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Factors associated with the well-being of family caregivers of people with dementia

Running title

Well-being of family caregiver

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ABSTRACT

Background: Improving the health and well-being of family caregivers of people with dementia has become an increasingly important public health and policy issue in China. The aims of this study were to clarify the factors associated with the well-being of family caregivers of people with dementia in China.

Methods: Data were collected from a sample of 132 family caregivers who volunteered to study and live together with people with dementia who had been treated as outpatients in three hospitals in China. The survey included questions on the family caregivers' characteristics, satisfaction with family support, positive aspects of caregiving, preparedness of caregiving, and characteristics of people with dementia. Multiple linear regression analysis was carried out to identify factors associated with the well-being of family caregivers.

Results: The mean age of the family caregivers (68.2% women) was 46.8 ± 14.9 years. The results of multiple linear regression analysis indicated that positive aspects of caregiving ($\beta=0.352$, $p<0.001$), satisfaction with family support ($\beta=0.219$, $p<0.01$), activities of daily living of people with dementia ($\beta=0.265$, $p<0.05$), and household size ($\beta=-0.184$, $p<0.05$) were related to the well-being of family caregivers.

Conclusions: The findings from this study indicated that positive aspects of caregiving, satisfaction with family support, activities of daily living of people with dementia, and household size were significant factors related to the well-being of family caregivers. These findings could be expected to aid health care providers in identifying the optimal solution to enhance the well-being of family caregivers in China.

Keywords

Caregivers, China, dementia, family support

INTRODUCTION

In 2019, Alzheimer's Disease International estimated that there were over 50 million people living with dementia globally, a figure set to increase to 152 million by 2050.¹ China has the largest population in the world, and as a result, has a large aging population.² At the end of 2017, the number of older people (age ≥ 60 years) in China was estimated to have been 249 million, 9.6 million of whom were suffering from dementia.³ This prompted the Chinese government to make adjustments for the aging population, including for people with dementia.³ "The global action plan on the public response to dementia 2017–2025" adopted by the World Health Organization signaled a crucial step toward achieving physical, mental, and social well-being for people with dementia and their caregivers.⁴ However, long-term care for dementia services and support outside of the home are not readily available in China.⁵ Owing to insufficient healthcare resources and the traditional Chinese custom of home care for aged parents, family members play a substantial role in home care for people with dementia.⁶ Meanwhile, improving the well-being of family caregivers has become an increasingly major public health and policy issue in China.⁷

Well-being, a conception comprising both cognitive and psychological dimensions, refers, in a general sense, to being well, as opposed to indicating a sense of contentment within any specific area of life, according to Diener's theory. In this regard, feelings of well-being provide the essential substructure to the entire health of an individual, enabling him or her to overcome challenges and achieve aims.⁸ It is generally assumed that well-being of family caregivers (defined here as family members who care for a person who is ill within the confines of the household) is directly related to their caregiving roles, which gives rise to considerable stress.⁹ In consequence, exploring the factors that can influence the well-being of family caregivers is critical for the development of sustainable health care.

The literature reveals a wide range of variables associated with the well-being of factors have already investigated the association with well-being of family caregivers. With respect to how a number of socio-demographic factors impact well-being, however, understanding remains incomplete.^{10–13} For example, precisely how family income impacts the caregiving family member remains ambiguous. In direct relevance to this study, the relationship between gender and age and the well-being of caregivers of dementia patients in China has not yet been established. On the other hand, regarding duration of caregiving, correlations of well-being of caregivers of chronic disease on the time horizon have been established;¹⁴ a negative association with well-being was demonstrated in cases involving more than five years of continuous caregiving.¹⁵ In order to clarify a high number of unknowns in dementia care, the hypothesis of this study proposed, as important factors for influencing the well-being of family caregivers, gender, age, household income and duration of caregiving.

