

# Exploration Into the Variance in Self-Reported Health-Related Quality of Life Between the Chronically-Ill Elderly and Their Family Caregivers

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**ABSTRACT:** Differences in perspective with regard to Health-Related Quality of Life (HRQOL) may significantly affect long-term care preferences. This study was developed to quantify the direction and magnitude of such differences and to explore factors accounting for HRQOL reporting differences between two groups, namely elderly individuals with chronic conditions and their primary family caregivers. Nurses in seven Taiwanese counties and cities interviewed 267 matched pairs of elderly individuals and primary family caregivers using a 28-item version of the World Health Organization Quality of Life questionnaire (WHOQOL-BREF) adapted for use in Taiwan. Our study used the standardized response mean (*SRM*) – the ratio of the mean difference to the *SD* of that difference – to compare scores assigned by the two groups. Family caregivers assigned higher scores in all four HRQOL domains, with scores “moderately higher” in the physical domain and “slightly higher” in the other three. In addition to gender, several activities of daily livings (ADLs) in the physiological, environmental and psychological domains were identified as predictors of HRQOL differences. Marital status and presence of a primary caregiver were the two predictors in the social relationship domain. This study found elderly ADLs, gender, marital status, and the presence of a primary caregiver to be significant predictors of HRQOL differences. Study findings offer guidance to elderly individuals with chronic conditions and their family caregivers with regard to long-term care program arrangement in order to enhance elderly ADLs and family relationships and to achieve a better overall HRQOL for the elderly.

**Key Words:** Health-Related Quality of Life (HRQOL), World Health Organization Quality of Life questionnaire (WHOQOL-BREF), elderly, caregivers.

## Introduction

Most developed countries are experiencing an increasing aging of their populations. In fact, Taiwan's proportion of elderly ranks second in Asia, after Japan's (Ministry of the Interior, 2005). This dramatic increase in average age in many countries has increased demand for long-term care. This has had a significant impact on families with disabled elders, with particular impact on

direct caregivers (Wang, Chung, Lai, Chou, & Kao, 2004).

Decision-making responsibilities are with regard to arrangements for long-term care often shared between the elderly and their family caregivers (McCullough, Wilson, Teasdale, Kolpakchi, & Skelly, 1993; Wang et al., 2004). Differing perceptions of personal health-related quality of life (HRQOL) may also affect overall demand for long-term care. Therefore, it is important to understand differences in reported HRQOL when counseling long-term care

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needs for the elderly. Guided by various groups, appropriate interventions may be subsequently administered (Lai et al., 2005).

The ultimate goal of health care for elders with chronic disease is not only to delay death but also to raise HRQOL, which has become an important measure of care outcomes for the elderly. In health care field, quality of life can be defined as individuals' perceptions of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (World Health Organization, 1995). In those aspects of quality of life, HRQOL relates specifically to an individual's health (Karen, 1999). Jakobsson, Hallberg, and Westergren (2007) demonstrated an association between pain, functional limitations, fatigue, sleeping problems and depression with low HRQOL in older persons (Jakobsson et al., 2007). Related studies revealed that HRQOL are influenced significantly by variables of age, medical status, physical performance and health behavior (Casellas, Lopez-Vivancos, Casado, & Malagelada, 2002; Kazis et al., 1998; Sullivan, Kempen, Van Sonderen, & Ormel, 2000) and that physical performance has the strongest impact on HRQOL in the physical domain (Lai et al., 2005). Other studies have indicated that self-reported health complaints such as fatigue and mobility impairments predict low HRQOL (Borglin, Jakobsson, Edberg, & Hallberg, 2005). These studies exploring the effect of physical, psychological and social function on quality of life indicated that quality of life correlated negatively with age, poor health status, and activities of daily livings (ADLs). Therefore, HRQOL measures allow elders to rate their perception of improvement, which assists health workers to identify and meet their needs.

Most prior studies in this area have explored the impact of various diseases on the HRQOL of patients or their families (Britto et al., 2004; Gonzalez-Salvador et al., 2000). However, this study was designed to explore the differences in perceived HRQOL between elderly individuals suffering from chronic diseases and their family caregivers. The study evaluated both the direction and the magnitude of differences and addressed factors associated with these differences in HRQOL.

