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# **Psychometric testing of the caregiver quality of life index-cancer on a Taiwanese family caregiver sample**

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# INTRODUCTION

- Cancer has ranked in the top 10 causes of death in Taiwan since 1982, with mortality increasing each year.
- Although cancer has a tremendous impact on patients, healthcare professionals should not ignore the burden, stress, and life changes faced by family caregivers in the caregiving process, especially in the terminally ill stage.



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- The major goal of end-of-life care, as suggested in several studies, is to achieve the best quality of life (QOL) for both patients and their family caregivers.
- The QOL of terminally ill patients' family caregivers has rarely been studied in the Asia Pacific zone. This gap in the literature may be due to the lack of a proper measurement tool.



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- To fill this gap, the present study was conducted to translate an internationally established QOL instrument for caregivers.
- The purpose of this paper is to describe our results establishing the initial psychometric properties of the **Mandarin** version of the **CQOL-C (CQOLC-M)**.



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# Research question and Hypothesis

- The reliability and validity of the CQOLC-M were tested by addressing the following research questions and hypotheses:

## **Question 1.**

What is the internal consistency reliability of the CQOLC-M?

## **Question 2.**

What is the underlying factor structure of the CQOLC-M?



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### **Hypothesis 1.**

Family caregivers with stronger social support will have better QOL.

### **Hypothesis 2.**

Family caregivers with better spiritual well-being will have better QOL.



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**Hypothesis 3.**

Family caregivers with more pain and/or caring for patients with more pain will have poorer QOL.

**Hypothesis 4.**

Family caregivers with a worse economic situation will have poorer QOL.



## Methods

To be included in the study, family caregivers had to meet the following criteria:

- (1) Have a relative with terminal stage cancer as judged by the patient's physician
- (2) Be identified by the patient as the unpaid person most involved with their actual care
- (3) Be 18 years of age or older
- (4) Be willing to participate and able to communicate with researchers.



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## Development of the CQOLC-M

- The CQOLC has been tested for major family caregivers of cancer patients who accepted active treatment and palliative care in both the US and Korea.
- The CQOLC was translated into Mandarin with Dr. Weitzner's approval.



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- Translation involved forward translation, back translation, and quantitative methods to evaluate the consistency of the translated content.



## Criterion Measures for Construct Validity

- The validity of the CQOLC-M was assessed by measuring patients' and caregivers' spiritual well-being, social support, degree of pain, and economic situation using established instruments:
  1. The Spiritual Well-Being Scale (SWBS)
  2. Medical Outcomes Study Social Support Survey (MOS-SS)
  3. American Pain Society Patient Outcome Questionnaire (APS-POQ).
  4. Economic situation scale



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**Table 1** Demographic Characteristics of Patients and Major Family Caregivers (N=359 Dyads)

Variable	Patients		Family Caregivers	
	Mean ± SD (range )	n (valid %)	Mean ± SD (range )	n (valid %)
Age (years)	60 ± 15.55 (16-92)		42.97 ± 13.59 (15-84)	
<b>Gender</b>				
Male		194 (55.3)		131 (36.8)
Female		157 (44.7)		225 (63.2)
Missing value		8 (--)		3 (--)
<b>Education background</b>				
Illiterate		83 (23.9)		29 (8.2)
Primary school		120 (34.9)		63 (17.8)
Middle school		50 (14.4)		53 (14.9)
Vocational and high school		78 (22.4)		163 (46.1)
Above college		17 (4.9)		46 (13.0)
Missing value		11 (--)		5 (--)



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Variable	Patients		Family Caregivers	
	Mean $\pm$ SD (range )	n (valid %)	Mean $\pm$ SD (range )	n (valid %)
<b>Marital status</b>				
Married		330 (93.8)		279 (78.6)
Single		22 (6.2)		76 (21.4)
Missing value		7 (--)		4 (--)
<b>Relation to patient</b>				
Spouse				113 (33.7)
Parents				55 (16.4)
Child				106 (31.6)
Other				61 (18.2)
Missing value				24 (--)



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Variable	Patients		Family Caregivers	
	Mean $\pm$ SD (range )	n (valid %)	Mean $\pm$ SD (range )	n (valid %)
<b>Living with patient</b>				
No				13 (3.7)
Yes				338 (96.3)
Missing value				8 (--)
<b>Employed</b>				
No				198 (55.6)
Yes				158 (44.4)
Missing value				3 (--)
<b>Economic situation</b>				
Very insufficient				59 (16.7)
Somewhat sufficient				93 (26.3)
Moderately sufficient				165 (46.6)
Very sufficient				37 (10.5)
Missing value				5 (--)



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**Table 2** Descriptive Analysis of Caregiver QOL and Related QOL Outcomes for Both Caregivers and Patients (N=359 Dyads)

