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Instruments Used in Assessment of Health-Related Quality of Life

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Abstract

Introduction. Health-related quality of life (HRQoL) and well-being are used in clinical practice to measure the effects of chronic illness, treatments, and short- and long-term disabilities on the quality of life. Currently, more than 1000 instruments are designed specifically for measuring the quality of life. While some are designed for assessing any disease, others are created for specific conditions.

Aim. To establish characteristics of instruments for assessing health-related quality of life.

Methods. A review of scientific papers was made to establish characteristics of most commonly used tools for assessing health-related quality of life.

Results. Questionnaires shown in this review paper have strong reliability; they use the Likert scale; they consist of approximately 30 items and most of them are holistic; and they evaluate the physical, psychological, social, and environmental domains through numerous questions. The criteria for selecting tools and judging the appropriateness of measures include the following: appropriateness, reliability, validity, responsiveness, precision, interpretability, acceptability, and feasibility.

Conclusion. Even though many different instruments for measuring HRQoL are available, none is perfect as they are only tools best suited to a particular condition. The choice of instrument depends on the reason for measurement, the primary concepts of interest and the purpose of the study.

Introduction

Health-related quality of life (HRQoL) is concerned specifically with health aspects while also accounting for general QoL components. Defining HRQoL has also been problematic and according to Karimi et al. (1), at least four definitions of HRQoL exist. Firstly, HRQoL can be defined as how well a person functions in their life, as well as his or her perceived well-being in physical, mental, and social domains of health. Secondly, if quality of life is an all-inclusive concept incorporating all factors that impact upon a person's life, health-related quality of life includes only those factors concerning health. Thirdly, HRQoL can be defined as those aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment. And fourthly, HRQoL can be defined as values assigned to different health states. HRQoL has been understood in several different ways and so has been measured using a variety of instruments. While authors McDowell and Newell have suggested that there is little difference between general health and the quality of life and that the two can be measured in similar ways, Mathers and Douglas draw the distinction between observable objective measures of health status, such as clinical profile and an individual's perception about the quality of life (2).

Health-related quality of life is a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning. It goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on the quality of life. A related concept of HRQoL is well-being, which assesses the positive aspects of a person's life, such as positive emotions and life satisfaction (3). HRQoL and well-being are used in clinical practice to measure the effects of chronic illness, treatments, and short- and long-term disabilities on the quality of life. While there are several existing measures of HRQoL and well-being, methodological development in this area is still ongoing. Quality of life can differ between individuals with identical resources, and across socioeconomic groups and generations. HRQoL is important for measuring the impact of chronic diseases, treatment, and short- and long-term disabilities on the quality of life. Physiologic measures provide important information to clinicians but are of limited interest to patients. This type of information often correlates poorly with functional capacity and well-being, the areas in which patients are most interested and about which they are well-informed. HRQoL is the commonly observed phenomenon whereby two patients with the same clinical criteria often have dramatically different responses (4).

There are many reasons to measure health-related quality of life, and some of them are:

- HRQoL measures provide useful information to care providers as they can be used to screen and monitor patients for psychosocial problems or when auditing healthcare practice
- HRQoL measures can be used in population surveys of perceived health problems or other aspects of health-services or evaluation research
- Regulators can use HRQoL measures to help their assessment of new technologies
- Patients and healthcare providers as well as payers are interested in the added value technology has to offer. HRQoL can serve as a common measure of gains from any technology (5).

Health-related quality of life (HRQoL) is especially concerned with health aspects while also accounting for general QoL components. In the last decade various instruments have been developed to measure quality of life. An important fact is that quality of life might be experienced differently and encompass different values within and across different cultural groups and country populations; in addition, there are often discrepancies between quality-of-life evaluations in people with a form of somatic or psychiatric illness and the general public.

The aim of this study is to establish the characteristics of instruments for assessing health-related quality of life.

Methods

A review of scientific papers was made to establish the characteristics of the most commonly used tools for assessing health-related quality of life. Medline

and PubMed were searched using the following key words: tools, health-related quality of life, and characteristics of instruments. Only papers written in English whose entire text was available were taken into account. The search was limited to the period between January 2002 and October 2022. The period is long because of the time when the instruments were created.

Instruments used in assessing health-related quality of life

At the time of writing, there are more than 1,000 instruments designed specifically for measuring quality of life. While some are designed for assessing any disease, others are created for specific conditions. Some of the questionnaires used in existing literature are 36 items Short Form Health Survey (SF-36) (6,7), The World Health Organisation Quality of Life (WHOQOL) (8); The European Quality of Life (EUROQOL) and the Euro-QoL 5 Dimensions (EQ-5D) (9). For assessing HRQoL in oncological patients, the Functional Assessment of Cancer Therapy: General (FACT-G) (10) and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (11) are widely used. The basic characteristics of EORTC QLQ-C30, FACT-G, SF-36, and WHOQOL are presented in Table 1. A review of existing literature has shown that the presented questionnaires are most often used.

