

Abstract

Purpose: The purpose of this study was to investigate the caregiving burden experienced by older family caregivers of homebound older individuals with dementia in Hong Kong, Singapore, and Japan before the COVID-19 pandemic. The study examined their attitudes towards supporting older parents and involved 540 family caregivers. Various scales and questionnaires were used to assess factors such as memory and behavior problems, perceived support, general health, burden, cultural justification, and coping strategies. The results revealed that greater memory and behavioral problems in dementia patients negatively impacted caregivers' mental health and influenced their coping strategies. The study found no direct correlation between support for older parents and mental health but identified a positive association with specific coping strategies. The similarities among family caregivers in Hong Kong, Singapore, and Japan were noted, including age, education, occupational status, and shared cultural values like Confucianism and respect for elders. It was observed that caregivers prioritize their own quality of life while addressing the challenges related to caring for older parents.

Key word : Older with Dementia at Home, Family Caregivers, East Asia, Care Burden, Filial Responsibility

I . Introduction

Since around 2020, the social situation has completely changed due to COVID-19 infection. The form of home care has also changed drastically before and after the coronary disaster. However, the number of older people receiving care at home with symptoms of dementia remains high.

Whenever national statistics are presented, they show an increase in the number of older people with dementia. The increase in the number of older people with dementia has been occurring on a global scale as well, and so has the impact of COVID-19. The prolonged COVID-19 situation is causing a transformation of perception from an unusual to an everyday event.

In recent years, East and Southeast Asia have seen remarkable development in various aspects, including economic growth. The population structure of East and Southeast Asia has been growing dramatically against a backdrop of rapid increases in life expectancy and declines in the total fertility rate. In addition to the various factors surrounding the daily caregiving life of family caregivers of older persons with dementia, the way they cope with the with-coronary period may differ depending on their original principles, arguments, culture, and beliefs. It is important to examine the factors surrounding family caregivers of older dementia patients at home in East and Southeast Asia, where the way of thinking, ideology, and beliefs are relatively similar to those in Japan, and to consider the possibility of applying these factors to measures for family caregivers in Japan.

Family caregivers of older persons with dementia living at home have many anxieties and burdens in their potentially prolonged caregiving life. However, the conditions and circumstances of caregiving differ from family to family. The attitude toward caregiving also differs greatly among individual caregivers, including regional characteristics. Therefore, we first targeted family caregivers in the pre-coronary phase, just before the major

social changes in COVID-19, and considered that a bird's-eye view of the family's perception of older persons receiving care at home, especially those with dementia symptoms, would provide clues for intervention in the post-coronary phase.

Therefore, in order to analyze the differences in cultural justification between Hong Kong, Singapore, and Japan during the pre-coronary period, the purpose of this study was to examine the burden of caregiving by family caregivers of older persons with dementia at home, based on their attitudes toward support of older parents.

II . Definition of Terms

The sense of filial piety of a child toward his or her parents, which means to provide assistance in daily life to those who are unable to live on their own labor and financial resources (Sodei,1993) .

III . Research Methods

Research Design

Cross-sectional study

1. Research period

May 2016~March 2019

2. Research Subjects

Family caregivers of older persons with dementia (with cognitive symptoms) living at home in Hong Kong, Singapore, and Japan who agreed to cooperate in the study.

3. Data collection methods

The researcher visited the hospitals and facilities that cooperated with the study and asked the family caregivers to fill out the appropriate survey forms while answering the questions of the study subjects.

A self-assessment questionnaire was administered to assess the family caregivers' physical, social, and psychological health status and coping methods. They were also asked about behavioral and memory problems of the person with dementia in their care.

