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## [原著] Investigation of the Health of Caregivers for the Aged in Taiwan

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## Investigation of the Health of Caregivers for the Aged in Taiwan

Chao Ching Lin and Satoshi Fukuzaki

School of Health Sciences, Faculty of Medicine, University of the Ryukyus

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### ABSTRACT

In this study, we interviewed 94 non-professional caregivers caring for the frail elderly members of their families residing in the Taichung area of Taiwan in order to explore the main caregiver's burden and the relative factors which influence their physical and mental health using the Today Health Index (THI). The three items which the caregivers experienced as the greatest burden were anxiety regarding the critical status of the elderly, accumulated fatigue, and social restriction. From the results of the stepwise multiple regression models, we ascertained that the caregiver's psychological state was greatly affected by this role. Depression was the most common mental problem, and vague complaints were the main physical health problem. The main factors which influenced the caregiver's physical and psychological health, in order of severity, were total burden, economic burden and accumulated fatigue. Taiwan has gradually become an aged society and research such as this may be useful in the future development of a social welfare policy for the aged.

### INTRODUCTION

Taiwan, or Formosa, which is located on the eastern edge of Asia in the southern sea of Okinawa, has a population of 20,110,000 and covers 3,600 square kilometers. Taiwan, like other developed nations, has gradually become an aged society because of its social and economic prosperity, advances in medical technology, and elevation of its standard of living. In 1990, the aged represented 6.1% of the population, and this proportion is estimated to approach 8.4% by the year 2000<sup>1)</sup>. From the medical and

health perspective, the proportion of the aged population, who are handicapped in body or mind, have senile dementia or various other diseases, and are confined to bed most of time, can be expected to increase as the life span of the elderly continues to increase. With a restriction on medical resources, the health care of the aged will be increasingly carried out by family members, and home care will become the main form of health care in Taiwan.

The purposes of this research were as follows:

1. to understand the main caregiver's con-

- cerns and burden.
2. to explore the factors which influence the main caregiver's psychosomatic health.
  3. to determine the relative contribution of each factor by means of statistical analysis.

## METHODOLOGY

### *Sampling*

The study was conducted in five towns, Ching Shui, Sha Lu, Wu Chi, Ta Tu, and Lung Ching, located along the coast of Taichung County, the central area of Taiwan Province. The overall economic structure is based on agricultural activities, and the social structure on a social group based on the family unit<sup>2)</sup>.

No comprehensive management system addressing the individual health concerns of the aged in Taiwan has yet been established. The subjects of this study were obtained, with difficulty, by both active sampling and snowball sampling<sup>3)</sup>. In all, there were 94 families whose caregiving member agreed to participate as a research subject. The characteristics of the cared for aged included: 1) age over 65 years; 2) required assistance in daily life due to disease or other infirmity; and 3) had received the caregiver's help for more than six months. The caregiver was the member of the aged's family who assumed the main responsibility for caregiving.

### *Methods*

A battery questionnaire was administered by directly interviewing the caregiver during a home visit. The questionnaire had been modified after two pre interview evaluation in six subjects; the test-retest reliability of the Today Health Index (THI) portion of the questionnaire was  $r = 0.93\%$ , and that of the index of the caregiver's burden factors was  $r = 0.52$ . The investigation inventory is described below. 1) General background data and circumstances of care for the aged person and the caregiver

