

Psychometric properties of the WHO Quality of Life questionnaire (WHOQOL-100) in patients with chronic diseases and their caregivers in China

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Objective To evaluate the psychometric properties of the WHO Quality of Life questionnaire (WHOQOL-100), a multi-dimensional, conceptualized, 100-item quality-of-life instrument.

Methods A total of 460 patients in China with chronic diseases (including hypertension, schizophrenia, stroke, end-stage renal disease, head and neck cancer and breast cancer) and 418 family members who were their caregivers were assessed at baseline and one year later.

Findings The WHOQOL-100 had acceptable internal consistency ($\alpha = 0.76$ – 0.90 across domains). There were strong correlations between the domains of WHOQOL-100 and the dimensions of the General Quality of Life Inventory ($\alpha = 0.72$ – 0.82 across related domains). Within domains most facet correlations were satisfactory, although some facets correlated more strongly with a domain other than that to which they had been assigned. Principal component analysis produced four factors accounting for 61% of the total variance.

Conclusion The WHOQOL-100 was able to discriminate between the different groups of patients and was sensitive to clinical change in patients' conditions. It proved to be a reliable and valid instrument for assessing the quality of life of patients with chronic diseases and their caregivers in China.

Keywords Quality of life; Questionnaires; Chronic disease; Caregivers; Reproducibility of results; Sensitivity and specificity; China (source: MeSH, NLM).

Mots clés Qualité vie; Questionnaires; Maladie chronique; Soignant; Reproductibilité des résultats; Sensibilité et spécificité (Epidémiologie); Chine (source: MeSH, INSERM).

Palabras clave Calidad de vida; Cuestionarios; Enfermedad crónica; Cuidadores; Reproducibilidad de resultados; Sensibilidad y especificidad; China (fuente: DeCS, BIREME).

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يمكن الاطلاع على الملخص بالعربية في صفحة 501.

Introduction

Consideration of quality of life (QOL) is becoming increasingly important in evaluations of health policy and medical intervention. However, definitions and standards for evaluating QOL vary dramatically from society to society, and even within a given society depend on the culture of the person being assessed (1–8). Most QOL instruments are therefore used only in the setting where they were developed. However, some have been translated into other languages and used without any attention being paid to making the cultural adaptations that are necessary to ensure that their results are valid locally.

The WHOQOL-100 instrument, which was developed collaboratively in more than 15 cultural settings over several years, has now been tested in 37 field centres, and its psychometric properties have been found to be satisfactory in some cultures (1–3, 9, 10). Therefore it may be possible to use it to

assess variations in QOL across different cultures, to compare subgroups within the same culture, and to measure change across time in response to change in life circumstances.

The WHOQOL-100 has many uses, particularly among chronically disabled patients and their caregivers, people living in highly stressful situations, people with difficulty communicating, and among children. However, few studies have reported on the psychometric properties of the WHOQOL-100 in China (11). The present study reports on the use of this instrument among patients in China with chronic illnesses and their family members who act as caregivers.

Methods

Study sample

Between September 1998 and April 2000, a total of 476 patients with chronic illnesses and 431 family members who were their

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caregivers were enrolled in the study. Participants were recruited from five clinical departments of the Second Xiangya Hospital of Central South University. To be eligible for the trial patients were required to:

- Be newly diagnosed with mild-to-moderate systemic arterial hypertension which was being treated on an outpatient basis.
- Have chronic schizophrenia which was being treated on an outpatient basis (duration of illness 3–10 years).
- Be newly diagnosed as having had a first stroke which was being treated in hospital.
- Have end-stage renal disease which was being treated in hospital and have no history of having had dialysis.
- Be newly diagnosed with head and neck cancer or breast cancer, which was being treated in hospital.

Patients also had to have no other serious co-existing mental illness or physical disease.

These patients were sampled because their diseases represent a spectrum from asymptomatic conditions (such as mild systemic arterial hypertension) to impairment in mental or physical ability that affects a person's ability to take care of him- or herself or maintain independence (patients who have had a stroke or who have schizophrenia) to life-threatening impairments (cancer or end-stage renal disease) (2).

To participate in this study, caregivers were required to satisfy all of the following conditions:

- Be the main caregiver for the patient.
- Be the legal guardian or immediate dependent of the patient.
- Have no serious mental illness or physical disease.

Participants were not eligible for the study if they could not complete the self-administered assessment in Chinese owing to impairments in cognitive function or mental or physical disability. Written or oral informed consent was obtained from each participant (or patient's family member for patients who had schizophrenia). Participants were given US\$ 5.00 on receipt of each completed questionnaire. This study had ethical approval from the WHO Regional Office for the Western Pacific, and the Institutional Review Board of the Xiangya Medical School, Central South University.

Research instruments

WHOQOL-100

WHOQOL-100 was developed using a standard cross-cultural approach to item generation and reduction, as described previously (2). A 235-item pilot version was tested in 15 countries, and this was refined to become the current 100-item self-administered version. The current version consists of six domains: physical, psychological, level of independence, social relationships, environment and spirituality. These domains contain 24 facets (each of which includes four items), giving a total of 96 items. One additional facet (also four items) pertains to global QOL and general health; it is not included in the WHOQOL-100 domain structure but is analysed as part of the instrument.

Facets are scored through summative scaling. Each item contributes equally to the facet score and each facet contributes equally to the domain score. All facet scores and domain scores in the WHOQOL-100 are transformed to reflect a scale from 0 to 100 (1), with higher scores denoting a better quality of life.

For this study, the original English-language version of the questionnaire was first translated into Chinese and then translated back into English to check the adequacy of the first translation.

Discrepancies were resolved by the translators. A pilot study was conducted with 45 patients who had one of the diseases being studied and 36 of their caregivers. No items were deleted, revised or added after the pilot study.

