


# BMJ Open Health and long-term care of the elderly with dementia in rural Thailand: a cross-sectional survey through their caregivers

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## ABSTRACT

**Objective** To describe the circumstances of the elderly with dementia and their caregivers' characteristics in order to examine factors related to activities of daily living (ADL) and household income to propose a long-term care policy for rural areas of Thailand.

**Setting** A cross-sectional study at the household level in three rural regions of Thailand where there were initiatives relating to community care for people with dementia.

**Participants** Caregivers of 140 people with dementia were recruited for the study.

## Primary and secondary outcome measures

Socioeconomic characteristics including data from assessment of ADL and instrumental ADL and the Thai version of Resource Utilisation in Dementia were collected. Descriptive statistics were used to explain the characteristics of the elderly with dementia and the caregivers while inferential statistics were used to examine the associations between different factors of elderly patients with dementia with their dependency level and household socioeconomic status.

**Results** Eighty-six per cent of the dementia caregivers were household informal caregivers as half of them also had to work outside the home. Half of the primary caregivers had no support and no minor caregivers. The elderly with dementia with high dependency levels were found to have a significant association with age, dementia severity, chance of hospitalisation and number of hospitalisations. Though most of these rural samples had low household incomes, the patients in the lower-income households had significantly lower dementia severity, but, with the health benefit coverage had significantly higher chances of hospitalisation.

**Conclusion** As the informal caregivers are the principal human resources for dementia care and services in rural area, policymakers should consider informal care for the Thai elderly with dementia and promote it as the dominant pattern of dementia care in Thailand.

## INTRODUCTION

A report from WHO<sup>1</sup> suggests that dementia is one of the critical causes of dependence and malfunction in old age, as it affects cognitive functions such as memory, logic, awareness and communication. Dementia is one of the

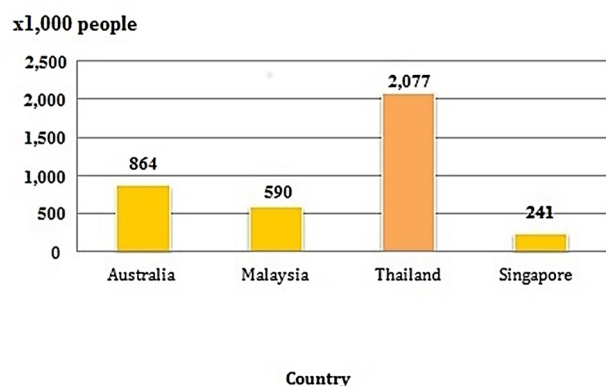
## Strengths and limitations of this study

- The present study was among the first cross-sectional studies on the burden of dementia in a rural area of an upper-middle-income country.
- The present study recruited only dementia cases with caregivers, most found to be informal caregivers who provided care in addition to other personal responsibilities.
- The present study recommends formal care units to support informal care, especially in rural areas, as the elderly are often dependent on their caregivers.

leading causes of death in old age.<sup>2</sup> Dementia is not a normal part of old age. There is a misconception that dementia is the regular part of ageing.<sup>3 4</sup> Moreover, dementia cannot be avoided or treated causally.<sup>5–7</sup>

It was estimated that there were approximately 600 000 elderly people with dementia in Thailand in 2015; this might reach more than a million people by 2030 and 2 million by 2050. This shows that the number of elderly with dementia in Thailand would be 2.4 times the number in Australia, 3.5 times more than in Malaysia and 8.6 times more than in Singapore as shown in figure 1.<sup>8</sup> Meanwhile, the low birth rate from more than 6 children per woman in 1960 down to about 1.5 children per woman in 2015<sup>9</sup> would have a negative impact on dementia care.

Caring for the elderly with dementia is difficult.<sup>10 11</sup> First and foremost, the caregivers do not necessarily realise that the elderly are struggling with ailing health conditions<sup>12</sup> as the problems occur in the brain and do not necessarily show obvious physical symptoms.<sup>13</sup> Caregivers are often faced with irrational behaviours from patients with dementia. Patients with dementia become forgetful. As the illness progresses, other



**Figure 1** The estimation of the number of people with dementia in 2050.<sup>8</sup>

behaviours can manifest as the patient's cognition functioning declines.<sup>14</sup>

In developed countries, patients with dementia have a higher rate of hospitalisation, for example, 41.9% in USA,<sup>15</sup> 40.8% in France<sup>16</sup> and 54.9% in Japan.<sup>17</sup> However, the World Alzheimer Report 2015 forecasted that we would find more people with dementia in low-income and middle-income countries, increasing from 58% of the total number of people with dementia globally in 2015 to 63% in 2030.<sup>18</sup> Fotenos *et al* found a higher risk of dementia in populations with lower socioeconomic status.<sup>19</sup> However, such dementia studies have never been carried out in Thailand.

