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ORIGINAL ARTICLE

THE PILOT STUDY OF WHOQOL-100 (MALAY VERSION)

C. I. Hasanah, M. S. Razali

Department of Psychiatry
School of Medical Sciences
Universiti Sains Malaysia
16150 Kubang Kerian
Kelantan, Malaysia

In confronting the advances in the new treatment for incurable illnesses there is an increasing need for doctors to be aware of their patients' cognition and feeling related to their quality of life (QOL). Recognizing this need the authors translated and pilot tested the WHOQOL-100, a genuinely international measure of QOL by the World Health Organization (quality of life group). The WHOQOL-100 Malay version was pilot tested on 50 healthy controls and 250 ill subjects, suffering from hypertension, diabetes mellitus, those suffering from both hypertension and ischaemic heart disease, epilepsy and schizophrenia. The results showed several unique features of the QOL, which were influenced by different types of illnesses. The information obtained is different and probably not observable from clinical consultations. This study will be an impetus for further studies using the WHOQOL-100 assessment tool in the local population.

Keywords: quality of life, subjective assessment, WHOQOL-100

Introduction

The consideration of patients' opinion and decision in their medical treatment has become a central issue in the last decade. With this development, the paternalistic or authoritarian role of doctors is de-emphasized. Thus there is an increasing need for doctors to become aware of their patients' cognition and feelings especially those related specifically to their health status and quality of life (QOL).

This need is more urgent in confronting the options of treatment of incurable illnesses like AIDS, cancers, Alzheimer's disease etc. Quality of life assessment will provide an additional source of information for comparisons with differing mode of life prolonging treatment and even with the choice of not opting for treatment. Thus, the cost benefits of treatment like donepezil that does not cure Alzheimer's disease but prolong the patients' functioning can be estimated.

QOL assessment can also be used to identify unobserved need for rehabilitation for patients already undergoing treatment. With this knowledge the allocation of health resources can be revised and reallocate accordingly. Other uses of QOL assessment include getting information from people who survived a tragedy or a catastrophic life event. Lastly the generic QOL assessment can be used to get the information of the general life satisfaction or well-being of population in the State, which can be used as a health indicator of the country. Generic measures focus on such basic human values as emotional well-being and the ability to function in everyday life.

Up to date there are several established quality of life measures. Ware (1) had first brought a conceptual order to the variables employed in health status and quality of life assessment. The 36-item questionnaire used in the Medical Outcomes Study General Health Survey has been revised to a shorter version, the SF-12 (2). However these existing questionnaires were developed primarily for the American target population. Ad hoc translation or translation and cultural adaptation of an existing measure carry the danger of distortion. Health related

quality of life constructs, which are valid in the source language setting, might no longer be valid in the target language setting (3). Equally important, there may be aspects of health related quality of life which are important in target culture, but which are not covered by the source instrument (4).

The World Health Organization Quality of Life (WHOQOL) Group resolved this issue by involving a "collaborative" or "simultaneous development" approach to international instrument development (5-7). Amongst the 15 centers that collaboratively developed the questionnaire at the grassroots level are Japan, India and Thailand. The inclusion of field centers that share a closer value and cultural systems with ours resulted in items that are also integral to the our quality of life, notably family support and spiritual domains that are not included in the other questionnaires. The WHOQOL group defined 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 because of these unique features that the authors felt that translation of the WHOQOL-100 is appropriate and useful. Further advantage is that the information obtained from the instrument can easily be compared with the other international collaborative centers.

Thus the aim of this pilot study is to validate the WHOQOL Malay version to the local population.

Method

The author (H.C.I) first obtained WHO's approval for the translation of WHOQOL-100. A standard procedure for the development work was provided by the WHOQOL group for new centers (8-9).

The translated questionnaires were pilot tested on 50 healthy controls and 250 subjects with either diabetes mellitus, hypertension, epilepsy, schizophrenia or suffering from two illnesses, i.e. hypertension and ischaemic heart disease (the co-morbid group). Each group with illness was made up of 50 subjects. Half of the subjects were male and the other half was female and all groups were matched for age and socio-economic status. The sample size and the illness groups had been suggested by the WHOQOL group in Geneva.