## Methods

### Sample and Data Collection

The procedures for random sampling and data collecting have been detailed elsewhere (Kao, Lai, Lin, Lee, &

Wen, 2005; Lai et al., 2005; Wang et al., 2004). Our study area included all seven counties and municipalities (incorporating 88 administrative districts) in Northern Taiwan, which contained. Study subjects were selected through multi-stage sampling. A list of the 88 districts was generated based on the percentage of those aged 65 years and above, grouped by county/municipality. Subsequently, 12 districts were selected through random sampling from which subjects were randomly selected. A total of 50 subject pairs (elderly patients and their family caregivers) in each district were selected, resulting in a total sample of 600 pairs from 7 counties/cities. Initial interviews with primary family caregivers were performed. Eligibility for participation in the study required that subjects be mentally fit and agree to be interviewed by public health nurses. After application of the eligibility criteria, a total of 587 matched pairs of elders and their families were included in this study. When checking goodness-of-fit and comparing data with the annual report on senior citizens conditions in northern Taiwan (Ministry of the Interior, 2002), we found no significant difference between study subjects and the overall senior population in terms of gender and age distribution. Following identification and selection of elders with chronic diseases such as hypertension and diabetes mellitus and exclusion of those whose families were not primary caregivers, a total of 267 matched pairs remained valid and included in data analysis.

### Questionnaire

Our study used the 28-item version of the World Health Organization Quality of Life questionnaire (WHOQOL-BREF), adapted for use in Taiwan. HRQOL was measured along the four domains of physical, psychological, social relationships, and environment. The score range for each WHOQOL-BREF item was 1–5 and the score range for each WHOQOL-BREF dimension was 4–20 which was calculated using item scores for each dimension and amplified by an artificial factor of 4 (The WHOQOL Group, 2000). A low score implies a lower quality of life in that dimension. After elderly patients and their family caregivers each assessed their own HRQOL, researchers conducted comparison analysis. Both the reliability and validity of the WHOQOL-BREF have been reported as excellent (The WHOQOL-Taiwan Group, 1998, The WHOQOL Group, 2000; Lin et al., 2002). Cronbach's alpha values for the four domains in this study ranged between .73 and .82 for elderly patients, and .75 and .77 for caregivers (Kao et

al., 2005; Lai et al., 2005; Wang et al., 2004). In addition to administering the Taiwan version of the WHOQOL-BREF, variables for both elderly patients and family caregivers were collected. These variables included age, gender, marital status, ethnic origin, relationship between the two paired subjects, ADLs, and influences on the work of family caregivers. ADLs were assessed by the "Eastern Cooperative Oncology Group" (ECOG) scale and graded from 0 to 4 (Jones, Fenton, & Husband, 2000). Grade 0 was defined as, "Fully active, able to carry on all activities without restriction"; grade 1 as, "Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework or office work"; grade 2 as, "Ambulatory and capable of full self-care but unable to carry out any work activities. Up and about for > 50% of waking hours"; grade 3 as, "Capable of only limited self-care, confined to bed or chair for 50% or more of waking hours"; grade 4 as, "Completely disabled, cannot carry out any self-care, totally confined to bed or chair". Because only an insignificant number of people were judged as grade 3 or 4, the three grades of 2, 3 and 4 were combined and considered as a single grade range.

### Statistical Analysis

Commercially available SPSS 12.0 statistical software was used for statistical analyses, with paired Student's *t*-tests used to compare reported differences for each of the scales between matched subject pairs. This study used the standardized response mean (SRM) – the ratio of the mean difference to the *SD* of that difference – to evaluate the magnitude of difference between the HRQOL scores of elderly patients and their family caregivers. Cohen (1988) suggested that an SRM of 0.2–0.5 should be considered 'small', 0.51–0.8 'moderate' and 0.81 or more 'large.' A linear regression model was used to predict changes between elderly patients and their families in the HRQOL for each of the four domains. *P*-values of less than .05 were considered statistically significant.

## Results

### Participant Characteristics

Table 1 summarizes the characteristics of 267 matched subject pairs. The mean age of elderly patients was 74.3 years; 54.3% were males; and 72.3% were married. The majority (82.8%) professed having a religion and only

10.5% had jobs. Spouses served as the primary family caregiver for most (54.7%) elderly patients; 62.2% had good relationships with their caregivers; and a considerable proportion (46.8%) demonstrated high functional status. Mean HRQOL scores in each of the four domains ranged from 12.3 to 13.6, which implies a "moderate" quality of life.