In Asia, informal family care plays a significant role in caring for the aged. The person who takes responsibility for dementia care is typically the daughter or daughter-in-law since they assume the caretaker's role especially with regard to the tradition of filial piety and familism.<sup>20,21</sup> The percentage of family caregivers in Thailand, according to a 2014 national health examination survey found that 45% of caregivers in Thailand were their daughters, 28% their marriage partners, 18.4% sons, 6.2% grandchildren and 2.4% others.<sup>22</sup> Most of them are unpaid caregivers. The caregivers are often placed in a circumstance that involves the elderly patient declining mentally, even if they remain physically healthy.<sup>23</sup> As hidden patients, caregivers increasingly need to use health services.<sup>24</sup>

Since 2005, the number of people aged 60 years and over has been more than 10.7% of the total population. In 2014, the number of these people was estimated to be 14.9%.<sup>25</sup> In 2018, their percentage was estimated to be 17.7%.<sup>26</sup> Thailand is now regarded as an aged society. Forecasts suggest that by 2021, the number of people aged 60 years and over will reach 20%. Thailand will be regarded as a super-aged society.<sup>27</sup> The dependency level increased with age. The elderly aged 80 years and above were 33% partially dependent and 2% totally dependent.<sup>22</sup> The increasing number of elderly is expected to result in an increase in the number of patients with dementia.<sup>2</sup> However, the circumstances of dementia

affect the ageing and the working populations who drive the country's economic development.<sup>28</sup>

The National Health Security Office has been established to manage the universal coverage scheme (UCS) since 2001. The National Health Security Office introduced development of the community-based long-term care (LTC) strategy during 2014–2016 to broaden the social aspect of health coverage. Also, the second National Elderly Plan (2002–2021) stated that 'the elderly should be entitled to recognition and support by their family, community and the state to the highest dignity, health, and living standards for as long as possible'.<sup>29</sup> This facilitates the integration of community-based LTC with the primary healthcare system.<sup>30</sup> However, the above-mentioned LTC policy focused on general formal care for non-specific chronic diseases which did not specifically fit with dementia care.

Dementia is a specific chronic illness occurring more often with the aged;<sup>31</sup> care management is much more specific at the dependency level and it differs from other chronic diseases.<sup>32</sup> As suggested by WHO,<sup>33</sup> Thailand needs to develop stronger visions and greater coordinated efforts to cope with the burden of dementia like in other countries. The Community Comprehensive Dementia Care was launched by one of the authors (SC) in collaboration with the Ministry of Public Health to provide a pilot community-based dementia care at the household level in selected regions of Thailand through public health personnel. The lesson learnt and experience gained would be forwarded to the Public Health Commission of the National Legislative Assembly.<sup>34</sup> The present study aims to describe the circumstances of elderly patients with dementia and their caregivers' characteristics in order to examine factors related to activities of daily living (ADL) or dependency level and household income to propose LTC policy for the elderly patients with dementia in rural areas of Thailand.

## METHODS

### Study design

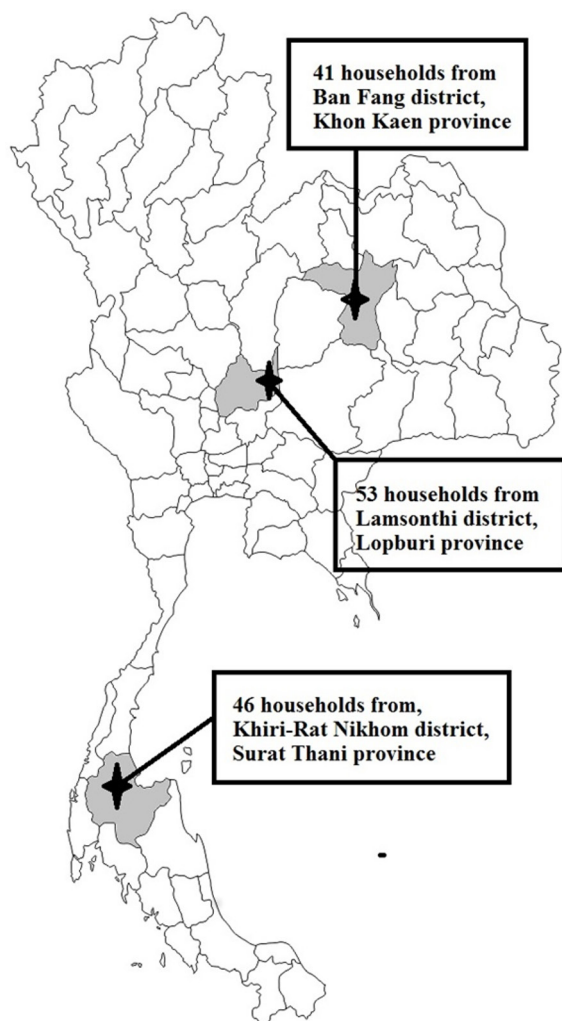
This cross-sectional study gathered information from rural areas where there were Comprehensive Dementia Care initiatives in the community.

