

# Factors Associated with the Quality of Life in Family Caregivers of People with Dementia in Taiwan

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## Abstract

**Objectives:** Previous studies showed that caregivers of patients with dementia (PWD) have lower quality of life (QoL) due to several clinical factors related to caregivers and their ill relatives. In this study, we intended to assess the associated factors of QoL in caregivers of PWD in Taiwan. **Methods:** A cross-sectional survey with 270 dyads of PWD and their caregivers was conducted. We assessed family members' depressive symptoms, anxiety, affiliate stigma, care burden, and QoL, and patients' cognition, severity of dementia, self-care, and mobility skills, as well as neuropsychiatry symptoms of PWD. **Results:** Caregivers' longer years of education were significantly associated with better QoL in environment domains ( $\beta = 0.21, p < 0.01$ ), while the children of caregivers had significantly better QoL in physical domains compared to spouses of caregivers ( $\beta = 0.28, p < 0.05$ ). Patients with a past history of psychiatric hospitalization ( $\beta = 0.11, p < 0.05$ ) and longer caregiving time ( $\beta = 0.13, p < 0.05$ ) were significantly related to better QoL in environment domain. High levels of depression were associated with significantly lower QoL in physical health ( $\beta = -0.24, p < 0.05$ ) and psychological domains ( $\beta = -0.32, p < 0.01$ ), while more anxiety symptoms were related to significantly lower QoL in physical health ( $\beta = -0.26, p < 0.01$ ) and environment domains ( $\beta = -0.27, p < 0.01$ ). Higher levels of affiliate stigma were significantly related to lower QoL of caregivers in psychological ( $\beta = -0.23, p < 0.01$ ), social relationships ( $\beta = -0.27, p < 0.01$ ), and environment ( $\beta = -0.19, p < 0.05$ ) domains. Higher levels of care burden were significantly related to lower QoL of caregivers in physical health ( $\beta = -0.24, p < 0.01$ ) and environment ( $\beta = -0.23, p < 0.05$ ) domains. **Conclusion:** Caregiver's depression, anxiety, affiliate stigma, and care burden were found to play a critical role in maintaining QoL of family caregivers. We suggest developing effective programs as a direction of future intervention for PWD to improve their QoL.

**Key words:** caregiver Burden Inventory, stigma, the Barthel Index, WHO Quality of Life-BREF  
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## Introduction

The population of dementia is growing rapidly with an estimated 35.6 million people worldwide in 2010, and the number is about to double every 20 years, to 115.4 million in 2050 [1]. The increasing population of people with dementia (PWD) leads to rising cost of care burden. According to the report of Alzheimer's Disease International in 2021, dementia is a costly long-term illness to society as 85% of the costs are related to social resources [2]. Therefore, caring people of dementia is one of the most important issues nowadays.

The WHO defines "quality of life (QoL) as an individual's perception of their position in life in the context of the culture

and value systems in which they live and in relation to their goals, expectations, standards, and concerns" [3]. The concept of QoL usually refers to health related [3]; however, there are also physical, psychological, social, and environmental aspects of QoL [4]. Studies have shown lower levels of the QoL in PWD and their caregivers [5].

Other than the cost of care burden, dementia also has great impact on PWD and their caregivers [6]. Research showed that people of dementia usually have comorbid depression [7] and

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anxiety [8]. Those factors often influence the QoL of PWD. Hence, healthcare authorities have allocated health resources and delivered quality treatments to this population [9].

Apart from the PWD, their caregivers also have lower QoL [5] due to caregiver–patient relationship, the demand for caring, and the level of caregivers' health and well-being [5]. Caregivers of PWD not only take more time for caring their ill family members but also suffer from negative consequences of mental and physical health-related problems [10]. Therefore, multiple psychosocial interventions are developed for caregivers of PWD, showing benefits to the caregivers' psychological morbidity [11]. The aforementioned research has examined factors associated with QoL among caregivers of PWD. Certain demographic variables of caregivers, caregiver–patient relationships, caregiver's emotional well-being, independence, and self-efficacy have been noted [5]. Long-term care burden also causes multiple negative impacts on mental and physical health of caregivers, which may subsequently lead to poor QoL [12].

