The Effect of Long Term Care Resources on Burdens for Caregiving People Living with Dementia in Taiwan

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Abstract

Background: There is an increasing awareness of caregiver's burden, especially in those caring for people with dementia. The caregiver burden has been studied extensively in Western countries; however, the interpretation of the results and replication of the intervention may deem unfit in the Chinese culture. Therefore, this study identifies the change in caregiver burden by interventional methods under current Taiwan's long-term care Act 2.0.

Method: A total of 2,598 newly diagnosed dementia outpatients was evaluated by the Changhua Christian Hospital dementia care team. Eighty patients utilize one of the three care resources, including community-based services ($n = 33$), home-based services ($n = 19$), or taking care by foreign caregivers ($n = 28$). Participants in the control group were selected by matching their global CDR score, gender, age, and caregivers' age with a 1:4 ratio. All caregivers completed the Zarit Burden Interview (ZBI) questionnaires before and six months after utilizing the care resources.

Results: The home-based and the foreign caregiver groups have the highest baseline ZBI scores with 37.63 ± 16.14 and 36.57 ± 17.14 , respectively. The second ZBI score was assessed about six months after the baseline showing that the home-based group remained the highest caregiver burden (ZBI = 31.74 ± 12.23) and the foreign caregiver group showed the lowest burden (ZBI = 25.68 ± 12.09). The mean difference in the ZBI score confirmed that the foreign caregiver group had the most improvement, averaging a decrease of 17.99 ± 31.08 points (adjust observation time). A linear regression model showed that home-based care and foreign caregiver contributes the most reduction in caregiver burden (-11.83 and -19.07 ZBI scores, respectively).

Conclusion: Caring for people with dementia includes caring for their caregivers. Dementia care team should provide proper social resources, which are crucial in the alleviation of caregiver burden.

Background

Taiwan has a unique healthcare system. Centralized national health insurance provided by the government and provides almost universal coverage to the Taiwanese citizens¹. Taiwan currently faces many common health issues shared by the aging society, with 14.6% of the population above 65².

Dementia is a degenerative disease that affects memory, judgment, language, and behavior. Its prevalence increases rapidly with age and has long become a quintessential medical issue in developed countries with a high proportion of the elderly population^{3,4,5}. Previous studies have shown that the demographic, health, socioeconomic status⁶, and mental well-being⁷ are related to caregivers' burden. Additionally, domestic literature found that the severity of mental and behavioral symptoms in a case predicted a higher care load^{8,9}, especially when a person with dementia started to experience delusional hallucinations¹⁰.

To address this issue Taiwanese are facing, the government established Taiwan's long-term care Act 2.0, which started in 2017, remains a tax-based financing scheme. The new policy provides home- and community-based service, a three-layer service network within towns and districts¹¹. The promotion of the Long-term care Act 2.0 included people with dementia over the age of fifty in its coverage. As part of this reform, the government implemented innovative programs including "Dementia integrated care centers" and "Community Dementia care centers." The former are hospitals or sites that diagnose, provide patient and caregiver education, social resources introduction, promotion of health literacy of dementia, and education of healthcare providers. The latter are community care sites that offer cognitive stimulation programs and respite services for people living with dementia.

Home-based services include home services such as bathing or household chores, providing by resident care attendants. Community-based services include daycare centers, community Dementia care centers, and community elderly stations. Community elderly stations are public spaces near every village in Taiwan, which provide congregate meals and health promotion programs. In selected population who qualifies for live-in foreign caregivers are preclude from the above social services.

As a regional medical center, the Changhua Christian Hospital (CCH) established first dementia integrated care center in Changhua County in cooperation with the Minister of Health and Welfare. The goal is to provide continuous care for people living with dementia and their care partners through a collaborative care model¹². This model generates individualized care plans by fully incorporating subjects' cognitive, physical, psychosocial status, and caregiver's relationship, employment, and care loading. Additionally, the program recognizes the caregiver's burden and allocates the resources to alleviate their care load. The goal is to assign and distribute appreciate social resources for people with dementia and their caregivers. This study aims to identify community-based, home-based, and live-in foreign caregivers' influences on primary caregivers' burden.

