

# Measure of quality of life for Taiwanese persons with early to moderate dementia and related factors

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## SUMMARY

**Background** This study validates the Chinese Dementia-Quality of Life instrument (DQoL) in patients with early to moderate stages of Alzheimer's disease (AD) (Clinical Dementia Rating Scale, CDR = 0.5, 1, and 2; MMSE  $\geq$  12).

**Methods** A cross-sectional design was used involving 98 participants (27 controls, 35 patients with questionable dementia (QD), and 36 patients with mild to moderate AD) and 51 paired family caregivers (FCs) (20 FCs of QD patients, 31 FCs of AD patients). FCs were recruited to evaluate patients' DQoL using the parallel form. Internal consistency, construct validity and concurrent validity of the DQoL were examined.

**Results** The findings indicated that the Chinese DQoL instrument has stable internal consistency but only moderate validity when used in early to moderate AD participants with MMSE greater than, or equal to 12. The DQoL and Self-esteem subscales were significantly different across the three dementia severity groups. The values of internal consistency of the DQoL and its five subscales were high for the ratings of both the patients and the FCs. The interscale correlations for the DQoL were almost all significant for patients' and FCs' ratings. Agreement of the DQoL and its subscales for patients and FCs was significant. However, two inconsistencies were found in the results of the factor analysis and the prior conceptualization of patients' DQoL, the subscales of Self-esteem and Negative Affect. Global cognitive impairment and self-care problems significantly correlated with the patients' DQoL, while the patients' depressive symptoms and self-care problems significantly correlated with the FCs' DQoL.

**Conclusions** The Chinese DQoL reported by early to moderate AD patients has good reliability, but moderate validity because the patients' depressive symptoms did not correlate with their DQoL and the major subscales. Both patients' and FCs' ratings on DQoL are important in research and treatment decision making. Copyright © 2007 John Wiley & Sons, Ltd.

KEY WORDS — Alzheimer's disease; Dementia Quality of Life instrument; informant; culture

## INTRODUCTION

Recently the quality of life (QoL) has become a major concern because of the social consequences of chronic diseases and the medical efforts aimed to increase the length and quality of survival (Carr *et al.*, 2001). This concern initiated important QoL research in dementia, including the development of new instruments (Edelman *et al.*, 2005) and investigations into the discrepancies between dementia patients and the reports of proxies (Sands *et al.*, 2004; Fuh and Wang, 2006). However, the related knowledge, largely

derived from Western developed countries, has not been validated in non-Western areas (Liang, 2003). Moreover, few studies have compared the QoL in dementia with cognitively intact elderly (Ready *et al.*, 2004) and those with questionable dementia (QD). Only one translated QoL in dementia instrument has been validated in Taiwan, but without QD patients (Fuh and Wang, 2006). Most of the newly developed QoL in dementia scales are based on Lawton's conceptual framework (1997) because it offers the most systematic attempt to conceptualize QoL in older people (Frytak, 2000). Of these, Brod's instrument—Dementia Quality of Life (DQoL) (Brod *et al.*, 1999a,b) covers most domains (Jonker *et al.*, 2004). Therefore the goals of this study were to: (1) validate the Chinese DQoL in early to moderate AD

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patients; (2) compare the differences in DQoL across the three dementia severity groups and (3) explore the related factors of DQoL.

#### *Quality of life in dementia and related factors*

There are various conceptualizations of QoL in dementia because of the different emphasis on the applicable dementia stage(s) (Ettema *et al.*, 2005). Enjoyment of discretionary activities is important in early to moderate stages, but may no longer be relevant in severe dementia (Hurley *et al.*, 1992). Dementia stages impact self-report capacity, but evidence shows that even moderate dementia patients can contribute their perspectives on QoL (Brod *et al.*, 1999a; Logsdon *et al.*, 1999).

Neuropsychiatric symptoms (Ready *et al.*, 2004; Fuh and Wang, 2006), dementia severity (Ready *et al.*, 2004), depressive symptoms (Logsdon *et al.*, 2002), and functional impairment (Kermer *et al.*, 1998) are associated with QoL in mild to moderate dementia. However, little is known for QD patients who are neither clearly demented nor healthy (Hughes *et al.*, 1982), with a Clinical Dementia Rating (CDR) score equal to 0.5 (Morris *et al.*, 2001; Lin and Liu, 2003). They have an increased risk for developing dementia (Daly *et al.*, 2000). Research on their QoL can estimate the disease impact compared with controls and moderate AD patients.