Those with cognitive impairment and substance misuse disorder were excluded. Only those above the age of 18 and consented were included. To ensure reliability of the interview process the same interviewer was assigned for all the subjects that need assistance. The research assistant was blind to the objectives, methodology and type of illness the subjects were suffering.

The study was conducted in the physician clinics and psychiatric outpatient clinics in a teaching hospital in Kelantan, the Northern State in Malaysia. The hospital has 600 beds and caters to a population of about 200,000, both suburban and rural. The control group consisted of subjects whom had accompanied their relatives to the physicians' clinic. Consecutive subjects that came to the specified specialized clinics fulfilling the inclusion and exclusion criteria were included into the study.

For the group with illness they must have been diagnosed and on treatment for more than 2 years and had no history of admission for more than 6 months before inclusion into the study. This is to avoid the influence of recent stressful events due to exacerbation of their illness. For those in the diabetes and hypertension groups, only those with no end-organ damage were included, and diabetic patients were only on oral hypoglycaemic drugs. For those in the co-morbid group; ischaemic heart disease was defined by history of admission into a coronary care unit and on treatment with an anti-angina drug. For the schizophrenic group they must be on an antipsychotic (minimum dose of haloperidol equivalent of 3 mg daily or monthly depot injection of fluphenazine decanoate or fluphethixol ethanoate at a dose of 25 mg and 20 mg respectively). They should not score more than 1 for Brief Psychiatric Rating Scale (10) items on delusions, hallucination and incoherence. Such exclusion criteria were specified to ensure homogeneity within groups. Thus the results will more correctly reflect outcome from the specified illness and not from confounding factors.

The two questionnaires were given once again to the same 50 healthy controls after a period of two weeks to test the re-test reliability.

Statistical analysis

The data were analyzed by the EPIINFO 6. Discriminant validity was determined via *t* tests to distinguish differences between ill and well subjects. Test re-test reliability was assessed using Pearson *r* correlations.

Results

It was difficult to match the age for the different groups of illnesses because the diseases chosen are prevalent in different age groups. Thus the mean age of the control and the ill groups showed a significant difference ($p<0.05$), the non-ill group being 34.9 years and the ill-group 43.5 years.

The WHOQOL-100 consisted of 100 items organized into six broad domains of quality of life and one general facet. Each facet has four questions and the highest score for each is 5, making a maximum facet score to 20. The highest possible score for each facet is 20, but facets 1, 8 and 11 are reversed scored. Refer to Table 1.

Table 2 shows the mean facet scores for the six groups of subjects.

The test re-test reliability showed a correlation coefficient ranging from 0.60 for the pain facet to 0.90 for the dependence on medication facet.

Table 1: WHOQOL-100 domain and facet structure

Physical Domain	
Facet 1	Pain and discomfort
Facet 2	Energy and fatigue
Facet 3	Sleep and rest
Psychological Domain	
Facet 4	Positive feelings
Facet 5	Thinking, learning, memory & concentration
Facet 6	Self esteem
Facet 7	Bodily image and appearance
Facet 8	Negative feelings
Level of independence	
Facet 9	Mobility
Facet 10	Activity of daily living
Facet 11	Dependence on Medication or treatment
Facet 12	Work capacity
Social Domain	
Facet 13	Personal relationship
Facet 14	Practical social support
Facet 15	Sexual activity
Environmental Domain	
Facet 16	Physical safety and security
Facet 17	Home environment
Facet 18	Financial resources
Facet 19	Health and social care: availability and quality
Facet 20	Opportunities for acquiring new information and skills
Facet 21	Participation and opportunities for recreation/ leisure
Facet 22	Physical environment
Facet 23	Transport
Religion/Spirituality/Personal Belief Domain	
Facet 24	Religion/spirituality/personal beliefs.

