

Caregiver Burden and Needs of Dementia Caregivers in Thailand: A Cross-Sectional Study

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Objective: To identify the burdens of Thai dementia caregivers and to determine the services that could support them in this function.

Material and Method: The authors surveyed 88 dementia caregivers attending "Caregiver Day". The questionnaire contained Caregiver Burden Inventory. The answers range from "not at all descriptive" (zero) to "very descriptive" (4). The authors also explored baseline characteristics of caregivers and care recipients as well as caregiver's needs of a supporting system.

Results: There was an 82% response rate. Responses in time-dependence burden distributed almost equally in the five possible scales. In developmental and physical burden, caregivers rate scores mainly from 0-2. The scores in social and emotional burden ranged mainly between 0-1. Dependency in basic activities of daily living correlated with higher caregiver burden (odd ratio 7.48, 95% confidence interval 1.42-39.53, $p = 0.02$), while sex and kinship did not. The top three caregiver's needs were 1) caregiver education and training, 2) telephone line provided for caregiver consultation and 3) special system in a hospital provided for dementia patients to have rapid access to see a doctor.

Conclusion: Caring for dementia patients can lead to high caregiver burden, particularly those caring for dependent patients. Physical and developmental burdens are affected more than social and emotional burdens. Culture, relationship quality and resources (coping, outlook on life and social support) might be contributing factors of this difference.

Keywords: Caregiver burden, Dementia

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Care givers are the key to successful dementia care. In particular, informal caregivers-adult family members or friends who provide uncompensated care are essential in caring for older adults with disabilities.

Care giving often seriously reduces the quality of life of caregivers, creating severe physical, psychological, emotional, social, and financial problems⁽¹⁻³⁾. Care giving may also increase early mortality among caregivers⁽⁴⁾. This caregiver burden is also associated with the poor outcomes of dementia patients^(5,6).

Interventions to reduce caregiver burden are a preventive strategy to reduce various health problems in both caregivers and care recipients. Care giving to demented patients places a heavier burden on the involved family members than providing care for normal older adults because patients require more supervision, have emotional as well as behavioral problems, and are less likely to express their gratitude for the care they received.

Only a few investigators have studied the burden of dementia caregivers in Asian countries⁽⁷⁻¹¹⁾. The perceptions of family responsibility and resources (coping, outlook on life and social support) vary among countries and are perceivably high in Asian countries. These cultural differences may affect caregiver burden.

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The authors sought to identify the burdens of Thai dementia caregivers and to determine the services that could support them in this function.

Material and Method

The Caregiver Burden Inventory (CBI) is a multidimensional instrument designed for caregivers of older adults suffering dementia⁽¹²⁾. It has high internal validity^(12,13). It consists of 5 dimensions: time-dependence burden (5 items), developmental burden (5 items), physical burden (4 items), social burden (5 items), and emotional burden (5 items). The answers range from “not at all descriptive” (zero) to “very descriptive” (4). The maximum total score for each dimension is 20, except for physical burden, which is 16. Scores can range from zero to 96. A total score higher than 24 indicates a high overall caregiver burden. The details of the questions are in Index 1.

The data were collected from participants coming to attend a “Caregiver Day” organized by the Department of Preventive and Social Medicine, Department of Medicine and Department of Rehabilitation Medicine, on August 19, 2009. The attendants were asked to join the survey by public announcement. The authors addressed the purpose and the details of the survey to all participants. If they were interested, the questionnaires would be distributed to them. The present study was approved by Siriraj Institutional Review Board.

Statistical analysis

Data were analyzed by SPSS version 13.0. Multiple logistic regression analysis was used to investigate the association of high caregiver burden with patient and caregiver’s characteristics. Alpha was set at 0.05 for statistically significant; all tests were two-tailed.

Results

Of 88 participants who approached the present study, 16 (18%) did not respond and 72 (82%) returned evaluable questionnaires. The mean (SD) age of caregivers was 51.6 (12.0) years, and 62 (86%) were women. Thirty caregivers (42%) were single and 31 (43%) were married. Fifty-five caregivers (76%) have educational levels of Bachelor degree and above. The majority of caregivers were daughters (41 cases, 57%). Sixty-two cases (82%) did not have financial problems. Sixty-nine percent worked full-time and spent their off work-hours taking care of their care-receivers, while 31 percent were not in the paid workforce.

Index 1. Caregiver burden inventory⁽¹²⁾

How descriptive is this statement of your situation (from 0, not at all descriptive; to 4, very descriptive?)