General Quality of Life Inventory

To evaluate the validity of the WHOQOL-100 in Chinese culture, we used a 64-item self-administered version of the General Quality of Life Inventory (GQOLI) that we developed previously (7). The GQOLI has satisfactory psychometric properties (7, 8, 12) and has been used in many studies of patients and family caregivers in China (13–20). It assesses four dimensions of quality of life: physical health, psychological health, social functioning, and living conditions. Each dimension contains items that assess perceived life status (such as, to what extent are you able to carry out your daily activities, for example, washing, dressing and preparing food?), and some items that assess subjective satisfaction with life status (such as, how satisfied are you with your ability to perform your daily activities?). Each item is rated on a 5-point scale, with higher scores denoting a better quality of life.

Procedure

At baseline, trained investigators visited participants and asked them to complete first the WHOQOL-100 and then the GQOLI. If they refused to complete both questionnaires, participants completed only the WHOQOL-100. Only 15.8% of respondents (143/907) needed help completing the instruments because of literacy problems or physical disability. Twelve months later, participants were asked to complete the WHOQOL-100 again, and most of the participants did so.

Patients received appropriate treatment during the year. The clinician in charge of the patient assessed the efficacy of therapies using the clinical diagnostic index of the disease. One year after enrolment, each patient was classified as either having deteriorated or not changed; or having improved or made a recovery.

Statistical analysis

Reliability was assessed by calculating Cronbach's α (coefficient of internal consistency) for patients and caregivers at baseline. Pearson's correlation coefficient was used to identify the convergent validity between the domains of the WHOQOL-100 and the dimensions of the GQOLI. Multi-trait analysis and principal components analysis were used to assess the construct validity of the scales. Discriminant validity was assessed using ANOVA to compare different groups of patients and caregivers. The paired *t*-test was used to assess the responsiveness to clinical change of scores on the WHOQOL-100 at baseline and post-treatment in the different groups.

Results

Characteristics of participants

Of the 476 patients who were enrolled and completed the WHOQOL-100 at baseline, 16 were excluded (owing to missing data on the questionnaire), leaving 460 eligible patients. Of these, 214 also completed the GQOLI at baseline. Table 1 shows the number of patients with each of the different conditions who were enrolled in the study. Twelve-month follow-up assessments were obtained for 385 of 460 (83.7%) patients. Of the remaining 75 patients, 25 withdrew from the study, 20 died, 18 were lost to follow up, 10 changed to different treatments, and data were missing for two.

Table 1. Number of patients included in study, by disease

Disease	No. of patients
Hypertension	90
Schizophrenia	90
Stroke	90
End-stage renal disease	70
Head and neck cancer	60
Breast cancer	60
Total	460

At baseline, the mean age of the patients who had hypertension and those who had had a stroke was higher than in other groups. The mean age of patients with schizophrenia was lowest. Most of the participants with head and neck cancer were male (81.7%; 49/60), while all participants with breast cancer were female. Among the patients with schizophrenia, 60% (54/90) had never been married and 18.3% (17/90) were divorced. Among the patients who had had a stroke, 12.2% (11/90) were widows or widowers. For all groups, the mean duration of illness was less than 5 years. The mean duration of illness was longest for patients with end-stage renal disease or schizophrenia. Patients who had had a stroke had been ill for the shortest time. Our findings represent the earlier stages of coping with lifelong conditions.

Of the 431 family caregivers who were enrolled and completed the WHOQOL-100 at baseline, 13 were excluded owing to missing data. Of the remaining 418 eligible family caregivers, 123 (29.4%) also completed the GQOLI at baseline. Eighty family members cared for someone with hypertension; 88 cared for someone with schizophrenia; 80 cared for someone with stroke; 65 cared for someone with end-stage renal disease; 45 cared for a patient with head and neck cancer; and 60 cared for a patient with breast cancer.

Twelve-month follow-up assessments using the WHOQOL-100 were obtained for 363 (86.8%) caregivers (39 withdrew and 16 were lost to follow up). The caregivers in the hypertension group and stroke group were older than those in the other groups. Altogether, 37/45 (82.2%) caregivers were female in the head and neck cancer group; and 53/80 (66.3%) were female in the stroke group. Most caregivers in the breast cancer group were male (57/60; 95%). Most of the family members who cared for someone with schizophrenia were the parents of the patient (60/88; 68.2%); whereas in the other groups most caregivers were spouses (228/330; 69.1%). The mean amount of time spent each

Table 2. Internal consistency of WHOQOL-100 domains as measured by Cronbach's α based on participants who completed the questionnaire at baseline

Domain	No. of items	Cronbach's α	
		Patients (n = 460)	Caregivers (n = 418)
Physical	12	0.84	0.81
Psychological	20	0.90	0.87
Independence	16	0.81	0.83
Social	12	0.82	0.80
Environment	32	0.76	0.79
Spiritual	4	0.82	0.83
Overall QOL	4	0.81	0.80

day caring for a patient was highest in the renal disease group and the stroke group and was lowest in the hypertension group.

Internal consistency

Table 2 shows the level of internal consistency of the WHOQOL-100 domains. Overall, Cronbach's α for each domain and the general QOL facet exceeded 0.76 in both the patients' group and the caregivers' group (range 0.76 to 0.90).

Convergent validity

Table 3 shows the Pearson's correlations between the WHOQOL-100 domains and the GQOLI dimensions. The four dimensions of GQOLI (physical, psychological, social and living conditions) correlated most highly with the related domains of the WHOQOL-100 (physical $r = 0.77$; psychological $r = 0.82$; social relationships $r = 0.72$; environment $r = 0.73$). The independence domain of WHOQOL-100 was most highly correlated with the physical and social dimensions of GQOLI. The spirituality domain of the WHOQOL-100 was reflected only moderately in the GQOLI psychological scale ($r = 0.45$). However, the overall QOL facet of the WHOQOL showed moderate correlations with all four dimension of GQOLI (range 0.33 to 0.59).