Male caregivers represented 33.3% of the study population. Caregivers had an average age of 57.3 years. Most (91.8%) were married; 83.9% professed having a religion; and 40.1% held jobs. The majority (55.8%) of family caregivers were spouses and 54.7% expressed sharing good relationships with care recipients; 87.6% had high functional status; and their care-taking experience influenced ability to work for some (15.7%). Mean HRQOL scores in the four domains ranged from 13.0 to 14.9, which also implies "moderate" quality of life.

### Mean Paired Differences in HRQOL

Mean WHOQOL-BREF domain scores for both subject groups, mean paired differences between their scores, and SRMs are presented in Table 2. The HRQOL ratings registered by family caregivers were significantly higher than those registered by elderly patients in all four domains. The greatest discernible differences were observed in the physical domain, where, on average, family caregivers rated their own HRQOL 1.8 points higher than the corresponding rating registered by elderly patients. Family caregivers, on average, rated their HRQOL 0.6 points higher in the psychological domain, 0.7 points higher in the social relationships domain, and 0.3 points higher in the environment domain. SRMs corresponded to a moderate difference in the score for the physical domain (0.60), and to small differences in scores for the psychological, social relationship, and environmental domains (0.21, 0.30, and 0.17, respectively).

### Predictors of Mean Paired Differences in HRQOL

Stepwise regression analyses were performed to determine the influence of various factors on HRQOL differences between elderly patients and their primary family caregivers. Regression results are presented in Table 3. Differences were calculated by subtracting the family caregivers' WHOQOL-BREF mean domain score from that of the corresponding elderly patients' score. The two most significant predictors of differences in HRQOL perception in the physical, psychological, and environmental domains

**Table 1.**  
**Characteristics of Elderly Patients and Caregivers, by Means and Frequencies (N = 267)**

Variables	Elders			Caregivers		
	<i>n</i>	%	<i>M ± SD</i>	<i>n</i>	%	<i>M ± SD</i>
Total No. of Subjects	267	100.0		267	100.0	
Male	145	54.3		89	33.3	
Married	193	72.3		245	91.8	
Religion	221	82.8		224	83.9	
Job	28	10.5		107	40.1	
Good relationship with caregiver	166	62.2		146	54.7	
Ethnic origins						
Taiwanese/Hoklo	141	52.8		177	66.3	
Mainland Chinese	88	33.0		48	18.0	
Taiwanese/Hakka	38	14.2		42	15.7	
Caregiver/Respondent						
Spouse	146	54.7		149	55.8	
Son	60	22.5		43	16.1	
Daughter-in-law	28	10.4		45	16.9	
Daughter or others	33	12.4		30	11.2	
ADLs						
High Functional Status	125	46.8		218	81.6	
Medium Functional Status	126	47.2		48	18.0	
Low Functional Status	16	6.0		1	0.4	
Influence on Caregivers' Work	–	–		42	15.7	
Age			74.3 ± 5.6			57.3 ± 14.0
Health-related Quality of Life						
Physiology			13.1 ± 2.8			14.9 ± 2.0
Psychology			12.3 ± 2.7			13.0 ± 2.2
Social relationship			13.5 ± 2.1			14.3 ± 1.9
Environment			13.6 ± 2.0			13.9 ± 1.9

*Note.* ADLs = activities of daily livings.

**Table 2.**  
**WHOQOL-BREF Domain Scores for Elderly Patients and Caregivers, by Standardized Response Mean (N = 267)**

WHOQOL-BREF domain	Elders	Caregivers	Paired Differences		Standardized Response Mean
	<i>M ± SD</i>	<i>M ± SD</i>	<i>M ± SD</i>	Paired <i>t</i> <i>p</i>	
Physical	13.1 ± 2.8	14.9 ± 2.0	1.8 ± 3.0	–9.49    .000	0.60
Psychological	12.3 ± 2.7	13.0 ± 2.2	0.6 ± 2.8	–3.63    .001	0.21
Social relationship	13.5 ± 2.1	14.3 ± 1.9	0.7 ± 2.3	–5.12    .000	0.30
Environment	13.6 ± 2.0	13.9 ± 1.9	0.3 ± 1.8	–2.52    .012	0.17

