

# 行政院國家科學委員會補助專題研究計畫成果報告

## 癌末患者選擇末期醫療行為與生活品質之研究<sup>(第二年)</sup>

( A study of behavior intention and quality of life for terminal cancer patients toward palliative care )

計畫類別： 個別型計畫          整合型計畫

計畫編號：NSC89 - 2314 - B - 002 - 547 -

執行期間：89年08月01日至90年07月31日

計畫主持人： 胡文郁 助理教授

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## Abstract

The purposes of this study were to investigate the life quality and medical behaviors of terminal cancer patients and related factors in Taiwan. The method of sampling was purposive sampling. The sample was composed of 64 terminal cancer patients from medical center. Data was collected by interview and questionnaire. The data analysis was used by SPSS computer programs. The major findings of the study were: 1) the SIS score was  $6.7 \pm 2.4$  and MQOL total mean score was  $6.1 \pm 1.5$ ; 2) the mean scores of MQOL subscale, the rank orders from high to low were support ( $8.0 \pm 2.8$ ), existential well-being ( $6.1 \pm 2.0$ ), psycho-logical symptoms ( $6.1 \pm 2.0$ ), physical symptom ( $4.2 \pm 2.8$ ), and physically well-being ( $4.2 \pm 3.2$ ); 3) The MQOL total score had moderate correlation with SIS ( $r=0.29, p<0.05$ ). The SIS correlated significantly with the psychological symptoms subscale of MQOL ( $r=0.33, p<0.01$ ); 4) ECOG-PSR had highly significant negative correlation with physical well-being ( $r=-0.34, p<0.001$ ) and physical symptoms ( $r=-0.44, p<0.001$ ). The most important predictor of received palliative care was attitude toward palliative care. The MQOL scale in Chinese version was constructed by physical symptoms (items 1-3), psychological well-being (items 5-8), existential well-being (items 9-14), and support (items 15-16). The item 4, 'Over the past two days, I have felt: physically (terrible/physically well)', was also treated as a single item (physical well-being) similar with English version. The results of factor analysis for the construct validity of the MQOL Chinese version is acceptable and similar to the results in two Cohen's studies for terminal cancer patient in palliative care unit (the English version, 1997 and 2001).

**Keywords:** Palliative care, knowledge, Quality of life, Good death, Behavior intention

## Introduction

In the last twenty years, cancer has been the leading cause of death.<sup>1</sup> One study estimated the terminal cancer care demand is projected to reach

more than three times the present demand in Taiwan, by the year 2012.<sup>2</sup> The goal of palliative care is achievement of the best quality of life for patients and their families. Selecting the most suitable QOL instrument for this terminal patients' study, is namely the MQOL. There must be considerable doubt as to the issues of the cross-cultural adaptation, cultural diversity and translation about using the existing QOL instruments. Therefore, The purposes of this pilot study were: 1) to assess the equivalence of conceptual and linguistic in translation process of MQOL questionnaire valued by Taiwanese terminal cancer patients; 2) to examine the validity and reliability of the Chinese version MQOL questionnaire in psychometric testing; 3) to determine the most important predictors to SIS between physical symptoms and MQOL subscales.

## Method

### Subjects

A purposive sampling method was used on the in-patient palliative care unit and hematology-oncology wards of the National Taiwan University Hospital. The patients who met the following inclusion criteria were considered eligible for the study: 1) the patient with advanced cancer, whose disease is not responsive to curative treatment; 2) believed to have a life expectancy of less than 6 months, based on the primary physician's judgement; 3) conscious clear and communicable; 4) gave meaningful informed consent or agreed to participate by oral; 5) not so weak that completing the questionnaire would be a burden. The patient's primary physician and nurse involved in the care of the participant determined eligibility.

### Instruments

Demographic data were collected to describe the patient, included the age, gender, diagnosis, educational level, religious denomination, location of care and patient's awareness of terminal stage. Four main variables were measured in the study including SIS, MQOL, ECOG-PSR and 27-item physical symptom instruments.