(such as gender, age, marital status, religion, diseases of the aged person, family structure, financial situation, medical expense burden, period of care, task difficulty, daily caring hours and whether performed with or without assistance); 2) The Activities of Daily Living (ADL) index for the aged person was used to assess such factors as mental status, toilet, feeding, mobility, dressing, hygiene and bathing). The aged were classified into the following three ADL index grades: Requires complete assistance (Grade1), requires partial assistance (Grade2), and independent (Grade3). 3) The caregiver burden index was used to assess the following seven factors; interpersonal relationship with the aged; social restrictions; family dynamic; caregiving motivation; financial burden; anxiety regarding the aged member's compromised health status; and accumulated fatigue. The index was completed by choosing one of 5 responses (a Likert 5 point scoring scale), as shown in Table 1. 4) The THI<sup>4)</sup>, which is a 130 item quantitative health index used to assess clusters of physical symptoms, such as respiration, eyes and skin, digestive organs, mouth and anus, irregular life style, and vague complaints, as well as psychosomatic disease. The remaining items are concerned with mental and psychological symptoms (irritability, lying scale, mental instability, depression, aggression, and nervousness). Each cluster was scored from 1 to 3: The 5 person research group, which included undergraduate nurses at a nursing college who were experienced in public health practice and had their nursing license, arrived at a consensus regarding the purpose of the study, questionnaire content, and interview techniques. Each researcher conducted the interview according to the agreed upon methodology. During the initial visit, oral consent was also obtained from the subjects. The interview time required to complete each questionnaire was about 2.5-3.0 hours.

Table 1. Frequency of burden items

Burdensome:	Strongly agree	Agree	Applicable	Disagree	( )%
Interpersonal relationship with the aged member:					
(1)	12(12.8)	24(25.5)	12(12.8)	28(29.8)	18(19.1)
(2)	8( 8.5)	21(22.3)	11(11.7)	37(39.4)	17(18.1)
(3)	17(18.1)	20(21.3)	11(11.7)	35(37.2)	11(11.7)
Social restriction:					
(1)	13(13.8)	28(29.8)	15(16.0)	33(35.1)	5( 5.3)
(2)	12(12.8)	41(43.6)	10(10.6)	27(28.7)	4( 4.3)
(3)	6( 6.4)	39(41.5)	17(18.1)	27(28.7)	5( 5.3)
Family dynamic:					
(1)	10(10.6)	39(41.5)	10(10.6)	29(30.9)	6( 6.4)
(2)	5( 5.3)	23(24.5)	18(19.1)	43(45.7)	5( 5.3)
Caregiving motivation:					
(1)	1( 1.1)	9( 9.6)	4( 4.3)	51(54.3)	29(30.9)
(2)	11(11.7)	31(33.0)	11(11.7)	35(37.2)	5( 5.3)
(3)	21(22.3)	38(40.4)	13(13.8)	18(19.1)	4( 4.3)
Financial burden:					
(1)	20(21.3)	22(23.4)	9( 9.6)	40(42.6)	3( 3.2)
(2)	19(20.2)	22(23.4)	18(19.1)	31(33.0)	4( 4.3)
Anxiety regarding the aged person's health:					
	23(24.5)	32(34.0)	18(19.1)	19(20.2)	2( 2.1)
Accumulated fatigue:					
	18(19.1)	33(35.1)	10(10.6)	29(30.9)	4( 4.3)

### Data analysis

The data were analyzed by assessing frequency, correlation, factor analysis and step-wise multiple regression analysis.

## RESULTS

### 1) Frequency of each variable

#### The caregiver

The number of females (71.3%) was about triple that number of males. The average age was 56.8 years old (SD = 15.9 years), and 92.6% of the subjects were married. Most of the subjects (47.9%) were illiterate. The length of

caregiving found in most of the subjects was 1-3 years. The average length of daily caregiving was 18.5 hours (SD=7.8 hours), and 72.3% of caregivers had assistant caregivers, most of whom were children (24.5%). The caregiver was most frequently the aged person's spouse (N = 43; 45.7%), followed by daughter-in-law (N = 31; 33.0%).

#### The aged

The age ranged from 65 to 93 years, and the average age was 75.6 years (SD = 7.3 years). The average period of incapacitation was 40 months (SD = 49.0 months). The most frequent

disease diagnosis was stroke, followed by diabetes mellitus (DM) and 56.4% of the elderly subjects had been diagnosed as having more than two diseases. Regarding ADL items, bathing was the item which required the most assistance (73.4%).