## DESIGN AND METHODS

### *Study design and participants*

A cross-sectional design was employed using a consecutive sample of 35 QD patients (CDR = .5), 36 AD patients (CDR = 1 or 2) and 27 age- and education- matched controls (CDR = 0) in northern Taiwan. Twenty QD family caregivers (FCs) and 31 AD FCs were recruited. IRB approval and informed consent was obtained from all participants. The diagnosis of AD was made according to DSM-IV criteria (APA, 1994). Data of complete patient demographics, DQoL and Mini Mental State Examination (MMSE) (Folstein *et al.*, 1975) equal to or greater than 12 (Brod *et al.*, 1999a) were used for analysis.

### *Measures*

DQoL consisted of 29 items, measuring five domains on a five-point scale: Positive affect, Negative affect, Feelings of belonging, Self-esteem, and Sense of aesthetics. High scores represented high QoL except for the Negative affect domain (Brod *et al.*, 1999a).

Overall scores and subscores were computed by summing the 29 item scores and the scores of the items in each subscale.

The Cornell Scale for Depression in Dementia (CSDD) is a 19-item, three-point scale, clinician-administered instrument using observational information from both patient and FC (Alexopoulos *et al.*, 1988). Behavioral Pathology in Alzheimer's Disease (BEHAVE-AD) consists of 25 items measuring behavioral problems using a four-point scale of severity (Reisberg *et al.*, 1996).

A Chinese self-care scale (13 items with a five-point scale) for the frail elderly (Chiu and Wang, 1987), was used to assess the ability of dementia sufferers to perform self care. The total scores, by summing the item score reported by FCs, had acceptable validity and reliability (inter-rater reliability 0.91, Chronbach's  $\alpha = 0.72$ ).

The Center for Epidemiologic Studies Depression Scale-10 (CESD-10) (Andresen *et al.*, 1994; Lewinsohn *et al.*, 1997; Boey, 1999) was used to measure the depressive symptoms of the FCs. They were asked to indicate the frequency of the symptoms using a three-point scale.

### *Data analysis*

The SPSS 12.0 was used to perform statistical analyses. One-way ANOVAs were calculated to test the group differences among patients, and *t*-tests were performed to examine group differences in FCs. For both patients' and FCs' DQoL, Cronbach's alpha was calculated to estimate the internal consistency and Inter-scale Pearson correlation coefficients was computed, as an index of construct validity. Agreements of DQoL between patients and FCs were estimated by calculating Inter-Class Correlation coefficients (ICC). A principal component factor analysis was performed to find the underlying conceptual structure of the Chinese DQoL. Since each patient and FC group had small sample sizes, Pearson correlation analyses were performed using the whole patient sample and paired FCs to explore the related factors.

## RESULTS

### *Descriptive statistics for participants and family caregivers*

Patients were 61.2% female, 51% were married, and 75.5% lived with families. Their mean age was 74.11 years (range: 50–90, SD = 8.21) with a mean education of 5.39 years (SD = 2.04). The ANOVA

results indicated that there were significant differences in MMSE, self-care problems, DQoL and Self-esteem across the three patient groups ( $p < 0.05$ ). Post hoc Tukey comparisons indicated that behavioral problems, Positive affect and Sense of aesthetics were significantly different between the control and QD groups, as well as between the control and AD groups, but not between the QD and AD groups (Table 1).

Family caregivers were 60.8% female, 25.5% spouse, 11.8% daughter, 23.5% daughter-in-law, and 35.3% son. Their mean age was 52.31 years (range: 33–81,  $SD = 13.05$ ), with a mean education of 3.25 years ( $SD = 1.52$ ). The  $t$ -test results indicated that there were significant differences in the DQoL scores between QD and AD FCs and in four of the five subscales (Table 2). The data of two FCs were not included in the analysis because of incomplete DQoL ratings. These FCs were younger, lower educated, and rated patients' QoL lower than those in the analysis.