In a recent meta-analysis, higher levels of depression, subjective burden, distress, and patients' neuropsychiatric symptoms and poorer QoL of PWD are associated with poorer caregiver's QoL [13]. But caregivers' income, age, and patients' cognitive functioning and activities of daily living do not have an effect size in the same study.

In addition to care burden, caregivers may suffer from stigma related to dementia, especially affiliate stigma [14, 15], indicating that caregivers internalize the public stigma of dementia toward themselves [16, 17]. Affiliate stigma associated with Alzheimer's disease includes cognitive attributions and emotional and behavioral reactions [18, 19]. Studies also indicated that caregivers with stigmatization experiences have more negative emotions and heavier care burden which may result in poorer QoL [20]. Moreover, spouses and children usually take the responsibility of caring for family members with dementia [21]; the relationship may lead to different stereotypes for the caregivers.

Although some studies revealed that important factors are related to the QoL in caregivers, the quality supporting each theme varied [5]. Previous studies showed that higher levels of care burden, anxiety, and depression have been found among caregivers of PWD [22]. Greater caregiver stigma is associated with poorer QoL [23]. But most studies have been done in Western countries. The relationships among these factors may not be the same in Asia countries due to various sociocultural contexts. In this study, we intended to study the relationships between QoL and important factors among caregivers of PWD in Taiwan.

## Methods

### Study subjects

The study protocol was approved by the institutional review board of Chang-Gung Memorial Hospital (protocol number = 102-3378B and date of approval = October 1, 2013), requiring to obtain signed informed consent from all the study

participants. The cross-sectional survey included 270 dyads of PWD and their caregivers from the outpatient department in a general hospital in Taiwan (i.e., Chang Gung Memorial Hospital in Chiayi) from October 2, 2013, to September 30, 2014.

The family caregiver was the one who returned to the consultation with the patient or was recommended by the patient. The caregivers who met the following inclusion criteria were eligible participants: (a) they had one family member aged at least 65 years and diagnosed with any type of dementia according to Diagnostic Criteria of Dementia from *The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)* [24]; (b) the caregivers were older than 20 years of age; (c) the caregivers were able to understand, speak, or read Mandarin Chinese or Taiwanese; and (d) both the caregivers and PWD (or a legally authorized representative) had signed written informed consent after they fully understood the study purpose and procedure.

### Study procedures

The caregivers and their family members with dementia received the study information from psychiatrists, who explained the study purpose and procedure in details during the outpatient department visits. If the impaired cognition and capacity were found in PWD, consent was obtained from their legally authorized representatives. For PWD, assessments were evaluated by their psychiatrists using various instruments which are to be explained in the following heading of this article.

At the outpatient clinics, caregivers completed copies of the self-administrated questionnaire including a background information sheet about caregiver and patient's demographics such as age, gender, marital status, years of education, employment status, relationship with the patients, whether living together or not, primary caregivers or not, time for caregiving, and past history of psychiatric hospitalization.

### Instruments

#### WHO Quality of Life-BREF

The WHO QoL-BREF (WHOQOL-BREF) is derived from the data collected using the WHOQOL-100 [4]. The Taiwan version of WHOQOL-BREF has 28 items in four domains (physical health, 7 items; psychological state, 6 items; social relationships, 4 items; and environment, 9 items) and additional two items for the Taiwanese context (being respected and eating, which was classified into social relationships and environment domains, respectively). Each item is to rate on a five-point Likert scale and four domain scores were calculated to a scale between 4 and 20 using a linear transformation. A higher score indicates a higher level of QoL [25]. The psychometric properties are good in the general Taiwanese population ( $\alpha = 0.70\text{--}0.77$ ) [4].

#### Taiwanese Depression Questionnaire

The Taiwanese Depression Questionnaire (TDQ) has 18 items to assess depressive symptoms in the previous 1 week. TDQ is scored by a four-point Likert scale and the scores are

summed to indicate the levels of depression. A higher score indicates higher levels of depression. It is developed by Lee et al. with satisfactory reliability and validity ( $\alpha = 0.90$ ) [26].