The number of studies investigating phenomenality pertaining to caregivers has accelerated in recent years. For example, quantitative research reported that positive emotional reactions by caregivers was correlated with the well-being of spouses.¹⁶ Another systematic empirical review found that the positive aspects of caregiving (defined as the gratifications and feelings of satisfaction derived from the caregiving

experience) were beneficial to caregiver well-being,¹⁷ a correlation affirmed by the IDEAL study in the United Kingdom as pertaining to caregivers of individuals suffering from dementia.¹⁸ Nevertheless, because of cultural differences, positive aspects of caregiving and well-being of dementia caregivers in China yet requires further study.

Numerous studies have indicated that the well-being of family caregivers may be impacted by a range of important factors common among individuals suffering from dementia.¹⁹⁻²³ It is also noteworthy that activity of daily living (ADL) was a considerable predictor of well-being of caregivers, evidence from qualitative researches showed that basic activity of daily living (ADL) care experience (such as assisting with toileting, washing or handling a fall and managing behavioral problems) was negatively related to well-being of family caregivers of people with dementia.^{19,20} Research on Swedish family caregivers showed that male gender predicted well-being, and additionally, a low incident of neuropsychiatric symptoms in dementia patients predicted well-being among family caregivers (as caregivers undergo stress as a result of disruptive behaviors and mood swings exhibited by dementia patients).^{21,22} It is also well-known that age was one of predictors of cognitive function of people with dementia.²³ Unfortunately, as yet, no quantitative studies have identified ADL, cognitive function, gender and age as related to the well-being of family caregivers of individuals suffering from dementia in a Chinese environment.

In China, due to the long-standing national “one-child” family-planning policy, implemented in 1979 to balance the sudden increase in population during economic stagnation, China underwent a range of socio-cultural and demographic changes, including the “4-2-1” family structure (four grandparents, two parents, and one child), along with migration and urbanization.²⁴ In previous studies, caregiving for people with dementia was recognized as a family issue that could be overwhelming for primary family caregivers^{25,26}. With the change of the household structure, however, family function was radically transformed. In this regard, a previous study reported that the degree of satisfaction with family support, as reported by caregivers, was positively correlated with well-being.²⁷ Nevertheless, whether satisfaction with family support similarly impacts well-being in China—and particularized to those caregivers looking after an individual suffering from dementia—remains unknown. Additionally, most Chinese family caregivers, and also nursing homes, provide only basic care, related to eating, dressing, and bathing, whereas specialized dementia care, such as memory and cognitive exercises and rehabilitation, is still very rare in China.²⁸ Family caregivers who have insufficient knowledge of dementia also tend to demonstrate a low level of caregiving preparedness, potentially impacting their mental health.²⁹ Few studies are in place to precisely elucidate the link between dementia caregiver well-being and preparedness for caregiving.

Therefore, with respect to the conceptual framework of this study, we hypothesized that gender, age, duration of caregiving, positive aspects of caregiving, household size, satisfaction with family support, preparedness for caregiving and characteristics of people with dementia would be associated with well-being of family caregivers of individuals suffering from dementia. In summary, the aim of this study was to clarify factors associated with the well-being of family caregivers of people with dementia in China.

MATERIALS AND METHODS

Design and participants

This study utilized a cross-sectional design and a convenience-sampling method. G*Power 3.1 was used to calculate the sample size. A linear multiple regression model was selected to conduct the F test, with well-being as the dependent variable. When the effect size f^2 was set as 0.15, α as .05, power as 0.8, with a total of 12 independent variables (gender, age, income, household size, duration of caregiving, positive aspects of caregiving, preparedness for caregiving, satisfaction with family support, gender of people with dementia, age of people with dementia, cognitive functions of people with dementia, activities of daily living of people with dementia), a sample size of 127 was needed. The inclusion criteria were as follows: a primary family caregiver of an individual suffering from dementia, age >18 years, absent language or mental disorders, living in the same household as the care recipient, and consenting to participate in this investigation. Family caregivers were eliminated if care recipients suffered from other major diseases.

Measures

In this study, four aspects were analyzed as independent variables: demographic characteristics of family caregivers and people with dementia, the positive aspects of caregiving, satisfaction with family support, and caregiving preparedness. Well-being as the dependent variable was measured by General Well-being Scale.