#### Verification of the dementia quality of life questionnaire

Internal consistency of patients' DQoL and its subscales ranged from 0.92 to 0.82, while the internal consistency of the FCs' rating ranged from 0.92 to

Table 1. Descriptive statistics for the demographics and the DQoL ratings of patients

	Control ( $n = 27$ )		QD ( $n = 35$ )		AD ( $n = 36$ )	
	M	SD	M	SD	M	SD
Age (years)	70.81	8.52	75.20	7.82	75.26	8.24
Education (years)	5.41	2.31	5.31	1.89	5.31	2.05
MMSE (0–30) <sup>a</sup>	25.56	3.59	18.97	4.13	16.25	3.26
BEHAVE-AD (0–75) <sup>b,c</sup>	1.22	2.44	2.03	3.46	3.94	3.87
CSDD (0–38)	2.74	3.99	2.09	3.73	3.65	4.13
Self-care (13–65) <sup>a</sup>	15.63	1.76	18.18	2.92	21.77	4.61
DQoL (0–145) <sup>a</sup>	109.70	14.32	103.57	14.44	99.89	19.93
Positive affect (0–25) <sup>b,c</sup>	21.22	3.52	18.49	4.02	16.58	4.32
Negative affect <sup>r</sup> (0–55) <sup>a</sup>	47.56	5.79	43.06	8.07	42.89	9.93
Self-esteem (0–20) <sup>a</sup>	17.11	2.50	14.03	2.91	14.28	3.57
Belonging (0–15)	11.85	3.34	10.71	2.95	10.58	2.37
Aesthetics (0–30) <sup>b,c</sup>	21.96	6.57	17.29	5.41	14.56	5.22

The scores in parentheses indicate the possible range for each specific instrument. BEHAVE-AD = Behavioral Pathology in Alzheimer's Disease Rating Scale; CSDD = Cornell scale for Depression in Dementia; DqoL = Dementia Quality of life; MMSE = Mini-Mental Status Exam;  $r$  = reversed scores.

<sup>a</sup>Significant difference across three dementia-stage groups ( $p < 0.05$ ).

<sup>b</sup>Significant difference between controls and QD ( $p < 0.05$ ).

<sup>c</sup>Significant difference between control and AD ( $p < 0.05$ ).

Table 2. Descriptive statistics for the demographics and DQoL ratings of FCs

	QD ( $n = 20$ )		AD ( $n = 31$ )	
	Mean	SD	Mean	SD
Age (years)	52.70	14.21	52.06	12.49
Education (years)	3.55	1.43	3.06	1.57
CESD-10 (0–30)	6.94	5.96	8.57	6.71
FCs' DQoL (0–145) <sup>a</sup>	95.95	14.33	82.45	17.00
Positive affect (0–25) <sup>a</sup>	17.40	3.52	14.48	4.16
Negative affect <sup>r</sup> (0–55) <sup>a</sup>	37.40	6.86	33.16	7.60
Self-esteem (0–20)	13.95	2.65	12.45	2.90
Belonging (0–15) <sup>a</sup>	10.55	2.44	8.90	2.06
Aesthetics (0–30) <sup>a</sup>	16.45	4.44	13.45	5.69

AD = mild to moderate Alzheimer's disease; CESD-10 = The Center for Epidemiologic Studies Depression Scale-10; QD = Questionable dementia;  $r$  = reversed scores.

<sup>a</sup>Significant difference between QD and AD groups ( $p < 0.05$ ).

0.84. Most of the interscale correlations were significant for both patients' and FCs' ratings (Table 3).

A preliminary exploratory principal component factor analysis with varimax rotation was performed, using the following criteria: (1) eigenvalues greater than 1.00; (2) factor loadings equal to or greater than 0.40 and (3) deletion of items or factors not having more than one item loading at 0.40 or above in that factor. A five-factor solution explained 65.7% of the variance, with the Kaiser-Meyer-Olin measure of sampling adequacy being equal to 0.84, (Table 4). Two items were double loaded: joking and laughing with others and making own decisions, but were classified into the positive affect factor, according to the original conceptualization. No item was deleted.