Table 1. **The characteristics of HRQoL questionnaires**

	EORTC QLQ-C30	FACT-G	SF-36	WHOQOL
Number of Items	30	27	36	100
Domains	5 functional scales: • physical, • role, • social, • emotional, • cognitive. Symptoms: • pain, • fatigue, • nausea/vomiting, • dyspnea, • insomnia, • appetite loss, • constipation, • diarrhea. Financial impact: • Global QOL/general health.	Physical well-being, Emotional well-being, Functional well-being, Social and family well-being.	Physical health: Physical functioning (physical), Bodily pain, General health, Mental health: Role limitation (emotional), Vitality, Mental health, Social functioning.	Physical domain, Psychological domain, Social domain, Environmental domain
Reliability	Cronbach's alpha of 0.70–0.90 for all scales	Cronbach's alpha of 0.70–0.90 for all scales	Cronbach's alpha of 0.70–0.90 for all scales	Cronbach's alpha of 0.70–0.90 for all scales

The criteria for selecting and judging the appropriateness of measures include the following:

- Appropriateness - match of a measure to the specific purpose and questions of research
- Reliability
- Validity
- Responsiveness - sensitivity to changes in important aspects
- Precision - the number and accuracy of the distinction made by the measure
- Interpretability - the meaning of scores
- Acceptability - how acceptable is the completion of a measure for respondents
- Feasibility - the extension of effort, burden and disruption to staff arising from using a measure.

All subjective responses are assessed by the use of a rating scale, which consists of a number of response alternatives, and the subjects are asked to make a judgment of the same on a scale. The most common techniques use either a Likert type scale or a bipolar scale in which the score is located on a single dimension. On the Likert scale the possible answers may be 1=very satisfied, 2=satisfied, 3=most satisfied, 4=dissatisfied, 5=very dissatisfied or 1=not at all, 2=a little, 3=quite a bit, and 4=very much. On the bipolar scale the answers are delighted – terrible. The individuals who participate in the research are asked to evaluate each item and then rate the response (12-16). Most researchers think that questions should be combined into discrete domains which help to define different areas of life. This kind of construction helps to ease conceptualization and measure (17,18). There is an increasing need for a standardized system to describe patients during and after therapy; for assessing the efficacy, effectiveness, and efficiency of new therapeutic interventions; and for obtaining data about reference groups from general population surveys (18).

Short Form Health Survey (SF-36)

The SF-36 is a 36-item multipurpose health survey, with a high score representing better HRQoL (6,7). It provides an eight-level profile of functional health and well-being: physical functioning, physical role, physical pain, general health, vitality, social functioning, emotional role, and mental health (range for all 0-100). Psychometrically-based summary measures of physical and mental health are also created: a mental component summary and a physical component summary. The mental component summary consists of the vitality, social functioning, emotional role, and mental health subscales, while the physical component summary consists of the physical functioning, physical role, physical pain, and general health subscales. The SF-36 has been useful in surveys of general and specific populations, in comparing the relative burden of disease, and in distinguishing the health benefits of a variety of different treatments (6,7). According to observed criteria, this instrument's characteristics are as follows: psychometric analyses of the translated versions provide evidence that the SF-36 is a reliable and valid measure in multiple populations; its reliability is shown in the table; it is appropriate for the general population and in patients with the burden of disease, which also make it responsive; it is a precise tool in assessing the quality of life; scores can be easily interpreted and are precise in the display of results; it is acceptable for the general population because it is not too long; and it is not a burden for researchers, i.e. data is easily collected.

European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30)

EORTC QLQ -The C30 questionnaire contains 30 questions. It is a proprietary instrument that has been translated and validated in over 110 languages and used in more than 3,000 studies worldwide (11). Currently, QLQ-C30 version 3.0 is the most current version and should be used for all new studies. For the response alternatives, the following ranges are offered: 1=not at all, 2=a little, 3=quite, and 4=very. For the last two questions, the scale ranges from 1 to 7, with 1 representing "very poor" and 7 representing "excellent." The EORTC QLQ -C30 questionnaire version 3 consists of a general health/quality of life scale and five functioning scales: physical functioning, role functioning, cognitive functioning, emotional functioning, and social functioning, and 13 symptom items. The functioning scale includes cognitive, emotional, physical, role, and social functioning. The symptom scale includes fatigue, nausea or vomiting, and pain, as well as individual items such as loss of appetite, constipation, diarrhea, and dyspnea, financial impact, and sleep disturbance.

For the general quality of life and functional scale, a higher range means better quality of life while a higher range for the symptom scale and single items means lower quality of life because there are more symptoms present (11). According to the observed criteria, this instrument's characteristics are as follows: it is a reliable and valid measure in patients with cancer; its reliability is shown in the table; it is appropriate for patients with the burden of cancer, so a specific condition demands use of a variation of the same questionnaire; it is a precise tool in assessing the health-related quality of life; scores can be easily interpreted and are precise in the display of results; it is acceptable for patients because it is not too long; and it is not a burden for researchers, i.e. data is easily collected.