#### *The family background*

The majority of the families studied had a three-generation structure (67.0%), and 13.8% consisted of aged couples. Among the means by which the aged paid their medical expenses, peasant insurance was the most frequent ( $N = 39$ ; 41.5%), followed by available funds ( $N = 33$ ; 35.1%). The most frequently chosen item regarding "present medical services received" was the item "other" (38.3%), which included informal consultation, Chinese medical treatment and traditional therapy. Only 9.6% received home care service. Among the ADL items, "bathing assistance" was reported to be required by 33.0%, and 17.0% reported "no difficulty bathing".

The frequency of each caregiver burden item is listed in Table 1. Restriction of social activity was frequently reported; 42.6% of caregivers felt that they had no free time, and 56.4% felt that their interest in social activities was restricted. A sense that caring for the aged person was a burden was widespread (44.7%), although about as many did not feel this way (42.5%). 62.7% hoped that they could take a rest for a short time; however, most, 85.2%, stated that they planned to continue caregiving. 43.6% were worried about the future financial situation. The expense for medical treatment was borne by the family in 35.1%, and these subjects reported a greater sense of financial burden (44.7%). The majority of the caregivers, 58.5%, were anxious about any future change in the elderly person's health status. 54.2% reported accumulated fatigue, and that they still felt tired even after a full night of sleep.

#### *2) Statistical analysis*

The data were ranked, and the most frequent five items of the caregiver burden index were subjected to correlation analysis with each THI scale prior to varimax rotation analysis. The proportion of the total variance was 49.3%. The factor structure was then examined with varimax rotation. As a result of the above procedure, the attributes of the variable groups were found to be independent of each other. Furthermore, interrelationship of the variables was analyzed with stepwise regression and the level model  $p=0.15$  was adopted.

As Table 2 shows, every THI scale except that for the mouth and anus is significantly ( $p < 0.01$  or  $< 0.05$ ) correlated with total burden, indicating that, due to caregiving demands, the caregiver's physical and psychological health and regularity of daily life were adversely affected.

Of the five THI physical system clusters, "vague complaints", which encompasses general fatigue, heaviness of the head, shoulder pain, and pantalgia, showed the highest correlation with total burden. In addition to total burden, financial burden, accumulated tiredness, and daily caregiving hours had an explained variance of  $R^2 = 0.310$ .

Of the mental and psychological clusters, the item "depression", which encompasses sadness, loneliness, distress and lack of confidence, was correlated the most significantly with total burden. In addition to total burden, it was also correlated with family dynamic, financial burden, accumulated fatigue, and the gender of the caregiver, and had the greatest variance ( $R^2 = 0.466$ ). A significant correlation was observed between the following factors: psychological extroversion with degree of positive aggressiveness present in the caregivers personality; anxiety with labor; nervous temperament with total burden and with daily caregiving hours; and financial burden, family finance, and social res-

Table 2. Stepwise multiple regression analysis of Todai Health Index (THI) scales and caregiver burden inventory factors

	SUSY	RESP	EYSK	MOUT	DIGE	IMPU	LYSC	MENT	DEPR	AGGR	NERV	LIFE	PSD
1. Burden inventory													
Total burden:	.179**	.087**	.065**		.025*	.143**	.075**	.156**	.284**	.153**	.147**	.180*	.227**
interpersonal relationship:						.131**							
social restrictions:											.078**	.149**	
family dynamic:		.102**					.101**		.277**				
caregiving motivation:													
financial burden:	.056*		.140**		.054*			.042**	.087**	.224**		.048**	.077**
anxiety regarding the elderly person's health status:											.163**		
accumulated fatigue:	.204**			.045*		.074**		.157**	.026*				.247**
2. Circumstances of care													
caregiver sex:								.087**	.053**				
caregiver age:						.058*						.084**	
family financial relationship:								.032*					
elderly family member:		.060**			.049**								
daily care-giving hours:	.032*								.038*	.047*	.028*		
cumulative R <sup>2</sup>	.310	.211	.191	.080	.103	.303	.190	.337	.466	.339	.309	.429	.324