Demographic questionnaire of family caregivers and people with dementia

Data were collected on the family caregiver's gender, age, ethnic group, marital status, work status, household income, education level, caregiving duration, relationship to the people with dementia, and household size (including the care recipient). Regarding their care recipients, gender, age, type of dementia, type of health insurance in China, activities of daily living (Barthel Index), and cognitive function (Mini-Mental State Examination) were from their medical records with family caregivers' agreement.

General Well-being Scale

The well-being of family caregivers was measured utilizing the General Well-being Scale (Fazio, 1977).³⁰ Advantageously, Duan has translated the GWBS scale into Chinese and reported its validation in China: the internal consistency and construct validity of GWBS prove reliable in a Chinese population.³¹ The General Well-being Scale is composed of six subscales, which included energy level; self-esteem; satisfying and interesting life; mood scale; emotional and behavioral control; and anxiety scale. 18 items in total, including the first 14 items (utilizing questions such as: *how have you been in general?*) harness a six-point rating scale, while the remaining items employ a 0-10 rating scale.³¹ A higher score indicates a higher level of well-being. All items refer to the experience of a participant transpiring over the previous

month. The scores for each subscale equal the sum of the corresponding items. Cronbach's α reliability coefficient in this study was 0.90.

Family Adaptation, Partnership, Growth, Affection, and Resolution (APGAR) Scale

Satisfaction with family support was measured using the Family Adaptation, Partnership, Growth, Affection, and Resolution (APGAR) Scale. Developed by Smilkstein, the Family APGAR Scale is a self-applicatory scale, whose validity and reliability is well established, wherein satisfaction with family support is based in general on family life and perception of its functioning according to each individual surveyed.^{32,33} The aforementioned five items corresponded to questions, such as, "I am satisfied that I can turn to my family for help when something is troubling me"; "I am satisfied with the way my family talks over things with me and shares problems with me"; along with three other items.³² The abovementioned five aspects of satisfaction with family support are assessed on a three-point scale, with scores ranging from 0 (hardly ever) to 2 (almost always); these are considered suitable for all ages. The Chinese version of the Family APGAR Scale has been shown to be reliable and repeatable and to have relatively good internal consistency.³⁴ Scores range from 0 to 10. Cronbach's α reliability coefficient in this study was 0.94.

Preparedness for Caregiving Scale (PCS)

The Preparedness for Caregiving Scale (PCS) was developed by Archbold as a self-evaluator instrument.³⁵ Preparedness for caregiving refers to how ready the family caregiver perceives him or herself to be with respect to the tasks related to the caregiving role, such as, providing physical care, emotional support and dealing with the stress of caregiving. Thus, preparedness for caregiving has both a practical and an emotional component: understanding how to act, but also, coping with emotions and stress.³⁵ It is composed of eight items regarding self-perception of preparedness across multiple domains of caregiving. Responses are rated on a five-point scale, with scores ranging from 0 to 4. A higher score signifies that the caregiver experiences a greater degree of preparedness for caregiving.³⁵ The Chinese version of the PCS has demonstrated a high level of sensitivity, with good validity, pertaining to identifying caregiving preparedness in family caregivers.³⁶ Cronbach's α reliability coefficient in this study was 0.88.

Positive Aspects of Caregiving (PAC)

Positive aspects of caregiving were measured by the Positive Aspects of Caregiving (PAC) questionnaire which was developed by Tarlow (2004).³⁷ Positive aspects of caregiving refer to "the gratifications and feelings of satisfaction derived from the caregiving experience".³⁷ The Chinese version of PAC was examined in terms of its validity and reliability.³⁸ PAC is composed of nine items and consists of two subscale scores: self-affirmation (5 items) and outlook on life (4 items). Each item began with the sentence, "Providing help to [care recipient] has. . .," followed by specific items such as "made me feel useful" and

"enabled me to develop a more positive attitude toward life." Each item is scored on a five-point Likert scale, with scores ranging from 0 to 4. A higher score indicates a more positive perception of the caregiving experience.³⁸ Cronbach's α reliability coefficient in this study was 0.92.

