

DRAFT

DEPARTMENT OF MENTAL HEALTH

WHOQOL

Annotated Bibliography

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DEPARTMENT OF MENTAL HEALTH

Annotated Bibliography of the WHO Quality of Life Assessment Instrument - WHOQOL

This document was created to help users of the WHOQOL identify various studies in which the WHOQOL-100 and the WHOQOL-BREF have been used. It contains references to articles published on the formulation of the instrument, its psychometric properties, its construction in specific languages, as well as articles published on studies conducted on specific populations. This annotated bibliography also outlines studies that are currently underway and future research and areas of interest involving the WHOQOL instrument.



DEPARTMENT OF MENTAL HEALTH
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If you wish to make corrections to the annotations, update them or include new submissions please send the information to:

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The views expressed herein by named authors are solely the responsibility of those authors.

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INTRODUCTION

Quality of Life has been defined by the World Health Organization 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 incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment.

This definition reflects the view that quality of life refers to a subjective evaluation, which is embedded in a cultural, social and environmental context. As such, quality of life cannot be simply equated with the terms "health status", "life style", "life satisfaction", "mental state", or "well-being". Rather, it is a multidimensional concept incorporating the individual's perception of these and other aspects of life.

The instrument is organized into six broad domains of quality of life. These are: physical domain; psychological domain; levels of independence; social relationships; environment; and spiritual domain. Within each domain a series of sub-domains (facets) of quality of life summarize that particular domain of quality of life. The WHOQOL's overall coverage of quality of life ensures a conceptual coherence, missing from many other measures of health status.

WHO's initiative to develop a quality of life assessment arises from a need for a genuinely international measure of quality of life, and restates its commitment to the continued promotion of an holistic approach to health and health care. Centres from several different countries were involved in operationalizing the instrument's domains of quality of life, question writing, question selection, response scale derivation and pilot testing. With this approach, standardization, equivalence between settings and translation issues were at the forefront of the development process.

The WHOQOL development process was made up of several stages. In the first stage, concept clarification involved establishing an agreed upon definition of quality of life and an approach to international quality of life assessment. In the second, a qualitative pilot involved the exploration of the quality of life construct across cultures and the writing of questions. In the third, the development pilot involved the administration of a standardised form in 15 culturally diverse field centres for scale construction. In the fourth stage, field testing involved establishing further psychometric properties of the WHOQOL.

It is anticipated that the WHOQOL will be used in broad-ranging ways, such as use in clinical trials, epidemiological research, clinical practice, health policy research and health and social service audits. The WHOQOL project is part of a larger goal towards "Health for All", and the promotion of physical, psychological and social well-being.

The purpose of this annotated bibliography is to provide a preliminary record of uses of the WHOQOL globally. Such a document will allow researchers to learn about the development of this instrument and studies using the WHOQOL. This annotated bibliography may also determine areas of research that are currently under explored. It is hoped that this first WHOQOL Annotated Bibliography will serve as a useful tool for those people who are interested in utilizing the WHOQOL to enhance the knowledge base of Quality of Life research globally.

General articles relating to Quality of Life issues are not included in this document. One can refer to "Quality of Life Assessment: An Annotated Bibliography" [WHO/MNH/PSF/94.1] for an overview of

quality of life publications and generic measures. World Health Organization internal documents are included in this Annotated Bibliography.

There are several points of qualification about this document. It should be noted that variations in the format and detail of this annotated bibliography reflect individual responses from WHOQOL Centres. In addition, unless otherwise stated, the language of the publication is English. Finally, this bibliography is a working document amenable to changes and additions as more research with the WHOQOL continues to progress.

This annotated bibliography is divided into five parts. Section A of the bibliography is concerned with articles about the formulation of the WHOQOL-100 and WHOQOL-BREF. Section B documents the completed articles that are general in nature about the WHOQOL. Specific language and population articles that include use of the WHOQOL are described in Section C. Research currently underway using the WHOQOL-100 or WHOQOL-BREF is included in Section D. Finally, Section E details many future projects involving the WHOQOL of various WHOQOL Centres.

You are invited to add to this bibliography any research you have completed, are undertaking or planning to do. To do this please send an annotated abstract to:

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The only articles which are available from WHO are numbered, WHO documents. All others can be obtained through the relevant journals or publishing houses. A list of WHOQOL centres including the names of some of the authors of articles listed here are presented in the annex.

A special thanks is due to those who have submitted entries and to Ms Pamela Cameron, of the University of Calgary in Canada, who compiled this edition.

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SECTION A: COMPLETED WHOQOL-100 AND WHOQOL-BREF ARTICLES ABOUT FORMULATION OF INSTRUMENT

The following annotations have been included in this bibliography because they outline the steps taken to develop the instrument, or discuss the inclusive elements of the WHOQOL-100 and the WHOQOL-BREF.

WHOQOL Group. The World Health Organization quality of life assessment (WHOQOL): Development and general psychometric properties. *Social Science and Medicine* 1998 ; 46(12) : 1569-1585.

This paper reports on the field testing, empirical derivation and psychometric properties of the World Health Organization Quality of Life assessment (the WHOQOL). The steps are presented from the development of the initial pilot version of the instrument to the field trial version, the so-called WHOQOL-100. The instrument has been developed collaboratively in a number of centres in diverse cultural settings over several years; the data are presented on the performance of the instrument in 15 different settings worldwide.

Key Words: development, psychometric properties, cross-cultural, quality of life.

WHOQOL Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine* 1998 ; 28 : 551-558.

The paper reports on the development of the WHOQOL-BREF, a 16 item short form version of the WHOQOL-100 quality of life assessment. Domain scores produced by the WHOQOL-BREF correlate highly with WHOQOL-100 scores. WHOQOL-BREF domain scores demonstrated good discriminant validity, content validity, internal consistency and test-retest reliability. These data suggest that the WHOQOL-BREF provides a valid and reliable alternative to the assessment of domain profiles using the WHOQOL-100.

Key Words: quality of life, brief assessment, development.

Szabo, S., Orley, J. & Saxena, S. (on behalf of the WHOQOL Group). An approach to response scale development for cross-cultural questionnaires. *European Psychologist* 1997 ; 2(3) : 270-276.

The objective of this article is to outline the WHOQOL response scale development. The instrument was developed simultaneously within a number of field centres in diverse cultural settings. The obtained results indicate that the derivation of response scale descriptors, separately in each culture, is a possible and necessary step in the process of cross-cultural adaptation of questionnaires.

Key words: response scale, cross-cultural, quality of life.

WHOQOL Group. What Quality of life? World Health Organization Quality of Life Assessment. *World Health Forum* 1996 ; 17(4) : 354-6.

[WHO Quality of Life Assessment Group. *Quelle Qualite de vie? Groupe OMS Qualite de Vie. Forum mondial de la Sante* 1996 ; 17(4) : 384-386. Language: French.]

[WHO Quality of Life Assessment Group. *Que calidad de vida? Grupo de la OMS sobre la calidad de vida. Foro mundial de la salud* 1996 ; 17(4) : 385-387. Language: Spanish.]

This article, in three languages, outlines the development of a questionnaire for assessing the subjective quality of life in health care settings, and explains the relevance of this instrument to treatment decisions, research and the training of health care professionals.

Key Words: quality of life, questionnaires, decision making methods.

WHOQOL Group. The World Health Organization Quality of Life Assessment (WHOQOL): position paper from the World Health Organization. *Social Science and Medicine* 1995 ; 41(10) : 1403-9.

This paper describes the World Health Organization's project to develop a quality of life instrument (the WHOQOL). It outlines the reasons that the project was undertaken, the method that has been followed in its development and the current status of the project. It has been developed collaboratively in several culturally diverse centres over four years. Piloting of the WHOQOL on some 4500 respondents in 15 cultural settings has been completed.

Key words: quality of life, questionnaires, World Health Organization, culture, pilot projects.

WHOQOL Group. La Qualità della Vita e la sua misura: la prospettiva del WHOQOL. *Psicoterapia Cognitiva e Comportamentale* 1995 ; 1(3) : 5-12. Language: Italian.

This paper briefly describes the World Health Organization's approach to quality of life measurement in the context of the WHOQOL project. The subjective nature of quality of life and the multidimensional approach to its assessment is emphasised. The methodology used in this project is described including the strategy of simultaneous development in a number of diverse cultures and languages, inputs from researchers, clinicians and the subjects themselves and the pilot field trial leading to the 24-facet, 100-item version (WHOQOL-100).

Key Words: quality of life, Methodology, WHO.

WHOQOL Group. Development of the WHOQOL: Rationale and current status. *International Journal of Mental Health* 1994 ; 23(3) : 24-56.