All variables in the model are significant at the 0.150 level

\*F values significant at p<0.05

\*\*F values significant at p<0.01

SUSY ... vague complaints

MOUT... mouth and anal

LYSC ... lying scale

AGGR ... aggression

PSD ... psychosomatic

RESP ... respiratory

DIGE ... digestive

MENT ... mental instability

NERV ... nervousness

EYSK ... eye and skin

IMPU ... irritability

DEPR ... depression

LIFE ... irregular of life style

triction with anxiety regarding the elderly person's compromised health status. In addition, a significant positive correlation, with an explained variance ( $R^2 = 0.337$ ) of mental instability with total burden, family finances, accumulated fatigue, and caregiver gender, was observed. The personalities of these caretakers were characterized by irascibility, restlessness, fidgeting, and tiredness. Impulsiveness, characterized by impulse, dissatisfaction and complaints, were correlated with total burden, accumulated fatigue, caregiver age, and relationship to the aged person, with an explained variance of  $R^2 = 0.303$ . In addition to total burden, other factors associated with irregular life style were social restrictions, financial burden, caregiver gender, and age, and daily caregiving hours ( $R^2 = 0.429$ ). Finally, psychosomatic disease, which is a psychological characteristic which can be identified as a clinical symptom, was significantly correlated with financial burden and accumulated fatigue, with an explained variance of  $R^2 = 0.324$ .

Based on results of stepwise multiple regression analysis, we were able to determine that the caregiver's mental state is markedly similar to that in severe depression. It was concluded that the five items most affecting a caregiver's mental status are, in order, total burden, financial burden, accumulated fatigue, daily caregiving hours, and gender.

## DISCUSSION

Stroke and diabetes were the two major diseases of the elderly in this study. According to Leu and Gray<sup>5)</sup>, hypertension and diabetes are the main factors which precipitate stroke. More than half of the elderly persons in our study required assistance with ADL, and bathing was the activity requiring the most assistance. Chiu *et al.*<sup>6)</sup> reported a similar finding in that about 62.8% of the patients in Kaohsiung City required

assistance while bathing. Helping their elderly family member bath is apparently the activity the caregivers experience as the greatest burden, suggesting that the caring skills and equipment require improvement. Although Poulshock and Deimling<sup>7)</sup> found less significant correlation of the aged person's ADL status with the caretaker burden, our research indicates that the ADL of the aged, is significantly correlated with the state of consciousness, Kosberg *et al.*<sup>8)</sup> and Chiu *et al.*<sup>6)</sup> found that the dependence and behavior of the aged person is related to the caregiver's sense of burden, in contrast to our results. Furthermore, Jones and Vetter<sup>9)</sup> point out incontinence as one of the frustrations of caregivers. This phenomenon was not found in our study, perhaps because of the good adaptability of the individual or family unit.

Cantor<sup>10)</sup>, Pruchno and Resch<sup>11)</sup>, Poulshock and Deimling<sup>7)</sup>, Zarit *et al.*<sup>12)</sup>, Baillie *et al.*<sup>13)</sup> and Chiu *et al.*<sup>6)</sup> all focused on female caregivers in their research. Moreover, Chie and Yaung<sup>14)</sup> found, as we did, that females play the main role in taking care of family members. The majority of family structures in our study were of three generations (67%), and Chiu *et al.*<sup>6)</sup> found 61.4%, indicating that the traditional family structure and values still prevail in Taiwan. Kosberg *et al.*<sup>8)</sup> found that elderly people and caregivers are more content when living with children, and, as we did, that members of large families can share money, time and the burden of caring with other members. Similarly, Dai and Yu<sup>15)</sup> also pointed out that distributing the burden of caring among generations reduces the impact on the family.