The ICC coefficients for consistency were significant (DQoL 0.64, Self-esteem 0.63, Positive affect 0.61, Negative affect 0.63, Sense of aesthetics 0.70,  $p < 0.01$ ; Feelings of belonging 0.40,  $p < 0.05$ ). The ICC coefficients for agreements were also significant (DQoL 0.56, Self-esteem 0.61, Positive affect 0.59, Negative affect 0.49, Sense of aesthetics 0.70,  $p < 0.01$ ; Feelings of belonging 0.39,  $p < 0.05$ ).

#### Correlations between demographic factors and neuropsychological variables of Chinese dementia quality of life

As a whole patient sample, DQoL was significantly associated with MMSE and self care problems, while Sense of aesthetics was significantly related to depressive symptoms and behavioral problems among patients (Table 5).

Table 3. Interscale correlations for the DQoL of both patients and family caregivers

	DQoL	Self	Positive	Negative	Belonging	Aesthetics
Patients' DQoL	1					
Self	0.77**	1				
Positive	0.82**	0.77**	1			
Negative	0.76**	0.44**	0.51**	1		
Belonging	0.59**	0.60**	0.46**	0.25*	1	
Aesthetics	0.62**	0.36**	0.43**	0.17	0.26*	1
FCs' DQoL	1					
Self	0.73**	1				
Positive	0.82**	0.75**	1			
Negative	0.77**	0.33*	0.43**	1		
Belonging	0.71**	0.56**	0.62**	0.40**	1	
Aesthetics	0.78**	0.52**	0.59**	0.38**	0.49**	1

\* $p < 0.05$ .

\*\* $p < 0.01$ .

Table 4. Factor Loading from the Principal-Component Analysis for patients' DQoL

Item number and brief description	Factor loading
Factor 1: Negative affect (Eigenvalue = 10.42)	
14. Felt depressed	0.81
16. Felt worried	0.79
12. Felt frustrated	0.79
17. Felt sad	0.71
15. Felt angry	0.69
11. Felt lonely	0.68
13. Felt embarrassed	0.64
10. Felt afraid	0.63
Factor 2: Positive affect (Eigenvalue = 3.76)	
5. Felt happy	0.73
8. Found something that made them laugh	0.73
6. Felt content	0.69
7. Felt hopeful	0.69
2. Satisfied with self	0.59
1. Felt confident	0.59
3. Felt to accomplish something	0.57
9. Jokes and laughs with others <sup>a</sup>	0.41
4. Making own decision <sup>a</sup>	0.33
Factor 3: Sense of aesthetic (Eigenvalue = 2.75)	
25. Listening to sounds of nature	0.80
26. Watching animals or birds	0.78
28. Looking at colorful things	0.76
27. Planting flowers or vegetables	0.71
29. Watching clouds or sky	0.65
24. Listening to music	0.64
Factor 4: Feelings of belonging (Eigenvalue = 1.43)	
23. Felt lovable	0.84
21. Felt useful	0.81
22. Felt people liked you	0.69
Factor 5: Anxiety (Eigenvalue = 1.18)	
18. Felt nervous	0.80
20. Felt anxious	0.79
19. Felt irritated	0.77

<sup>a</sup>Double loaded.

Patients' CSDD was negatively associated with the FCs' DQoL and its four subscales. Patients' self care problems also significantly and negatively related to the FCs' DQoL and all subscales (Table 5).

DISCUSSION

The findings of this study indicated that the Chinese DQoL reported by early to moderate AD patients has good reliability and moderate validity because the patients' depressive symptoms did not correlate with their DQoL and the major subscales. Yet, the disease impact is so severe that even QD patients suffered significantly from decreased life satisfaction as compared with cognitively intact elderly people.

There is a significant agreement between the DQoL of patients and that of the FCs. However, the FCs rated patients with lower levels of QoL than the patients' self rating. Additional correlation analyses found that the depressive symptoms of the FCs negatively impacted their rating on DQoL ( $r = -0.37, p < 0.05$ ) and absence of Negative affect ( $r = -0.52, p < 0.01$ ). FCs' depressive symptoms also negatively impacted the patients' rating on DQoL ( $r = -0.41, p < 0.01$ ), Positive affect ( $r = -0.32, p < 0.05$ ), and absence of Negative affect ( $r = -0.51, p < 0.01$ ) (Table 5). Previous studies (Karlawish *et al.*, 2001; Ready *et al.*, 2004) reported that caregiver depression is associated with caregiver reports about their patient's QoL. The depressive symptoms of informants may bias their reports, or those informants with depressive symptoms may be faced with more difficult situations, leading to a detrimental QoL of their patient.