Factor 1: Time dependence

1. My care-receiver needs my help to perform many daily tasks
2. My care-receiver is dependent on me
3. I have to watch my care-receiver constantly
4. I have to help my care-receiver with many basic function
5. I don’t have a minute’s break from my caregiving chores

Factor 2: Developmental burden

1. I feel that I am missing out on life
2. I wish I could escape from this situation
3. My social life has suffered
4. I feel emotionally drained due to caring for my care-receiver
5. I expected that things would be different at this point in my life

Factor 3: Physical burden

1. I’m not getting enough sleep
2. My health has suffered
3. Caregiving has made me physically sick
4. I am physically tired

Factor 4: Social burden

1. I don’t get along with other family members as well as I used to
2. My caregiving efforts aren’t appreciated by others in my family
3. I have had problems with my marriage
4. I don’t do as good a job at work as I used to
5. I feel resentful of other relatives who could but do not help

Factor 5: Emotional burden

1. I feel embarrassed by my care-receiver’s behavior
 2. I feel ashamed of my care-receiver
 3. I resent my care-receiver
 4. I feel uncomfortable when I have friends over
 5. I feel angry about my interactions with my care-receiver
-

Dementia patients cared for by these caregivers are likely to have moderate to severe illness, as reflected by the need for assistance in basic activities of daily living in 52 of 72 cases (72%) and have been suffering from dementia for a median of 2.6 years (interquartile range, 2 to 5 years). Forty-four caregivers (61%) have taken care of patients at least for 1 year (Table 1).

The most frequent behavioral problems arising from dementia which were rated as the most burdensome for caregivers were: memory loss (n = 31), repeating

Table 1. Characteristics of 72 Thai dementia caregivers

Characteristics	
Mean (SD) Age, y [range]	51.6 (12.0) [27 to 74]
Women, n (%)	62 (86%)
Marital status	
Single	30
Married	31
Others	11
Education, n	
No study	1
Primary school	3
Secondary school	9
Diploma	4
Bachelor degree	37
Higher than Bachelor degree	18
Employment status, n	
Full time employment	50
Retired or unpaid workforce	22
Self-reported income, n	
Not enough	10
Enough	44
Saving	18
Relationship to patient, n	
Son/daughter	6/41
Son-in-laws or daughter-in-laws	6
Spouse	6
Grandchildren	8
Siblings	4
Others	1
Health status, n	
Ill	53
Healthy	15
Never checked	4
Illness, n	
Dyslipidemia	19
Hypertension	14
Diabetes mellitus	11
Osteoarthritis	11
Insomnia	5
Cancer	4
Migraine	3
Peptic ulcer	3
Back pain	3
Depression	2
Anxiety	2
Duration of being a caregiver, n	
< 1 month	5
1-6 months	11
6 months-1 year	11
1-4 years	26
> 4 years	18
Help in activities of basic daily living, n	
Yes	52
No	20

questions (n = 28), insomnia (n = 25), impaired activities of daily living (n = 20) and irritability (n = 18) (Fig. 1).

In terms of CBI, the median and interquartile range of the time-dependence burden, developmental burden, physical burden, social burden and emotional burden scores were 12 (5.25, 16), 5 (2, 8), 4 (1, 7), 2 (0.75, 4), and 2 (0, 3), respectively. The total CBI score was 24 (12, 34). Overall, responses in time-dependence burden were distributed almost equally in the five possible scales. In developmental and physical burden, a caregiver's rate score was mainly from 0-2. The scores in social and emotional burden ranged mainly between 0-1 (Fig. 2).

The multiple logistic regression analysis showed that caregivers of patients who need assistance in basic activities of daily livings had significantly higher caregiver burden compared to those caring for independent patients (odd ratio 7.48, 95% confidence interval 1.42-39.53, p = 0.02). There was no significant association between sex and kinship ties and caregiver burden (Table 2).

In terms of caregiver needs, caregivers rated the 3 most required supports as the following.

1. Caregiver education and training (39)
2. Telephone line provided for caregiver consultation (30)

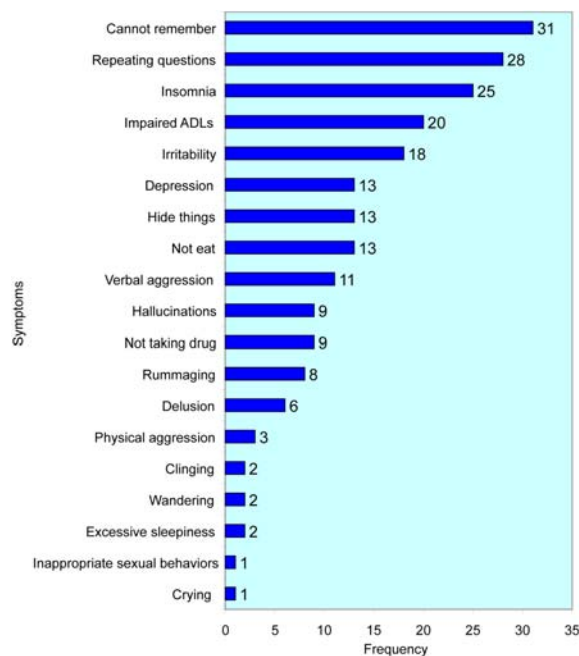


Fig. 1 Frequency of the most burdensome behavioral problems arising from dementia rated by caregivers