The research of Barusch<sup>16)</sup>, Cantor<sup>10)</sup> and Schulz *et al.*<sup>17)</sup> indicates that caregivers are anxious about the aged person's future condition. Nearly 58.5% of the caregivers felt anxious in the event of a potential emergency, which was the main cause of neurosis. Obviously, caregivers are compelled to remain in an anxious state,

because of the possibility of deterioration in the elderly person's health. In addition, Barusch and Spaid<sup>18)</sup> and Jones and Vetter<sup>9)</sup> indicated that caregiver stress is inversely related to the accessibility of a supports network.

About 54.2% of the caregivers reported that the accumulated fatigue, they felt, in addition to psychosomatic disease, was another main factor affecting their physical and mental condition. Kohra<sup>20)</sup> reported that long-term caregivers of the bedridden aged show progressive fatigue with alteration in physical condition and mental status. Chiu *et al.*<sup>6)</sup> reported that caregivers felt tired when taking care of patients, and Young and Kohana<sup>19)</sup> indicated that 61% of caregivers who take care of patients on a long-term basis have exhausted their energy. Moreover, the degree of physical and mental deterioration associated with this task show no cultural or regional variation.

Barusch and Spaid<sup>18)</sup> reported that 51% of caregivers did not know how they spent their care-taking time. Poulshock and Deimling<sup>7)</sup> reported that because the caregiver's options are limited by society their sense of burden is increased. Cantor<sup>10)</sup> indicated that the caregivers complained that they did not have free time and/or the opportunity to make friends. Chiu *et al.*<sup>6)</sup> also indicated that their opportunities for travel and going outdoors were restricted. Furthermore, our research indicates that almost half of the caregivers who report similar thoughts are also affected by factors associated with neurosis and irregular life style. Because the caregivers lives had become hectic and disorderly, pursuing a high quality of life was the common desire of all caregivers.

Cantor<sup>10)</sup> and Pruchno and Resch<sup>11)</sup> indicated that stronger caregiver motivation to care for the patient was associated with more affectionate treatment. Furthermore, the greater the pressure on the caregiver, the more depressed they are. We found that 62.7% of the caregivers

would like to take a temporary rest. The percentage of caregivers who experienced caretaking as a great burden was 44.7%, which is much higher than the 23.7% reported by Chiu *et al.*<sup>6)</sup> However, 85.2% of the caregivers expressed that they would like to continue being responsible for the care of the elderly person. The stepwise regression analysis indicated no obvious correlation between the motivation to take care of the elderly person and mental or physical status. These results could reflect the role of the family unit in maintaining health and in taking care of the elderly, or traditional Chinese moral concepts, which continue to have a powerful influence. In a non-Taiwan study, Young and Kahana<sup>19)</sup> also reported that 78% of those interviewed would like to continue caring for the elderly.

Barusch and Spaid<sup>18)</sup>, Schulz *et al.*<sup>17)</sup> and Zarit *et al.*<sup>12)</sup> reported that the family economic status had been adversely affected, i. e., the family experienced financial difficulties and worried about future expenses. We found similar results. Furthermore, finance is an important factor influencing the caregiver's physical and mental health and contributing to the irregularity of their daily lives. It is obvious that economic problems cause the caregiver much worry and anxiety. In countries with a well-developed social medical insurance system, family economic problems still remain; however, in Taiwan they are more severe. The research of Chiu *et al.*<sup>6)</sup> as well as ours indicates that the proportion of people paying for their own medical expenses is 35.1%; not all families were covered by medical insurance. Economic considerations influence the willingness of family members to consult a doctor, and it is difficult to predict how long the elderly infirm will require care. Consequently, promotion of not only social welfare programs for the elderly but also a long-term medical and economic support system is required.