Discussion

The hypertensive and the diabetic groups show a similar trend in the areas (F1, F2, F4, F8, F10, F11, F12, and F15) in which quality of life is compromised. The co morbid group also showed a similar pattern but the degree of impairment is greater in those affected areas. It was interesting to note that even though the author had tried to match the socio economic status of the subjects, the hypertensive ($p < 0.005$) and the diabetic patients ($p < 0.05$) subjectively rated their financial resources better than the healthy subjects. These three groups also perceived their social support as better than the healthy or the rest of the groups. The spirituality of the hypertensive ($p < 0.05$) and the diabetic groups are better if compared to the other groups.

The patients with epilepsy seemed to suffer more pain ($p< 0.00005$) and discomfort (F1), more than the hypertensive, diabetic or the schizophrenic groups. As in the epilepsy group we did not specify recent seizure as the exclusion criteria, thus subjects may still have frequent seizures, which made them worry about pain and discomfort, preventing them from doing things they would like to do. Measures like this should alert the physicians to possible ways of reducing this either in more effective medications to control the seizures or in helping the patients to get more support from their families and the support group. The patients included in this study were not involved in an epilepsy support group. Thus it is not surprising that they also suffered as much negative feeling (F8) as the co-morbid group ($p < 0.005$) and interestingly they have more negative feelings compared to patients with schizophrenia. This is also shown in Figure 1 where the psychological domain of the schizophrenic group is not significantly worse than the other groups.

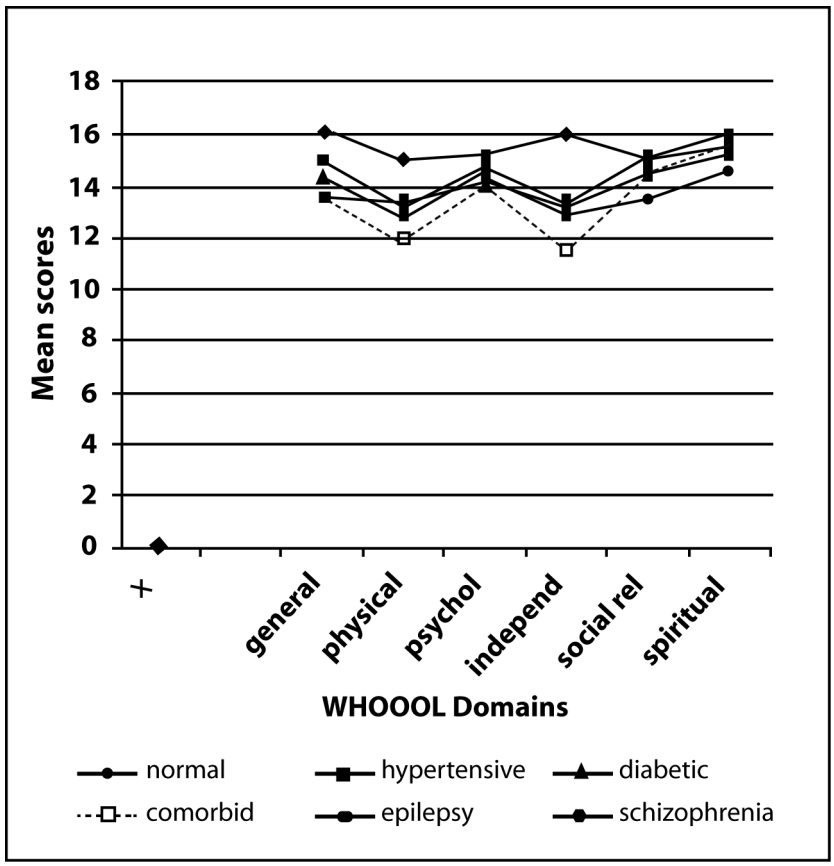
The sexual activity (F15) is impaired in the comorbid ($p > 0.0005$), epilepsy ($p < 0.0005$) and schizophrenia groups (0.000005). The poor health status of the co-morbid group may explain for this impairment, but in epilepsy and schizophrenia groups, the impairment may be influenced by the stigma of the illness. The stigma of the illness may have a far-reaching influence on the self-esteem for epilepsy i.e. negative feelings ($p< 0.005$) and social skills i.e. personal relationship ($p<0.005$) for schizophrenia. The severe impairment in sexual activity in the patients with schizophrenia corresponds to impairment in the personal

Table 2: The mean scores of each facet for the 6 groups of subjects.