The availability of an international quality of life assessment such as the WHOQOL will make it possible to carry out relevant research in a number of national centres and to compare the results obtained in different parts of the world. At the national/regional level it is anticipated that the WHOQOL will have multiple applications in research, clinical practice, audit and health policy planning, and evaluation. This paper describes the process of the WHOQOL's development. To date a pilot form of the measure has been developed and administered in numerous centres around the world.

Key Words: quality of life, development, pilot instrument.

WHOQOL Group. Study protocol for the World Health Organization project to develop a quality of life instrument (WHOQOL). *Quality of Life Research* 1993 ; 2(2) : 153-159.

The World Health Organization (WHO) has undertaken a project to develop an instrument (the WHOQOL) for measuring quality of life. The instrument will be developed in the framework of a collaborative project involving numerous centres in different cultural settings. This paper outlines the characteristics of the planned instrument and the study protocol governing work on its development.

Key Words: WHO, questionnaires, psychometrics.

World Health Organization. Quality of life can be measured. *World Health Forum* 1989 ; 10 (3/4) : 483-484.

The WHO Division of Mental Health is working to develop quantitative methods to measure health-related quality of life as a means of evaluating the full impact of new health care procedures on individuals and communities. Actual use of the quality of life approach will generate additional rules of thumb, or will at least provide a more comprehensive set of choices from which to make a qualitative judgement.

Key Words: quality of life, development, biopsychosocial.

SECTION B: COMPLETED WHOQOL-100 AND WHOQOL-BREF GENERAL ARTICLES

The following references are completed WHOQOL-100 and WHOQOL-BREF articles which are general in scope. Included are references from books, journals and WHO publications, which document the utilization of the WHOQOL. Each reference has been included because it makes specific reference to the WHOQOL-100 or WHOQOL-BREF.

Herdman, M., Fox-Rushby, J & Badia, X. 'Equivalence' and the translation and adaptation of health-related quality of life questionnaires. *Quality of Life Research* 1997; 6:237-247.

The increasing use of health-related quality of life (HRQOL) questionnaires in multinational studies has resulted in the translation of many existing measures. Guidelines for translation have been published, and there has been some discussion of how to achieve and assess equivalence between source and target questionnaires. The approach of the WHOQOL at cultural equivalence is noted.

Key Words: Cross-cultural equivalence, health-related quality of life, questionnaires.

Lucas, R. Desarrollo del instrumento WHOQOL. Qualitat de vida en psiquiatria. *Malalt, familia I equip assistencial*. Ed. Institut Pere Mata, 1996. Language: Spanish.

Abstract: not available.

Key Words: quality of life.

Szabo, S (on behalf of the WHOQOL Group). World Health Organization assessment instrument. In: Spilker, B. [Ed]. *Quality of life and pharmacoconomics in clinical trials*. 2nd ed. Philadelphia : Lippincott-Raven, 1996. P.355-362.

The World Health Organization Quality of Life (WHOQOL) assessment instrument inquires into the respondent's perception and subjective evaluation of various aspects of his/her life. The instrument is being developed within a cross-cultural multi centre project. This article introduces the conceptualization and operation of quality of life for the WHOQOL. Question generation, response scale generation, pilot testing and establishing psychometric properties for the WHOQOL, and further work on the WHOQOL are also discussed.

Key Words: quality of life, health policy, outcome and process assessment.

Bowling, A. *Measuring disease: a review of disease-specific quality of life measurement scales.* Buckingham : Open University Press, 1995. 374 pages.

This book is intended to supplement the author's previous work *Measuring Health: A Review of Quality of Life Measurement Scales*. This book reviews disease specific measures of quality of life and, where appropriate, pertinent symptom and single domain scales which are still sometimes used to supplement them. It is intended as a source book for health services researchers, health care professionals, and others who are involved in the measurement of outcome of therapies in relation to broader health status and quality of life.

Key Words: quality of life, health status indicators, disease specific measures.

De Girolamo, G., De Leo, D. & Galassi, L. *Il progetto OMS sulla valutazione della qualità della vita. Clinimetria, Bologna : Patron, 1995. 25-35. Language: Italian.*

The WHOQOL instrument has been developed cross-culturally in 15 field centres all over the world, following different stages: concept clarification, qualitative pilot, development pilot, field test of the WHOQOL-100. The WHOQOL may be used in different settings: in medical practice, in the attempt to improve the doctor-patient relationship, in assessing the effectiveness and relative merits of different treatments, in health services evaluation, in research and in policy making.

Key Words: WHOQOL, quality of life, use of instrument.

De Girolamo, G., De Leo, D. & Galassi, L. *Il progetto OMS sulla valutazione della qualità della vita. Bollettino OMS di Salute Mentale e Neuroscienze 1994 ; 2(8-9). Language: Italian.*

Abstract: not available.

Kuyken, W., Orley, J., Hudelson, P. and Sartorius, N. *Quality of life assessment across cultures. International Journal of Mental Health 1994 ; 23(2) : 5-27.*

This paper examines cultural aspects of the health-related quality of life construct and discusses the current approaches to cross-cultural quality of life assessment. At least four different approaches have been used to develop quality of life assessments with a cross-cultural context. These approaches are critically examined in the light of cultural factors; and methods for establishing conceptual, semantic, technical, and psychometric equivalence of QOL assessment tools are suggested.

Key Words: quality of life, assessment, cross-cultural context.

Orley, J. & Kuyken, W. [Eds]. *Quality of Life Assessment: International Perspectives.* Heidelberg : Springer-Verlag, 1994.

Contributions from a number of the investigators and advisers involved in the development of a WHO quality of life assessment instrument have been brought together in this book. The chapters focus in particular on some of the issues that have been taken into account when we wish to compare the measures obtained in one country or culture with those obtained in another. General topics are dealt with as are more specific issues having to do with a particular disease such as cancer or with specific groups of people.

Key Words: quality of life instrument, culture, disease.

De Girolamo, G. Il progetto OMS sulla qualità della vita: una breve overview. *Rivista di Riabilitazione Psichiatrica e Psicosociale* 1993 ; 2(3). Language: Italian.

WHO has undertaken a project to develop an instrument (the WHOQOL) for measuring quality of life, that can be used in a variety of cultural settings. This instrument will have many uses, including use in medical practice, research, audit, and in policy making, and it will allow a better understanding of the complex variables which affect the course and outcome of various pathological conditions, and different therapeutic and care interventions. This instrument is likely to become an essential tool in psychiatric rehabilitation. This paper describes the characteristics and the use of the WHOQOL.

Key Words: Quality of life, Questionnaire, Mental and physical disease.

Sartorius, N. A WHO method for the assessment of health-related quality of life (WHOQOL). In, Walker, S.R. & Rosser, R.M. [Eds]. *Quality of Life Assessment: Key Issues in the 1990s*. Dordrecht : Kluwer Academic Publishers 1993 : 201-207.

This book reviews current methodology for assessing patients' quality of life, and shows how this methodology can be applied to specific diseases such as cancer, rheumatoid arthritis, angina and Parkinson's disease. This book contains reviews of the quality of life philosophy, concepts and key instruments, together with an update on assessing quality of life in a number of major disease areas. Included is a chapter about the WHO method for the assessment of health-related quality of life (WHOQOL).

Key Words: quality of life, methodology, instruments.

Rajkumar, S. & Kumar, S. *Quality of Life in Health: A Modern Concern*.

This book is a compilation of papers on the subject of Quality of Life in Health, and is based largely on work done in India. The book essentially aims at giving the reader a wide angle perspective of the concept of Quality of Life in Health, apart from outlining basic methodological issues inherent in the study of such a polymorphous concept. This book contains a detailed chapter that describes the project to develop the WHOQOL.

Key Words: quality of life, chronic illnesses, assessment instruments.

SECTION C: COMPLETED WHOQOL-100 AND WHOQOL-BREF SPECIFIC LANGUAGE AND POPULATION ARTICLES

This section of the Annotated Bibliography includes research projects related to language and population specific studies using the WHOQOL-100 or WHOQOL-BREF. This research illustrates the cross-cultural applicability of this assessment tool.

Saxena, S., Chandiramani, K. And Bhargava R. WHOQOL-Hindi: A questionnaire for assessing quality of life in health care settings in India. *The National Medical Journal of India* 1998; 11(4).

Quality of life is becoming an important component of overall assessment in health care settings. However, satisfactory instruments are not available for use in India. Qualitative and quantitative work was conducted at the Delhi centre as a part of the WHOQOL (World Health Organization Quality of Life) project at 15 centres in developing and developed countries to construct a new quality of life instrument (WHOQOL). The pilot field trial at Delhi was conducted on 304 adult subjects using the 236-item questionnaire. Based on the pilot field trial data, item reduction could be done to develop a 100-item version (WHOQOL-100, Hindi). The items are distributed into 4 domains (physical; psychological, social and environmental health) and 25 facets. Each facet has four items, rated on a five-point scale. The initial psychometric properties of this instrument are satisfactory. A 26-item short version has also been developed (WHOQOL-BREF, Hindi). The WHOQOL-100 Hindi appears to be a suitable instrument for comprehensively assessing quality of life in health care settings. WHOQOL-BREF Hindi can be used for intervention studies including drug trials.