### Caregiver Burden Inventory

The Caregiver Burden Inventory (CBI) is a 24-item subjective care burden assessment instrument with five dimensions: emotional, social, time-dependent, developmental, and physical burden. CBI is scored using a five-point Likert scale and a higher score indicated higher levels of caregiver burden. It is developed by Novak and Guest [27] and is translated into Chinese by Chou et al., with excellent internal consistency ( $\alpha = 0.91$ ) and appropriate content validity [28].

### Affiliate stigma scale

The affiliate stigma scale (ASS) was used to assess internalized stigma among caregivers of patients with dementia in our study. It consists of 22 items and is rated on a four-point Likert scale. The higher scores suggest higher levels of affiliate stigma. It is invented by Mak and Cheung [16] and validated with the Taiwanese population by Chang et al. [29, 30]. Good internal consistency ( $\alpha = 0.822\text{--}0.855$ ) and concurrent validity were shown in the study [29].

### Beck Anxiety Inventory

The Beck Anxiety Inventory (BAI) comprises 21 items and is scored from 0 to 3 [31]. A higher score indicates a higher level of anxiety. The inventory has been translated to Chinese with satisfactory internal consistency ( $\alpha = 0.95$ ) and validity [32].

### Neuropsychiatric Inventory

The Neuropsychiatric Inventory (NPI) is used to assess 12 symptoms of behavioral disturbances occurring in PWD. If those symptoms present, the severity and frequency of symptoms are assessed later. The severity is rated from 1 (mild) to 3 (severe) and frequency is rated from 1 (occasionally, less than once per week) to 4 (very frequently, once or more per day or continuously). Individual item score was generated from the severity score multiplied by frequency score. A total NPI score is the sum of 12 items scores, ranging from 0 to 144. A higher score indicates higher levels of behavioral disturbances. The internal consistency reliability is high ( $\alpha = 0.88$ ) and the concurrent validity has been supported [33].

### The Barthel Index

The Barthel Index (BI) is introduced by Mahoney and Barthel in 1965 [34] for following progress in self-care and mobility skills in the elderly. It has 10 items with a summed score ranging from 0 to 100. A higher score indicates higher levels of independent activity of daily life. The internal consistency and reliability of the instrument is satisfactory ( $\alpha = 0.92\text{--}0.93$ ) [35].

### Statistical analysis

Multiple linear regression models were used to analyze the factors contributing to QoL of caregivers. The dependent variables in the models were four domain scores of WHOQOL-

BREF. The regression models shared the same independent variables, including the caregivers' information (i.e., their demographics and the scores of TDQ, BAI, CBI, and ASS) and the information of PWD (including demographics and the scores of NPI, BI, Clinical dementia rating (CDR), and Mini-mental status examination (MMSE)).

Statistical Package for the Social Science version 25.0 for Windows (SPSS Inc., Chicago, Illinois, USA) was used for analyzing all study variables. The differences between the groups were considered significant if *p*-values were smaller than 0.05.

## Results

We collected 270 dyads in this study. Table 1 shows the demographic characteristics of the family caregivers (142 women and 128 men with mean age of  $52.3 \pm 12.2$  years). The average duration of caregiving was  $29.7 \pm 29.4$  months. Most of the caregivers were the children of the PWD (61.9%), followed by spouses (13.3%). The mean scores of TDQ, BAI, ASS, CBI, and WHOQOL-BREF are also shown in Table 1.

Table 2 shows the demographics of the PWD (174 women and 74 men with mean age of  $79.0 \pm 6.3$  years). Most of them had never received any psychiatric hospitalization (94.8%). Table 2 also reveals the severity of dementia on various scales. The average score of the NPI, MMSE, and BI was  $23.2 \pm 23.2$ ,  $13.2 \pm 5.5$ , and  $70.1 \pm 33.3$ , respectively. Most patients had their CDR score at 1 (43.3%), following by 0.5 (33%) and 2 (20.4%).