IV. Analysis methods

1 . Statistics Analysis

Descriptive analyses and reliability of the scales were performed using IBM SPSS version 25.0. The proposed model was tested using AMOS version 25.0. Missing values were imputed based on country group means of the valid data for all variables. A confirmatory factor analysis was conducted to validate the measurement model for each variable before developing the structural equation models. The significance level was set at $p < .05$. The goodness of fit of the model was evaluated by a root mean square error of approximation (RMSEA) of less than .06 for a good fit, a comparative fit index (CFI) and an incremental fit index (IFI) of greater than .90, and a standardized mean square residual of less than .08 (Hu & Bentler, 1999). Bootstrapping (500 times) was used to test the statistical significance of direct, indirect, and total effects.

Questionnaire (survey content)

The questionnaires were analyzed and published in English, Chinese, and Japanese. The CJCS was translated into Japanese and Chinese, and four bilingual translators verified the English translation.

(1) Attributes of the subjects

Demographic variables such as age, gender, ethnicity, education level, economic status of caregivers, and age, gender, and education level of

dementia patients they cared for were collected.

(2) Assessment of the frequency of memory and behavioral problems and responses exhibited by older adults with dementia: RMBPC

In this study, the Revised Memory and Behavior Problems Checklist; RMBPC (Teri et al., 1992), consisting of 24 items, was used to assess the frequency of and responses to memory and behavior problems exhibited by older dementia patients cared for by their caregivers. The reliability alpha of the frequency scale was .90 and that of the response scale was .94. Based on the responses to the frequency and response scales, the respondents were recoded as (1) yes and (0) no to whether or not they had ever engaged in a particular behavior. Higher scores indicate higher levels of caregiver burden.

(3) Self-perceived support: PSS

Self-perceived support was measured using the Perceived Support Received Scale; PSS (Krause & Markides, 1990). This 11-item scale measures perceived tangible, emotional, and informational support received from others on a 4-point Likert scale ranging from (1) never to (4) very often. The reliability alpha of the scale in this study was 0.86.

(4) Mental health of caregivers: GHQ-12

The 12-item General Health Questionnaire; GHQ-12; (Goldberg, 1972, Goldberg & Williams, 1988) was used to measure the mental health of the subjects. This scale is a shortened version of the original 60-item questionnaire (Goldberg & William, 1970) and measures respondents' mental health on a four-point liking scale. Higher scores indicate poorer mental health. The reliability alpha of the scale in this study was 0.90.

(5) Caregiver's sense of caregiving burden: ZBI

The subject's caregiving burden was measured using The Zarit Burden Interview (Zarit, Reever, & Bach-Peterson, 1980). A revised 22-item version was used in this study (Zarit, Orr, & Zarit, 1985). This scale measures the

caregiver's burden regarding economic, social life, physical health, interpersonal, emotional, and psychological pressures on a 5-point Likert scale ranging from (0) never to (4) almost always. The reliability alpha of this scale was 0.92.

(6) Attitudes toward culturally justified caregiving for the older: CJCS
The Cultural Justification for Caregiving Scale (CJCS; developed by Dilworth-Anderson et al. The scale consists of 10 items on a 4-point Likert scale ranging from (1) strongly disagree to (4) strongly agree. In this study, the reliability alpha of the scale was 0.87.

(7) Caregiver coping

Subjects' coping was measured using The Brief COPE scale (BCOPE) (Carver, 1997), a shortened version of the 60-item COPE scale developed by Carver, Scheier & Weintraub (1989). The 28-item BCOPE consists of 14 coping strategies, two items for each type, on a four-point Likert scale from (1) not at all to (4) often. The four coping strategies were selected for analysis based on their correlation with the dependent variable, the GHQ. The Spearman-Brown reliability ρ was .60 for self-transference, .61 for behavioral withdrawal, .86 for substance use, and .76 for self-blame.

V. Ethical considerations

In Japan, family caregivers of older dementia patients at home were the subjects of this study. The director of the hospital, nurses, and clinical psychologists were briefed on the purpose of the study and ethical considerations, and their consent was obtained before the survey.