Methods

Participants

Changhua Christian Hospital is a tertiary medical center in central Taiwan. In October 2015, the hospital established a dementia collaborative care model, includes multi-disciplinary healthcare professional, including physicians (neurologists, psychiatrists, gerontologists, and primary care physicians), psychologists, social workers, dieticians, occupational therapists, pharmacists, and nursing case managers. The purpose is to carry out community-residential demented patients and their partner and/or primary caregiver.

The collaborative team enrolled newly diagnosed persons with dementia and arranged a face-to-face interview with the patient and their primary caregiver. The interview assesses cognitive function, living status, living environment, behavioral and psychological symptoms of the patient, and the care burden and mood of the caregiver. Individualized recommendations and care plans tailored to their needs were

arranged¹². Specifically, based on the severity of dementia, caregiver's ability, socioeconomic support, and personal preferences, the care team provided long-term care resources according to family and patient's needs and preferences¹³. Patient's living status, utilization of long-term care resources, and caregiver's mood and burden are regularly evaluated every six months to adjust care needs promptly. All information mentioned above were recorded in the electronic chart.

The clinical study was approved by the Institutional Review Board of Changhua Christian Hospital (CCH IRB 191251). Because all data needed in the present study were extracted from the electronic chart after deleting personalized information, informed consent was waived by the Institutional Review Board of Changhua Christian Hospital.

There were 2,598 newly diagnosed dementia outpatients at the Changhua Christian Hospital between October 2015 and December 2019 who entered the collaborative model. The diagnosis of dementia was based on the criteria of the Diagnostic and Statistical Manual of Mental Disorders, DSM-5. After the dementia care team's assessment, eighty patients utilize one of the three care resources, including community-based services, home-based services, or taking care by foreign caregivers. This study excluded subjects utilize care resources before care team's assessment and subjects use more than two kinds of care resources. Participants in the control group were selected by matching their global CDR score, gender, age, and caregivers' age with a 1:4 ratio. Subjects in the control group did not receive any care resources despite the recommendation by the collaborative team.

Measurements

The study documented participants' basic demographic information, including age, gender, and the relationship and age of their caregivers. Participants' cognitive function was measured using a structured-interview protocol established by Charles Hughes and colleges, the Global Clinical Dementia Rating (Global CDR)¹⁴. A score of zero suggests no apparent cognitive impairment, and a score of three indicates severe dementia. Caregivers' relationship can either be spouse, children, or other.

The caregiver burden is measured using the standardized Zarit Burden Interview (ZBI) scale¹⁵. The ZBI scales in the control group were the first two ZBI scales recorded after joining into the dementia care model. The closest ZBI scales before and after utilization of care resources were used in the comparison group as the primary outcome of the present study.

Statistical analysis

Data were analyzed using R software (R Foundation for Statistical Computing). Nominal variables using Pearson's chi-square test or Fisher exact test; while continuous variables using Student t-test or Kruskal-Wallis Rank Sum Test. A multivariate linear regression model was applied to predict factors associated with the change of ZBI scores. A p-value < .05 was considered statistically significant.

Results

The study recruited 400 participants, including 80 individuals in the resource-utilized group matched to the control group with the global CDR score, age, and gender of the participants with a 1:4 ratio. Table 1a showed the baseline characteristics between the control and the resource-utilized group. Participants' mean age was 80.26 ± 7.26 years old and 80.31 ± 6.79 years old in the resource-utilized and control groups. The age of caregivers is similar between the groups, with an average of 59.24 ± 12.78 years old in the resource-utilized group and 59.65 ± 13.51 in the control group. Participants' children were the most common type of caregiver, following by spouse.