Darikarnon, S. Quality of life and suicide ideation in people living with AIDS. *Journal of Mental Health* 1998; 5(3). Language: Thai.

The objectives of this study were to survey quality of life (QOL) and factors influencing QOL and suicidal ideation in people living with AIDS. For quality of life, 75.7% have moderate QOL and 12.8% have good QOL. Factors negatively influencing quality of life were marital status (divorced), financial status (inadequate income), and family size (more family members). Those who scored lower in the physical and psychological domains of the WHOQOL had more suicidal ideation.

Key Words: WHOQOL-BREF-THAI, suicide ideation, quality of life.

Lucas, R. (1998). Version espaqola del WHOQOL. Version espaqola del WHOQOL. Ed. Ergon. Language: Spanish.

Abstract: not available.

Key Words: Quality of life, WHOQOL.

Mahatnirunkul, S. et al. Comparison of the WHOQOL-100 and the WHOQOL-BREF. *Journal of Mental Health of Thailand* 1998 ; 5(3). Language: Thai.

The purpose of this study was to compare the properties of the WHOQOL-BREF with the WHOQOL-100. An expert panel was used to review the content and suitability of the language in the WHOQOL-BREF. Also, comprehensibility testing with people from different backgrounds was done. The final version of the WHOQOL-BREF was then tested against the WHOQOL-100. The WHOQOL-BREF-THAI version was concluded to be a shorter and more convenient to use in the community. The language used was modified from the WHOQOL-100, for better comprehensibility.

Key Words: quality of life, WHOQOL-100, WHOQOL-BREF.

Orley, J., Saxena, S. & Herrman, H. Quality of life and mental illness. Reflections from the perspective of the WHOQOL. *British Journal of Psychiatry* 1998 ; 172 : 291-293.

This article discusses quality of life for individuals with mental illness. Quality of life as an aspect of mental state, the subjectivity of quality of life, and the utilisation of generic versus disease-specific instruments are discussed. The authors conclude by noting the importance of quality of life assessments for people with mental illness.

Key Words: quality of life, mental illness, assessment instruments.

Pibernik-Okanovic, M., Szabo, S. & Metelko, Z. Quality of life following change in diabetes therapy. *Pharmacoeconomics* 1998 ; 14(2).

The study objective was to evaluate and compare quality of life (QOL) parameters between patients with type 2 diabetes mellitus who changed therapy from an oral hypoglycemic agent (OHA) to insulin therapy and those who remained on an OHA. The WHOQOL was used to assess quality of life among 2 groups of patients with type 2 diabetes at baseline and after a 2-month follow-up period. After the follow-up period, overall quality of life and level of independence remained higher for group 2. Results indicate that introducing insulin therapy in patients with type 2 diabetes might positively affect their quality of life.

Key Words: Type 2 diabetes, change of therapy, quality of life.

Skevington S. Investigating the relationship between pain and discomfort and quality of life, using the WHOQOL. *Pain* 1998 ; 76 : 395 - 406.

The aim of this study was to examine the impact of pain on quality of life and its components in a representative sample of 320 well people, and patients selected from all major categories of illness. Quality of life was assessed using a new, multidimensional, multilingual, generic profile designed for cross-cultural use in health care - the WHOQOL. It was found that pain and discomfort made a significant impact on perceptions of general quality of life related to health.

Key Words: pain, WHOQOL, psychometric properties.

Tazaki, M., Nakane, Y., Endo, T., Kakikawa, F., Kano, K., Kawano, H., Kuriyama, K., Kuroko, K., Miyaoka, E., Ohta, H., Okamoto, N., Shiratori, S., Takamiya, S., Tanemura, K. & Tsuchiya, R. Results of a Qualitative and Field Study Using the WHOQOL Instrument for Cancer Patients. *Japanese Journal of Clinical Oncology* 1998 ; 28(2) : 134-41. Language: English.

The main purpose of the study was to evaluate quality of life (QOL) among cancer patients using the WHOQOL-100 instrument and to see if any significant differences were seen in cancer stages, treatment status and prognosis. This study consisted of two parts; qualitative and quantitative. The results indicated that the WHOQOL core instrument was sensitive enough to evaluate the QOL of cancer patients.

Key Words: focus groups, psychology, quality of life.

Bonomi, A.E., Patrick, D.L., Bushnell, D.M. & Martin, M. Validation of the United States' version of the World Health Organization Quality of Life Instrument. Accepted for publication, *Journal of Clinical Epidemiology*.

Bonomi, A.E., Patrick, D.L., Bushnell, D.M. & Martin, D. Quality of life of women and their partner before and after childbirth: Further testing of the World Health Organization Quality of Life instrument. In preparation for *Social Science and Medicine*.

Bonicatto S, Soria J.J, & Seguezzo M. WHOQOL-BREF: Some Psychometric Considerations of the Argentine Version. Presented as a poster in the *Fourth Annual Conference of the ISOQOL*, November 4-9, 1997, Vienna, Austria.

The objective was to analyse some psychometric properties of the WHOQOL-BREF, and compare these with the WHOQOL-100 item version, when they are consecutively administered to a sample of cancer patients in Argentina. Conclusion: the WHOQOL-BREF shows high levels of reliability and item domain correlation. The domain scores were strongly correlated with those obtained for the WHOQOL-100, so we think that the short version is a good and rapid alternative to assess the domain profiles of the WHOQOL-100.

Key Words: Argentina, cross cultural, psychometrics.

Butorin, N., Mihailova, J. & Petkov, V. Preliminary pilot study data from the cultural adaptation of WHOQOL-100. Report at the Annual Conference of the Bulgarian Psychiatric Association, September 26-28, 1997, Sofia. Language: English.

This report documents the comparison of the QOL of well persons, and psychiatric, oncological, and somatic patients. Well persons had significantly higher scores. Psychiatric patients had the lowest scores which were significantly lower for Personal Relationships, Social Support and Home Environment. All groups showed the lowest scores in "Financial Resources", "Physical Safety and Security" and "Physical Environment". Presumably, this results from the economic crisis which affects basic human necessities of all studied groups.

Key Words: Pilot study, adaptation, psychiatric patients.

De Girolamo, G. & Mangelli, L. (1997). Malattia, stress e qualità della vita: il progetto dell'Organizzazione Mondiale della Sanità. *Doctoral Dissertation*. Language: Italian.

Abstract: not available.

De Vries, J., Drent, M., Wirnsberger, R.M., Wouters, E.F.M. & Van Heck, G.L. Quality of life in a Dutch population of sarcoidosis patients. *Quality of Life Research* 1997 ; 6(7/8) : 637-638.

Abstract from 4th Annual Conference of the International Society for Quality of Life Research (ISOQOL).

De Vries, J., Drent, M., Wirnsberger, R.M., Wouters, E.F.M., & Van Heck, G.L. Quality of life in a Dutch population of patients suffering from sarcoidosis. *Sarcoidosis* 1997 ; 14 (Suppl. 1) : 44.

Abstract from conference.

De Vries, J., Drent, M., Wirnsberger, R.M., Wouters, E.F.M. & Van Heck, G.L. Quality of life in sarcoidosis: A random sample versus members of the Dutch Sarcoidosis Society. *Sarcoidosis* 1997 ; 14 (Suppl. 1) : 12.

Abstract from conference.

De Vries, J., Drent, M., Wirnsberger, R.M., Wouters, E.F.M. & Van Heck, G.L. The influence of gender on the quality of life in sarcoidosis patients. *Quality of Life Research* 1997 ; 6(7/8) : 637.

Abstract from 4th Annual Conference of the International Society for Quality of Life Research (ISOQOL).

De Vries, J. & Van Heck, G.L. The World Health Organization Quality of Life assessment instrument (WHOQOL-100): Validation study with the Dutch version. *European Journal of Psychological Assessment* 1997 ; 13(3) : 164-178.

This article discusses the reliability and validity of the WHOQOL-100. Two-hundred-and-twenty persons, 147 healthy individuals, and 73 chronic fatigue syndrome (CFS) patients completed the WHOQOL-100 and a test battery of related measures. The WHOQOL-100 has a fairly good internal consistency and a good reliability.

Key words: quality of life, psychometrics, assessment.

Drent, M., Wirnsberger, R.M., De Vries, J., Wouters, E.F.M. Symptoms of patients suffering from sarcoidosis. An epidemiological study. *Sarcoidosis* 1997 ; 14 (Suppl. 1) : 44.