The director of the hospital recommended subjects who were considered to be eligible for the study. The recommended subjects were informed of the ethical considerations before the survey, and their consent was obtained. Ethical considerations in Hong Kong and Singapore, the target countries,

were conducted after preparing materials on ethical considerations equivalent to the ethical considerations in the target countries and obtaining approval through the ethical review committee of the institution to which the research subjects belonged.

The study was approved by the review committee of the investigator's university and was conducted in accordance with the principles of the Declaration of Helsinki.

VI. Results

1. Attributes of Study Subjects

The attributes of the study subjects are shown in Table 1. The sample size for this study was 540 persons (156 in Hong Kong, 152 in Japan, and 232 in Singapore). Almost 70% of the respondents in all three countries were female. The average age of the respondents was 59 years, 69.1% were Chinese, and 28.1% were Japanese. More than one-third (36.7%) had higher education, nearly half (49.2%) had secondary education, and the rest had primary education or less (14.1%). Most of the respondents were economically active: 44.3% were employed full time, 11.2% part time, 2.7% informal, 25.8% unemployed, and 16.1% retired. The average age of PWD was 82.6 years, mostly women (69.7%). 4.1% had completed higher education, 34.9% had completed secondary education, and 61.0% had completed elementary school or lower education.

Table 1

Table 1	Participants Attributes								
	Hong Kong (N=156)		Japan (N=152)		Singapore (N=232)		Total(N=540)		
			N	%	N	%	N	%	
Caregiver	Mean age		59.0±11.4(20-92)						
	Primary caregiver	Yes	144	92.9%	138	91.4%	194	83.6%	476(88.5%)
		No	11	7.1%	13	8.6%	38	16.4%	62(11.5%)
	Gender	Male	34	21.8%	42	27.6%	70	30.2%	146(27.0%)
		Female	122	78.2%	110	72.4%	162	69.8%	394(73.0%)
	Ethnicity	Chinese	156	100.0%	0	0.0%	217	93.5%	373(69.1%)
		Malaysian	0	0.0%	0	0.0%	6	2.6%	6(1.1%)
		Indian	0	0.0%	0	0.0%	5	2.2%	5(0.9%)
		Filipino	0	0.0%	0	0.0%	0	0.0%	0(0%)
		Japanese	0	0.0%	166	100.0%	0	0.0%	152(28.1%)
		Others	0	0.0%	0	0.0%	4	1.7%	4(0.7%)
	Relationship with PWD	Spouse	24	15.5%	39	25.8%	0	0.0%	63(11.8%)
		Son/ Daughter	118	76.1%	73	48.3%	55	24.0%	246(46.0%)
		Son/ Daughter-in-law	8	5.2%	22	14.6%	151	66.0%	181(33.8%)
		Others	5	3.1%	17	11.2%	23	10.0%	45(8.4%)
	Education level	No schooling/pre-primary	2	1.3%	0	0.0%	14	6.0%	16(3.0%)
		Primary	19	12.2%	0	0.0%	41	17.7%	60(11.1%)
		Secondary	67	42.9%	106	70.2%	92	39.7%	265(49.2%)
		Tertiary	68	43.6%	45	29.8%	85	36.6%	198(36.7%)
	Marital Status	Single	52	33.5%	12	7.9%	71	30.6%	135(25.0%)
		Married	93	60.0%	124	81.6%	150	64.7%	367(68.1%)
		Divorced	6	3.9%	8	5.3%	4	1.7%	18(3.3%)
		Widowed	4	2.6%	8	5.3%	7	3.0%	19(3.5%)
	Employment status	Unemployed	20	13.1%	47	32.9%	69	29.7%	136(25.0%)
		Employed-Full Time	56	36.6%	47	32.9%	131	56.5%	234(44.3%)
		Employed-Part Time	21	13.7%	12	8.4%	26	11.2%	59(11.2%)
		Employed-Casual	2	1.3%	7	4.9%	5	2.2%	14(2.7%)
		Retired	54	35.3%	30	21.0%	1	0.4%	85(16.1%)
	Live with the PWD	Yes	105	67.7%	92	62.2%	156	67.2%	353(66.0%)
		No	50	32.3%	56	37.8%	76	32.8%	182(34.0%)
	PWD	Mean age		82.6±7.3(56-101)					
PWD being diagnosed with dementia by medical doctor		Yes	154	99.4%	139	92.1%	231	100.0%	524(97.6%)
		No	1	0.6%	12	7.9%	0	0.0%	13(2.4%)
Doctor/ any health professionals told the stage of dementia		Yes	119	83.8%	127	88.8%	226	100.0%	472(92.4%)
		No	23	16.2%	16	11.2%	0	0.0%	39(7.6%)
Stage of dementia		Early stage	33	30.8%	55	47.4%	99	43.8%	187(41.6%)
		Moderate stage	52	48.6%	42	36.2%	101	44.7%	195(43.4%)
		Late stage	22	20.6%	19	16.4%	26	11.5%	64(14.3%)
Gender		Male	36	23.2%	51	34.0%	75	32.6%	162(30.3%)
		Female	119	76.8%	99	66.0%	155	67.4%	373(69.7%)
Marital status		Single	2	1.3%	2	1.3%	9	3.8%	13(2.4%)
		Married	60	40.3%	80	53.3%	102	44.0%	242(45.6%)
		Divorced	3	2.0%	4	2.7%	5	2.2%	12(2.3%)
		Widowed	84	56.4%	64	42.7%	116	50.0%	264(49.7%)
Education level		No schooling/pre-primary	71	48.6%	0	0.0%	113	48.7%	184(35.5%)
		Primary	44	30.1%	15	10.7%	73	31.5%	132(25.5%)
		Secondary	24	16.4%	118	84.3%	39	16.8%	181(34.9%)
		Tertiary	7	4.8%	7	5.0%	7	3.0%	21(4.1%)
* p<0.05; ** p<0.01; *** p<0.001									