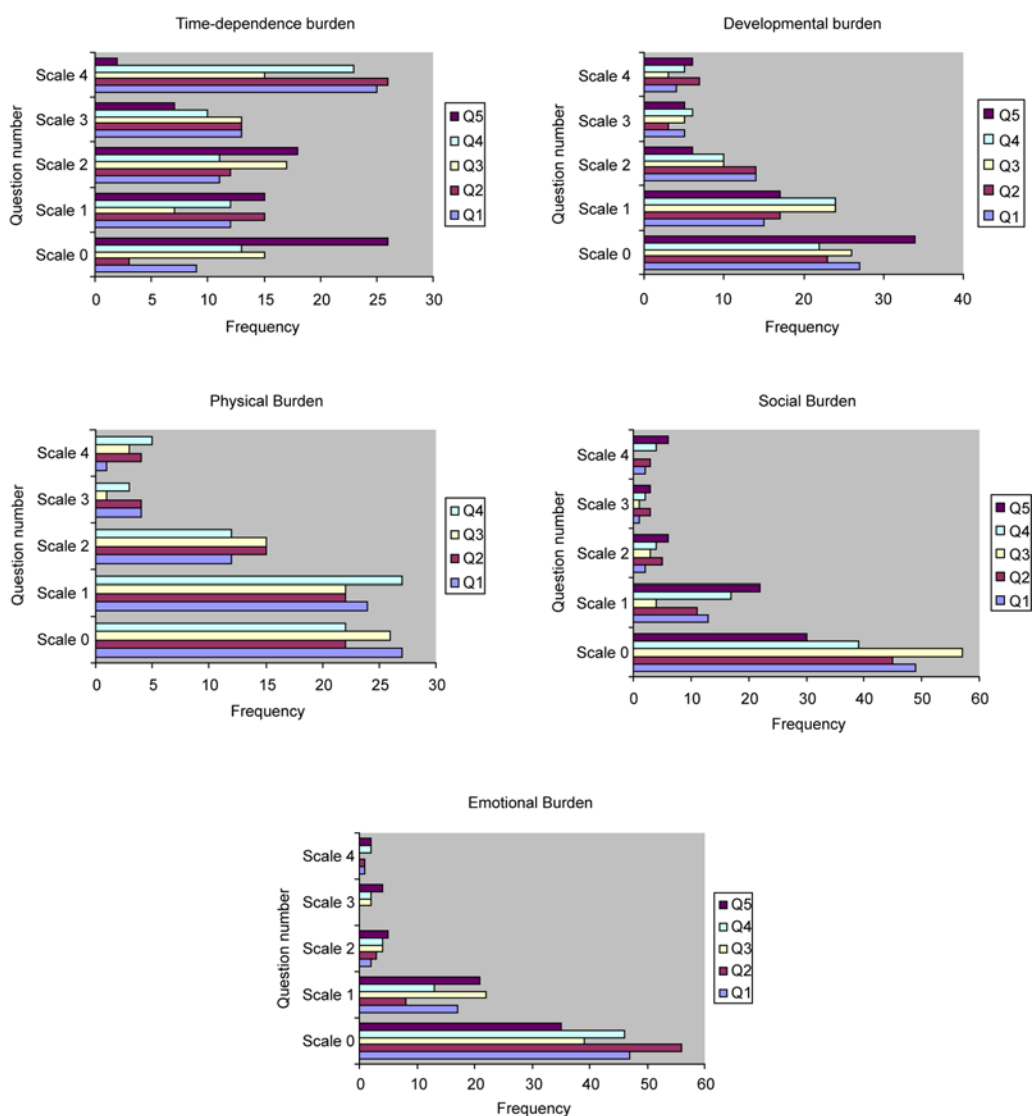


Fig. 2 Distribution of caregiver burden for 5 factors rated by caregivers

Table 2. Simple logistic regression analysis of the relationship between sex, kinship, and dependency, and high or low caregiver burden