Data collection

This study utilized a cross-sectional design and a convenience-sampling method. Individuals suffering from dementia and their family caregivers were recruited from outpatient units at three hospitals in Sichuan, China. With cooperative commitments from these hospitals, we obtained permission to recruit family caregivers of individuals with dementia and the patients themselves from outpatient units. We explained the purpose of the study, obtained consent, and invited the participants to complete the survey. Anonymous, self-administered questionnaires were distributed to all participants. The completed questionnaires were then placed in a specially designated collection box. All collected questionnaires were sent to Kobe University in Japan for entering and analysis.

Ethical considerations

This study was approved by IRB of the Graduate School of Health Sciences, Kobe University (No. 847). Eligible family caregivers were informed of the purpose and methods of the study and the voluntary nature of participation. In addition, family caregivers were asked to check a testimony column before answering the questionnaire.

Data analysis

All statistical analyses were performed using SPSS 25 (SPSS Inc., Chicago, IL, USA). *P* values <0.05 were considered statistically significant. Descriptive characteristics of family caregivers and their care recipients were evaluated in numbers and percentages. Mean scores and standard deviations were used in assessing independent variables (gender, age, household income, caregiving duration, household size, satisfaction with family support, preparedness of caregiving, positive aspects of caregiving, care recipient's age, care recipient's ADL, care recipient's cognitive functions) and family caregivers' well-being, and for examining the relationship between independent factors and family caregivers' well-being, correlation analysis was conducted. Multiple linear regression analysis was conducted using the enter method to explore the hypothesis model in this study.

RESULTS

138 family caregivers who volunteered to participate in the study, with six questionnaires incomplete, the final sample size consisted of 132 family caregivers. The characteristics of the 132 family caregivers who participated in this study are shown in Table 1. Family caregivers' mean age was 46.8 (14.9) years old, 68.2% were women. The children relationship accounted for the largest proportion. The characteristics of

the family caregivers' care recipients (people with dementia) are shown in Table 2. The average age of elderly with dementia was 73.9 (8.1) years old, most of them had been diagnosed with Alzheimer's dementia, most of them had medical insurance.

Table 3 shows the correlations between all variables investigated in this study. The majority of the study measures related to the well-being of family caregivers of people with dementia were negatively correlated with longer duration of caregiving, female gender and age of people with dementia. The well-being of family caregivers was positively correlated with PCS, PAC, and Family APGAR Scale scores and with the ADL and cognitive function of people with dementia.

We first conducted tolerance tests for collinearity among all factors. None had tolerance scores > 0.1 or Variance Inflation Factor (VIF) > 5 , suggesting no multicollinearity among independent variables. The results of the multiple linear regression analysis showed that PAC Scale scores ($\beta = 0.352, p < 0.001$), Family APGAR Scale scores ($\beta = 0.219, p < 0.01$), the ADL of people with dementia ($\beta = 0.265, p < 0.05$), and household size ($\beta = -0.184, p < 0.05$) were significantly related to the well-being of family caregivers. These significant factors explained 47.8% of the variance in the well-being of the family caregivers (Table 4).

DISCUSSION

The results of this study revealed pertinent factors associated with the well-being of family caregivers of individuals suffering from dementia in China. The present findings, thereby, advance the current understanding with respect to the variables that can be employed in the development of interventions for family caregivers of individuals suffering from dementia (including the positive aspects of caregiving and the ADL of people with dementia). We also found that the degree of satisfaction of family caregivers with respect to family support was a significant factor in enhancing well-being. The well-being of family caregivers was also found to be negatively associated with household size.

As hypothesized, satisfaction with family support proved a critical factor associated with the well-being of family caregivers. To the best of our knowledge, this is the first study to show that satisfaction with family support may play a particularly important role in enhancing the well-being of family caregivers of individuals suffering from dementia. Regarding support from family members, family caregivers of individuals suffering from dementia require sustained support from their families, and the importance of increased satisfaction with such support has been reported.³⁹ Satisfaction with family support was found a high correlation in all the domains of caregivers' quality of life.⁴⁰ The involvement of other family members rising consequent with satisfaction indices may increase the well-being of individuals with dementia and their family caregiver.⁴¹ Family caregivers who report higher satisfaction with family support will be likely to be receiving effective caregiving support, and consequently, to experience improved well-being. In a large proportion of countries, including China, family caregivers still perform the greater proportion of dementia care. Health professionals should consider that encouraging other family members to substantially

support the primary caregiver in dementia care at home may help family caregivers increase their well-being.