2. Measurement model

The measurement model was used to test the model fit of each measure based on the factor structure of the scale development and the validation of the scales in the literature. Criteria for selection of the factor structure The errors of covariance were specified with theoretical justification to ensure that each scale fits appropriately based on the adjusted indices, and the model fit for each measure is presented in Table 2. For scales with a large number of items, the mean score for each compartment was created, and

Table 2

item partitioning was conducted. For the GHQ, random parsing was conducted, and a total of six compartments were created, with two items in each compartment. In addition, the In the RMBPC, Content-based Parcelling was conducted and 6 compartments were created with 3 to 5 items (Matsunaga, 2008). Among the 14 coping strategies in the BCOPE, 4 coping strategies that were significantly correlated with the GHQ were included in the analysis. (Self-Attention, $r = 0.23$, Behavioral Disengagement, $r = 0.30$, Substance Use, $r = 0.18$, and Self-Responsibility, $r = 0.25$; $p < 0.01$). Factor loadings below .50 were not eliminated to preserve the conceptual integrity of each variable and all factor loadings were at significance levels.

Table2. Model fit indices of the six measurement scales

	CFI	IFI	RMSEA	SRMR	Factor structure based on:
RMBPC	0.985	0.985	0.063	0.038	
ZBI	0.92	0.92	0.076	0.054	Smith, George, and Ferreira (2018)
CJCS	0.976	0.976	0.057	0.031	Dilworth-Anderson, Goodwin, and Williams (2004) and Dilworth-Anderson et al. (2005)
PSS	0.956	0.956	0.07	0.057	Krause and Markides (1990)
BCOPE	0.986	0.986	0.046	0.025	Carver (1997)
GHQ	0.988	0.988	0.077	0.022	

Note. PSS, Perceived Support Received Scale; CJCS, Cultural Justification for Caregiving Scale; RMBPC, The Revised Memory and Behavior Problems Checklist; ZBI, The Zarit Burden Interview; BCOPE, The Brief COPE scale; GHQ, General Health Questionnaire.