The structure of WHOQOL-100

Table 4 gives the results of the multi-trait analysis showing correlations between the facets of the WHOQOL-100 and its six domains. As expected, most facets had their strongest correlations within the domains to which they had been assigned. However, for five facets the strongest correlation was not with their related

Table 3. Pearson's correlation coefficient for comparison between WHOQOL-100 domains and GQOLI based on 337 participants who completed both questionnaires

GQOLI dimension	WHOQOL-100 domains						Overall QOL facet
	Physical	Psychological	Independence	Social relationships	Environment	Spirituality	
Physical health	0.77 ^a	0.54 ^a	0.69 ^a	0.51 ^a	0.11 ^c	0.17 ^b	0.48 ^a
Psychological health	0.56 ^a	0.82 ^a	0.49 ^a	0.33 ^b	0.16 ^c	0.45 ^a	0.59 ^a
Social health	0.43 ^a	0.47 ^a	0.61 ^a	0.72 ^a	0.31 ^b	0.21 ^b	0.33 ^a
Living conditions	0.22 ^b	0.21 ^b	0.34 ^a	0.35 ^a	0.73 ^a	0.10 ^c	0.46 ^a

^a $P < 0.01$.^b $P < 0.05$.^c Not significant.

Table 4. Correlations between the facets and domains of the WHOQOL-100 based on responses of 878 patients and caregivers who completed the questionnaire at baseline

Facet	Domain					
	Physical	Psychological	Independence	Social relationships	Environment	Spirituality
Pain and discomfort	0.68 ^a	0.61	0.72 ^b	0.46	0.41	0.12
Energy and fatigue	0.73 ^a	0.58	0.66	0.40	0.38	0.21
Sleep and rest	0.59 ^a	0.53	0.42	0.38	0.34	0.12
Positive feeling	0.54	0.80 ^a	0.50	0.63	0.44	0.31
Thinking, learning, memory and concentration	0.39	0.61 ^a	0.49	0.54	0.32	0.08
Self-esteem	0.38	0.71 ^a	0.58	0.72 ^b	0.56	0.28
Body image and appearance	0.42	0.64 ^a	0.48	0.67 ^b	0.22	0.09
Negative feeling	0.58	0.72 ^a	0.51	0.60	0.53	0.23
Mobility	0.70	0.63	0.74 ^a	0.59	0.37	0.11
Activities of daily living	0.66	0.57	0.71 ^a	0.54	0.36	0.06
Dependence on medication or treatments	0.61 ^b	0.57	0.55 ^a	0.45	0.28	0.03
Working capacity	0.51	0.48	0.78 ^a	0.69	0.59	0.07
Personal relationships	0.48	0.68	0.47	0.76 ^a	0.63	0.29
Social support	0.44	0.61	0.53	0.68 ^a	0.61	0.26
Sexual activity	0.25	0.56	0.41	0.60 ^a	0.28	0.09
Physical safety and security	0.33	0.49	0.37	0.42	0.63 ^a	0.15
Home environment	0.34	0.48	0.41	0.53	0.76 ^a	0.22
Financial resources	0.48	0.57	0.45	0.54	0.66 ^a	0.18
Health and social care	0.31	0.35	0.26	0.31	0.59 ^a	0.17
Opportunities for acquiring new information and skills	0.41	0.60	0.37	0.51	0.70 ^a	0.24
Leisure opportunities	0.44	0.46	0.35	0.65 ^b	0.63 ^a	0.30
Physical environment	0.43	0.42	0.38	0.46	0.68 ^a	0.11
Transport	0.51	0.37	0.54	0.39	0.64 ^a	0.16
Spirituality/religion/personal beliefs	0.13	0.44	0.23	0.29	0.00	1.00 ^a

^a WHOQOL-100 domain to which the facet belongs.

^b Facet that do not correlate most highly with their related domains.

domains. The pain facet (physical domain) was most strongly correlated with the independence domain ($r = 0.72$). The medication facet correlated with the independence domain ($r = 0.55$), but was even more strongly correlated with the physical domain ($r = 0.61$). The self-esteem facet and body image and appearance facet correlated slightly more strongly with the social domain ($r = 0.72$ for esteem and $r = 0.67$ for body) than their related psychological domain ($r = 0.71$ for esteem and $r = 0.64$ for body). The leisure opportunities facet correlated slightly more strongly with the social domain ($r = 0.65$) than with the environment domain ($r = 0.63$).

Principal components analysis with varimax rotation was carried out and yielded four factors with eigenvalues >1 , explaining 61% of the variance. The first factor included facets relating to the physical health and independence domains (except the work facet). The second factor was defined by cognitive skills (thinking, learning, memory and concentration), self-esteem, positive and negative feelings, and information sources. Spirituality also was part of this factor. The third factor encompassed nearly all facets relating to the environment domain except the facets reflecting leisure opportunities and opportunities to acquire

new information. The fourth factor comprised all three facets relating to the social domain and work capacity, body image, and leisure. All of these facets contribute to satisfaction with social relationships. The facet relating to overall quality of life contributes to all four factors. This supports the validity of this facet as an overall indicator of quality of life.

Discriminant validity

Patient

Substantial mean differences existed for many of the facets when examined across groups in either the patients' sample or the caregivers' sample (Table 5). The best quality of life was found among patients with hypertension, with scores in all domains and the overall QOL facet being highest among these patients. However, scores on the social relationships facet and the social support facet were higher in patients with breast cancer.