## Procedure of establishing content validity and equivalence

Each item in the equivalence of MQOL questionnaire was appraised from very inappropriate (1) to very appropriate (5). It was then successfully back translated from Chinese into English. The equivalence of the English and Chinese versions was verified. The corrected Chinese language version of the MQOL questionnaire was determined the content validity by eleven experienced experts with four physicians, four nurses, psychologist, social worker and chaplain (Buddhist) in palliative or oncology care unit prior to the study. A content validity index (CVI) was used to determine the content validity of the MQOL questionnaire. In the total sample, 10 of 1152 values (0.9%) were missing (10 MQOL).

## Results & Discussion

### 1. Results

Sixty-four patients consented to participate in the study. The sample was almost equally divided between palliative care unit (46.9%) and Hematology-Oncology ward (53.1%). The Fifty-four (84.4%) participants completed the questionnaires. The participants were predominantly male (62.5%) and with a mean age of 47.8 years. The religions of the patients were predominantly Buddhism and Taoism (68.7%). The most common cancers were Hematological (39.1%). The mean score on the ECOG-PSR for the terminal cancer patient was 2.44. Only 60.1% of participants were fully aware and knowledgeable of the terminal nature of their disease and their prognosis.

The results found the SIS score was  $6.7 \pm 2.4$  and MQOL total mean score was  $6.1 \pm 1.5$ . And the mean scores of MQOL subscale, the rank orders from high to low were support ( $8.0 \pm 2.8$ ), existential well-being ( $6.1 \pm 2.0$ ), psychological symptoms ( $6.1 \pm 2.0$ ), physical symptom ( $4.2 \pm 2.8$ ) and physically well-being ( $4.2 \pm 3.2$ ).

### Validity and reliability of MQOL Chinese version

#### 1) Validity

The culturally equivalent testing by five expert judgment, all in which the means of 17 items were above 4 and with a standard deviation less than 1.0. Eleven experts rated all 17 items in the MQOL questionnaire for the CVI analysis. Except item 7 and 14 all other items were rated '4' (quite relevant) or '5' (very quit relevant and succinct) which yield a 100% agreement for the 15 items. The item 7 and 14 which yielded 90.0% and 81.8% agreement. Additionally, 15 terminal cancer patients filled out the questionnaire and revised to establish the face validity.

In the scale, the value of the Bartlett's test of sphericity (BT) was 447.35, significant value was 0.00; and Kaiser-Meyer-Olkin (KMO) value was 0.72 respectively. Therefore, the MQOL scale was suitable for exploratory factor analysis. Then, the Principal component analysis with orthogonal varimax rotation

was performed for the 16 items. Based on the theoretical base, the most interpretable and maintaining consistency with the previous Cohen's studies, the four-component solution was selected. The four components account for 64% of the total variance explained in the variables. The factor loadings of the four subscale rotated component matrix underlined in each item in table 3. Finally the MQOL scale in Chinese version was constructed by physical symptoms (items 1-3), psychological well-being (items 5-8), existential well-being (items 9-14), and support (items 15-16). The item 4, 'Over the past two days, I have felt: physically (terrible/physically well)', was also treated as a single item (physical well-being) similar with English version. The results of factor analysis for the construct validity of the MQOL Chinese version is acceptable and similar to the results in two Cohen's studies for terminal cancer patient in palliative care unit (the English version, 1997 and 2001).

#### 2) Reliability

For reliability analysis, the internal consistency of the MQOL total score and each MQOL subscale was calculated by using Cronbach's  $\alpha$ . The MQOL subscale and the complete 16-item scale are good ( $\alpha > 0.70$ ), with the exception of the support subscale (16-item MQOL,  $\alpha = 0.83$ ; physical symptoms,  $\alpha = 0.90$ ; psychological symptoms,  $\alpha = 0.77$ ; existential well-being,  $\alpha = 0.73$ ; support,  $\alpha = 0.69$ ).

#### 3) The relationships among the SIS, MQOL and other variables

The MQOL total score had moderate correlation with SIS ( $r = 0.29$ ,  $p < 0.05$ ). The SIS correlated significantly with the psychological symptoms subscale of MQOL ( $r = 0.33$ ,  $p < 0.01$ ). Similar to our expectation, ECOG-PSR concerning performance status had non-significant correlation with SIS. And it also had non-significant correlation with MQOL total score, psychological, existential well-being and support subscale. But ECOG-PSR had highly significant negative correlations with physical well-being ( $r = -0.34$ ,  $p < 0.001$ ) and physical symptoms ( $r = -0.44$ ,  $p < 0.001$ ). It provided the satisfactory diversity validity for the MQOL instrument. After Scheffe's test, there were no significant different between demographic characteristics (wards, gender, age, marital status, education, religion, primary cancer and patient aware the terminal stage) with SIS and MQOL total scores (ANOVA,  $P > 0.05$ ). There were significant differences between ECOG-PSR scores on wards ( $F = 4.41_{(1,62)}$ ,  $P < 0.05$ ). Those who were in palliative care unit more dependent than those who in non-palliative care unit (means were 2.1 and 2.8).

