

Introducing the WHOQOL instruments

The Constitution of the World Health Organization (WHO) defines health as "A state of complete physical, mental, and social well-being not merely the absence of disease . . .". It follows that the measurement of health and the effects of health care must include not only an indication of changes in the frequency and severity of diseases but also an estimation of well being and this can be assessed by measuring the improvement in the quality of life related to health care. Although there are generally satisfactory ways of measuring the frequency and severity of diseases this is not the case in so far as the measurement of well being and quality of life are concerned. WHO, with the aid of 15 collaborating centres around the world, has therefore developed two instruments for measuring quality of life (the WHOQOL-100 and the WHOQOL-BREF), that can be used in a variety of cultural settings whilst allowing the results from different populations and countries to be compared. These instruments have many uses, including use in medical practice, research, audit, and in policy making.

WHO defines Quality of Life as an individual's perception 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. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.

Strengths of the WHOQOL instruments

The WHOQOL instruments were developed cross-culturally

The WHOQOL-100 was developed simultaneously in 15 field centres around the world. The important aspects of quality of life and ways of asking about quality of life were drafted on the basis of statements made by patients with a range of diseases, by well people and by health professionals in a variety of cultures. The instrument was rigorously tested to assess its validity and reliability in each of the field centres and is currently being tested to assess responsiveness to change. The WHOQOL-BREF, an abbreviated 26 item version of the WHOQOL-100, was developed using data from the field-trial version of the WHOQOL-100. The WHOQOL instruments can be used in particular cultural settings, but at the same time results are comparable across cultures. The WHOQOL is now available in over 20 different languages and its development in further languages is progressing.

The WHOQOL instruments place primary importance on the perception of the individual

Most assessments in medicine are obtained by examinations by health workers and laboratory tests. The WHOQOL instruments, by focusing on individuals' own views of their well being, provide a new perspective on disease. For example, that diabetes involves poor body regulation of blood glucose is well understood, but the effect of the illness on the perception that individuals have of their social relationships, working capacity, and financial status has received little systematic attention. The WHOQOL instruments are tools that will enable this type of research to be carried out. They not only inquire about the functioning of people with diabetes, across a range of areas but also how satisfied the patients are with their functioning and with effects of treatment.

Systematic development of the WHOQOL-100

The method used to develop the WHOQOL-100 involved considerable research and checking over several years to ensure that it accurately measures the issues that are important to a person's quality of life, and that it does so reliably. The institutions which participated in this research now serve as reference centres and can provide technical support to users in their cultural setting (see later section for contact information). In return for this support, centres request a copy of data collected to be sent to them.

The Instruments have different forms for different uses

The core WHOQOL instruments can assess quality of life in a variety of situations and population groups. In addition, modules are being developed to allow more detailed assessments of specific populations (e.g. cancer patients, refugees, the elderly and those with certain diseases, such as HIV/AIDS).

Administration of the WHOQOL instruments

The national versions of the WHOQOL

The WHOQOL instruments are available in over 20 different languages. The appropriate language version, and permission for using it, can be obtained from the appropriate national centre, as listed on pages 7-8. Centres may request a copy of data collected for collation in a national data set. A methodology has been developed for new centres wishing to develop further language versions of the WHOQOL-100 or the WHOQOL-BREF. This information can be obtained from The WHOQOL Group, Programme on Mental Health, World Health Organisation, CH-1211, Geneva 27, Switzerland. The WHOQOL-BREF is self-administered if respondents have sufficient ability: otherwise, interviewer-assisted or interview-administered forms should be used.

Scoring the WHOQOL instruments

The WHOQOL-100 produces scores relating to particular facets of quality of life (e.g. positive feelings, social support, financial resources), scores relating to larger domains (e.g. physical, psychological, social relationships) and a score relating to overall quality of life and general health. The WHOQOL-BREF produces domain scores, but not individual facet scores. Details on scoring are included in manuals available from The WHOQOL Group, Programme on Mental Health, World Health Organisation, CH-1211 Geneva 27, Switzerland. Syntax files for checking and cleaning data, and for computing facet and domain scores are also available from The WHOQOL Group.

Psychometric properties of the WHOQOL instruments

Both the WHOQOL-100 and the WHOQOL-BREF have been shown to display good discriminant validity, content validity and test-retest reliability. Their sensitivity to change is currently being assessed. Domain scores produced by the WHOQOL-BREF have been shown to correlate at around 0.9 with The WHOQOL-100 domain scores.

The Uses of the WHOQOL instruments

In medical practice

In clinical practice the WHOQOL instruments may be used with other forms of assessment, giving valuable information that can indicate areas in which a person is most affected and help the practitioner in making the best choices in patient care. In addition they may be used to measure change in quality of life over the course of treatment.

Improving the doctor-patient relationship

By increasing the physician's understanding of how disease affects a patient's quality of life, the interaction between patient and doctor will change and improve. This gives more meaning and fulfilment to the work of the doctor and leads to the patient being provided with more comprehensive health care. Because a more complete form of assessment covering different aspects of patients' functioning is being carried out, patients themselves may find their health care more meaningful.

In assessing the effectiveness and relative merits of different treatments

The WHOQOL instruments can form a part of the evaluation of treatments. For example, chemotherapy for cancer may prolong a person's life, but may only do so at considerable cost to their quality of life. By using the WHOQOL instruments to look at changes in the person's well being over the course of treatment, a much fuller picture can be gained.