Variables	Coefficient (β)	Standard error	Wald χ^2	p-value	Odds ratio	95% confidence interval
Sex	0.47	0.88	0.28	0.60	1.59	0.29, 8.90
Kinship	0.52	0.66	0.62	0.43	1.68	0.46, 6.15
Dependency	2.01	0.85	5.61	0.02	7.48	1.42, 39.53
Constant	-0.93	0.96	-	-	-	-

3. Special system in a hospital provided for dementia patients to have a rapid access to see a doctor (27)
4. Association or network among dementia caregivers in a hospital (26)
5. Home delivery of brochures to educate caregivers (25)
6. Nursing home or daycare center run by the government (23)
7. Home visits from healthcare professionals (22)
8. The organization for meeting up to exchange knowledge and care experience among caregivers (15)
9. Public support for dementia patients from the government such as transportation (7)

Discussion

Traditionally, the responsibility of caring for the frail older Asian people has typically fallen on women, especially daughters and daughters-in-law. Around 60 percent of Thai caregivers for the elderly are sons/daughters/sons-in-laws and daughters-in-laws⁽¹⁴⁾. In Korea, 43-70% of caregivers are daughters-in-law, followed by daughters (22.3%) and wives (21.4%)⁽⁷⁾. Older Thai men have a higher proportion of spouse caregivers compared to older Thai women⁽¹⁴⁾. Home care and community care for the elderly are the usual practice in Asian countries. Even in Japan with a large number of nursing homes, ageing-in-place practice is still the encouraged policy. Informal care is the main supportive system for Asian dementia patients. As dementia patients have both cognitive and behavioral problems leading to high demand of continual care, caregiver burden is almost inevitable.

Overall, taking care of dementia patients consumed time of caregivers as seen in the time-dependence domain of CBI. The self-rated developmental and physical burden is borderline high; however, the social and emotional burdens seem not to be a major concern to caregivers. Asian caregivers might be reluctant to express the problems in the care for their parents with other people, which could lead to less social and emotional support. However, the Asian cultures of great sense of responsibility to care for senior family members might influence the self-report of low social and emotional burden. Also, relationship quality and resources might result in this discrepancy. However, self-rating of CBI can be over- or under-reported relying on caregiver's psychological well-being, attitude towards the care, and cultural constraint.

Thai caregivers might be reluctant to express their feeling toward such kind of the burdens.

Several predictors of caregiver burden have been reported^(7,8,15-18). Two main important factors could influence caregiver burden. The first group is the caregiver-dependent factors, including age, sex, kinship, income, education, relationship quality, health status, experience of adverse life events, neuroticism, caregiver confidence, self efficacy, coping strategies, family functioning and social support^(7,8,16,19-21). The other one is patient dependent factors such as type, severity and duration of dementia, cognitive ability, behavioral and psychological symptoms, mobility status and ability to carry out day-to-day tasks^(9,10,16,18,22). In the present study, the main caregivers of dementia patients are daughters, a result similar to that for caregivers of overall older adults of the country. There was no relationship between kinship and caregiver burden and caregiver sex and caregiver burden. The predictor of caregiver burden in the present study is a patient's dependency. The greater caregiver burden is associated with the dependency on day-to-day tasks of dementia patients which reflects the severity of dementia status.

Limitations of the Study

The present study has some limitations. Most respondents are well educated, had no financial problems, and had several years of experience in caring for their patients. They might have more support both socially, and financially. Also, they might have learned coping strategies for the stress, which are important contributors to perceptions of caregiver burden. However, most studies of people who volunteer to participate in a study usually have more concern toward the studied condition and may differ from those who decline to join the study. Nevertheless, the authors should be cautious in generalizing the findings to the general population of Thai caregivers.

Although dementia caregivers have different needs and one intervention will not suit everyone, the support system that caregivers need should be addressed. The development of effective interventions to reduce caregiver burden is crucial to improve the quality care for dementia patients. Several studies show that interventions could reduce the behavioral symptoms of dementia patients, delay institutionalization, and increase the quality of life of caregivers⁽²³⁾. Some of the caregiver's needs in the present study could be easily met and should be initiated. Caregiver education and training are needed and are considered

by caregivers to be the first strategy to help them in caring for the patients better. The telephone line to provide information for caregivers can also facilitate better care. A hospital or clinic should have special access for dementia patients to healthcare. Also, healthcare professionals taking care of dementia patients should organize the network in their hospital for caregivers and provide them updated information regarding dementia knowledge and skills.

The majority of caregivers suffer from their own medical illnesses as a large proportion of them are middle-aged or older. Some of them have never had any health check-up. A physician should also periodically assess caregiver burden and health problems of this “hidden patient” and provide proper management.