#### 4) The Predictor variables of SIS

Multiple regression analysis revealed that the four MQOL subscales, physical well-being item plus the disturbance degree of 27-item physical symptom. They were able to predict 15.7 % of the variance SIS

( $R^2$  adjusted=0.157,  $P<0.01$ ). The standardized beta ( ) coefficients for this regression equation indicated that the first important predictor is insomnia (  $\beta=-0.27$ ,  $p<0.05$ ), and the second predictor is psychological well-being (  $\beta=-0.26$ ,  $p<0.05$ ) in this equation. Advanced to put MQOL each item into the regression equation indicated the only item was depressed (  $\beta=-0.48$ ,  $p<0.001$ ). It is able to predict 21.5% of the variance SIS ( $R^2$  adjusted=0.215,  $P<0.01$ ). These results lead to the conclusion that if the terminal patient had higher degree of disturbance by insomnia and psychological symptoms then their SIS were lower.

## 2. Discussion

The results of factor analysis for the construct validity and internal consistent reliability of the MQOL Chinese version is acceptable and similar to the English version. The slight difference from Cohen's study (English version) may be due to the challenge of language and culture translation and adaptation.

The purpose of factor analysis is to reduce variables (from complex to simple) to apply in clinical practice conveniently. Future research should focus on the item 13 and 14 require rewording to ensure that it is relating to existential factor rather than psychological or support factor. Explore additional cultural sensitive and diversity items into MQOL questionnaire using qualitative methods.

What is not so widely understood, nearly forty percent of terminal patients did not fully aware and knowledgeable of the terminal nature of their disease and their prognosis. There is sufficient evidence to show that the religious beliefs of the patients were predominantly Buddhism, Taoism and Folks nearly seventy percent.<sup>3</sup> Particularly, Chinese culture are affected by Confucian school had been five thousand years. To quote Analects of Confucius "un-recognize through to life, how could you recognize through to death?" 'Death' is a taboo for Chinese people, as can be seen in the above quotation. It should also be added that it is not popular of death education in medical curriculum and emphasize curing more than caring. Traditional medical care believes death is a failure of medical treatment.

Therefore it is difficult to tell the truth for the primary physician of terminal patient. Even if the physician would like to tell the truth for the patient, the families were barriers. Because Chinese culture is family orientation, the autonomy of individual is not similar the west culture and not be stressed. It is noteworthy ethical issue to exploratory in clinical practice in Taiwan.

The perception of patients feel existentially at ease, feel supported by family and professional caregivers in spite of physical problems, overall QOL is perceived higher than functional scale scores. It may be positively modified to maintain one's QOL with

appropriate care, thereby relieving the suffering of those who are actively facing death. The philosophy of palliative care also mentioned, when the patient's physical declined but psychological and spiritual has the potential for growth. In this study, we also found "depressed" were very important predictor of SIS. Therefore caring the body and mind are fundamental and important. The total explained variance for SIS is 15.7 % ( $R^2$  adjusted) only, nearly 84.3% of variances remained unexplained. Some variances might be explored in future study.

### 、 Self evaluation of result

There was consistent between result and proposal. Although psychometrically, the Chinese version of the MQOL questionnaire had shown statistically acceptable level of reliability, validity and equivalency for initial testing. The limitations of this study come from did not use a randomized design to test the equivalency of the instrument with the original version. It may not reflect some of the cultural characteristics or connotative meanings of the English version. In addition, it is not able to accurately measure the QOL change of an individual over time. Validation is a continuous process. The nursing intervention of palliative knowledge and referral procedure has been established (see Figure 1). And there were twelve patients were treated. Because the sample size was not enough. Therefore it is continuous to do the study. Future research in the development of a translated instrument, we should systematically test the applicability, respondent and administrative burden of instrument. A longitudinal study may demonstrate that MQOL has sufficient stable (test-retest reliability) and responsiveness to reflect changes in an individual's quality of life over time. It can be study to choose another appropriate QOL instrument for convergent validity. Cross-cultural differences remain to be explored in future qualitative studies. The MQOL short-form could be developed and be quick and easy to administer to audit quality of terminal care for clinically useful everyday.