3. Structural model

The default model showed a satisfactory fit to the data with $\chi^2/df = 1.960$, $RMSEA = .042$ (90% confidence interval, .040 - .044), $CFI = .903$, $IFI = .904$, $SRMR = .068$. The standardized direct, indirect, and total effects of the model are presented in Table 3. Memory and behavior problems of PWD were

positively correlated with caregiver burden ($\beta = 0.34$, $p < .01$), and caregiver burden was negatively correlated with perceived social support ($\beta = -0.18$, $p < .01$). Sense of burden was positively correlated with mental health ($\beta = 0.53$, $p < .01$). Sense of burden was positively correlated with four coping strategies ($\beta = 0.43$ for self-distraction; $\beta = 0.44$ for behavioral withdrawal; $\beta = 0.21$ for substance use, and $\beta = 0.34$ for self-blame, $p < .01$). Cultural values related to caregiving were positively correlated with social support ($\beta = 0.12$, $p < .05$), but negatively correlated with three coping strategies: behavioral withdrawal, substance use, and self-blame ($\beta = -0.30$, $p < .01$; $\beta = -0.13$, $p < .05$, $\beta = -0.15$, $p < .01$, respectively). Social support was negatively correlated with mental health ($\beta = -0.12$, $p < .05$). None of the coping strategies were associated with mental health.

There was a significant positive indirect effect of memory and behavior problems in older adults with dementia on the four coping strategies ($\beta = 0.07-0.15$, $p < .01$), but the effect on mental health was not significant. A significant negative indirect effect was found between memory and behavior problems and perceived social support for older adults with dementia ($\beta = -0.06$, $p < .01$). Caregiver burden had a significant positive indirect effect on mental health ($\beta = 0.10$, $p < .01$), but there was no significant indirect effect between cultural values related to caregiving and mental health ($\beta = -0.06$, $p = .06$). There was also a significant indirect effect between memory and behavioral problems of the older with dementia and caregivers' mental health ($\beta = 0.22$, $p < .01$).

Table 3. Standardized direct, indirect and total effects

	Standardized direct effect	Standardized indirect effect	Standardized total effect
	β	β	β
PSS > GHQ	-0.117*		-0.117*
BCOPE > GHQ			
Self-distraction > GHQ	0.04		0.04
Behavioural disengagement > GHQ	0.089		0.089
Substance use > GHQ	0.017		0.017
Self-blame > GHQ	0.056		0.056
CJCS > BCOPE			
CJCS > Self-distraction	0.061		0.061
CJCS > Behavioural disengagement	-0.294**		-0.294**
CJCS > Substance use	-0.130*		-0.130*
CJCS > Self-blame	-0.136**		-0.136**
ZBI > BCOPE			
ZBI > Self-distraction	0.430**		0.430**
ZBI > Behavioural disengagement	0.439**		0.439**
ZBI > Substance use	0.213**		0.213**
ZBI > Self-blame	0.344**		0.344**
RMBPC > BCOPE			
RMBPC > Self-distraction		0.148**	0.148**
RMBPC > Behavioural Disengagement		0.151**	0.151**
RMBPC > Substance use		0.073**	0.073**
RMBPC > Self-blame		0.119**	0.119**
RMBPC > ZBI	0.344**		0.344**
CJCS > PSS	0.119*		0.119*
ZBI > PSS	-0.180**		-0.180**
RMBPC > PSS		-0.062**	-0.062**
CJCS > GHQ		-0.047	-0.047
ZBI > GHQ	0.530**	0.100**	0.630**
RMBPC > GHQ		0.217**	0.217**
* $p > .05$; ** $p > .01$			

Note. PSS, Perceived Support Received Scale; CJCS, Cultural Justification for Caregiving Scale; RMBPC, The Revised Memory and Behavior Problems Checklist; ZBI, The Zarit Burden Interview; BCOPE, The Brief COPE scale; GHQ, General Health Questionnaire.