In health services evaluation

In the periodic review of the completeness and quality of medical services, the patients' concerns are of importance. The instruments provide an invaluable supplementary appraisal of health care services, by yielding a measure of the relationship between the health care service and patients' quality of life, and also by directly presenting a measure of patients' perception of the quality and availability of health care.

In research

The WHOQOL instruments provide new insights into the nature of disease by assessing how disease impairs or impacts the subjective well being of a person across a whole range of areas.

In policy making

When health providers implement new policies it is important that the effect of policy changes on the quality of life of people in contact with health services is evaluated. The WHOQOL instruments allow such monitoring of policy changes.

The Structure of the WHOQOL-100

The structure of the WHOQOL-100 reflects the issues that a group of scientific experts as well as lay people in each of the field centres felt were important to quality of life. The six broad domains of quality of life, and the twenty-four facets covered are shown below. Four items are included for each facet, as well as four general items covering subjective overall QOL and health, producing a total of 100 items in the assessment. All items are rated on a five point scale (1-5).

| Domain | Facets incorporated within domains |
|--------------------------|--|
| | <ul style="list-style-type: none">• Overall Quality of Life and General Health |
| 1. Physical Health | <ul style="list-style-type: none">• Energy and fatigue• Pain and discomfort• Sleep and rest |
| 2. Psychological | <ul style="list-style-type: none">• Bodily image and appearance• Negative feelings• Positive feelings• Self-esteem• Thinking, learning, memory and concentration |
| 3. Level of Independence | <ul style="list-style-type: none">• Mobility• Activities of daily living• Dependence on medicinal substances and medical aids• Work capacity |

| | |
|---|--|
| 4. Social Relations | <ul style="list-style-type: none">• Personal relationships• Social support• Sexual activity |
| 5. Environment | <ul style="list-style-type: none">• Financial resources• Freedom, physical safety and security• Health and social care: accessibility and quality• Home environment• Opportunities for acquiring new information and skills• Participation in and opportunities for recreation/leisure• Physical environment (pollution/noise/traffic/climate)• Transport |
| 6. Spirituality/Religion/Personal beliefs | <ul style="list-style-type: none">• Religion/Spirituality/Personal beliefs (Single facet) |

Structure of the WHOQOL-BREF

The WHOQOL-BREF contains two items from the Overall Quality of Life and General Health, and one item from each of the 24 facets included in The WHOQOL-100. Recent analysis of The WHOQOL-100 structure has suggested the possibility of merging domains 1 and 3, and also merging domains 2 and 6, thereby creating four domains of quality of life. In our current approach to scoring the WHOQOL-BREF, these domains have been merged therefore and four major domains are assessed: physical, psychological, social relationships and environment. The WHOQOL-BREF is currently being field tested.

The Development of the WHOQOL Instruments

| Stage | Method | Products | Objectives |
|---------------------------------------|---|--|--|
| Concept clarification | International expert review. | Quality of life definition. Study protocol. | Establishing an agreed upon definition of quality of life and an approach to international quality of life assessment. |
| Qualitative pilot | Expert review. Focus groups. | Definitions of domains and facets. Global item pool. | Exploration of the quality of life concept across cultures. Item generation. |
| Development pilot | Administration of WHOQOL Pilot Form in 15 field centres to 250 patients and 50 "healthy" respondents. | 300 item standardised questionnaire. | Refine the WHOQOL structure. Reduce the global question pool. |
| Field test of the WHOQOL-100 | Series of smaller scale studies involving clear and homogeneous populations, longitudinal design and parallel use of other national / international QOL measures. | Common 100 item pool. Standardised and cross-nationally equivalent response scales. | To further establish the psychometric properties of the WHOQOL. |
| Development of the WHOQOL-BREF | Analysis of data from the WHOQOL-100. | Abbreviated 26 item assessment | Develop a brief version of the WHOQOL-100 for use in large studies, audit and clinical work, where use of a longer questionnaire is not practicable. |

Future Developments

A number of WHOQOL centres have begun to develop additional modules to The WHOQOL which will provide greater detail on particular aspects of the quality of life of those, for instance, with certain diseases. Some studies have led to the development of national items to supplement the core WHOQOL. These reflect special aspects of quality of life not included in the core because they are not universally valued. A scoring system is being developed which will permit these national items or modules to be included in national data analyses.

WHOQOL-Old

The WHOQOL-Old is in validation phase concurrently in the following sites:

| | |
|-------------------------------------|-------------------|
| Edinburgh, UK (Coordinating Center) | Seattle, USA |
| Bath, UK | Be'er Sheva, ISR |
| Leipzig, GER | Tokyo, JAP |
| Barcelona, SPA | Umea, SWE |
| Copenhagen, DEN | Guangzhou, CHI |
| Paris, FRA | Hong Kong, CHI |
| Prague, CZE | Porto Alegre, BRA |
| Budapest, HUN | Montevideo, URU |
| Oslo, NOR | Izmir, TUR |
| Victoria, CAN | Switzerland |
| Melbourne, AUS | Vilnius, LITH |

It has gone through a pilot test resulting with a module containing 33 items asking for thoughts and feelings about certain aspects of quality of life and addressing issues that came from qualitative work showing them to be important to older adults. It is now being field tested in all centers listed above. It is a module intended to be given alongside either the WHOQOL-100 or the BREF (it tested well with both of them in the preliminary analyses). There is also an "Attitudes to Ageing" measure being developed and validated. It currently consists of 38 items describing how elderly people feel about growing older.