOL must be viewed on a number of levels. The author presents the different levels as a pyramid in which the top consists of a very general level, the middle a group of domains, and the lower level all the aspects of each domain.

The assessment at a general QOL level can be a question such as: "How would you rate your overall quality of life during past week?" It can be answered by everyone either healthy or sick, and the results compared.

The second level must include different domains, physical, psychological or social domains. It can be applied to everyone, like the SF-36 or the WHO-QOL-Bref both widely used measures of general HRQOL that can be applied to people with or without disease.

The third or more specific level can include the domains of the second level as well as specific characteristics of the disease. The QLQ-C30, a measure developed by The European Organisation for Research and Treatment of Cancer (EORTC) includes scales (a group of items that measure the same construct) and items-dimensions (items expressing disease symptoms).

QOL models

We can find many models with which to explain QOL, here are a few examples:

Hyland,[33] refers that HRQOL used to be presented in two different approaches: One which he calls ''the multifaceted approach'' consists of an aggregation of several, conventionally agreed, health indices. Another approach, ''the causal process approach'' describes HRQOL as a causal sequence resulting from an interaction between morbidity and psychological factors. Hyland states that the conventional approach in medicine is the multifaceted approach. QOL is commonly considered as an outcome measure that is independent of mortality and morbidity data,[33] i.e. QOL and morbidity are analysed as unrelated dependent variables. In opposition to that traditional position, Hyland proposes the causal sequence approach which assumes that QOL must be affected by morbidity, and therefore correlated with it. Since QOL is also affected by psychological factors, QOL measures must represent some kind of causal interaction between morbidity and psychological aspects.

Spilker[32] proposes a model of how clinical aspects influence patient QOL domains. It includes: medical treatment (safety, efficacy and additional measures), any adverse reactions due to treatment, beneficial clinical effects and convenience and costs. The above aspects are perceived or filtered through patients' values, beliefs and judgements, and the net result of all the aspects is the QOL.

Ormel et al.[31] propose a model for understanding how consequences of disease affect QOL. Symptoms and functional limitations place constraints on an individual's activities, endowments and resources, thereby increasing their costs, and thus reducing the behavioural means for achieving the instrumental goals with subsequent negative effects on QOL.

Leventhal and Colman[34] assume that the patients' representations of a disease will affect the salience, meaning and importance of the domains involved in making QOL judgements. They propose a process view model including the representation of the disease threat, of the affective reactions that serve both as motivators and inhibitors of thoughts and actions, of the procedures of rules of thought and action designed to more fully define, control, cure and prevent a disease threat, and of the contextual factors within the persons' lives.

Wilson and Cleary[27] propose a model that includes five levels in the model: biological and physiological variables, symptoms, functional status, general health perceptions and overall QOL. This diagram is mediated by the characteristics of the individual (motivation, values, preferences) and the characteristics of the environment (psychological, social and economic support).

QOL measurement: composition, domains, dimensions or factors

The multidimensionality of HRQOL measurement considers various domains and various scores. The number of domains should be determined either empirically and/or theoretically. The number of domains depend on the nature of the HRQOL evaluation: whether we are using general QOL instruments or disease-specific instruments.

Disease-specific instruments include items that are symptoms of the disease (pain in arthritis) or side effects of the treatment (nausea in cancer). Measurements that include side effects or symptoms lead to the question of knowing if we are measuring the QOL or what determines it. Some scientists consider that they are separate, others that it must be included in the measurements. The ISPOR panel[12] defends that collecting information about symptoms or side effects is important for clinical decisions but it is questionable if they represent QOL.

Ware and Sherbourne[35] described eight functional domains of QOL: physical functioning, physical role, bodily pain, general health, vitality, emotional role, mental health, social functioning. Each domain is expressed by a score, and the total result is expressed as a scattergram.

Ferran and Powers[22] described four QOL satisfaction dimensions. Each dimension as a score and the sum of the dimension scores provide a total QOL score.

The EORTC Group[36] proposes a measure (QLQ-C30) with 30 items, distributed by five functional scales, one global health status scale, three symptom scales, plus six item domains.

Many other ways of measuring QOL can be found, such as well-being measures, functional measures, or symptom measures.

Properties of the QOL paradigm

Schipper et al.[37] defend a number of operational characteristics of the QOL paradigm: Multifactoriality, self-administration, time variable, and subjectivity.

Multifactoriality means that the QOL parameter includes more than a single aspect or domain. QOL represents a broad range of human experiences related to one's overall well-being, and is influenced by one's perception of various personal dimensions like physical, psychological, social, economic, and political environment.[28]

Self-administration means that the person, whose QOL we are trying to evaluate is the one who knows best. Physicians and nurses tend to focus on physiological measures. Psychologists, social workers and family tend to focus more on psychosocial measures. QOL ratings performed by medical doctors, nurses, caregivers, and others are often divergent and exhibit poor correlation statistics. Therefore, the patient's own judgement is assumed to be the best measure of QOL. That is why it is designed to use patients as their own internal control.