### Patient and public involvement

Patients and the public were not involved in the design, planning or the analysis of the study.

#### Study site

In Thailand, there are no community guidelines for dementia care in the country's LTC system, however, some communities are participating in developing a new model of community dementia care following suggestions by experts in the LTC system. The three areas that joined the Community Comprehensive Dementia Care are Lamsonthi district in Lopburi for the central region, Ban Fang district in Khon Kaen for the north-eastern



**Figure 2** Map of Thailand shows the location of the investigated household participants.

region and Khiri Rat Nikhom district in Surat Thani for the southern region (see [figure 2](#)).

### Diagnosis of dementia

Persons with dementia in the present study were patients who had been diagnosed by a doctor, who differentiated the severity of their illness into mild, moderate and severe levels.

### Population

The elderly with dementia in the present study included those aged 60 years and above according to the retirement age in Thailand. All patients with dementia in the Community Comprehensive Dementia Care within the three provinces were recruited as target populations of this cross-sectional study. The inclusion criteria were the elderly with dementia who had caregivers that supplied the necessary data regarding their patients and themselves. A non-response rate of 22.2% of 180 patients was observed because caregivers were not present. In total, there were 50 patients with dementia in Ban Fang, 70 in Lamsonthi and 60 in Khiri Rat Nikhom who were recruited as our study samples. After all of the 140 caregivers understood

the study requirements, they agreed to participate by signing a consent form. The researcher (NNC) then interviewed them with structured questionnaires to determine the characteristics of the patient, the caregiver and the circumstances of the dementia care.

### Instruments and data collection

#### Sociodemographic data of the elderly with dementia and the caregivers

The data collection questionnaire covered general data such as age, sex, education and health coverage schemes; it comprised two parts. The first part included questions on the characteristics of the elderly with dementia, while the second part included questions on the characteristics of the caregiver. Based on Poomontre,<sup>35</sup> the eight classes of rural households (E, D, C-, C, C+, B, A and A+ based on household asset) were regrouped by the authors of this study into three groups on the basis of household income for accurate statistical analysis. The first level combined E to D having a household income of 0–6500 baht per month; the second level was C- to C with a household income of 65 001–20 000 baht per month; the third level was C+ to A+ with a household income of 20 001 baht per month and higher.

#### Dependency level: the assessment for ADL and instrumental ADL

The ADL and instrumental ADL (IADL) used in this study comprised 16 items with three Likert Scales to assess the capacity of a person to perform an activity of daily life. This version came from the synthesis of the National Health Commission Office of Thailand<sup>36</sup> as the standard instrument for assessing the quality of clinics for the elderly. Two domains in this instrument measured basic and complex activities. The highest score was 48, with the score from 16 to 20 being categorised as less dependent, the score from 21 to 35 was categorised as partially dependent, and the score from 36 to 48 categorised as totally dependent.<sup>37</sup>

#### The Thai version of Resource Utilisation in Dementia

The present study employed the Thai version of Resource Utilisation in Dementia (RUD) as a tool for investigating the reasons why caregivers took the decision to be dementia carers. The RUD V.3.2 was translated into Thai and back-translated which complied with standard psychometric instrument development by using acceptable validity and reliability test.<sup>38</sup> The Thai version was used to assess the amount of time given to patients with dementia by their caregivers, and their related characteristics.<sup>39 40</sup>

The researcher contacted health personnel of Community Comprehensive Dementia Care to obtain information on the dementia population in the study areas. Primary data were collected during a 60 min face-to-face interview at the patient's home or the place of participant's choice. The demographic data of both patients and caregivers were asked. The caregivers were asked about the reasons and circumstances for caring for the



the elderly with dementia during the past 12 months before the interview in 2017, which included the health services used, such as hospitalisations, outpatient visits to primary healthcare settings and day-care services (home visiting) for both patient and caregiver. The reasons for being informal dementia caregivers were asked. Their health data comprised hours of sleep per day and health services used (hospitalisations, outpatient and home visits). For the health of the elderly with dementia, the researcher asked the caregiver about the dependency level using ADL/IADL items. For the severity of illness, the researcher (NNC) collected the data from the health professional records in each area.