Variable (possible score range)	Patients		Family Caregivers	
	Mean $\pm$ SD (actual range )	n (%)	Mean $\pm$ SD (actual range )	n (%)
Caregiver QOL (0-140)			81.72 $\pm$ 19.56 (31-126)	
Spiritual well-being(20-120)	79.08 $\pm$ 14.08 (39-119)		79.53 $\pm$ 13.75 (48-120)	
Social support(20-100)	71.58 $\pm$ 14.60 (21-95)		67.20 $\pm$ 15.99 (19-95)	
Pain intensity (0-10)				
Without pain		167 (46.8)		240 (66.9)
With pain		192 (53.2)		119 (33.1)
Current pain	3.78 $\pm$ 2.96 (0-10)		1.41 $\pm$ 2.36 (0-10)	
Worst pain in the past 24 hours	5.85 $\pm$ 3.36 (0-10)		2.09 $\pm$ 2.96 (0-10)	
Average pain in the past 24 hours	4.63 $\pm$ 2.84 (0-10)		1.65 $\pm$ 2.43 (0-10)	



## Results-Validity of the CQOLC-M

- Pearson's correlations showed that CQOLC-M scores were moderately, positively and significantly correlated to both MOS-SS scores ( $r=.26, p<.01$ ), and to SWBS scores ( $r=.30, p<.01$ ).



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**Table 3** Differential Analysis of Economic Situation, Degree of Pain, and QOL for Family Caregivers (N=359 Dyads)

Variable	CQOLC-M Mean ± SD	F/t	Scheffe's Follow-up test
<b>Patients</b>			
Average pain in the past 24 hours			
No/mild pain (1)	87.16 ± 18.8	<b>F=4.90*</b>	1>3
Moderate pain (2)	80.22 ± 20.9		
Severe pain (3)	76.04 ± 18.9		
<b>Family caregivers</b>			
Pain in the past 24 hours			
With pain	74.72 ± 20.3	<b>t=- 4.22**</b>	
Without pain	85.04 ± 19.4		
<b>Economic situation</b>			
Very insufficient (1)	68.37 ± 21.9	<b>F=12.28**</b>	1<2; 1<3;1<4
Somewhat sufficient (2)	79.03 ± 15.7		
Moderately sufficient (3)	86.14 ± 19.5		
Very sufficient (4)	88.24 ± 18.7		



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Exploratory factor analysis – 7 factors model

cumulative variance: **48.15%**

Cronbach's  $\alpha = 0.87$ .

- Factor 1: burden
- Factor 2: caregiving trouble
- Factor 3: life interference
- Factor 4: social support
- Factor 5: financial concerns
- Factor 6: spiritual well-being {Cronbach's  $\alpha = 0.64$ }
- Factor 7: other {Cronbach's  $\alpha = 0.28$ }



## Discussion

- The internal consistency reliability of the overall CQOLC-M was adequate (Cronbach's  $\alpha = 0.87$ ).
- However, the internal consistency reliability for factor 6 (spiritual well-being) and factor 7 (other) were too low ( $\alpha = 0.64, 0.28$  for subscales 6 and 7). The sixth subscale (factor 6: spiritual well-being) only includes 2 items, while the factor loading of the seventh subscale (factor 7: other) is  $< 0.4$ , possibly leading to its low  $\alpha$  value.



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- In exploratory factor analysis, a good scale item should have a high loading onto its related factor. If the factor loading is too low ( $< 0.40$ ), or one item has similar loadings onto different factors, the item should be deleted or revised.
- Items 4, 5, 25, 27 with factor loading  $< 0.40$  were deleted in this study.



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- The items originally belonging to the disruptiveness subscale divided into two factors (factor 2: caregiving trouble, and factor 3: life interference), but are suggested to be incorporated into a single factor due to their similar meaning.



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- Finally, 5 factors were named according to the driving items (items with the highest factor loading), i.e., burden; disruptiveness; spiritual well-being; social support, and financial concerns.
- A detailed comparison of the original CQOLC and CQOLC-M in terms of adjusted factors and items is shown in my paper (Tang et al., 2009).



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- The construct validity of CQOLC-M was verified through hypothesis testing and known-group comparison.
- The QOL of major family caregivers was related to their perception of their economic situation, in consistent to previous results from the US and Korea.
- Taiwanese family caregivers of hospitalized terminally ill patients have to bear not only the cost of medical treatment and family expenses, but also tend to hire additional nurse aides at their own expense to provide around the clock care to their loved one.
- Economic pressure on caregivers is most likely higher than on patients, so its influence on caregivers' QOL should not be ignored.



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- Over half of the patients in this study experienced moderate pain in the past 24 hours, yet 33.1% ( $n=119$ ) major family caregivers also experienced mild pain, influencing their quality of life.
- Interestingly, the correlation between the family caregivers' QOL and their own pain was higher than with the patients' pain (data not shown). This result contradicts with a previous report that emphasizes the effect of patients' pain on caregivers' QOL more than the caregivers' physical state, pain or physical discomfort.
- Thus, we highly recommend that future researchers consider the influence of family caregivers' physical state on their QOL.



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- The preliminary support for using the CQOLC-M and confirmation of its reliability and validity in Taiwan allow this tool to be used widely not only throughout Taiwan, but also in other Mandarin-speaking counties, e.g., China, and Hong Kong. Studies based on this tool might facilitate the development of hospice care in those countries.