Table 1
a. Baseline characteristics between the control and the intervention group

		Intervention	Control	P value
	Total = 400	80	320	
Global_CDR (%)	0.5	23 (28.7)	92 (28.7)	0.778
	1	37 (46.2)	163 (50.9)	
	2	15 (18.8)	46 (14.4)	
	3	5 (6.2)	19 (5.9)	
Gender (%)	1	23 (28.7)	90 (28.1)	1.00
Age (mean (SD))		80.26 (7.26)	80.31 (6.79)	0.953
Carers' age (mean (SD))		59.24 (12.78)	59.65 (13.51)	0.805
Carers' relationship (%)	Spouse	23 (28.7)	95 (29.7)	0.516
	Children	48 (60.0)	174 (54.4)	
	Other	9 (11.2)	51 (15.9)	
CDR = clinical dementia rating scale, SD = standard deviation				

The participants utilized resources in the forms of community-based services, home-based services, or care provided by a foreign caregiver. Table 1b shows the population demography between the groups. Subjects receiving home-based services or care by foreign caregivers were older than subjects receiving community-based services.

Table 1
b. Baseline characteristics in all four groups

D. Baseline characteristics in all four groups						
		Community based services	Home-based services	Foreign caregiver	Control	P-value
	Total = 400	33	19	28	320	
Global_CDR (%)	0.5	12 (36.4)	6 (31.6)	5 (17.9)	92 (28.7)	0.207
	1	17 (51.5)	9 (47.4)	11 (39.3)	163 (50.9)	
	2	3 (9.1)	4 (21.1)	8 (28.6)	46 (14.4)	
	3	1 (3.0)	0 (0.0)	4 (14.3)	19 (5.9)	
Gender (%)	1	8 (24.2)	6 (31.6)	9 (32.1)	90 (28.1)	0.902
Age (mean (SD))		76.45 (7.40)	82.53 (5.30)	83.21 (6.32)	80.31 (6.79)	0.001
Carers' age (mean (SD))		56.85 (11.43)	59.26 (14.93)	62.04 (12.61)	59.65 (13.51)	0.505
Carers' relationship (%)	Spouse	10 (30.3)	5 (26.3)	8 (28.6)	95 (29.7)	0.96
	Children	19 (57.6)	12 (63.2)	17 (60.7)	174 (54.4)	
	Other	4 (12.1)	2 (10.5)	3 (10.7)	51 (15.9)	
CDR = clinical dementia rating scale, SD = standard deviation						

Table 2 shows the average score of ZBI among the four groups before and after utilizing care resources. The home-based and the foreign caregiver groups have the highest baseline ZBI scores with 37.63 ± 16.14 and 36.57 ± 17.14 , respectively. The second ZBI score was assessed about six months after the baseline showing that the home-based group remained the highest caregiver burden ($ZBI = 31.74 \pm 12.23$) and the foreign caregiver group showed the lowest burden ($ZBI = 25.68 \pm 12.09$). The mean difference in the ZBI score confirmed that the foreign caregiver group had the most improvement, averaging a decrease of 17.99 ± 31.08 points (adjust observation time). The percentage of caregivers without an increase in care burden is highest in the foreign care group (67.9%), followed by the community-based service group (63.6%). However, there was no significant difference across the groups ($p = 0.233$).

Table 2
Caregiver burden score before and after utilization of care resources

	Community- based services	Home-based services	Foreign caregiver	Control	P-value
Total = 400	33	19	28	320	
Pre-ZBI score (mean (SD))	28.12 (13.33)	37.63 (16.14)	36.57 (17.14)	24.97 (16.66)	< 0.001
Post-ZBI score (mean (SD))	28.27 (14.95)	31.74 (12.23)	25.68 (12.09)	25.76 (16.21)	0.36
Δ ZBI score [¶] (mean (SD))	1.44 (21.30)	-10.89 (27.09)	-17.99 (31.08)	1.23 (23.66)	< 0.001
ZBI not-aggravated (%)	21 (63.6)	11 (57.9)	19 (67.9)	165 (51.6)	0.233
[¶] Δ ZBI score = change of time-adjusted ZBI score after intervention= [(Post-intervention ZBI score) – (Pre-intervention ZBI score)]/observation time(year) ZBI = Zarit Burden Interview					

Table 3 is the result of linear regression to predict factors associated with the change of ZBI scores. The utilization of various care resources results in a significant decrease in the care burden. In home-based services and foreign caregiver groups, the estimated ZBI change being – 11.83 (p-value = 0.04) and – 19.07 (p-value < 0.001), respectively.