Abstract from conference.

Lucas, R., Salcedo, A., Susin, C., Roca, B., Zimmer, M., Jorda, E., Guillen, A., Garrido, I. & Puche, J. Calidad de vida en pacientes esquizofrénicos y en parientes de esquizofrénicos. *Revista de Psiquiatría de la Facultad de Medicina de Barcelona* 1997 ; 24 (6) : 143-155. Language: Spanish.

Abstract: not available.

Key Words: Quality of life, esquizofrenics, caregiver.

Mombers, F.M.C., De Vries, J., & Van Heck, G.L. Quality of life of healthy persons and patients with a chronic disease: A study with the Dutch WHOQOL-100. *Quality of Life Newsletter* 1997 ; 17 : 14-15.

Provides information about the use of the WHOQOL-100 in healthy and ill patients.

Petkov, V., Butorin, N. & Mihailova, J. Attitudes towards quality of life: results from the cultural adaptation of WHOQOL-100 in Bulgaria. *Quality of Life Research* 1997 ; 6(7/8). Language: English.

The purpose of this study was to identify the validity of the QOL concept and the attitudes towards it in focus groups. The relevance of the QOL concept in the present socio-economic crisis and paternalistic health care is questionable. Many patients delegate the responsibility of their health to the state and do not act as clients requesting care based upon their needs and QOL. The inclusion of questions about stigma, goal attainment, coping skills and individual facet importance was proposed.

Key Words: Adaptation, focus-group, validity.

Skevington S, M.; Mac Arthur P.; Somerset M. Developing Items for the WHOQOL : An Investigation of Contemporary Beliefs about Quality of Life Related to Health in Britain. *British Journal of Health Psychology* 1997 ; 2(1) : 55-72.

The aim of this study was to develop the items for a new quality of life assessment-the WHOQOL-which would simultaneously create a UK national instrument as well as contribute to an international pool of items for a cross-cultural measure. The relevance, importance and comprehensiveness of 33 facets of quality of life, and five domains proposed for the WHOQOL, was largely confirmed. Free-listing highlighted omissions of job insecurity, fears of loss or bereavement, the need for loving relationships and specific environmental concerns like pollution.

Key Words: United Kingdom, focus groups, contemporary issues.

Trimble, M.R. & Dodson, W.E. [Eds]. *Epilepsy and Quality of Life*. New York: Raven Press, 1997.

There has been a proliferation of instruments for measuring health-related quality of life. A few have been reported; several others are under development. For this reason a survey of technical approaches and methods is timely. This book includes a chapter about the WHOQOL Project. The development and structure of the WHOQOL are explained, and methods for exploring facets and issues with regard to instrument development are noted. Finally, the development process for the WHOQOL and a proposal for a module for those with Epilepsy are discussed.

Key Words: quality of life, epilepsy, instruments.

Wirnsberger, R.M., De Vries, J., Jansen, T.L.Th.A., Van Heck, G.L., Wouters, E.F.M. & Drent, M. Evaluation of quality of life in rheumatoid arthritis and sarcoidosis. *Quality of Life Research* 1997; 6(7/8): 744.

Abstract from 4th Annual Conference of the International Society for Quality of Life Research (ISOQOL).

Wirnsberger, R.M., De Vries, J., Jansen, T.L.Th.A., Van Heck, G.L., Wouters, E.F.M. & Drent, M. Evaluation of quality of life in rheumatoid arthritis and sarcoidosis. *Sarcoidosis* 1997 ; 14 (Suppl. 1): 45.

Abstract from conference.

Wirnsberger, R.M., De Vries, J., Van Duurling, R.A.H., Wouters, E.F.M., & Drent, M. A comparison between the psychological state in sarcoidosis and chronic obstructive pulmonary disease. *Sarcoidosis* 1997; 14 (Suppl. 1): 45.

Abstract from conference.

Wirnsberger, R.M., De Vries, J., Van Heck, G.L., Breteler, M.H.M. & Drent, M. Quality of life (QOL) in sarcoidosis. *American Journal of Respiratory Critical Care Medicine* 1997 ; 155 : A332.

Abstract from conference.

Bonicatto S, Soria J.J., Tagliero J, & Sica S. Development of the WHOQOL-100, version for use in Argentina. Presented as a poster in the *Third Annual Conference of the ISOQOL*, October 24-27, 1996, Manila, Philippines.

The purpose is to describe the methodology for developing the WHOQOL-100 version for use in Argentina and to report on a preliminary analysis of its psychometric properties. Conclusion: the WHOQOL-100 is an instrument in development, but our preliminary analysis shows it is easy to understand and shows high levels of reliability.

Key Words: Argentina, cross cultural, psychometrics.

Pibernik-Okanovic, M., Szabo, S. & Metelko, Z. Quality of life in diabetic, otherwise ill and healthy persons. *Diabetologia Croatica* 1996 ; 25(3) : 117-121.

Sixty-five diabetic subjects were compared with 185 otherwise ill and 50 healthy subjects in order to highlight the quality of life issues. The World Health Organization Quality of Life Questionnaire (WHOQOL) was used to assess the individual quality of life. Diabetic subjects gave higher ratings for the physical domain than other ill subjects did. the results indicating psychological state, social relationships, personal beliefs and environmental factors did not differ between the groups.

Key Words: Diabetes mellitus, quality of life.

Sartorius, N. Rehabilitation and quality of life. *International Journal of Mental Health* 1995 ; 24(1) : 7-13.

Abstract: not available.

De Vries, J. & Van Heck, G.L. Quality of Life and Refugees. *International Journal of Mental Health* 1994; 23(3): 57-75.

Because of the prominent role of post-traumatic stress disorder (PTSD) in studies on refugees, this paper first presents an overview of this syndrome. Prevention and intervention activities concerning traumata, the concept of quality of life (QOL), specific aspects of QOL in refugees, and the available assessment instruments for measuring QOL are then considered. Finally, there is a description of the development of a new assessment technique for the measurement of QOL in general populations and groups of refugees: the WHOQOL and the WHOQOL-R.

Key Words: quality of life, refugees, WHOQOL.

Sartorius, N. The Chronic Patient: Rehabilitation and Quality of Life. *Hospital and Community Psychiatry* 1992 ; 43(12) : 1180-1181.

Abstract: not available.

Sartorius, N. Cross-Cultural Comparisons of Data about Quality of Life: a Sample of Issues. In: Aaronson, N.K. & Beckmann, J. [eds]. *The Quality of Life of Cancer Patients* 1987 : 19-24. New York: Raven Press. (Republished in *Lebensqualität in der Urologischen Onkologie*, 1997).

Abstract: not available.

De Vries, J. Beyond Health Status: Construction and Validation of the Dutch WHO Quality of Life Assessment Instrument.

Publication information may be obtained from:

Dr J. De Vries, Rijksuniversiteit Limburg, Vakgroep Sociale Psychiatrie, Postbus 616
6200 MD Maastricht, The Netherlands

This book begins with a discussion about different aspects of quality of life. Research, measurement and types of studies are noted. The background of the development of the WHOQOL is explained, and includes information about the structure, features and uses of the instrument. The procedure and results of focus groups are also explained. The field trial of the WHOQOL-100 and the reliability and validity of this instrument are discussed. Future developments for the WHOQOL conclude the book.

Sartorius, N. Quality of Life and Mental Disorders: A Global Perspective. In: *Quality of Life in Mental Disorders*. Chichester: John Wiley & Sons. ISBN 0-471-96643-6.

Abstract: not available.

SECTION D: WHOQOL-100 AND WHOQOL-BREF RESEARCH CURRENTLY UNDERWAY

This section of the annotated bibliography references research studies reported which are currently underway in various WHOQOL centres around the world. The projects range from the development of language-specific manuals, to testing the reliability and validity of the instrument. Details about each project varies, and expected dates of completion are not known in some cases. "In Press" projects are documented here. Contact persons for each centre are included.

Longitudinal Investigation of Depression Outcomes (LIDO).

WHOQOL Centres:

- Australia.** Contact Person: Professor H. Hermann.
- Brazil.** Contact Person: Dr M. Fleck.
- Israel.** Contact Person: Dr M. Amir
- Russia.** Contact Person: Dr A. Lomachenkov.
- Spain.** Contact Person: Dr R.L. Carrasco.
- The Netherlands.** Contact Person: Professor G. Van Heck.
- USA.** Contact Person: Dr D. Patrick.

Study Coordinators: **Health Research Associates Inc. (HRA).**
Contact Person: Ms Mona Martin, Director

The purpose of this project is to explore the relationship between major depressive disorder in primary care patients and their quality of life and resource use. This will be accomplished in a multi-centre, cross-national observational study with a prospective cohort of patients in primary care.