For 12 of the 30 comparisons between domains and facets, scores were lowest among patients with schizophrenia in the psychological domain, social relationships domain, environment domain, and overall QOL facet. For 9 of 30 comparisons made for patients with renal disease, scores were lowest in the QOL

Table 5. Comparison of scores on the WHOQOL-100 across different groups of patients measured at baseline. Higher scores indicate a better quality of life. $P < 0.01$ for all scores

	Group of patients					
	Hypertension ^a (n = 90)	Schizophrenia ^a (n = 90)	Stroke ^a (n = 90)	End-stage renal disease ^a (n = 70)	Head and neck cancer ^a (n = 60)	Breast cancer ^a (n = 60)
Physical	57.9 (18.5)	51.6 (11.7)	36.7 (14.2)	32.7 (16.6)	39.1 (7.7)	44.8 (16.8)
Pain and discomfort	58.3 (19.8)	57.9 (19.8)	34.5 (16.2)	31.2 (11.4)	31.7 (20.7)	33.7 (15.4)
Energy and fatigue	58.3 (21.8)	38.9 (16.9)	31.2 (13.9)	28.9 (21.9)	45.3 (12.4)	49.8 (15.7)
Sleep and rest	57.5 (22.4)	58.7 (21.9)	44.5 (19.1)	38.1 (18.7)	41.1 (10.6)	51.1 (22.0)
Psychological	60.2 (13.4)	41.2 (17.3)	44.7 (11.3)	44.5 (15.3)	43.5 (18.6)	48.8 (22.2)
Positive feeling	58.8 (17.9)	31.7 (19.4)	51.9 (21.8)	48.9 (22.1)	49.2 (18.6)	52.8 (23.3)
Thinking, learning, memory and concentration	58.9 (18.2)	45.7 (21.4)	38.8 (12.6)	51.7 (17.6)	59.7 (15.6)	58.1 (16.5)
Self-esteem	58.3 (18.5)	38.4 (21.3)	46.2 (16.3)	51.3 (18.3)	51.5 (18.2)	53.9 (15.8)
Body image and appearance	67.9 (19.8)	56.6 (17.7)	48.7 (21.3)	43.2 (21.2)	31.8 (11.0)	41.2 (14.8)
Negative feeling	61.2 (23.6)	31.9 (19.3)	36.7 (15.4)	28.9 (15.7)	27.3 (19.5)	39.9 (21.0)
Level of independence	60.1 (18.7)	47.3 (11.7)	36.8 (9.8)	38.6 (17.8)	48.3 (11.6)	54.9 (17.6)
Mobility	62.9 (22.1)	56.7 (15.4)	27.9 (8.9)	45.3 (22.1)	54.1 (14.2)	60.1 (15.4)
Activities of daily living	63.1 (21.1)	58.9 (17.3)	34.5 (11.2)	53.9 (23.7)	52.4 (11.1)	62.3 (13.2)
Dependence on medication or treatments	49.8 (24.5)	34.5 (22.1)	45.6 (20.7)	22.3 (11.7)	41.0 (21.3)	42.8 (20.9)
Working capacity	63.1 (25.0)	41.3 (23.4)	36.7 (23.4)	31.7 (11.5)	46.4 (18.7)	54.2 (21.4)
Social relationships	58.3 (16.5)	30.7 (11.2)	46.1 (14.2)	43.1 (14.3)	51.0 (11.3)	56.1 (20.1)
Personal relationships	58.7 (19.3)	30.7 (12.8)	57.9 (21.3)	54.3 (16.2)	54.5 (12.2)	65.5 (22.7)
Social support	60.3 (20.9)	28.4 (19.6)	56.6 (24.8)	52.8 (25.1)	60.1 (17.9)	63.3 (21.3)
Sexual activity	55.7 (19.8)	31.1 (19.8)	23.4 (21.3)	22.1 (11.8)	38.5 (16.4)	40.1 (20.0)
Environment	58.6 (16.3)	42.8 (14.9)	53.7 (16.7)	49.2 (21.7)	44.1 (9.7)	51.1 (18.9)
Physical safety and security	60.0 (17.7)	61.5 (24.8)	59.6 (22.8)	56.7 (24.3)	49.3 (15.7)	52.3 (19.8)
Home environment	60.3 (22.6)	41.2 (25.6)	62.8 (17.2)	58.6 (21.5)	59.1 (16.1)	56.6 (23.1)
Financial resources	58.6 (23.1)	32.6 (19.0)	60.7 (19.0)	52.1 (19.6)	45.6 (11.1)	49.9 (22.7)
Health and social care	56.5 (13.4)	34.7 (12.1)	58.2 (17.3)	32.1 (13.4)	54.8 (17.5)	48.3 (23.4)
Opportunities for acquiring new information and skills	56.5 (21.9)	33.2 (11.8)	57.9 (21.3)	50.0 (16.4)	48.9 (19.2)	46.9 (19.5)
Leisure opportunities	52.9 (20.9)	27.5 (9.8)	27.3 (15.4)	38.7 (17.6)	47.5 (16.3)	46.4 (21.0)
Physical environment	59.5 (19.3)	51.6 (9.5)	58.9 (17.9)	55.5 (24.3)	47.8 (12.4)	54.9 (18.2)
Transport	65.2 (17.8)	59.9 (29.8)	40.4 (24.3)	56.1 (18.9)	49.8 (13.6~)	55.2 (21.7)
Spirituality/religion/ personal beliefs	58.9 (22.7)	45.6 (23.1)	59.8 (27.1)	53.9 (23.5)	53.6 (24.3)	61.1 (23.5)
Overall	62.8 (18.8)	43.2 (17.9)	54.6 (21.3)	49.8 (18.3)	48.5 (17.2)	54.7 (18.6)

^a ANOVA results controlling for age and sex. Scores are means (SD).

for the physical domain, especially for physical functioning and independence. Stroke patients had the lowest score for level of independence. Patients with head and neck cancer scored lowest for four of 30 comparisons; patients with breast cancer scored worst for none. Patients with breast cancer had a moderate-to-high quality of life in the physical, psychological, level of independence, and social relationships domains and in the overall QOL facet.