Table 3 lists factors associated with four domains of QoL among caregivers. Overall, lower QoL was associated with high levels of depression, anxiety, affiliate stigma, and caregiver burden in this study. The overall model explained that 48%, 49%, 26%, and 37% of the variance in the QoL were in physical, psychological, social, and environment domains, respectively.

## Discussion

There is little known about factors related to the QoL in family caregivers of PWD in Asian countries. Therefore, this study was intended to provide evidence from the Taiwanese population. In the meanwhile, we would like to examine the relationship between stigma and the QoL because many studies have shown that stigma impacts psychological disturbances and care burden in families and individuals with psychiatric disorders [13, 36-38]. To our knowledge, this was the first study to examine the relationship between stigma and QoL among caregivers of PWD in Taiwan. Our findings showed the importance of caregivers' psychological and related factors on QoL of caregivers. In general, our results showed that score of QoL in the four domains were ranged from 12.8 to 14.2 (Table 3), which is similar to the findings of a previous study [39].

Regarding the relationships between patients' basic demographics and caregivers' QoL, no significant factors were found in our study findings (Table 3). This means that patients' age, gender, marital status, and education levels did

**Table 1.** Demographic and clinical data of the caregivers ( $n = 270$ )

	$n$ (%)
Age (years), mean $\pm$ SD	52.3 $\pm$ 12.2
Gender	
Male	128 (47.4)
Female	142 (52.6)
Marital status	
Married	206 (76.3)
Separated/divorced/widowed/single	64 (23.7)
Years of education, mean $\pm$ SD	11.3 $\pm$ 4.2
Employment status	
Full-time/part-time employment	144 (53.3)
Retired/no employment	126 (46.7)
Relationship with patient	
Parent	1 (0.4)
Spouse	36 (13.3)
Child	167 (61.9)
Other	66 (24.4)
Living with patients	
Yes	193 (71.5)
No	77 (28.5)
Primary caregiver	
Yes	226 (83.7)
No	44 (16.3)
Months of caregiving, mean $\pm$ SD	29.7 $\pm$ 29.4
Clinical profiles, mean $\pm$ SD	
Depression	12.8 $\pm$ 11.3
Anxiety	8.0 $\pm$ 8.9
Affiliate stigma	1.6 $\pm$ 0.5
Care burden	40.2 $\pm$ 19.2
QoL, mean $\pm$ SD	
Physical health	14.2 $\pm$ 2.6
Psychological	12.8 $\pm$ 2.9
Social relationships	13.8 $\pm$ 2.6
Environment	13.7 $\pm$ 2.4

SD, standard deviation; QoL, quality of life

not affect caregivers' QoL. Previous studies have not shown a consistent association between patients' age and caregivers' QoL [40, 41].

With respect to the association between patient's clinical condition and caregiver's QoL, increased patient's age of dementia diagnosis was significantly related to lower caregiver's QoL in social relationship domain while caregivers whose relative had a past history of psychiatric hospitalization had better QoL in environment domain. These findings may indicate that early medical intervention including psychiatric treatment may be beneficial to caregiver's QoL. Our findings also showed that patients' higher levels of independent activities in daily life were associated with better caregivers' QoL (physical health domain). This may be contributing to the greater capacity of one's autonomy that the caring stress was less. However, the relationship was not supported due to no significant effect size in the meta-analysis [13].

**Table 2.** Demographic and clinical profiles of the patients with dementia ( $n = 270$ )

	$n$ (%)
Age (years), mean $\pm$ SD	79.0 $\pm$ 6.3
Gender	
Male	96 (35.6)
Female	174 (64.4)
Marital status	
Married	147 (54.4)
Separated/divorced/widowed/single	123 (45.6)
Years of education, mean $\pm$ SD	3.4 $\pm$ 4.4
Employment status	
Full-time/part-time employment	9 (3.3)
Retired/no employment	261 (96.7)
Ever psychiatric hospitalization	
Yes	14 (5.2)
No	255 (94.8)
Age when diagnosis was confirmed, years, mean $\pm$ SD	75.6 $\pm$ 12.2
Clinical profiles, mean $\pm$ SD	
Neuropsychiatry inventory	23.2 $\pm$ 23.2
Mini-mental status examination	13.2 $\pm$ 5.5
Barthel activity of daily living index	70.1 $\pm$ 33.3
Clinical dementia rating	
0.5	89 (33)
1	117 (43.3)
2	55 (20.4)
3	8 (3.0)
4	1 (0.4)