Expected Date of Completion:

Phase I: recruitment 11/1997 - 12/1998
Phase II: follow-up 10/1997 - 02/2000
Phase III: analytic phase 12/1999 - 10/2000

Argentinean WHOQOL Centre. Contact Person: Dr S. Bonicatto.

Argentine version of the WHOQOL Manual.

This manual includes information about the development, psychometrics, and scoring of the WHOQOL-100 and WHOQOL-BREF, and information about the Argentinean version of the WHOQOL-100 and WHOQOL-BREF.

Expected date of completion: Summer, 1998.

Bonicatto S, Zaratuiegui R, Lorenzo L, Pecina P. Quality of Life in Adult Outpatients with Depression. A Preliminary Report. To be presented as a poster at the *Fifth Annual Conference of the ISOQOL*, 15-17 November 1998, Baltimore, USA.

The objective was to assess the QOL of a small sample of patients with the diagnosis of depression, as measured with the validated Argentine version of the Beck Depression Inventory (BDI). QOL was assessed in 28 outpatients using the WHOQOL-100 and the WHOQOL-BREF. Conclusion: in our sample of patients, both WHOQOL-100 and WHOQOL-BREF were able to find differences between different levels of depression. The quality of life was significantly better in those with lower levels of depression, as expected.

Brazilian WHOQOL Centre. Contact Person: Dr Marcelo Fleck.

Fleck, M., Leal, O., Louzada, S., Xavier, M., Chachamovich, E., Vieira, G., Santos, L. & Pinzon, V. Desenvol Vimento Da Versão Em Português Do Instrumento De Avaliação De Qualidade De Vida Da Organização Mundial Da Saúde (WHOQOL-100). [Development of the Portuguese-language version of the World Health Organization Instrument to evaluate quality of life (WHOQOL-100).]

A. *Revista ABP/APAL* (Revista da Associação Brasileira de Psiquiatria e da Associação Psiquiátrica de la América Latina). [accepted for publication] Language: Portuguese.

B. *Acta Psychiatrica Scandinavica* [submitted for publication]. Language: English.

The methodology and the different stages of developing the WHOQOL are described. The development of the Portuguese version is presented. Using a unique methodology, translation and discussion in focus groups with community members, patients and health professionals was performed, followed by back translation. The goals of the focus groups were to discuss adequacy of translation and items selection for assessing quality of life in a Brazilian city (Porto Alegre). The work in focus groups showed that the WHOQOL-100 is ready to be piloted in Brazil with its Portuguese version.

Key Words: Quality of life, World Health Organization, cross-cultural.

Fleck, M., Louzada, S., Xavier, M., Chachamovich, E., Vieira, G., Santos, L. & Pinzon, V. Aplicação Da Versão Em Português Do Instrumento De Avaliação De Qualidade De Vida Da Organização Mundial Da Saúde (WHOQOL-100). [Application of the Portuguese Version of the World Health Organization Quality of Life Instrument (WHOQOL-100).]

A. *Revista de Saúde Pública* (Journal of Public Health) [accepted for publication]. Language: Portuguese.

B. *Acta Psychiatrica Scandinavica* [submitted for publication]. Language: English.

The WHOQOL Group developed an instrument to evaluate quality of life, the WHOQOL-100, available in 20 different languages. The authors present the field trial of the Portuguese version of the instrument in a sample of 300 individuals in Porto Alegre, south Brazil. The instrument showed good psychometric performance with good internal consistency, discriminant validity, criterion validity, concurrent validity and reliability. The authors concluded that the instrument is ready to be used in Brazil, and that its performance be evaluated in other regions with different samples.

Key Words: Quality of life, World Health Organization, rating scale.

Fleck, M., Louzada, S., Xavier, M., Chachamovich, E., Vieira, G., Santos, L. & Pinzon, V. Aplicação Da Versão Abreviada Do Instrumento De Avaliação De Qualidade De Vida Da Organização Mundial Da Saúde (WHOQOL-BREVE). [Application of the Portuguese Abbreviated Version of the World Health Organization Quality of Life Instrument (WHOQOL-BREF)].

A. *Revista de Saúde Pública* (Journal of Public Health) [submitted for publication]. Language: Portuguese.

B. *Acta Psychiatrica Scandinavica* [to be submitted for publication]. Language: English.

In this paper the authors present the field trial of the Portuguese version of the WHOQOL-BREF in a sample of 300 individuals in Porto Alegre, south Brazil. The instrument showed good psychometric performance with good internal consistency, discriminant validity, criterion validity, concurrent validity and test-retest reliability. The authors concluded showing that the instrument is both psychometrically consistent and practical for use, proposing that it is an interesting option as an instrument to evaluate quality of life for the Portuguese language.

Key Words: Quality of life, World Health Organization, rating scale.

Fleck, M., Louzada, S., Xavier, M., Chachamovich, E., Santos, L. & Pinzon, V. Development and application of the Portuguese language of the World health Organization Instruments to evaluate quality of life (WHOQOL-100 and WHOQOL-BREF). To be submitted to Acta Psychiatrica Scandinavica. Language: English.

The World Health Organization Quality of Life Group (WHOQOL Group) developed an instrument to evaluate Quality of Life (WHOQOL-100) with 100 questions that evaluate quality of life in different domains: physical, psychological, level of independence, social relationships, environment and spirituality. The studies using quality of life as a parameter of evaluation are increasing, and short instruments are more economical and time costless. The WHOQOL Group developed an abbreviated version of the WHOQOL-100, the WHOQOL-BREF. This instrument is composed of 26 questions divided into four domains: physical, psychological, social relationships and environment. In this paper the authors present the field trial of the Portuguese version of both instruments in 300 individuals sample in Porto Alegre, South Brazil. Both instruments showed good psychometric performance with good internal consistency, discriminant validity, criterion validity, concurrent validity and test-retest reliability. The authors concluded showing that both versions are psychometrically consistent and practical for use proposing that they are interesting options as instruments to evaluate quality of life for the Portuguese version.

Key words: Quality of life, World Health Organization, rating scale

Bulgarian WHOQOL Centre. Contact Person: Dr V. Petkov.

Petkov, V. Measuring quality of life in people suffering from schizophrenia or depression. Submitted for presentation at the 5th Annual Conference of the International Society for Quality of Life Research, November 15-17, Baltimore, Maryland, USA.

This study examined QOL in depression and schizophrenia. Depressive symptoms explain to a great extent, subjective QOL scores. The correlation between severity of symptoms and QOL scores is low to moderate. QOL declines together with the exacerbation of symptoms and functioning, but when the impairment in reality testing becomes considerable the QOL scores get higher again. The validity of the QOL score is questioned in people with considerable impairment in reality testing.

Key Words: Depression, schizophrenia, quality of life.

Canadian WHOQOL Centre (English). Contact Person: Dr Anita Molzahn.

Field testing of the WHOQOL-100.

The purpose of this project is to examine the psychometric properties of the WHOQOL-100, including concurrent validity, discriminant validity, construct validity, consistent reliability and stability reliability.

Expected date of completion: December 1998.

Field testing of the WHOQOL-BREF.

The purpose of this project is to examine the psychometric properties of the WHOQOL-BREF.

Expected date of completion: December 1999.

Danish WHOQOL Centre. Contact Person: Dr Per Bech.

Norholm, V., Bech, P. Pilot test of the WHOQOL-100. Applicability study of Danish WHOQOL. [In Preparation].

This report indicates the test-retest reliability and construct validity of the WHOQOL-100 using traditional psychometrics and Loevinger, item response theory and Criterion validity. The WHOQOL-100 is compared to SF-36 in two groups.

Norholm V, Bech, P. WHOQOL-BREF in the first Danish Applicability Studies. To be presented at the AEP Congress in Copenhagen, September 1998.

When psychometrically analysing questionnaires, measuring quality of life, we have preferred latent structure analysis compared to factor analysis and Loevinger's coefficient of homogeneity compared to Cronbach's coefficient of internal consistency. The total score of the WHOQOL-BREF was found to be a sufficient statistic. The results of the Danish population study will be presented.

Key words: WHOQOL-BREF, applicability, population study.

Norholm, V., Bech, P., Rasmussen, N.A. et al. WHOQOL-BREF II. A study about the reliability and construct validity of the WHOQOL-BREF in a general population sample. [Abstract in preparation].

Norholm, V., Bech, P., Rasmussen, N.A. et al. WHOQOL-BREF III. A study about criterion validity and general population norms for WHOQOL-BREF. [Abstract in preparation].

Dutch WHOQOL Centre. Contact Person: Dr J. De Vries.