Caregivers

Scores for those caring for patients with hypertension were highest for the physical and psychological domains. Neither those who cared for patients with hypertension nor those who cared for patients with breast cancer scored lowest for any of

the comparisons. In contrast, the scores of those who cared for patients with schizophrenia were the lowest for the psychological domain, social relationships domain, environment domain and on the overall QOL facet. Those who cared for patients with schizophrenia had the lowest scores on 17 of the 30 comparisons between domains and facets.

Among those who cared for patients with strokes, the scores on the social relationships domain and environment domain were highest, whereas the scores on the physical domain and level independence domain were lowest.

The highest scores on the level of independence domain and overall QOL facet were found among caregivers for patients with breast cancer. Among those who cared for patients with renal disease, scores on five facets were the lowest of any group.

These facets were: activities of daily living, physical environment, participation in and opportunities for recreation and leisure, sexual activity, and health and social care.

Responsiveness to change

Fig. 1, Fig. 2, Fig. 3 and Fig. 4 show changes in the QOL of patients during the year of the study. The change in quality of life was consistent with patients' medical condition: it was positive for patients who were rated as having improved or recovered and negative for patients whose condition deteriorated or didn't change. This was true no matter which group of patients was analysed.

Fig. 5 presents the results in the change in QOL among patients with breast cancer and head and neck cancer. Patients with these cancers were analysed separately and not divided into different outcome groups because few patients fell into the category of deterioration/no change.

Discussion

Several studies have shown that the WHOQOL-100 questionnaire is valid for use in different cultural contexts (1–3, 9, 10). We have shown that in China the WHOQOL-100 meets accepted psychometric standards (21, 22) and has satisfactory psychometric properties to assess the quality of life in patients with chronic diseases and their caregivers. Our results are similar to those found by Fang's study of patients in China with cardiological disease, arthritis, cancer, diabetes and bone fractures (11).

Reliability

Because the inter-rater reliability and test-retest reliability have already been shown for this questionnaire (2, 9, 10), we used only internal consistency as an index of reliability. Cronbach's α was >0.75 across domains and the general QOL facet for both patients and caregivers (Table 2). Other studies have found α -values ranging from 0.87–0.95 (10), 0.82–0.95 (9), and 0.71–0.86 (2). The WHOQOL-100 had acceptable consistency within the facets and their domains in our sample.

Validity

The validity of instruments measuring QOL is difficult to assess because of the relative abstractness of the concept of quality of life. Hence we used the following approaches: construct validity; convergent validity; and discriminatory power.

We measured the correlation between mean scores in facets and domains to examine the conceptual structure of the instrument. As expected, within domains, most facet correlations were satisfactory, mainly exceeding the criterion of $r = 0.40$ (range, 0.55–0.80). Occasionally facets correlated more strongly with a domain other than that to which they had been assigned. One possible explanation for this may be that inter-correlated domains overlap. On the principal components of the instrument, we found that four factors had eigenvalues >1.0 .

It is often difficult to assess the convergent validity of QOL instruments because there is a lack of generally accepted validation criteria. We used the GQOLI for comparison because it has

Fig. 1. Changes in scores on the WHOQOL-100 during one year of follow-up in two different groups of hypertension patients. Facets are in same order as in Table 4. The last point is the overall quality of life facet

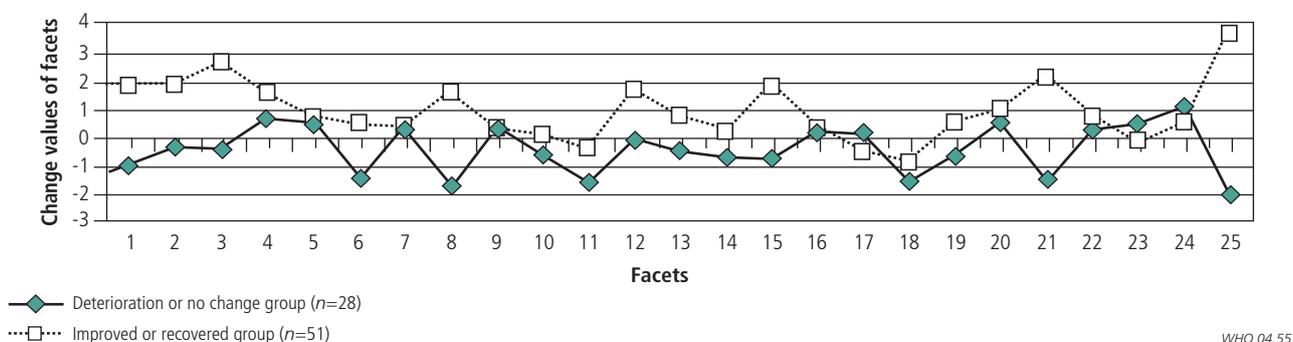


Fig. 2. Changes in scores on the WHOQOL-100 during one year of follow-up in two different groups of patients with schizophrenia