According to Barusch<sup>16)</sup>, 67% of long-term caregivers felt depressed, 42% had problems with health, and 55% had experienced loneliness. Poulshock and Deimling<sup>7)</sup> point out that the burden of taking care of the patient is the primary cause of a caregivers' depression and deteriorating health. According to Pruchno and Resch<sup>11)</sup>, anxiety, depression and hostility are the typical psychological problems of caregivers; Zarit *et al.*<sup>12)</sup> reported that taking care of the patient affects the caregiver's physical health, and contributes to mood and mental problems such as distress, depression, and even "burn out". Young and Kahana<sup>19)</sup> and Jones and Vetter<sup>9)</sup> obtained similar findings. Furthermore, according to the research of Chiu *et al.*<sup>6)</sup> the caregiver's physical status, mental health and total burden were all highly interrelated. In our research, consistent with that of Chiu *et al.*<sup>6)</sup>, the primary factors influencing a caregiver's physical and mental health were found to be their sense of burden. With respect to mental status, the most common trait was depression ( $\beta = 0.284$ ,  $p < 0.01$ ) followed by Psychosomatic disease ( $\beta = 0.227$ ,  $p < 0.01$ ) and mental instability ( $\beta = 0.156$ ,  $p < 0.01$ ). The most common item on the THI scale was vague complaints ( $\beta = 0.179$ ,  $p < 0.01$ ). According to the Japanese Physical and Mental Medicine Association<sup>21)</sup>, psychosomatic disease is diagnosed by patients complaints. Mental, social, or personality factors are important in the process of therapy. Moreover, tension and pressure in daily living are the common causes. Thus, we consider that both the physical and mental burdens of caregivers are considerable. Schulz *et al.*<sup>17)</sup> point out that the daily hours of caring and the relationship between the aged and the caregiver are related to caregiver depression. According to Young and Kahana<sup>19)</sup> the sense of burden and tension are related to the gender of the caregiver and their relationship with the aged. Baillie *et al.*<sup>13)</sup> suggested that caregiver pressure and

depression are related to their age and number of years of caring. However, We found that, except for the gender of the caregiver and the daily caregiving hours, other items, such as the relationship between the aged and the caregiver, duration and task difficulty of caregiving, and the elderly persons level of consciousness, had no obvious connection with the parameters reflecting a caregiver's physical and mental health.

The THI, the main measurement tool used in this research, was developed based on Japanese subjects, and is highly accurate due to continuous research and improvement. The health questionnaire effectively assesses a subject's physical and mental state. Moreover, the test-retest reliability in this research was  $r = 0.93$ , indicating its applicability in other cultures. The average time required to complete the questionnaire was about 2.5 to 3.0 hours, indicating that this questionnaire was well-accepted. The caregivers interviewed felt comfortable because they felt that they themselves were cared about, and their attitudes were quite kind and sincere. Some of them were quite tearful while trying to express their inner feelings, and the interviewers were moved by their sincerity. Despite the length of the questionnaire, all interviews were conducted in a harmonious manner; thus, the truthfulness of their statements seems undoubted. The result that variables such as the duration of care, the ADL of the aged person, and difficulties encountered while caring, were not related to the caregiver's physical and mental health may be due to the good adaptability of the family unit and its members. We plan to examine the nature of adjustment in our next research project.

The difficulty of locating subjects was the most troublesome problem we encountered in the process of this research, and it is still unknown how many elderly people need assistance in this society and where they are. Through in-

interviews, we found that few had received active medical services from the community. The provision of practical assistance to caregivers who take responsibility for the long-term care of the elderly, who require care and support from others, as well as addressing the well-being of the caregivers, is an important social welfare policy issue.

Since this research was carried out by visiting families, we had the opportunity to observe the conditions under which the caregivers attended the aged and their family dynamic and other factors which influence the caregiver's lives, as well as relating to their mental pressure. Therefore, it was meaningful research from the viewpoint of medical health, society and nursing. The value of the art of listening and its role in community nursing were particularly evident.

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