De Vries, J., & Drent, M. (1998). *Kwaliteit van leven van sarcoïdosepatiënten [Quality of life in sarcoidosis patients]. Gedrag & Gezondheid, in press. Language: Dutch.*

The aim of this study was to evaluate the influence of sarcoidosis on patients' life. Results indicated that compared to patients without current symptoms, patients with current symptoms had significantly worse QOL scores in a wide range of areas. Between the control group and sarcoidosis patients without current symptoms, differences emerged with respect to the domains Physical Health and Level of Independence and six of their facets as well as on the global facet. In conclusion, it appeared that the QOL of patients with sarcoidosis is impaired, especially when the patients had symptoms.

Key Words: quality of life, sarcoidosis, WHOQOL.

De Vries, J., Drent, M., Van Heck, G.L., & Wouters, E.F.M. (1998). *Quality of life in sarcoidosis: A comparison between members of a patient organisation and a random sample. Sarcoidosis Vasculitis and Diffuse Lung Diseases, in press.*

The aim of this study was to evaluate whether the quality of life (QOL) of members of the Dutch Sarcoidosis Society (DSS) is comparable with the QOL of a random non-member sample of the Dutch sarcoidosis population. It appeared that more members of the DSS indicated to suffer from physical symptoms than non-members. However, when the experience of symptoms was partialled out, the DSS members were, in general, comparable to the random sample of sarcoidosis patients.

Key Words: quality of life, sarcoidosis, WHOQOL.

Wirnsberger, R.M., De Vries, J., Breteler, M.H.M., Van Heck, G.L., Wouters, E.F.M., & Drent, M. (1998). *Evaluation of quality of life in sarcoidosis patients. Respiratory Medicine, in press.*

The aim of this study was to assess the impact of sarcoidosis on QOL. The WHOQOL-100 revealed a number of areas in which sarcoidosis patients A major symptom in both groups of sarcoidosis patients was fatigue. No association between the facet Fatigue and the domain Psychological Health was found. Depressive symptoms (BDI) were associated with psychological function (WHOQOL-100). The WHOQOL-100 appeared to be a sensitive instrument to measure fatigue - one of the most common symptoms in sarcoidosis - which otherwise is difficult to assess objectively.

Key Words: quality of life, sarcoidosis, WHOQOL.

Israeli WHOQOL Centre. Contact Person: Dr M. Amir.

Amir, M. Subjective Quality of Life among kibbutz and city inhabitants. To be submitted for publication. Language: To be published in English, data collection in Hebrew.

The present study was part of the validation of the WHOQOL-100 in Hebrew. One hundred and twenty-eight persons living on three different kibbutz (Group I) were compared to one hundred twenty persons living in the city (Group II) matched for education and age. Results showed that Group I reported a lower quality of life in the psychological domain and level of independence. A regression analysis showed similar patterns for the two groups: in both groups the environmental domain was the best predictor of quality of life.

Key Words: quality of life, kibbutz, WHOQOL-100, Israel.

Amir, M. & Bar-Levav, P. The relationship of sex-roles, coping styles, control modes and perceived social support to quality of life. [In preparation as a thesis]. Language: English and Hebrew.

The study examined the relationship of four personality variables – sex-roles, coping styles, modes of control and perceived social support – to quality of life in a normal, healthy population. Three hundred students answered a battery of questionnaires. Results showed significant positive correlations between subjective quality of life and psychological androgyny; perceived social support; positive asserting and positive yielding control modes; and coping styles of minimisation, mapping and replacement. Results usually supported the hypothesis concerning the flexible personality style as the best predictor of subjective quality of life, compared to the other personality styles.

Key Words: Quality of life, Israel, WHOQOL-BREF.

Amir, M. & Cohen, M. Quality of life among burns patients. [In preparation for publication]. Language: To be published in English, data collection in Hebrew.

Twenty-eight burns patients were compared to a group of twenty-eight healthy patients matched for age, gender and education. They were administered the WHOQOL-100 in addition to a disease specific quality of life questionnaire. The results showed good discriminative validity and good construct validity for the WHOQOL-100.

Key Words: Burns, quality of life, Israel.

Amir, M. & Ezra, M. Validation of the WHOQOL-BREF in Hebrew. [In preparation for publication]. Language: To be published in English, data collection in Hebrew.

The objective of the study was to collect data on the validity and reliability of the WHOQOL-BREF in Hebrew. Ninety students were administered the WHOQOL-BREF, SCL-90, Satisfaction with Life Schedule (Diener) and a short demographic questionnaire. A correlational design was used. The results showed good reliability for the domains and facets. Regarding validity, the results showed good construct validity, concurrent validity, convergent validity and discriminant validity.

Key Words: validation, Israel, WHOQOL-BREF.

Amir, M., Roziner, I., Knol, A. & Neufeld, M. Self-efficacy and social support as mediators in the relationship between disease severity and quality of life in epileptic patients. [Not yet published].

Eighty-nine epileptic patients were studied in order to inquire into the influence of two psychosocial variables mediating between disease severity and quality of life in epilepsy. A model testing these two variables as mediators between disease severity and quality of life was tested with Structural Equation Modelling. The patients were administered the WHOQOL-100, the Liverpool Seizure Severity Scale, Interpersonal Support Evaluation List and the Epileptic Self-efficacy Scale. Ninety percent of the variance of the WHOQOL was explained by a combination of disease severity, self-efficacy, social support and locus of control.

Key Words: Epilepsy, mastery, quality of life.

Amir, M. & Sharf, Y. Quality of life in people who recovered from breast cancer. Presently completing data analysis. Language: to be published in English, data collection in Hebrew.

Forty women who recovered from cancer (minimum five years symptom free) were compared to 40 healthy women (with no history of serious disease) on measures of post traumatic stress disorder symptoms, coping styles and quality of life. It is hypothesised that the women who suffered cancer in the past will be lower on the measures of quality of life than the women who have never suffered serious disease.

Key Words: quality of life, recovery from cancer, Israel.

Amir, M. & Taya, M. Quality of life among Israeli Arabs and Israeli Jews. [Submitted for publication]. Language: English.

The present study was part of the validation of the WHOQOL-100 in Israel. 97 Israeli Jews and 95 Israeli Arabs matched for age, income, education and gender were administered the WHOQOL-100 in Hebrew and Arabic respectively. Results showed that on the general facet there was no significant difference between the two groups. However, regarding the content domains, the Jews scored higher than the Arabs on five of the six domains. The results are discussed in terms of a minority group confronting a continuous complex political situation.

Key Words: Quality of life, Israel, WHOQOL-100.

Italian WHOQOL Centre. Contact Person: Dr G. de Girolamo.

De Girolamo, G. (On behalf of the Italian WHOQOL Collaborating Centre). Il progetto WHOQOL dell'OMS: risultati dello studio pilota italiano dell'WHOQOL-100. *Recenti Progressi in Medicina*. Language: Italian. [In preparation]

Abstract: not available.

De Girolamo, G., De Leo, D., Neri, G., Becchi, A. & Scocco, P. [Eds]. *Health and Quality of Life*. Rome: Il Pensiero Scientifico.

This book will discuss general and methodological issues related to quality of life, a description of the WHOQOL project as a core component, and future perspectives for this area of research.

Korean WHOQOL Centre. Contact Person: Dr S. Kil Min.

Kil Min, S., & Il Kim, Kwang. Standardization of Korean version of WHOQOL-100 and WHOQOL-BREF. Language: Korean.

The purpose of this study to the standardization of the Korean version of the WHOQOL-100 and the WHOQOL-BREF, including translation and back translation, adding new items, validity and reliability tests, etc. Expected date of completion: end of 1998.

Key Words: WHOQOL, Korea-version, standardization.

Spanish WHOQOL Centre. Contact Person: Dr R. Lucas.

Lucas, R. Depression and quality of life among primary care patients.

The purpose of this research is to conduct a national follow-up study. Expected date of completion: end of 1998.

Key Words: Quality of life, depression, primary care.

Lucas, R. Quality of life among relatives of patients with schizophrenia. [Unpublished].

Abstract: not available.

Key Words: quality of life, schizophrenics, relatives.

Lucas, R. Quality of life in caregivers of patients with Dementia.

The objective of this research is an international pilot study. Expected date of completion: to be analysed by september, 1998.

Key Words: Quality of life, caregivers, dementia.

Thai WHOQOL Centre. Contact Person: Mr Kitikorn Meesapya

Mahatnirunkul, S. Evaluation of quality of life in Thai population. Language: Thai.

The purpose of this study is to evaluate QOL in the Thai population. The WHOQOL-BREF-THAI version was used to measure quality of life for 7,500 persons.
Expected date of completion: December, 1998.

UK WHOQOL Centre. Contact Person: Dr Suzanne Skevington.

Skevington, S.M. Psychometric properties of the UK version of the World Health Organization Quality of Life instrument. Submitted.