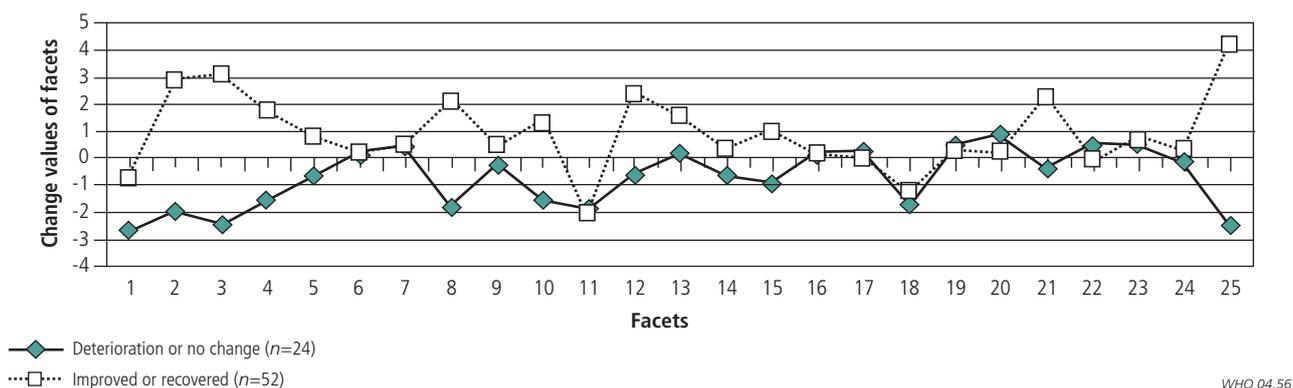


Fig. 3. Changes in scores on the WHOQOL-100 during one year of follow-up in two different groups of patients with stroke

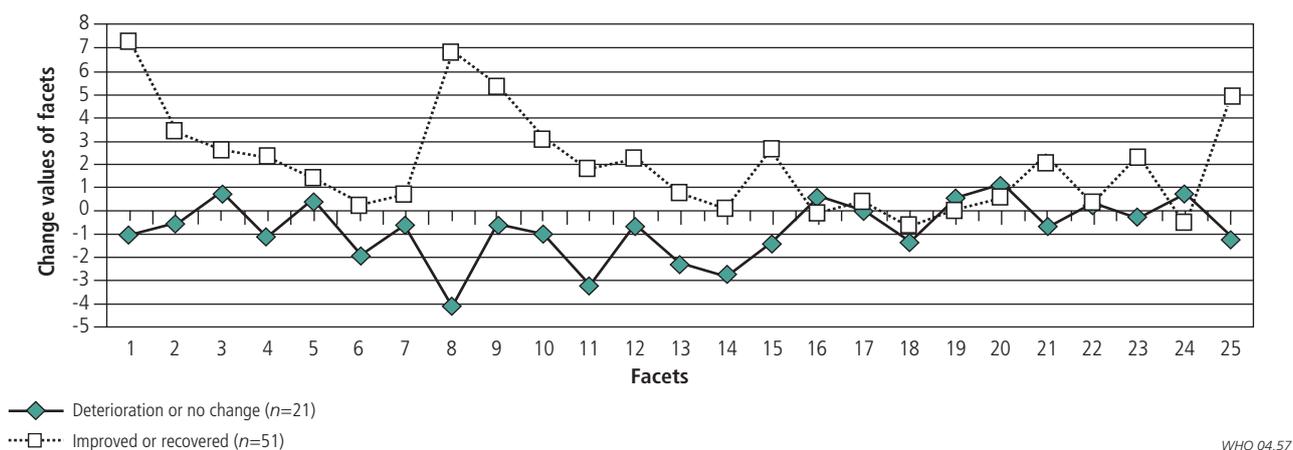
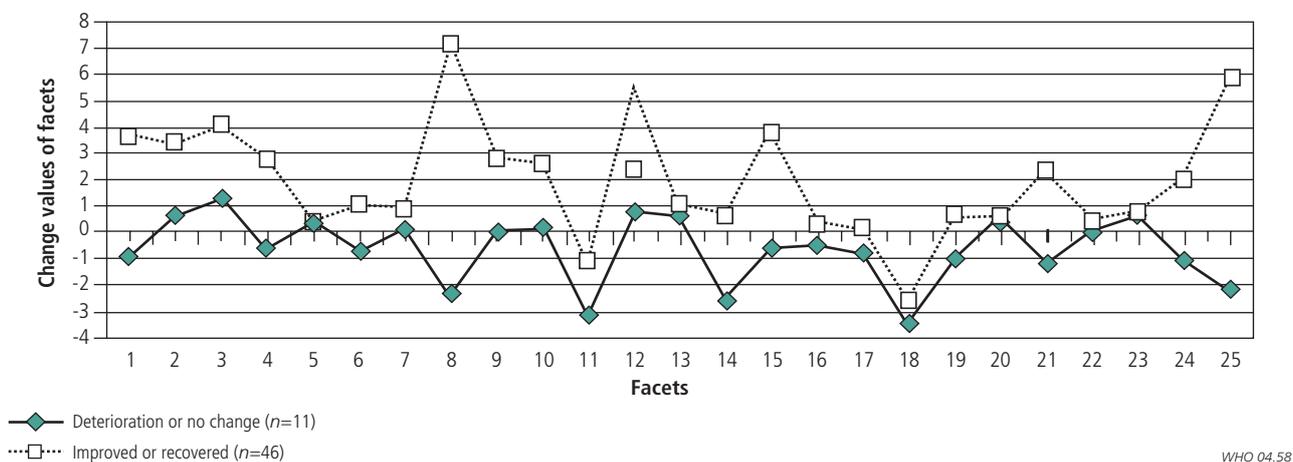


Fig. 4. Changes in scores on the WHOQOL-100 during one year of follow-up in two different groups of patients with end-stage renal disease



been used in China (7, 8, 13–20). Overall, the related domains of the WHOQOL-100 were strongly correlated with the physical, psychological, social and environmental dimensions of the GQOLI — the living conditions dimensions of the GQOLI.

The level of independence domain of the WHOQOL-100 correlated highly with both the physical dimension and the social dimension of GQOLI. The spiritual domain of WHOQOL-100 was most strongly correlated with the psychological dimension of the GQOLI but it was only a moderate correlation ($r = 0.45$). These results show that the WHOQOL-100 may be more concise if the six original domains were compressed into four domains. We have also shown that the WHOQOL-100 has good convergent validity when compared with the GQOLI.