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Table 1. Rotated Factor Matrix by Varimax with Kaiser Normalization for MQOL (N=64)

MQOL items	Physical symptom	Psychological symptoms	Existential well-being	Support	Mean (SD)	Rank
<b>Physical symptoms</b>					<b>4.2(±3.2)</b>	
1) 1 <sup>st</sup> Physical problem	<b>.87</b>	-.05	.20	.06		16
2) 2 <sup>nd</sup> Physical problem	<b>.93</b>	.07	.19	.12		15
3) 3 <sup>rd</sup> Physical problem	<b>.86</b>	.14	.02	.07		10.5
<b>Physical well-being</b>					<b>4.2(±2.8)</b>	
4) Physically well/terrible	<b>.30</b>	-.10	<b>.68</b>	-.11		14
<b>Psychological symptoms<sup>a</sup></b>					<b>6.1(±2.0)</b>	
5) Depressed	-.05	<b>.68</b>	.15	.15		7
6) Nervous and worried	.13	<b>.77</b>	.21	-.09		9
7) Time did	.17	<b>.79</b>	-.04	.22		5.5
8) Fear future	-.03	<b>.69</b>	.01	.05		8
<b>Existential well-being<sup>b</sup></b>					<b>6.1(±2.0)</b>	
9) Existence meaningful	.07	.10	<b>.77</b>	.41		10.5
10) Achieving goals	-.05	.14	<b>.62</b>	.01		13
11) Life worthless	.27	.03	<b>.37</b>	.59		5.5
12) Control over time	.20	.25	<b>.66</b>	.29		12
13) Like self	.06	<b>.48</b>	<b>.10</b>	<b>.61</b>		3.5
14) Every day is a gift	.23	.04	<b>.13</b>	<b>.75</b>		3.5
<b>Support<sup>d</sup></b>					<b>8.0(±2.0)</b>	
15) World is caring	-.01	.27	.37	<b>.62</b>		2
16) Felt supported	-.12	.01	-.15	<b>.83</b>		1
<b>SIS</b>					<b>6.7(±2.4)</b>	
<b>MQOL<sup>e</sup></b>					<b>6.1(±1.5)</b>	
<b>Cronbach's alpha</b>	<b>.90</b>	<b>.75</b>	<b>.78</b>	<b>.67</b>		

All score range were 0-10 except: 1-10 a ; 1.6-10 b ; 0-9.5 c ; 2.7-10d ; 2.4-9.2 e

Note: The Cronbach's alpha of total MQOL score: 0.83

Table 2. Pearson correlation between SIS, MQOL, and ECOG (N=64)

Global QOL scores	SIS	MQOL TOAL	Physical well-being	Physical symptoms	Psychological symptoms	Existential well-being	Support	ECOG-PSR
<b>SIS</b>	1.00	.29*	-.01	.22	.33**	.21	.07	.02
<b>MQOL TOTAL</b>		1.00	.29*	.69***	.59***	.78***	.64***	-.18
<b>Physical well-being</b>			1.00	.34**	.04	.32*	.04	-.34**
<b>Physical symptoms</b>				1.00	.14	.35**	.09	-.44***
<b>Psychological symptoms</b>					1.00	.36**	.28*	-.06
<b>Existential well-being</b>						1.00	.52***	.04
<b>Support</b>							1.00	.17
<b>ECOG-PSR</b>								1.00

MQOL: McGill quality of life Questionnaire SIS: single item scale

\* P < 0.05; \*\* P < 0.01

Table 3. The important predicting variables for predicting SIS from MQOL subscales and physical symptoms

Variables	$\hat{a}$	S.E.	T value	P value
<b>Constant</b>	<b>5.16</b>			
<b>Insomnia</b>	-.27	0.24	-.270	0.030
<b>Psychological well-being</b>	.26	0.15	.257	0.039

Figure 1. The nursing intervention of palliative knowledge and referral procedure