Background. Selected psychometric properties of a new quality of life instrument - the UK WHOQOL - are presented for use in British health care. The study forms part of an international project to design a multi-lingual, multi-dimensional profile for cross-cultural use, initiated by the World Health Organization in 1991 between 15 participating countries world-wide (the WHOQOL Group).
Objectives. Aspects of reliability (internal consistency) and construct and discriminant power were examined for the UK WHOQOL-100.

Design and Subjects. In addition to a healthy sample, the measure was administered to British patients attending GP surgeries, out-patient clinics and inpatient wards and was representative of 16 ICD categories (N=320). Patients were also selected for age, sex and disease severity.

Results. The UK WHOQOL-100 is found to be highly reliable for individual use ($\alpha=0.97$) with alpha's for all 6 domains and subgroups exceeding 0.9. Moderate to high positive correlations within 25 facets across 6 domains largely confirmed the structure of the UK instrument and good discriminant power is reported. Seven national items specific to Britain are earmarked for further testing in the UK.

Conclusions. The excellent psychometric properties obtained indicate that this subjective measure promises to be the most comprehensive profile for generic use in health care, to date.

Key Words: quality of life, health, reliability, validity, WHOQOL

Skevington, S.M. & Bradshaw, J. Validating the WHOQOL-100: a study of the quality of life of well people in the UK. [In preparation].

Abstract: not available.

Key Words: healthy, validation, longitudinal.

Skevington, S.M., Bradshaw, J. & Saxena, S. Selecting national items for the WHOQOL: conceptual and psychometric considerations. *Social Science and Medicine*, in press.

The WHOQOL is a new measure designed to assess quality of life cross-culturally in health and health care. An international core of 276 items covering 26 facets of quality of life, organised into 6 domains was established first, conceptually and then assessed in psychometric terms. The method also allowed for the inclusion of extra items to enable the concept of quality of life to be complete for the language and culture in each participating centre, to achieve conceptual equivalence between centres and language versions. The present study investigates the properties of these national items using data obtained from 3740 participants who completed the instrument. Five statistical criteria were applied to data on 144 national items submitted by 10 centres world-wide to see how well each performed when competing with internationally selected core items from its own facet within that centre and these results directed the inclusion or exclusion of items. Multi-dimensional scaling and cluster analysis enabled the structural relationship of items to be examined within its own facet. Summarised results show that 38 (27%) national items could be selected for inclusion in a national module. Detailed examples demonstrate the selection methods used and show how entirely new facets, as well as individual items may be assessed for inclusion in the WHOQOL-100.

Skevington, S.M., Carse-Jones, M, & Williams, A.C. de C. The quality of life of chronically ill patients entering a pain management program. [In preparation].

Abstract not available.

Key Words: chronic pain, treatment, longitudinal.

S. Skevington, J. Bradshaw, C. Lovell, A Hepplewhite & K. Dawkes. Treating Psoriasis: Does it Make A Difference to Quality of Life? Validating the WHOQOL-100 in Britain.

The aim of this study was to find out whether psoriasis has an adverse effect on quality of life compared to health people and if so on what dimensions, based on predictions about group differences for each of the 25 facets and 6 domains of the WHOQOL-100. A second aim was to examine some of the psychometric properties of the scale. The WHOQOL-100 and SF-36 were completed together with the Profile of Mood States (POMS) before topical treatment for diagnosed psoriasis. The results show that compared to 104 carefully screened healthy people, psoriasis patients have significantly poorer quality of life on most facets in the physical, psychological, independence and spirituality domains, and in the facet opportunities for recreation and leisure, but have similar social and environmental quality of life to those who are healthy. Their positive and negative mood, as measured by the POMS, is also significantly poorer for patients. Standardised Cronbach's alpha calculated for each facet are good, largely ranging from 0.75 (cognitions) to 0.93 (spirituality), with the exception of physical environment (0.58). Intercorrelations between the 6 domains were significant but poorer for spirituality. Correlations between WHOQOL-100 domains and SF-36 subscales showed that the physical and independence domains are closely associated with the physical subscales of the SF-36, and role emotional and mental health with the psychological and spirituality domains of the WHOQOL-100. But facets in the social and environment domains are not well associated with SF-36 dimensions, so highlighting the original areas within the WHOQOL-100. Psychometric and practical implications are discussed.

Key Words: psoriasis, treatment, psychological.

Skevington, S.M. & Tucker, C. Designing response scales for cross-cultural use in health care: data from the development of the UK WHOQOL. *British Journal of Medical Psychology*, in press.

Designing response scales for use in cross-cultural situations presents several semantic and conceptual challenges. Here we report response scales designed in the UK, using a method developed collaboratively by the WHOQOL Group to tackle some of these issues. The response scales were generated for use with items established for a British version of a new cross-cultural quality of life measure for health and health care - the UK WHOQOL. A quota sample of 20 sick and well people assigned 60 descriptions to separate 100 mm lines (15 for each of 4 types of response scale) where the polar anchor points had been internationally agreed as meaningful in 10 countries. Means and standard deviations (SD) were calculated for each label appropriate to that response scale. The closest mean and smallest SD earmarked labels for each type of scale at the 25%, 50% and 75% interval. This research provides a set of contemporary, 5-point interval response scales that have the potential to be used in any number of British health and health care questionnaires where subjective measures are needed.

Skevington, S. M. & Wright, A. *Users Manual for the WHOQOL in Britain. WHOQOL Centre for the Study of Quality of Life, University of Bath, 1998.*

A guide for UK users and reported UK findings on the pilot study of WHOQOL-100 and WHOQOL-BREF.

Skevington, S.M. & Wright, A. Changes in the quality of life of patients receiving antidepressant medication in primary care: evidence of validation for the WHOQOL-100.

This study describes changes in the quality of life of patients receiving a course of anti-depressant medication from their General Practitioners. It was also designed to examine the validity, sensitivity and other psychometric properties of the WHOQOL-100 in the UK. One hundred and six patients were recruited by their GPs to the study following diagnosis of mild/moderate depression using DSM-IV. They completed the WHOQOL-100, the Beck Depression Inventory and the SF-36 at the start of treatment then again 6-8 weeks later. The results show the excellent properties of the UK instrument with internal consistency (α) at .96 and good convergent validity. Concurrent validity was assessed by correlating WHOQOL domains and facets with subscales of the SF-36. Physical, psychological and independence domains are similar in the two scales but the environment and spiritual health are original to the WHOQOL-100. The power of the instrument to discriminate between patients with different levels of depression was good for 15 out of 25 facets. BDI scores decreased during the study with 74% reporting they were better after treatment. Patient improvements in depression were significantly correlated with increases in 15 facets of quality of life. Changes over time showed significant improvements in quality of life scores on 24 out of 25 facets so demonstrating the efficacy of antidepressant treatment in primary care as well as construct validity and sensitivity to change for the WHOQOL-100. Regressions between quality of life and depression across time was used to examine predictive validity. Only the level of positive feelings at the start of the study predicted level of depression at the end. Positive feelings at the outset provides the best prognosis for the relief of depression after 6-8 weeks. Mood significantly affects the ways patients make ratings of many aspects of their quality of life.

Byrne, L. & Skevington, S. The Development of the WHOQOL Cancer Module and the psychometric properties of the WHOQOL-100 in people with cancers.

The WHOQOL-100 is a quality of life measure developed by the World Health Organization Quality of Life (WHOQOL) Group (1993, 1995, and 1996) in a general population. The WHOQOL Group suggested that there may be a need for special modules to add to the WHOQOL-100 containing questions pertinent to the quality of life of people with certain diseases, but not to the quality of life of the general population. This study aimed to assess some of the psychometric properties of the WHOQOL-100 and to determine if there were any issues pertinent to quality of life in this population that are not included in the WHOQOL-100, by analysis of the questionnaire and focus group methodology. It was found that, with the exception of 3 of the 107 questions, the measure had construct validity and internal reliability in this population. Additionally, it was found that people with cancer had significantly lower quality of life in the physical and level of independence domains of the WHOQOL-100 than in the psychological, social relationships, environment and spirituality domains. People with moderate stages of disease were found to have a significantly higher quality of life than people with advanced disease, and people in remission were found to have a higher quality of life than people not in remission in the level of independence domain. Focus group analysis determined that there were two issues pertinent to the quality of life of this population which are not covered in the WHOQOL-100; relationship with medical professionals and, for those people who did not have terminal disease, knowing that you did not have a recurrence.

Jirojanakul, P. & Skevington, S. Developing the Quality of Life Measure for Children aged 5-8 years. Submitted.