Table 3
Linear regression model to predict factors associated with change of ZBI scores

	Estimate	Std. Error	t value	P-value
(Intercept)	0.17	10.847	0.02	0.988
Carers' age	0.03	0.14	0.22	0.828
Carers' relationship (Reference: spouse)	-1.99	4.01	-0.50	0.619
Child				
Others	1.98	5.36	0.37	0.711
Utilization of care resources (Ref: control)	0.43	4.46	0.10	0.922
Community based services				
Home-based services	-11.83	5.73	-2.06	0.04
Foreign caregiver	-19.07	4.80	-3.97	< 0.001

Table 4 further breaks down community-based services into three categories: daycare centers, community dementia care centers, and community elderly stations. In the daycare centers group, the average ZBI

score increased by 10.48 points. Community dementia care centers showed a reduction in mean ZBI score by 3.43, followed by the community elderly stations group with a 0.71 point decrease. However, these changes did not show statistical significance.

Table 4
Subgroup analysis of community-based services

	Day care centers	Community dementia care centers	Community elderly stations	Control	P value
n =	10	15	8	320	
Pre-ZBI score (mean (SD))	27.60 (15.86)	31.47 (12.80)	22.50 (10.04)	24.97 (16.66)	0.445
Post-ZBI score (mean (SD))	32.30 (17.19)	29.20 (13.72)	21.50 (13.70)	25.76 (16.21)	0.421
Δ ZBI score [¶] (mean (SD))	10.48 (25.44)	-3.43 (21.04)	-0.71 (13.56)	1.23 (23.66)	0.532
ZBI not-aggravated (%)	4 (40.0)	11 (73.3)	6 (75.0)	165 (51.6)	0.174
[¶] Δ ZBI score = change of time-adjusted ZBI score after intervention= [(Post-intervention ZBI score) – (Pre-intervention ZBI score)]/observation time(year)					

Discussion

Multiple strategies were developed to alleviate caregivers' burdens, including community-based service, popular in Western countries. On the other hand, a home-based service model is more acceptable in the Asian community. Additionally, the deep-rooted filial piety and the sense of obligation for caring for elderly family members¹⁶ make hiring a foreign caregiver the favored option in Chinese culture.

Supported by the findings in this study, both home-based service and foreign caregiver provided a significant reduction in primary caregivers' burden. Currently, there are many home-based services for people with dementia similar to the model in Taiwan worldwide. The Maximizing Independence (MIND) at Home is a home-based dementia care program in the United States that offers specific needs to the person with dementia and their caregiver. In a prospective study, the caregivers showed a reduced burden (ZBI score) and distress after receiving 18 months of the MIND at Home program¹⁷. In Singapore, the Hua Mei Dementia Care System (HMDCS) that provides multidimensional care, including caregiver support, also improves ZBI score in 38% of the caregivers¹⁸. Meta-analysis has shown home-based service, in either dyadic or carer-directed form, can reduce caregivers' burden with physical activity programs^{19,20}, education and skill training (Williams et al., 2018), support and counseling²⁰.

A study conducted in Northern Taiwan showed that the ZBI score was higher in families with a foreign caregiver than the families without (median ZBI score: 38.5 vs. 34, $p = 0.033$)²¹. The authors suggested

that patients with foreign caregivers were older and had more severe neuropsychiatric symptoms than patients without foreign caregivers. Although the control and resource-utilized groups in the present study were relatively matched based on global CDR, gender, and age, the pre-ZBI score in the foreign caregiver group was also higher than the control group (mean pre-ZBI score 24.97 vs. 36.57). The breakdown of global CDR by points showed that the foreign caregiver group had a higher percentage of patients with higher CDR scores ($CDR \geq 2$: 42.9% vs. 20.3%); this finding echoes with Lin et al. inferring the severity of dementia contributes to a more significant burden. To take a step further, in the six-month follow-up, the families hiring foreign caregivers showed a significant burden reduction, $\Delta ZBI = 17.99$ in the foreign caregiver group compared to ΔZBI of 1.23 in control. A qualitative study conducted in Singapore found caregivers' relief mostly came from the physical support brought by the hired foreign helper, such as cooking, feeding, and bathing¹⁶.