Time-variable means that QOL can change over time. Because of its fluctuating nature meticulous follow-up and careful attention to the timing of measurement along the treatment becomes important.

Subjective means that QOL measures must be based on the assumption that the ultimate observer is the involved patient, and that QOL is based on the patient's perceptions. QOL implies values based on subjective functioning in comparison with personal expectations and is defined by subjective experiences states and perceptions. By its very nature it is idiosyncratic to the individual. One of its characteristics is the incorporation of values and judgements according to individual preferences.

QOL scores

QOL can be expressed in global scores, summary scores or as a scatter. Global scores refer to the scores of a global measure, or a response to questions such as ''how would you rate your overall QOL?''. Summary scores mean that multiple dimensions are grouped and summed in one score. This kind of summary measures may obscure changes in different domains, especially if changes in different domains occur in different directions. A scatter or the use of one score for each dimension is one solution and we can compare the form of the plot to compare the evolution of the patient in longitudinal studies or compare the scatter of the patient with the one from the reference group.

Because QOL is multifactorial it is assumed that the result can be expressed more adequately as a scatter instead of a single number. The SF-36 questionnaire produces only a scatter, while the WHOQOL-Bref questionnaire produces a scatter and a summary score.[38]

Metric characteristics of HRQOL measures

There is no single instrument that can be used to evaluate outcomes and generate claims across all HRQOL domains, populations, diseases and treatments.[28]

To measure QOL or HRQOL we need appropriate and accurate measures. These characteristics are a function of the respondent, the instrument used to measure, and the objectives of the measurement. There is no magic bullet instrument. A good instrument is always dependent on a good choice by the researcher. Once the domains of interest are identified we need to choose an instrument that covers those domains.

The number of instruments developed to measure HRQOL is enormous. Thus, we need to choose the ones that fit our objectives best. To do so we need to consider the seriousness of the studies published on the instrument and the seriousness of the organisations that published them, namely the metric properties. We must consider profit organisations and scientific organisations. Some times they do not match. Some profit organisations are very interested in the economic stream and not in the scientific quality of the instruments. In the field of HRQOL, we have some good organisations.

QOL measures can be used as an outcome measure or as a clinical tool. The objective of the assessment influences the type of measure. When we discuss measures of this type we can consider two types of metric properties: psychometric properties and clinimetric properties.[39] The choice of the metric properties depends on the objective of the evaluation.

When we choose to use a HRQOL instrument we are interested in producing a measurement. Therefore, we need to consider the metric properties that guarantee the quality of the scores. Selection

of QOL or HRQOL instruments must consider some metric properties, namely: validity, i.e. the guarantee that the instrument measures the construct it is supposed to measure. It is possible that an instrument consistently measures a construct other than the intended one, making it reliable but not valid. We must consider three types of validity: construct, content, and criterion-related.

Reliability is the consistency with which an instrument measures a given construct, or the property that guarantees that the instrument produces the same score if used by a different person or in different moments. Evidence of this property can be given through internal consistency or test–retest. Because QOL varies with time, when we use test–retest techniques we need to consider the time gap. Longer gaps mean lower correlation between the two measures.

Responsiveness is the extent to which a measure reflects accurately changes in patients' conditions due to disease progression or in the expected direction as consequence of effective treatment.

Clinical significance expresses meaningful changes in HRQOL. Sometimes differences in clinical trials can be statistically significant but not important in a clinical sense (e.g. if a drug reduced the mean systolic blood pressure from 24 to 20, that can be statistically significant but it is not clinically significant). The definition of clinical significance must be defined a priori.

QOL history

Historically, we can consider the Karnofsky performance status (KPS)[40] as one of the first QOL measurement scales. It is a measure based on providers observations of patient functions. Recent instruments reflect the increasing regard of patients' perspectives.

We can find many QOL or HRQOL measures. They can be general (SF-36) and in that way they are applicable to any patient regardless of the prevailing medical condition, or they can be specific for a certain disease (QLQ-C30).

Some international organisations propose QOL measures for international studies. As an example we can consider The EORTC cited above. It is a non-profit organisation founded in 1962 to provide guidelines for cancer treatment and developed QOL measures (QLQ-C30) for cancer patients. QLQ-C30 is a multidimensional questionnaire with 30 items that measure physical functioning, role functioning, emotional functioning, cognitive functioning, social functioning and health status/QOL.[36] These are multi-items scales. The QLQ-C30 also includes items to measure fatigue, nausea and vomiting, pain, dyspnoea, insomnia, appetite loss, constipation, diarrhoea, and financial difficulties. This is a specific measure for cancer patients but it is also a generic measure as it can be used in all types of cancer. The QLQ-C30 also provides specific modules to add to the generic 30 items. These modules are specific for certain type of cancer.[36]

How to use QOL measures

Researchers use QOL measures to evaluate different outcomes. Two such outcomes are the QALY and Q-TWIST. They are generally considered inside the field of QOL.