This paper describes the development process of the Quality of Life Measure for Thai children aged 5-8 years, which is a part of a study on the quality of life of urban children and construction workers' children in Bangkok, Thailand. The underlying concepts, the method of development, how the measure was piloted and the results of the pilot study are described. The psychometric properties of the measure are also reported. The underlying concepts of this measure are based on the WHOQOL (The World Health Organization Quality of Life Assessment). Focus groups were used as the technique to examine whether the WHOQOL construct was relevant to the quality of life of Thai children and gain baseline information from the children and mothers to develop the Quality of Life Measure (QLMC). Ten focus groups (6 with children and 4 with mothers) were conducted in Thailand, then qualitative and quantitative data were analysed and showed that the quality of life construct derived by WHO was relevant to the quality of life of Thai children. These results enabled two sets of questionnaires to be developed - a children's form and a carer's form - which were then further tested with the children and their carers in Thailand. The respondents were urban children who were healthy or sick in hospital and also construction workers' children together with their carers. The data were analysed from 30 children and 35 carers and the psychometric properties of the measure were investigated. The results confirmed the content and face validity of the measure and showed good Cronbach's alpha and test-reliability. The results show that the scale is not sensitive to age or sex differences. In addition item analysis has been performed to select the good items and some alterations were made in revising the scale. This measure relies upon the experience of the children and their mothers and uses their reports in developing the scale. It is a multi-dimensional and child-centred measure.

Key Words: children, quality of life measure

WHOQOL Group.

The WHOQOL Group. *Subjective importance of various aspects for people's quality of life: Results from a cross-cultural study by WHO.* [in preparation].

The WHOQOL Group. **The World Health Organization WHOQOL-100: Test of the universality of quality of life in fifteen different cultural groups world-wide.** [in preparation].

WHOQOL HIV / AIDS Group.

A module to the WHOQOL is being developed to assess the quality of life of people living with HIV / AIDS. The project began in January 1997 and is presently in the pilot testing analysis phase. Collaborating sites are as follows:

Australia, La Trobe University. Contact Person: Mr. M. Bartos.

Brazil, University of the State of Rio Grande do Sul. Contact Person: Dr. M. Fleck.

Hong Kong, The Chinese University of Hong Kong. Contact Person: Dr. J. Thomas.

India, All India Institute of Medical Sciences. Contact Person: Dr. S. Saxena.

India, Chennai Medical College. Contact Person: Dr. S. Kumar.

India, NIMHANS. Contact Person: Professor P. Chandra.

Thailand, Ministry of public Health. Contact Person: Mr. K. Meesapya.

Zambia, University of Zambia. Contact Person: Dr. A. Haworth.

Zimbabwe, University of Zimbabwe. Contact Person: Dr. J. Mutambirwa.

SECTION E: PLANNED WHOQOL-100 AND WHOQOL-BREF RESEARCH

Section E indicates future projects that are planned by various WHOQOL Centres around the world. Proposed dates of completion are included where appropriate, and the contact person for each centre is included. This list may not be exhaustive.

Argentinean WHOQOL Centre. Contact Person: Dr S. Bonicatto.

An assessment of quality of life in people who quit smoking.

Proposed date of completion: March 1999.

An assessment of quality of life in a population with high levels of alcoholism.

Proposed date of completion: March 1999.

An assessment of quality of life in patients with differing levels of depression in a larger sample.

Proposed date of completion: March 1999.

Australian WHOQOL Centre. Contact Person: Dr H. Herrman

Study using QOL is evaluation of war veterans - Dr G.J. Pohlen

Proposed date of completion: December 1999

This study is intended to provide a 400-item standardised questionnaire to help medical practitioners and other professionals in the evaluation of war veterans' psychiatric disabilities for the commonwealth of Australia's Repatriation Commission. The questionnaire will be derived from an analysis of the Criteria recommended in the "Guide to the Assessment of Rates of Veterans' Pensions (GARP-V)" released in April 1998. Goldberg's 60-item general Health Questionnaire (GHQ), the Australian edition of the World Health Organization's Quality of Life measure (WHOQOL), as well as other recognised instruments will be used as a measure of internal validation. The first version of the 400-item composite questionnaire will be further developed and validated by application to some fifty Viet Nam veterans and their witnessing partners. Respondents will be interviewed separately at the beginning and end of a three month interval. The same questionnaire will be reapplied to the non-military civilian partners of the known veterans but with the bonded veteran acting as the verifying witness. The data will be analysed and the questionnaire refined to a shorter and more improved version. The shorter version will then be applied in the same way to a fresh population of fifty Viet Nam veterans and their partners.

Hungarian WHOQOL Centre. Contact Person: Dr L. Kullmann.

A joint publication with Dr. Harangozó about the WHOQOL concept and its Hungarian adaptation process. The aim would be to familiarise physicians with the method, and its applicability. Proposed date of completion: end of 1998.

Bulgarian WHOQOL Centre. Contact Person: Dr. V. Petkov.

A transcultural study comparing the quality of life of people with chronic mental disorders. A comparison of the data obtained from Measuring Quality of Life in People Suffering from Schizophrenia or Depression and the results received in other countries using the WHOQOL would be undertaken. The purpose of this study would be to determine in what way our cultural context affects the QOL of people with schizophrenia or depression.

Proposed date of completion: data collection will be complete in September 1998.

Canadian WHOQOL Centre (English). Contact Person: Dr Anita Molzahn.

A project to investigate quality of life of schizophrenics in outpatient programs. Objective of the study: to evaluate the success of an outpatient program for schizophrenics.

Proposed date of completion: uncertain (in proposal phase).

Croatian WHOQOL Centre. Contact Person: Dr S. Szabo.

A publication referring to the psychometric properties of the WHOQOL-100 in diabetic patients.

Proposed date of completion: end of 1998.

Czech WHOQOL Centre. Contact Person: Dr E. Dragomirecka.

A publication about the development of the Czech Version of an International Quality of Life Assessment Instrument (WHOQOL).

At present quality of life is considered as criterion capable to assess the impact of illness on the patient's life and the changes in his/her global state in a more complex way than health state indexes used before. The project objective is the development of the Czech versions of WHOQOL-100 and WHOQOL-BREF in collaboration with the World Health Organization and to offer the training to specialists from the field interested in the method. The WHOQOL-100 instrument finds a broad application in the field of clinical research of various orientations and in the area of health care economy and planning.

Key words: assessment, international, WHO study.

Proposed date of completion:

1999 - cultural adaptation of WHOQOL into Czech
2000 - validation of WHOQOL; final Czech version
2001 - Czech WHOQOL manual; final Czech WHOQOL-BREF version

Danish WHOQOL Centre. Contact Person: Dr Per Bech.

**Norholm, V. WHOQOL-BREF IV. Quality of life in Schizophrenia compared to the Danish population. University of Copenhagen, *dissertation*.
Language: Danish.**

The purpose is to examine the correlation between Quality of Life and Depression, both in a group of schizophrenic patients and in the Danish population. Included will be an examination of the correlation between quality of life and positive/negative symptoms in schizophrenic patients, and an examination of quality of life evaluations for schizophrenic patients. The WHOQOL-BREF, SF-36, Lehman QOLI and MDI are the instruments which will be used.

Proposed date of completion: 1998-2000.

Key words: quality of life, schizophrenia, WHOQOL-BREF.

Dutch WHOQOL Centre. Contact Person: Dr G. Van Heck.

An article about QOL and depression in cryptogenic fibrosing alveolitis (CFA) patients.

Proposed date of completion: data generation by end of 1998. Publications will follow.

A project on vascular surgery.

Proposed date of completion: data generation by end of 1998. Publications will follow.

Greek WHOQOL Centre. Contact Person: Dr M. Coccossis

Field testing of the WHOQOL-100 Greek version to examine the psychometric properties of this instrument, including internal consistency, test-retest reliability, content validity, criterion validity, convergent validity.

Expected date of completion: end 1999.

Field testing of the WHOQOL-BREF Greek version to examine the psychometric properties of this instrument.

Expected date of completion: end 1999.

Evaluation of quality of life in schizophrenic patients. The aim of the study is to assess the relationship of social adjustment (work status, residential conditions, social functioning) aspects of the illness (positive/negative symptoms, hospitalizations), the use of hospital and treatment services, to quality of life using the WHOQOL-100 and to psychological dimensions of self-esteem and well-being.

Expected date of completion: end 2000.

Development of the WHOQOL-100 version for use in Greece. To be presented as a poster in the WPA Regional Congress on preventive Psychiatry, 24-28 February 1999, Athens, Greece.

New Zealand WHOQOL Center .Contact Person: Dr William Taylor

Investigating the convergent validity of WHOQOL –BREF with a number of other instruments in people with rheumatoid arthritis. A study underway expected date of completion mid 2000

Comparison of WHOQO-BREF with other instrument in a study looking at change sensitivity following inpatient treatment of rheumatoid arthritis. Expected date of completion mid 200