The caregiver burden increased in the community-based services group, which was an unexpected finding. In a previous study, Sussman et al. found that the community-based services (adult day program, institutional respite services, geriatric clinic services, or emotional support services), caregivers' burden has an inverse relationship to the frequency of day program attended²². An increase in day program attendance in people with dementia tends to relieve caregivers' burden. A study conducted in sixteen specialized dementia community-based service providers in Maryland, U.S.A. found that offering specialized medical needs attributes to 26% of the changes in ZBI score²³. Several possible explanations of conflicting findings include the heterogeneity of the resource type and diverse use frequency in the community-based service group. Factors related to caregivers' health, which could be a possible confounding variable, were also not considered in the current study.

Yet another possible explanation for the lack of improvement in ZBI score in the community-based service group may be the difference in clinical severity in this group. As mentioned above, participants in the home-based services and foreign caregiver groups have a higher baseline CDR score (21.1% and 42.9% with $CDR \geq 2$, respectively), suggesting more severe dementia symptoms, loss of mobility, and a higher level of dependence. On the other hand, the participants in the community-based service group tend to be more mobile, thus causing a higher burden on the caregivers because of behavioral problems but not physical handicaps²⁴. The burden attributed to behavioral symptoms may be less directly responsive to care resources. Future studies can elucidate this further by accounting for mobility when matching the groups.

The subgroup analysis compares three different community-based services to the control group, though not statistically significant. The community elderly stations and the community dementia care center tend to have decreased burden and a higher percentage of not-aggravated ZBI scores than the control group. However, the increased burden was observed in the daycare group. One possible explanation is that care attendants have relatively low care ability and familiarity with dementia patients in daycare centers than community dementia care centers. Other factors that may affect the outcome; the definition of community-based services varies in different studies, leading to the group's heterogeneity. In addition, the un-uniformed subgrouping method (for example, subgroup by the nature of the services such as

medical, emotional, or respite support, or subgroup by type of institution such as daycare center, dementia specialized center, or community center) causing inherited differences in the subgroup analysis in each study and thus its' external validity suffers.

Several limitations exist in the current study. One common disadvantage is the risk of loss to follow-up; however, this is mitigated by shortening the length of data collection, but doing so generates issues with insufficient observation time. Additionally, the retrospective cohort study's nature renders unknown confounding factors during data collection, such as participants' motility status, behavioral and psychological symptoms of dementia, and caregivers' health conditions.

Conclusion

Caring for people with dementia is a worldwide concern; this study showed that referral and utilization of supplementary social resources effectively alleviate caregivers' burden. The authors suggest that health professionals in Taiwan take advantage of the collaborative care model to establish an individualized care package for both people with dementia and their caregiver.

Declarations

Ethics approval and consent to participate:

The study was carried out in accordance with the Declaration of Helsinki and was approved by the Ethics Committee of Changhua Christian Hospital, Taiwan. (CCH IRB approval number 191251). Informed consent was not obtained from the patients because it was not requested for this retrospective study. Data were collected from electronic medical records and the data used were anonymous. No any administrative permission was required to access and use the medical records described in the study.

Consent for publication:

Not applicable.

Availability of data and material:

Dataset generated and analyzed can be available from the corresponding author on reasonable request.

Competing interests:

The authors declare that they have no competing interests.

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Authors' contributions:

YO and MC wrote the main manuscript text. WW and KJ prepared tables 1-4. All authors reviewed the manuscript.

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