QALY

QALY, acronym of quality-adjusted life year, is a concept developed by economists, more specifically by health economists as a response to the interest of health policy makers in cost–benefit indicators as aids to good decision making. It is a utility approach to measuring HRQOL.

QALY has been proposed as a standard outcome measure for cost-effectiveness analysis but also to express the benefits of medical care, behavioural intervention, or preventive programmes in terms of well-years.[41] It uses QOL measures to allocate limited resources or patient choices among competing health programmes. Cost-effectiveness studies are now common in evaluation of medical therapies, surgical procedures and new pharmaceutical products. Cost–utility studies need a common measure of health outcome. A QALY is a year of full QOL gained.[42] In this sense, the cost of an intervention is related to the number of QALYs. QALY is expressed on a scale between 0 and 1. One representing perfect health and zero representing death. QALY builds the scale by combining changes in survival and QOL of patients.

Various techniques are used to identify QALYs[43] such as standard gamble and time trade-off. Standard gamble was designed to assess the amount of risk that the respondent is willing to accept in order to live in the best health state for a given amount of time. The time trade-off method respondent chooses between two options: living in the assessed health state for a given period or living in perfect health for a shorter period of time.

The value of health states depends on the personal judgement. Research shows that trade-offs can be

considered and that the position of patients is not the same as that of the health-care providers.

Otto et al.[44] in a study that attempted to evaluate the impact of a laryngectomy in 46 post-laryngectomy patients, found that 80.4% of the patients would not be willing to trade off expectancy of QOL for voice preservation. But 19.6% indicated a willingness to trade 2 to 10 years of their anticipated life expectancy in order to maintain their laryngeal voice and preoperative QOL. Forty-six per cent of the health-care providers perceived that their patients would be willing to accept a reduced life span in order to preserve their larynx and QOL.

Tsevat et al.[45] in another trade-off study designed to identify the values of 440 hospitalised elderly patients, submitted to different treatments found they equated 1 year in their current state of health with living 9.7 months in excellent health. Of these patients, 40.8% were unwilling to give up any time in exchange for a shorter life in excellent health. And 27.8% were willing to give up at the most 1 month out of 12; 6% were willing to live 2 weeks or less in excellent health rather than 1 year in their current state of health. Their surrogates underestimated the patients time trade-off, and the correlation between patients and their surrogates health values was modest ($r = 0.36$).

These studies point out that the majority of patients are unwilling to exchange years of life for better health. However, a significant number of patients are willing to exchange many years of life for better QOL and health-care providers, surrogates, and patients have different points of view about the time trade-off.

Q-TWiST

Q-TWiST is the acronym of time without symptoms of treatment. It was developed in the field of oncology and is a crude cost–benefit formula instead of a QOL indicator. The objective is to determine the amount of good time that adjuvant therapy adds to no treatment. The overall survival time is divided into time with experience of toxicity, time without symptoms and toxicity, and time after systemic relapse. It represents a major attempt to include QOL issues in the decision-making process in clinical trials.

Size of the questionnaires

In general, QOL questionnaires are small in number of items. For some patients (like the elderly, critically ill, or illiterate) more than 10 min answering the questionnaires is too much. For that reason, questionnaires tend to be short in size and in time needed to answer. Number of items used in the questionnaires can vary from one to more than 50. The shorter questionnaires prevail, however, they depend on the objective of the study and the conditions of the patients.

International comparisons

It is becoming normal to study people from different countries, cultures, and languages. To do that, it is necessary to design the questionnaires in different languages. The methodology to translate questionnaires is complex. To consider the same questionnaire in different languages or culture as identical is just an assumption that is probably not true. We need to consider different equivalencies, such as item-translation equivalence, operational equivalence, scale equivalence, and metric equivalence. It is very difficult to meet these standards. This kind of instrument is based on language and language means different things in different cultures. We cannot assume that a questionnaire in Japanese, or in French, or in Portuguese, means exactly the same as the original version in English. This has been discussed in the literature.[46,47]

Limitations of QOL evaluation

One important question remains: Do we evaluate QOL or what influences it?

Since the 1990s, some authors have discussed these issues. For Shumaker et al.,[48] QOL "has been conceptualised in a variety of ways and there is disagreement regarding what constitutes quality of life versus what influences it".

For Leventhal and Colman,[34] "the focus on outcome assessment has led to an overly inclusive definition of quality of life and to the development of scales that do not distinguish between the possible determinants of quality of life and the quality of life per se".

QOL evaluation is yet in its early stages. Further collaborative studies are required to develop a better international convergence in the definition and assessment of QOL.

Where to find a good list of QOL instruments

We can find free access to synthesised QOL instruments at a new database < www.qolid.org >.

QOLID is the acronym of the QOL instruments database.

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