Functional Assessment of Cancer Therapy: General (FACT-G)

The Functional Assessment of Cancer Therapy - General (FACT-G) is a 27-item questionnaire designed to measure four domains of HRQOL in cancer patients: physical, social, emotional, and functional well-being (10). It is intended for people over the age of 18 with cancer. The response scale is of the 5 Likert-type, with values as follows: 0=not at all, 1=a little bit, 2=somewhat, 3=quite a bit, and 4=very much. It takes 5-10 minutes for completion. Available translations of the FACT-G can be obtained by registering for permission. This instrument shows sensitivity to discriminate patients on the basis of stage of disease, performance status rating (PSR), and hospitalization status. It has also demonstrated sensitivity to change over time (10). According to the observed criteria, this instrument's characteristics are as follows: it is a reliable and valid measure in patients with cancer; its reliability is shown in the table; it is appropriate for patients with the burden of cancer, so a specific condition demands use of a different questionnaire; it is a precise tool in assessing health-related quality of life; scores can be easily interpreted and are precise in the display of results; it is acceptable for patients because it is not too long; and it is not a burden for researchers, i.e. data is easily collected.

The World Health Organisation Quality of Life (WHOQOL)

The WHOQOL is a quality of life assessment developed by the WHOQOL Group with fifteen international field centers, simultaneously, in an attempt to develop a quality of life assessment that would be applicable cross-culturally (8). The WHOQOL-100 assesses individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. The WHOQOL-100 and WHOQOL-BREF have many uses, including use in medical practice, research, audit, policy making and in assessing the effectiveness and relative merits of different treatments. They can also be used to assess variation in quality of life across different cultures, to compare subgroups within the same culture and to measure change across time in response to changes in life circumstances. The WHOQOL-100 contains 100 questions. This is based on four questions per facet, for 24 facets of quality of life. In addition, four questions address overall quality of life and general health. Around 30 language versions of the WHOQOL-100 have been developed. Patient focus groups should be made up of a sample of individuals who are representative of the population of patients in the field centre. It uses five-point Likert scales for all items in the instrument. The domains are: physical capacity, psychological, level of independence, social relationships, environment, spirituality/religion/personal beliefs, and overall quality of life and general health perceptions (8). According to observed criteria, this instrument's characteristics are as follows: it is a reliable and valid measure in multiple populations; its reliability is shown in the table; it is appropriate for the general population and in patients with the burden of disease, which also make it responsive; it is a precise tool in assessing the quality of life; scores can be easily interpreted and are precise in the display of results; it is less acceptable for the general population because it is too long; and it can be a burden for researchers since the length of the questionnaire can lead to possible difficulties with data collection.

Conclusion

Even though many different instruments for measuring HRQoL are available, none is perfect as they are only tools best suited to a particular condition.

The choice of instrument depends on the reason for measurement, the primary concepts of interest, and the purpose of the study.

All instruments that are shown have strong reliability and are valid instruments that are appropriate for the general population and patients with the burden of disease. Most of them have around 30 items to evaluate and require little time for data collection, their scores can be easily interpreted, and they are precise in the display of results. However, the final choice of instrument depends on the researcher and the aim of the study.

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INSTRUMENTI KOJI SE PRIMJENJUJU U PROCJENI KVALITETE ŽIVOTA POVEZANE SA ZDRAVLJEM

Sažetak

Uvod. Kvaliteta života povezana sa zdravljem i dobrobit primjenjuju se u kliničkoj praksi za mjerenje učinka kroničnih bolesti, liječenja te kratkoročnih i dugotrajnih invaliditeta na kvalitetu života. Trenutačno postoji više od 1000 instrumenata dizajniranih posebno za mjerenje kvalitete života. Dok su neki dizajnirani za procjenu bilo koje bolesti, drugi su dizajnirani za određene medicinske dijagnoze.

Cilj. Utvrditi karakteristike instrumenata koji se primjenjuju za procjenu kvalitete života povezane sa zdravljem.

Metode. Učinjen je pregled znanstvenih radova kako bi se utvrdile karakteristike najčešće korištenih alata za procjenu kvalitete života povezane sa zdravljem.

Rezultati. Upitnici prikazani u preglednom radu imaju veliku pouzdanost, upotrebljavaju skalu za odgovore Likertova tipa, sastoje se od otprilike 30 čestica i većina holistički pristupa ciljanoj skupini procjenjujući fizičku domenu, psihološku domenu, društvenu domenu i okolišnu domenu kroz brojna pitanja. Kriteriji za odabir alata i prosuđivanje prikladnosti mjera uključuju sljedeće: prikladnost, pouzdanost, valjanost, prilagodljivost, preciznost, mogućnost interpretacije, prihvatljivost te izvedivost.

Zaključak. Iako je dostupno mnogo različitih instrumenata za procjenu kvalitete života povezane sa zdravljem, nijedan od njih nije savršen jer su to samo alati koji najbolje odgovaraju određenom stanju. Izbor instrumenta ovisi o razlogu mjerenja, primarnom interesu i svrsi istraživanja.

Ključne riječi: instrumenti, kvaliteta života povezana sa zdravljem, karakteristika instrumenta