SD, standard deviation

Surprisingly, more severe psychiatric symptoms were positively associated with better caregivers' QoL in physical health, social relationships, and environment domain in our study. This is inconsistent with previous studies [40, 42]. One of the possible reasons is that family caregivers should be capable enough to manage patients' diseases, daily routines, and housekeeping. In other words, competent members in the whole family would take the care responsibility in our culture.

In caregivers' demographics, years of education (Table 3) was significantly positively associated with better caregivers' QoL in environment domain ( $p < 0.01$ ). It is reasonable to assume that better socioeconomic status leads to better QoL although caregivers' income does not have association with their QoL in previous studies [13]. Compared to spouses, children of patients (Table 3) had significantly better QoL in physical health domain ( $p < 0.05$ ). Children caregivers should be younger and have fewer chronic medical diseases than spouse caregivers. We also found that longer caregiving months was significantly positively related to better caregivers' QoL in environment domain ( $p < 0.05$ ). It is probably because caregiving and interaction with the patient need time to adapt, especially in the material and physical environment.

All caregivers' psychological and related factors in our study were closely related to caregiver's QoL. First, being consistent with previous research in other countries [13, 43-45], higher levels of depression were significantly linked to poorer

**Table 3.** Factors associated with World Health Organization quality of life analyzed by regression model

	Physical health <sup>a</sup>		Psychological <sup>b</sup>		Social relationships <sup>c</sup>		Environment <sup>d</sup>	
	$\beta$	<i>t</i>	$\beta$	<i>t</i>	$\beta$	<i>t</i>	$\beta$	<i>t</i>
Patient's demographics								
Age	-0.08	-1.12	-0.01	-0.14	0.04	0.42	0.00	0.02
Gender (reference: Female)	-0.05	-0.92	-0.01	-0.17	-0.01	-0.12	-0.04	-0.70
Marital status (reference: Unmarried)	-0.06	-1.09	-0.02	-0.41	0.06	0.91	-0.09	-1.42
Years of education	0.04	0.66	0.08	1.33	0.09	1.21	0.10	1.54
Patient's clinical condition								
Age when diagnosis was confirmed	0.00	-0.04	-0.05	-0.79	-0.14*	-2.05	-0.03	-0.43
Ever psychiatric hospitalization (reference: No)	0.05	1.01	0.08	1.61	-0.02	-0.29	0.11*	2.14
Neuropsychiatry inventory	0.14*	2.48	0.06	1.06	0.26***	3.99	0.14*	2.23
Clinical dementia rating	0.08	1.06	0.03	0.34	-0.14	-1.51	0.04	0.49
Mini-mental status examination	-0.08	-1.01	0.00	0.05	-0.14	-1.60	-0.04	-0.53
Barthel activity of daily living index	0.18**	2.90	0.01	0.12	0.00	-0.06	0.12	1.75
Caregivers' demographics								
Age	0.04	0.44	0.15	1.52	-0.03	-0.23	0.18	1.64
Gender (reference: Female)	-0.05	-0.84	-0.02	-0.29	-0.04	-0.49	-0.10	-1.48
Marital status (reference: Unmarried)	0.04	0.71	-0.06	-1.11	0.02	0.29	0.03	0.47
Years of education	0.10	1.48	0.12	1.69	0.15	1.79	0.21**	2.73
Employment status (reference: Unemployment)	-0.06	-1.17	-0.05	-0.85	-0.06	-0.90	-0.04	-0.62
Relationships with the patient (reference: Spouse)								
Child	0.28*	2.20	0.00	-0.03	-0.18	-1.19	-0.12	-0.85
Other	0.21	1.62	0.05	0.37	-0.13	-0.82	-0.07	-0.47
Months of caregiving	0.06	1.02	0.08	1.51	0.05	0.81	0.13*	2.18
Caregivers' psychological and related factors								
Depression	-0.24*	-2.47	-0.32**	-3.41	-0.20	-1.73	-0.03	-0.32
Anxiety	-0.26**	-3.07	-0.14	-1.70	-0.09	-0.88	-0.27**	-2.91
Affiliate stigma	-0.10	-1.43	-0.23**	-3.32	-0.27**	-3.23	-0.19*	-2.47
Care burden	-0.24**	-2.88	-0.14	-1.67	-0.13	-1.31	-0.23*	-2.58