VII. Consideration

In all three countries, family caregivers of older persons with dementia at home were mainly in their late 50s, and were the main caregivers, and about 70% of them were female. In addition, in all three countries, the

family caregivers are not the spouses of the older with dementia. In addition, in all three countries, the generation of children, not spouses, accounted for about 80%, 60% were married, 50% to 60% were engaged in full-time work, and 60% to 70% were living together. The educational background of the family caregivers was high school graduate or above for 80% of them. On the other hand, more than 80% of the older with dementia at home were in their early or middle stage of dementia, mainly in their 80s. the percentage trends of the attributes of caregivers and care recipients were very similar in the three countries, which experienced rapid economic growth during reconstruction after the social turmoil following World War II. Those three countries are considered to have a unique Asian tendency to synchronize in their thoughts toward family members and in the way they build relationships.

Caregivers feel a strong sense of psychological burden when older dementia patients at home experience memory loss, unusual behavior, and discomfort in expressing emotions. This may lead to mental instability such as insomnia and depression.

In addition, family caregivers who feel stressed and burdened by the actual behavioral and memory decline of older dementia patients at home are more dissatisfied with and negative about the instrumental and emotional support they receive from their surroundings. However, they are able to cope with this.

Focusing on the burden of caregiving by family caregivers of older dementia patients at home, we analyzed four of the 14 coping strategies of the BCOPE, which were found to be significantly correlated with the GHQ; self-attention, behavioral withdrawal, substance use, and self-blame. This is a feature of the BCOPE scale that allows only the necessary subscales to be used in the analysis (Otsuka, 2008). Coping is said to be a process of

cognitive and behavioral efforts to handle external or internal demands that are rated as overloading an individual's resources(Lazarus,1991).

For family caregivers of homebound seniors with dementia, trying to see events from a different perspective when problems arise, giving up, self-criticism, and drugs and alcohol as a means to an end are common tools during emotional turmoil in the long caregiving process. The higher these feelings are, the more likely they are to have to put aside their passion for older parental support to get by on their own. This is even more so if you have a full-time, full-time occupation, which is more than half of the subjects of this study. The burden is naturally higher then.

VIII. Limitations of the Study and Future Issues

This study was limited to Hong Kong, Singapore, and Japan in terms of the amount of data. In the future, we would like to take into account the results of the present study and determine the relationship between factors related to attitudes toward older parental support and cultural aspects of family caregivers of older persons with dementia, based on the caregiving situation of the Corona Disaster.

IX.CONCLUSIONS.

This study examined the burden of caregiving based on family caregivers' attitudes toward older parental support for homebound older with dementia in Hong Kong, Singapore, and Japan during the precoronary period. The results showed that the more memory and behavioral problems the homebound older dementia patient had, the more the family caregivers' mental health was negatively affected and the more they were able to perform coping strategies; self-attention, behavioral withdrawal, substance use, and self-blame, but the more unsatisfied they were with instrumental

and emotional support and the more negative they rated it. There was no correlation between the sense of old-age parental support and mental health, but there was a positive correlation with coping strategies; behavioral withdrawal, substance use, and self-blame.

Implications for Practice

1. The trends of attributes such as educational background, age, and gender of family caregivers of older dementia patients at home in Hong Kong, Singapore, and Japan during the pre-coronary period tended to be similar.
2. The more memory and behavioral problems the older with dementia at home had, the more they negatively affected the family caregivers' mental health.
3. The more supportive the family caregivers were of their older parents, the more they engaged in coping behaviors such as drugs, alcohol, and blaming themselves.
4. The trends in family caregivers' perceptions of the burden of caring for older dementia patients at home in Hong Kong, Singapore, and Japan during the pre-coronary period were clarified, which will help to examine countermeasures for the post-coronary period.

Conflicts of Interest

There were no conflicts of interest in this study.

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