*Note.* 1. 'Standardize response mean' refers to the mean difference in relation to the *SD* of that difference; 2. Paired differences were set as the caregivers' WHOQOL-BREF mean domain score minus that of the elderly.

were, in rank order, elderly patient ADLs and gender. Stepwise regression analyses showed that elderly patient gender, ADLs, and family caregiver age explained 36.5% of total variation in physical domain differences. Elderly

patient gender and ADLs explained, respectively, 20.7% and 13.8% of total difference variation in psychological and environmental domains (see Table 3: R<sup>2</sup> in the bottom row). In the social relationships domain, marital status and

**Table 3.**  
**Predictors of Mean Paired Differences in the WHOQOL-BREF Domain, by Stepwise Regression Analysis (N = 267)**

WHOQOL-BREF domain	Physical		Psychological		Social Relationships		Environment	
	$\beta$	<i>p</i>	$\beta$	<i>p</i>	$\beta$	<i>p</i>	$\beta$	<i>p</i>
Elders								
Male	-0.24	.000	-0.27	.000	-	-	-0.21	.000
Married	-	-	-	-	-0.27	.000	-	-
ADLs								
High function	-0.83	.000	-0.63	.000	-	-	-0.40	.002
Medium function	-0.46	.000	-0.41	.001	-	-	-0.24	.056
Caregivers								
Age	-0.13	.009	-	-	-	-	-	-
Spouse	-	-	-	-	0.14	.162	-	-
Son	-	-	-	-	-0.00	.993	-	-
Daughter-in-law	-	-	-	-	0.18	.019	-	-
<i>R</i> <sup>2</sup>	.365		.207		.151		.138	

*Note.* ADLs = activities of daily living.

the relationship of caregivers with elderly patients were significant predictors of difference, explaining 15.1% of total domain variance. There was a significantly positive correlation with HRQOL difference in cases where the family caregiver was a daughter-in-law. Conversely, a significantly negative correlation was also noted between the marital status of the elderly patient and HRQOL differences.

## Discussion

The data from this study provided a unique opportunity to compare differences in reported HRQOL between matched pairs of elderly patients and their family caregivers. The four HRQOL domains depict the experiences of elders within the community more comprehensively than do overall univariate-measures. Specifically, within the four WHOQOL-BREF domains, family caregivers rated their HRQOL higher than did their elderly wards. The most significant differences were found in the physical domain, where family caregivers rated themselves, on average, 1.8 points higher than elderly patients (Table 2), with the SRM of 0.60 corresponding to a moderate effect (Britto et al., 2004; Cohen, 1988). Examining individual items within the scale, the greatest differences were observed with regard to questions related to elderly patient mobility and general level of satisfaction with personal health. Previous studies indicated that perspectives reflecting greater dependent may arise in elderly patients, reflect-

ing their declined functional status and chronic diseases, and causing greater distress (Hellstrom, Persson, & Hallberg, 2004). Therefore, these differences may reflect greater dependence by elderly patients on caregivers or, perhaps, a greater degree of degeneration among elders who are less mobile. These disabilities would also lead them to make greater demands on their family caregivers and to feel more limited in their ability to perform general tasks when family caregivers are unavailable – particularly when caregivers leave for part of the day to work outside the home.

Among the smaller but still significant differences in the psychological, social relationships, and environment domains, our exploration of individual items within these domains found that the largest differences occurred in the ability to concentrate, level of satisfaction with sexual life, and opportunities for leisure. Reports provided by elderly patients on issues such as attention and sexual life may be affected by their overall view of functional status (Sullivan et al., 2000). We speculate that those elderly who reported their own physical functions as “poor” may also tend to rate their HRQOL lower in this study. This phenomenon may be due to a less optimistic outlook regarding such behavior among ethnic Chinese elderly suffering from chronic diseases or degeneration. Future studies will be required to gain a better understanding of this association.

A few of the characteristic factors were found to have explanatory power with regard to the differences in reporting between the two groups. While the magnitude of

HRQOL differences between the two groups in the physical, psychological, and environmental domains increased as elderly functional status declined, this was not true in the social relationships domain, where lower functional status increased elderly patient dependency. If a chronic disease were not appropriately treated, an elderly patient can suffer complications that reduce overall mobility (The WHOQOL-Taiwan Group, 1998). As a result, they rated their overall HRQOL scores lower and, therefore, there was a greater likelihood of larger differences.