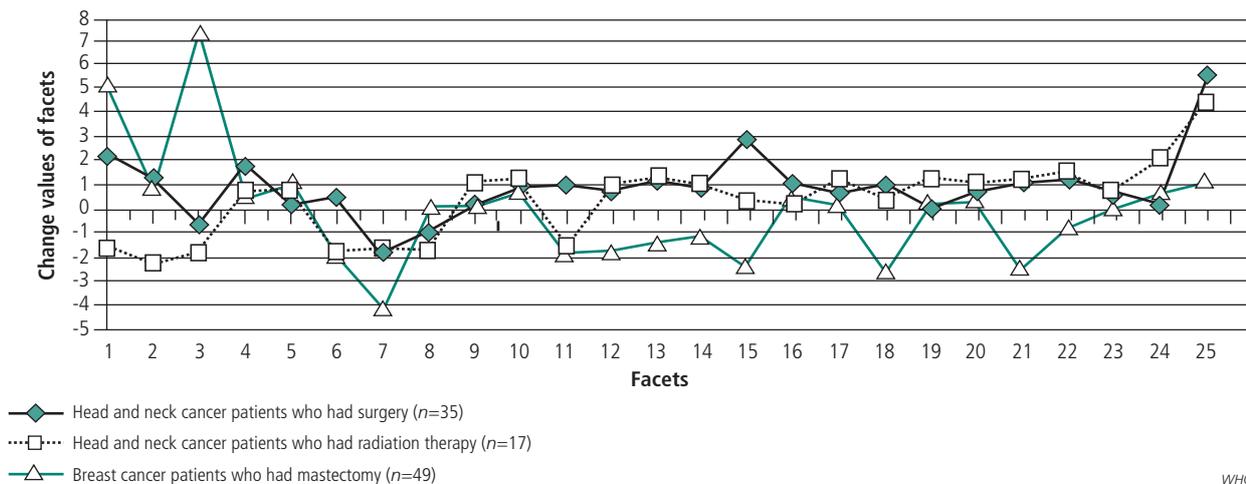
We had three striking results in assessing the discriminant validity of the WHOQOL-100. Firstly, the results provided strong and consistent evidence that the WHOQOL-100 works well in measuring QOL among patients with these chronic diseases (23–31).

Secondly, the QOL profiles in our sample varied widely across diseases. The more severe the impact of a disease on functioning, the poorer the QOL, i.e., QOL was related to the severity of functional impairment caused by each disease. For example, QOL was best among patients with hypertension because there

are few symptoms and little impairment in function in patients with mild-to-moderate hypertension (23–25). Patients with schizophrenia, however, had the lowest scores on 12 out of the 30 domains and facets. Obviously, the impact on QOL was related to dysfunction caused by the disease (23–31). It may also partly explain why many of the facets of QOL in patients with head and neck cancer and breast cancer were not the lowest. Although cancer was regarded as a disease that could never be cured and patients felt their lives were threatened, the actual impairment caused by it may be less than that for patients who have end-stage renal disease, schizophrenia or stroke (28). Among patients with cancer, impairments were mainly found in the psychological domain, such as the body image facet and negative feelings.

Thirdly, disease affected the QOL of caregivers as well as the patients. Several studies have documented the considerable impact that a disease has on a caregiver's QOL (32, 33). Our study showed that, except for the social support facet and financial facet, the scores on nearly all facets and domains were lower among caregivers than in the 3187 healthy people sampled in another study of the WHOQOL-100 (1). The quality of life facets most affected among caregivers were energy and fatigue, sleep, positive feelings, negative feelings, and sexual activity. These facets, mainly in the physical and psychological domains,

Fig. 5. Change in scores on the WHOQOL-100 during one year of follow-up among patients with head and neck cancer or breast cancer



were related to the burden of caring for patients. Scores on the WHOQOL-100 can sensitively reflect different levels of health impairment. Such findings are useful for clinicians.

Responsiveness

An instrument needs to be responsive to measure the QOL of people undergoing important life changes, such as patients with chronic diseases. This responsiveness can help clinicians determine how physical, psychological and social interventions affect a patient's QOL. However, few studies have reported on the responsiveness of the WHOQOL-100 using longitudinal data, with the exception of studies of patients with depression or pain (34, 35).

Our study showed that the WHOQOL-100 is able to respond to changes in patients' and caregivers' quality of life over time. The patients whose health improved or who recovered had positive changes in many facets of QOL and these were reflected in scores on the WHOQOL; whereas those patients whose health deteriorated or who had no change in their clinical outcome had negative changes and these, too, were reflected in the scores (Fig. 1, Fig. 2, Fig. 3 and Fig. 4). Furthermore, changes in QOL among patients with head and neck cancer and breast cancer who had different treatments can also be detected by the WHOQOL-100, thus showing that the instrument responds to changes across time. However, the points discussed below should be kept in mind when longitudinal data in QOL measurements are applied to clinical practice. Consideration should be given to more than simply the patient's clinical outcome following treatment; for example, for patients with hypertension, clinicians should be concerned also about any changes in the physical and psychological functioning of their patients and not only about their blood pressure; while for head and neck cancers or breast cancer, clinicians should be concerned also about their

patients' self-esteem, and self-image of their appearance. Because these changes in facets or domains of QOL vary according to patient groups or clinical outcome, it is better to use the domain or facet scores rather than the global scores for evaluating the QOL; there is thus no total score for the WHOQOL-100 (3).

The limitations of the study should be borne in mind; for example, many facets of QOL in the head and neck cancer and breast cancer patients were not worse than those of other patients, and our findings may therefore apply only to the earlier stages of disease (the average time of illness in head and neck cancer and breast cancer subjects was only 0.61 years and 1.40 years, respectively) and not to end-stage cancer patients.