The results of this study also revealed that the positive aspects of caregiving will tend to influence the well-being of family caregivers; a finding that mirrors those of previous studies.^{17,18,42} Accordingly, for family caregivers, understanding the positive aspects of caregiving constitutes an essential part of improving well-being.¹⁷ Attaining a better understanding of the positive aspects of caregiving can render the caregiving experience more satisfying and rewarding,³⁷ which in turn, will tend to promote a higher level of well-being.⁴³ Family bonds are momentous in all human societies, but the ways of expressing value for family varies across cultures. From the perspective of Chinese culture, family caregivers can perceive the positive experience as an opportunity to enhance the family's cohesion and functionality.⁴⁴ There is a significant positive correlation between family cohesion and well-being.⁴⁵ Therefore, in interventions, promoting positive aspects of caregiving is expected to improve the well-being of family caregivers.

In this study, the ADL of individuals suffering from dementia proved a significant variable bearing upon the well-being of family caregivers, which is consistent with the findings of other studies.^{46,47} The Stress Process model of Pearlin et al. has provided evidence that objective stressors, such as having to assist with ADL, are related to subjective caregiver stressors, and that these stressors could lead to intra-psychic strain and ultimately, poorer caregiver well-being.⁴⁸ Assisting individuals suffering from dementia with ADL can be stressful for caregivers, with potential consequences to their well-being.⁴⁸ Caregivers of individuals with little need for assistance with ADL may be considered as presenting fewer objective burdens or less exposure to actual primary stressors as compared to caregivers of individuals who need more assistance with ADL.⁴⁷

Our results demonstrated that household size was negatively associated with the well-being of family caregivers. This finding differs from a prior study reporting that large family size was positively associated with the well-being of family caregivers.²⁶ In this study, the average household size was 3.7, and 40% of family caregivers were the children of those suffering from dementia. The family caregiver of an individual with dementia is customarily the spouse, but if the spouse has died or was incapable of providing care, the child would bear the responsibility for care, and the household size would increase. A prior study reported that family caregivers who are the children of care recipients demonstrate an increased likelihood of experiencing a greater burden resulting from conflicts between career and caregiving tasks.⁴⁹ Consequently, this unprecedented finding provides an incentive for Chinese health professionals to prioritize this area and to furnish additional support to family caregivers who are the children of people with dementia.

Although significant correlation was established between cognitive function and well-being of family caregivers, this association was not identified in the multiple linear regression analysis. Based on previous reports showing that the severity of dementia decreases the well-being of family caregivers, we assumed a correlation between cognitive function and well-being;^{20,21} an expectation that was not, however, borne out by the results. Research on caregiver strain also showed the cognitive function to be correlated with

caregiver strain with no significance in the regression model.⁵⁰ In addition, in our study, the ADL and the cognitive function of individuals with dementia showed positive correlation in the analysis, which suggests that improvements in cognitive function might lead to improvements in ADL. The ADL level of people with dementia may imply a mediator function between cognitive function and well-being of family caregivers.⁵¹ It is therefore asserted that future studies on the relationship between cognitive function, ADL of people with dementia and the well-being of family caregivers are needed.

This study bore a number of limitations. First, causal relationships could not be determined because of the cross-sectional survey design. Second, convenience sampling from a geographically defined area limited the generalizability of the findings.

In conclusion, the results of this study indicated that positive aspects of caregiving, satisfaction with family support, the ADL of individuals suffering from dementia, and household size were significant factors influencing the well-being of family caregivers. These findings constitute important information applicable to identifying the optimal solution to enhance the well-being of family caregivers.

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DISCLOSURE STATEMENT

The authors have no potential conflicts of interest to disclose.