\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$ ; <sup>a</sup> $R^2 = 0.53$ , adjusted  $R^2 = 0.48$ ; <sup>b</sup> $R^2 = 0.53$ , adjusted  $R^2 = 0.49$ ; <sup>c</sup> $R^2 = 0.33$ , adjusted  $R^2 = 0.26$ ; <sup>d</sup> $R^2 = 0.43$  adjusted  $R^2 = 0.37$ 

caregivers' QoL ( $p < 0.01$ ) in our study (Table 3). Depression may affect individual's perception to interpret information including somatic symptoms and psychological distress [46, 47]. Therefore, depression may have direct impact on physical health and psychological domains in QoL, which is compatible with our study results. However, an association was not found between depression and social relationships/environment domains in the same study. It indicates that different domains of QoL may be influenced by depression in different way [46].

Second, this study showed that higher levels of anxiety were significantly associated with poorer caregivers' QoL, which is in line with the findings of Santos et al. [40]. However, only a few studies have examined the relationships between caregivers' anxiety or distress and their QoL [13]. In our study, physical health ( $p < 0.01$ ) and environment ( $p < 0.01$ ) domains of QoL were significantly affected by anxiety. The causal relationships need more studies to confirm the direction.

Third, our study results (Table 3) showed that a significant negative association was found between affiliate stigma (self-stigma among family members) and caregivers' QoL in psychological ( $p < 0.01$ ), social relationships ( $p < 0.01$ ), and environment ( $p < 0.05$ ) domains. Weisman de Mamani et al. reported that caregivers' perceived stigma leads to poor QoL through direct and indirect effects through high expressed

emotion [23]. Some studies in other psychiatric disorders demonstrated that self-stigma exerts the negative impact on QoL through the mediator of psychological distress [48, 49]. We found that stigma (Table 3) from the caretaker was significantly related to QoL in psychological domain ( $p < 0.01$ ). Nevertheless, little dementia research focused on relationships between stigma and caregivers' QoL. The exact mechanism how stigma influences QoL should be explored in the future.

Fourth, heavier care burden was associated with poorer caregivers' QoL in the study (Table 3). This relationship was congruent with other studies [13, 50], which means that interventions focus on reducing and coping with caregiver burden may be helpful to improve caregivers' QoL. Although care burden is an important factor to affect caregivers' QoL, we found that only physical health ( $p < 0.01$ ) and environment ( $p < 0.05$ ) domains were significantly involved (Table 3). Because of diverse measures for care burden and QoL used in the past research [13], the clear and detail relationship should be examined in further studies.

### Study limitations

The readers are warned not to over-interpret the study results because our study has three limitations.

- Our study was conducted in southern Taiwan, which may not be fully representative of the general population.

- We did not include several important factors, such as patients' physical comorbidity and patients' QoL, which may affect caregivers' QoL much. These variables may confound the finding.
- It could not assume the causality of these factors and QoL because of the cross-sectional study design.

### Summary

This study indicated that the QoL of caregivers of PWD was associated with depression, anxiety, affiliate stigma, and caregiving burden. All those findings are important. Furthermore, caregivers' QoL, mental health, and stigma also deserve more attention. Peer and professional support, stress management, and provision for family caregivers counseling should be considered.

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### Conflicts of Interest

Jian An Su and Chih Chen Chang, executive editorial board members at *Taiwanese Journal of Psychiatry* (Taipei), had no rôle in the peer review process of or decision to publish this article. The other author declared no conflicts of interest in writing this paper.

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