Additionally, we found that some facets in the environment domain (including safety, home environment, health and social care, opportunities to acquire new information, and physical environment) did not change significantly during the study. One possibility is that these facets did not actually change; however, another possibility is that the WHOQOL-100 is not responsive to changes in these facets and that real change in QOL cannot be detected using it. We found that these facets varied significantly across groups of patients and caregivers, although previous studies (13–20) have reported that items in the environment domain often did not change for long periods. We believe that in our study these facets did not really change, raising the question as to whether they need to be measured repeatedly in longitudinal studies and whether they need only be assessed at baseline. ■

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Conflicts of interest: none declared.

Résumé

Propriétés psychométriques du questionnaire OMS sur la qualité de vie (WHOQOL-100) chez des patients atteints de maladies chroniques et leurs soignants en Chine

Objectif Évaluer les propriétés psychométriques du questionnaire OMS sur la qualité de vie (WHOQOL-100), un outil multidimensionnel et structuré de 100 items pour la mesure de la qualité de vie.

Méthodes L'évaluation a été réalisée en Chine sur 460 patients atteints de maladies chroniques (hypertension, schizophrénie, accident vasculaire cérébral, maladie rénale en phase terminale,

cancers de la tête et du cou et cancer du sein) et 418 soignants membres de leur famille, interrogés à la date de référence et un an plus tard.

Résultats Le WHOQOL-100 avait une cohérence interne acceptable ($\alpha = 0,76-0,90$ entre domaines). Il existait une forte corrélation entre les domaines du WHOQOL-100 et les dimensions de l'inventaire général de la qualité de vie ($\alpha = 0,72-0,82$ entre domaines connexes). A l'intérieur des domaines, la plupart des corrélations entre facettes étaient satisfaisantes, même si

certaines facettes présentaient une corrélation plus forte avec un domaine autre que celui auquel elles appartenait. L'analyse des principales composantes a donné 4 facteurs expliquant 61 % de la variance totale.

Conclusion Le WHOQOL-100 était capable de distinguer les différents groupes de patients et était sensible aux modifications de l'état clinique. Il s'est montré fiable et utile pour évaluer la qualité de vie des patients atteints de maladies chroniques et celle de leurs soignants en Chine.

Resumen

Propiedades psicométricas del Cuestionario sobre Calidad de Vida de la OMS (WHOQOL-100) en los pacientes con enfermedades crónicas y sus cuidadores en China

Objetivo Evaluar las propiedades psicométricas del Cuestionario sobre Calidad de Vida de la OMS (WHOQOL-100), un instrumento multidimensional y conceptualizado de medición de la calidad de vida que abarca 100 elementos.

Métodos Al inicio del estudio y un año más tarde se evaluó a un total de 460 pacientes de China afectados por enfermedades crónicas (como hipertensión, esquizofrenia, accidente cerebrovascular, nefropatía terminal, cáncer de cabeza y cuello y cáncer de mama) y a 418 miembros de sus familias que los atendían como cuidadores.

Resultados El cuestionario WHOQOL-100 mostró una coherencia interna aceptable ($\alpha = 0,76-0,90$ entre dominios). Se observaron estrechas correlaciones entre los dominios del WHOQOL-100 y las

dimensiones del Inventario de la Calidad General de Vida ($\alpha = 0,72-0,82$ entre dominios relacionados). Dentro de los dominios, la mayoría de las correlaciones de facetas fueron satisfactorias, aunque algunas facetas estaban más correlacionadas con un dominio distinto de aquel al que habían sido asignadas. El análisis de componentes principales permitió aislar cuatro factores que explicaban un 61% de la variación total.

Conclusión El cuestionario WHOQOL-100 permitió discriminar entre los diferentes grupos de pacientes y fue sensible a los cambios de su estado clínico, lo que hace de él un instrumento fiable y válido para evaluar la calidad de vida de los pacientes con enfermedades crónicas y de sus cuidadores en China.

ملخص

خصائص القياس النفسي في استبيان منظمة الصحة العالمية لجودة حياة مرضى الأمراض المزمنة ومقدمي الرعاية لهم في الصين

الغرض: تقييم خصائص القياس النفسي لاستبيان المنظمة لجودة الحياة (100- WHO QOL)، الذي يعتبر وثيقة مفاهيمية متعددة الأبعاد تتكون من 100 بند لجودة الحياة.

الطريقة: تم تقييم 460 مريضاً بأمراض مزمنة في الصين (تشمل فرط ضغط الدم، والفصام، والسكتة، والمراحل الأخيرة لأمراض الكلى، وسرطان الرأس والعنق، وسرطان الثدي)، كما تم تقييم 418 من أفراد أسر المرضى ومقدمي الرعاية لهم بشكل قاعدي وبعد عام.

الموجودات: اتسم الاستبيان باتساق داخلي مقبول ($\alpha = 0.76 - 0.90$ بحسب الميدان). ولوحظ ترابط قوي بين ميادين الاستبيان وبين أبعاد قائمة

الجرد العامة لجودة الحياة ($\alpha = 0.72 - 0.84$ بحسب الميادين ذات الصلة). وكانت معظم الارتباطات داخل المجالات مرضية، بالرغم من أن ارتباط بعض الأوجه بميدان ما كان أكثر قوة من ارتباطها بالميدان الذي من المفترض أن ترتبط به. وأسفر التحليل الأولي للمكونات عن أربعة عوامل مسؤولة عن 61% من التباين الكلي.

الخصيلة: نجح استبيان المنظمة WHO QOL - 100 في التفرقة بين مختلف فئات المرضى، وكان حساساً للتغير السريري في حالة المرضى. كما أثبت الاستبيان فعالية وصلاحيته لتقييم جودة حياة المرضى المصابين بأمراض مزمنة ومقدمي الرعاية لهم.

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