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TABLES

Table 1 Demographic characteristics of family caregivers (n = 132)

Variables	n	%
Gender		
Male	42	31.8
Female	90	68.2
Education level		
Elementary	25	18.9
Middle school	27	20.5
High school	29	22.0
University degree	49	37.1
Other	2	1.5
Work status		
Employed	86	65.2
Unemployed	46	34.8
Income/year (wan yuan) †		
<10	29	22.0
11-20	66	50.0
21-30	21	15.9
31-50	15	11.4
>50	1	0.8
Relationship with PWD		
Spouse	31	23.5
Brother/Sister	3	2.3
Child	54	40.9
Child-in-law	27	20.4
Grandchild	17	12.9
Variables	Mean	SD
Age (years old)	46.8	14.9
Household size (including PWD)	3.7	1.4
Duration of caregiving (years)	2.6	2.2
Well-being of family caregivers	79.6	12.6
Satisfaction with family support	6.7	3.1
Positive aspects of caregiving	29.5	6.1
Caregiving preparedness	17.2	5.2

†1 wan yuan= 1,412USD; SD: standard deviation; PWD: people with dementia

Table 2 Demographic characteristics of People with dementia (n = 132)

Variables	n	%
Gender		
Male	64	48.5
Female	68	51.5
Main Diagnosis		
Vascular dementia	34	25.8
Alzheimer's disease	87	65.9
Other dementia	11	8.3
Health insurance types		
Publicly funded healthcare [†]	35	26.5
Self-paid	19	14.4
Medical insurance [‡]	78	59.1
Variables	Mean	SD
Age (years old)	73.9	8.1
Min-Mental State Examination (Cognitive function)	18.2	5.6
Barthel Index (Activity of daily living)	61.2	34.7

[†] Publicly funded healthcare is a form of health care financing designed to meet the cost of all or most health care needs from a publicly managed fund (Chinese government or some State-own companies).

[‡] In China, there are different types of medical insurance, including social medical insurance (Chinese government entitlement covering 40-60% of the cost) and private medical insurance.

Table 3 Correlations between dependent variable and independent variables (n = 132)

Variables	Well-being of family caregivers	<i>p</i> -value
1 Gender of family caregivers	-0.234	0.007**
2 Age of family caregivers	-0.084	0.338
3 Income of family caregivers	0.084	0.341
4 Household size	-0.039	0.658
5 Duration of caregiving	-0.251	0.004**
6 Positive aspects of caregiving	0.558	<0.001***
7 Preparedness for caregiving	0.330	<0.001***
8 Satisfaction with family support	0.474	<0.001***
9 Gender of PWD	0.086	0.069
10 Age of PWD	-0.182	0.037*
11 Cognitive functions of PWD	0.489	<0.001***
12 Activities of daily living of PWD	0.452	<0.001***

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. Spearman correlation coefficients between well-being of family caregivers and gender, gender of PWD. Pearson's correlation coefficients between other variables. PWD: people with dementia.

Table 4 Factors related to well-being of family caregivers according to the multiple linear regression analysis (n = 132)

Variables	B	SE	β	<i>t</i>	<i>p</i> -value
1 Gender of family caregivers	-2.463	1.956	-0.090	-1.259	0.210
2 Age of family caregivers	0.014	0.069	0.016	0.199	0.843
3 Income of family caregivers	0.070	0.081	0.063	0.862	0.390
4 Household size	-1.623	0.647	-0.184	-2.507	0.014*
5 Duration of caregiving	-0.676	0.517	-0.118	-1.309	0.193
6 Positive aspects of caregiving	0.737	0.174	0.352	4.244	<0.001***
7 Preparedness for caregiving	0.193	0.190	0.080	1.014	0.313
8 Satisfaction with family support	0.885	0.326	0.219	2.712	0.008**
9 Gender of PWD	0.272	1.747	0.011	0.156	0.877
10 Age of PWD	0.049	0.121	0.031	0.401	0.689
11 Cognitive functions of PWD	0.055	0.276	0.024	0.199	0.843
12 Activities of daily living of PWD	0.097	0.045	0.265	2.155	0.033*
Adjusted R²=0.478					

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. PWD: people with dementia