Our study showed that, in terms of physical, psychological and environmental domains, HRQOL differences were greater for elderly female subjects than their male counterparts (Table 3). These results are similar to those found in other studies (Borglin et al., 2005; Tannenbaum & Mayo, 2003). Our study also indicated a negative correlation between family caregiver age and differences in the physiological domain (Table 3). Older caregivers typically are capable of providing less caring time and, often, their functional status is little better (or the same) as their wards. According to Morimoto, Schreiner, and Asano (2003), caregivers who provided fewer care hours also had the smallest burden. Nonetheless, that study also indicated that reduced burden had a significant relationship with reporting a higher HRQOL. This implies that, with increasing caregiver age, HRQOL differences between the elderly and their caregivers generally decrease.

Study results revealed a negative correlation between marital status and HRQOL reporting differences. However, in cases where the caregiver was a daughter-in-law, there was a positive correlation between differences in the social relationships domain of the WHOQOL-BREF (Table 3). A significant proportion of the elderly in Taiwan live with their spouses, children, or grandchildren, with sons and their spouses serving as primary and secondary family caregivers, respectively. Clearly, family members are taking care of many of their elderly relatives, which helps enhance HRQOL (Morimoto et al., 2003). However, daughters-in-laws are typically less familiar than other family members with the general needs of elderly family members, which naturally increases HRQOL differences between the two groups.

Although our study covered all of the counties and municipalities in northern Taiwan, care should be taken when attempting to generalize these study-specific findings. An additional limitation of the study was that undiagnosed chronic diseases are, by nature, unrecognized in

self-reported data. In this study, we relied upon interviewer assessments of elderly patient ADLs rather than clinical reports, which may provide significantly different results.

## Conclusions and Implications

Family caregivers had higher HRQOL scores, implying a higher quality of life in comparison to elderly patients. Elderly patient ADLs, gender, marital status, and the presence of a primary caregiver were predictors of HRQOL differences between elderly patients and their family caregivers. This study was designed to reveal HRQOL as reported by chronically-ill elderly living at home and their caregivers. These elderly patients, upon rating their HRQOL, were concerned about their ADLs and family relationships. This study may help nurses better understand the HRQOL experiences of elderly patients and their family caregivers. Since chronic disease is the major factor explaining increased demand from the elderly for long-term care services, elders often worry about the arrangement of long-term care together with ADL degeneration. Study findings may provide nurses guidance to help actively maintain elders' health and abilities in order to enhance ADLs. In addition, this study should help encourage family caregivers to improve family relationships and interaction in order to achieve better HRQOL for their elderly relatives.

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## 社區慢性病老人及其主要照顧者自述 其健康相關生活品質差異之探討

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**摘要：**老人及家屬的健康生活品質上差異對長期照護服務的選擇有關鍵的影響，本研究目的在利用量化的方式來探討老人與照護者健康相關生活品質差異及其影響因素。本研究由台灣七個縣市的護士訪問社區內 267 對老人及其主要照護家屬，使用 28 題型的「台灣簡明版世界衛生組織生活品質問卷 (WHOQOL-BREF, Taiwan version)」為研究工具。本研究使用標準回答平均值 (Standardized Response Mean, SRM)，即平均差比差異的標準差 (SD)，來比較老人與其主要照護家屬間的健康相關生活品質分數。照護家屬在所有四個健康相關生活品質範疇的分數均較高：在生理範疇，照護者的分數較高，而在其他三項只是些微高於老人。除性別外，在生理、環境及心理範疇，日常生活活動 (ADLs) 依賴程度是造成兩者生活品質差異的主因。婚姻狀況和主要照護者的身份則是社會關係範疇的預測因子。本研究發現：老人的 ADLs、性別、婚姻狀況、主要的照護者的身份等，是老人與其照護家屬在健康相關生活品質差異的預測因素。此結果可提供慢性病老人及其主要照顧者在長期照護的安排上之適當建議。據此提升老人的日常生活功能獨立程度，以及加強家人間的親密關係均能有效的提升老人的健康相關生活品質。

**關鍵詞：**健康相關生活品質、台灣簡明版世界衛生組織生活品質問卷、老人、照顧者。

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