Conclusions and Recommendations

Caring for dementia patients can lead to high caregiver burden, particularly those caring for especially dependent patients. The physical and developmental burdens are affected more than the social and emotional burdens. Culture, relationship quality and resources might be underlying factors of this difference. Most caregivers have their own health problems and are middle aged or older. They should receive periodic assessment of caregiver burden and health check-up. As a result of the increasing numbers of these caregivers, we should start supporting systems to help reduce their burden. Supporting the patient’s caregiver could lead to better care for the patient and better health outcome of the caregiver.

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ผลกระทบและความต้องการของผู้ดูแลผู้ป่วยภาวะสมองเสื่อมในประเทศไทย: การศึกษาวิจัยแบบตัดขวาง

วิรัชศักดิ์ เมืองไพศาล, รุ่งนิรันดร์ ประดิษฐ์สุวรรณ, จินตนา อาศนะเสน, วราลักษณ์ ศรีนนท์ประเสริฐ, ประเสริฐ อัสสันตชัย, สมบูรณ์ อินทลาภาพร, วิชัย ฉัตรธนาวาริ, ปิยะภัทร เดชพระธรรม, วิไล คุปต์นริติศัยกุล, ดุจปรารธนา พิศาลสารกิจ

วัตถุประสงค์: เพื่อสำรวจผลกระทบของการดูแลผู้ป่วยภาวะสมองเสื่อมต่อผู้ดูแล และหาระบบบริการที่อาจช่วยลดปัญหาที่เกิดขึ้นได้

วัสดุและวิธีการ: คณะผู้นิพนธ์ได้สำรวจผู้ดูแลผู้ป่วยภาวะสมองเสื่อม 88 คน ที่มาเข้าอบรมการดูแลผู้ป่วยภาวะสมองเสื่อม โดยใช้แบบสอบถามประเมินผลกระทบต่อผู้ดูแล คำตอบที่เป็นไปได้มีได้ตั้งแต่ “ไม่เหมือนเลย” (0) ถึง “เหมือนมาก” (4) คณะผู้นิพนธ์ยังเก็บรวบรวมข้อมูลพื้นฐานของผู้ดูแลและผู้ป่วย ตลอดจนสำรวจความเห็นของผู้ดูแลผู้ป่วยถึงความต้องการระบบช่วยเหลือ

ผลการศึกษา: ผู้ดูแลร้อยละ 82 ตอบแบบสอบถาม คะแนนในส่วนผลกระทบที่ขึ้นกับเวลา มีลักษณะการกระจายเกือบเท่ากันในคะแนนตั้งแต่ 0 ถึง 4 ผู้ดูแลให้คะแนนผลกระทบในส่วนการพัฒนาการ และผลกระทบทางกายอยู่ในช่วง 0 ถึง 2 เป็นส่วนใหญ่ ส่วนคะแนนในผลกระทบด้านสังคมและอารมณ์กระจายอยู่ระหว่าง 0 ถึง 1 เป็นส่วนใหญ่ ภาวะพึ่งพาในการประกอบกิจวัตรประจำวันมีความสัมพันธ์กับคะแนนผลกระทบที่มาก จากการดูแลผู้ป่วยต่อผู้ดูแล (odds ratio 7.48, 95% confidence interval 1.42-39.53, $p = 0.02$) ในขณะที่เพศและความสัมพันธ์ทางเครือญาติ ไม่มีความสัมพันธ์กับผลกระทบดังกล่าว ความต้องการของผู้ดูแลผู้ป่วยสูงสุด 3 อย่างแรกคือ 1) การให้ความรู้ และการฝึกอบรมผู้ดูแลผู้ป่วย 2) การรับปรึกษาปัญหาผ่านทางโทรศัพท์ 3) ระบบพิเศษในโรงพยาบาลที่เอื้ออำนวยให้ผู้ดูแลผู้ป่วยสมองเสื่อมได้พบแพทย์เร็วขึ้น

สรุป: การดูแลผู้ป่วยสมองเสื่อมสามารถก่อให้เกิดผลกระทบอย่างมากต่อผู้ดูแล โดยเฉพาะผู้ที่ต้องดูแลผู้ป่วยที่มีภาวะพึ่งพา ผลกระทบทางกายและทางการพัฒนามีมากกว่าผลกระทบทางสังคมและอารมณ์ วัฒนธรรม คุณภาพของความสัมพันธ์ และพื้นฐานดั้งเดิม (ความสามารถในการรับมือ มุมมองในชีวิตและการสนับสนุนของสังคม) อาจเป็นปัจจัยที่ทำให้เกิดความแตกต่างนี้