Table 5. Correlation coefficients between patients' demographic and neuropsychological variables and DQoL

	Age	Edu.	MMSE	CSDD	BEHAVE-AD	Self care	CESD-10
Patients' DQoL	-0.09	-0.10	0.51*	-0.13	-0.09	-0.45**	-0.41**
Self	-0.10	-0.04	0.38**	-0.03	-0.02	-0.31**	-0.19
Positive	-0.17	-0.12	0.49**	-0.09	-0.08	-0.31**	-0.32*
Negative	-0.05	0.01	0.27*	0.00	-0.01	-0.30**	-0.51**
Belonging	-0.11	-0.03	0.22*	-0.02	0.05	-0.23*	-0.19
Aesthetics	-0.12	-0.20*	0.50**	-0.26*	-0.21*	-0.29**	-0.09
FC's DQoL	0.04	-0.02	0.13	-0.45**	-0.25	-0.47**	-0.37*
Self	-0.07	0.03	0.00	-0.32*	-0.17	-0.37**	-0.07
Positive	0.04	0.26	-0.04	-0.37**	-0.09	-0.35**	-0.26
Negative	0.03	-0.10	0.16	-0.40**	-0.24	-0.43**	-0.52**
Belonging	0.02	0.02	0.22	-0.18	-0.26	-0.29*	-0.29
Aesthetics	0.10	-0.14	0.12	-0.35*	-0.17	-0.29*	-0.11

Only paired data were used for family caregivers' CESD, their ratings on the DQoL and the subscale.

\*Significant at 0.05 level.

\*\*Significant at 0.01 level.

The factor analysis results are congruent with the previous conceptualization, with two inconsistencies in the subscales of Self-esteem and Negative affect. All items of Self-esteem were loaded in the positive affect factor. The Western view of self emphasizes the ability to express self, while the Chinese culture emphasizes the maintaining of harmony within a social context (Markus and Kitayama, 1991). These positive self-esteem feelings, therefore, do not stand out to form a factor, but rather integrate into a positive affect factor in Chinese culture.

Items in the Negative affect were split into two factors: negative affect and anxiety. Increasing evidence shows that early dementia is associated with neuropsychiatric symptoms (Hwang *et al.*, 2004; Jorm *et al.*, 2004). It shows that it not only includes depressive moods, but that anxiety, irritability, apathy, and dysphoria are also prevalent, even in pre-clinical stages (Hwang *et al.*, 2004). Future studies may wish to incorporate anxiety as part of the negative affect domain to measure QoL in dementia.

Finally, patients' global cognitive impairment and self care problems negatively impact their DQoL. Patients' depressive symptoms also negatively influence their ability to appreciate aesthetics. These results correspond with the findings of Logsdon *et al.* (2002) that the overall higher QoL is associated with lower levels of depression, better day-to-day functioning, which is closely related to cognition (Willis, 1996). However, somewhat different patterns were found in the rating of DQoL of the FCs. From the family caregiver's point of view, the cognitive impairment of the patient was not as important as the patient's self care problem or their depressive symptoms. This is similar to the findings of Logsdon *et al.* (1999).

Several limitations are acknowledged. First, all patients were recruited from memory clinics, representing a unique population with a possible increased self awareness of their deficits (Clare *et al.*, 2005). Second, there was no data by informants of the controls. This limits the comparison of informant rating on DQoL. The third limitation is the cross-sectional design of this study which does not allow the detection of the responsiveness of DQoL. Only a few longitudinal studies have examined the changes in QoL in dementia (Lyketsos *et al.*, 2003; Funaki *et al.*, 2005; Selwood *et al.*, 2005), and they ranged from 3 months to 2 years and only had small sample sizes. Within a 2-year period, the QoL in dementia remained unchanged (Lyketsos *et al.*, 2003). Therefore, a research period of longer than 2 years may detect QoL responsiveness and explore possible predictors for this change.

#### CONFLICT OF INTEREST

None.

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