Facets	Normal N=50	HPT N=50	Diabetic N=50	Comorbid N=50	Epilepsy N=50	Schizophrenia N=50
F1	9.1	10.7 *	12.9*	12.8 *****	12.4 ****	11.6 **
F2	14.8	11.0 *****	11.5*****	10.0 *****	12.3 ***	12.6 **
F3	15.3	14.6	15.5	14.6	16.2	15.0
F4	14.3	12.9 **	13.8*	12.5 *	12.9*	13.5
F5	15.1	15.1	15.7	14.7	14.2	13.6*
F6	16.0	15.8	16.7	15.1*	14.9*	14.7**
F7	15.8	15.4	16.3	15.4	15.3	15.7
F8	8.8	10.0*	10.2*	11.1**	10.6**	11.2*
F9	16.1	16.3	15.4	14.6*	15.9	15.1
F10	15.2	13.5**	13.6*	12.5***	13.4*	13.7*
F11	7.6	13.2*****	13.6*****	16.0*****	14.2*****	14.0*****
F12	17.1	12.6*****	13.4*****	10.2*****	13.5*****	12.4*****
F13	16.1	16.1	15.9	15.0	15.4	14.4**
F14	14.0	15.5*	15.5*	15.0*	14.5	13.8
F15	15.3	13.7**	13.9**	13.5***	13.0***	12.4*****
F16	14.2	14.8	14.7	13.3	13.0*	14.1*
F17	15.7	15.5	15.3	15.1	15.1	14.4*
F18	14.1	16.2**	15.5*	14.8	15.1	13.8
F19	15.6	15.4	15.5	15.4	15.0	15.2
F20	14.9	14.2*	14.1	13.5**	13.1**	13.0**
F21	13.9	13.0	12.8*	12.0**	12.3*	12.7*
F22	15.0	15.0	14.6	14.6	15.0	14.7
F23	15.9	15.0	15.8	15.0	15.0	13.6**
F24	15.4	15.9*	15.9	15.0	14.9	14.6
G	16.1	14.9**	14.4***	13.5****	13.2*****	13.5**

** $p < 0.05$ ** $p < 0.005$ *** $p < 0.0005$ **** $p < 0.00005$ ***** $p < 0.000005$*

Figure 1: The WHOQOL-100 domain scores for the 6 groups of subjects



relationship facet (F13). It is only in patients with schizophrenia that personal relationships are impaired significantly ($p < 0.005$) and not in other illnesses. This is also reflected on calculation of the social relationship domain (Figure 1) where the score for the schizophrenic group is the lowest.

The results from this pilot study show that certain problems or incapacity amongst our patients might not be obvious or observable on clinical interview, but are picked up on subjective quality of life assessment. Thus a subjective assessment on the quality of life is useful in planning rehabilitation for specific groups of patients on long-term follow-up. From this study such need is reflected most in the epilepsy group.

One of the lessons from this is that, on average, the patient's point of view is valid. A healthy group should not necessarily do better in all domains, as shown in Figure 1. As expected, the healthy group generally have a better quality of life, less pain and discomfort and better level of independence, however, they would not necessarily be spiritually better than the ill subjects. Sometimes having an illness may improve one's appreciation spirituality. This study re-emphasized the importance of spirituality in consideration of healing and strength to cope with illnesses.

As this study is the first of its kind conducted in Malaysia, the result from this study will be an important reference for other similar studies in the future. From this liaison work with WHO Geneva, the author's center had been endorsed as the new collaborative center for WHOQOL work.

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