### Statistical analysis

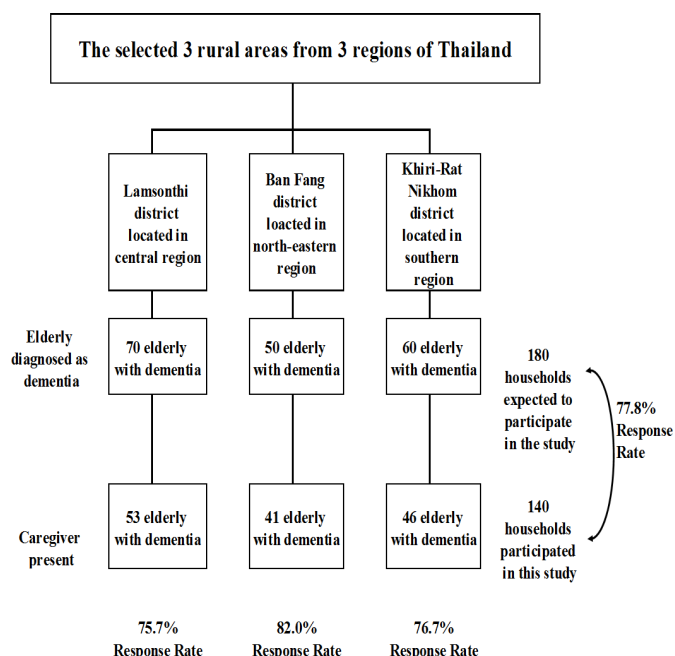
The descriptive statistic was used for the initial analysis. The Kolmogorov statistical test was performed to see whether continuous data were distributed in a normal manner for age, number of family caregivers, caregiver's hours of sleep per day, number of hospitalisations of the patient and of the caregiver. Analysis of variance (ANOVA) was used to explore the relationship between normally distributed variables such as age. For non-normally distributed variables such as the number of family caregivers, caregiver's hours of sleep per day, the number of hospitalisations for the elderly patients with dementia and the number of caregiver hospitalisations, the Kruskal-Wallis test was used. The  $\chi^2$  test was performed for the associations of the dependency level of elderly patients with dementia and household income level with gender, dementia severity, health coverage scheme, hospitalisation of elderly patients with dementia and of the caregiver.

### Ethical consideration

To comply with the research ethics consideration focusing on the confidentiality of data, all documents and electronic records were kept in locked storage. All computer files needed a password code to open. No names of people were mentioned in the transcript. The participants gave informed consent before participation in the study. The present study was funded by the Thailand Research Fund (Grant No. PHD/0049/2556). The funder has no control on the publication of research findings.

## RESULTS

Of the total dementia households in the selected areas 77.8% participated in this study (see figure 3). Table 1 shows the characteristics of patients with dementia and their caregivers. There were more female than male patients in every area (a ratio of 1.7:1), and almost three-quarters of the caregivers were female. The minimum age of the patients was 60 years and the maximum was 104 years, while of the caregivers was 21 years and 53 years. Most patients and caregivers were covered by UCS (about 85%), which became the dominant health benefit<sup>41</sup> after 2001. Most patients were vulnerable to financial hardship



**Figure 3** Population and response rate.

due to having income less than 1000 baht (around US\$30) per month. Of the caregivers, only 5.7% of them reported a monthly income more than 20 000 baht (around US\$614).

When focusing on the caregiver's characteristics (see table 2), more than half of them only completed primary school or lower, while 28.3% of them in the south earned a bachelor's degree or higher, which is significantly different from the 5.7% of the central, and 9.8% of the north-eastern region ( $\chi^2(4)=16.86$ ,  $p<0.00$ ). Nearly half (47%) of all the caregivers were employed, yet more than half of them in the north-east reported no paid job. The present study found that more than half of the caregivers (55.7%) were suffering from health conditions and reported that they had to take medications provided by health professionals. Most of the caregivers (80%) had children, and 85% of them were living with their elderly patients with dementia while half of them reported that they had to take care of their patients without any extra assistance even when they were busy or ill. About 30% had another person as backup caregiver, while 20.7% of them reported that they had more than one person to help take care of their patients, and not more than five households in each area (7% of total) were fortunate enough to be able to hire respite care services to relieve the caregiver's burden. The carers were most likely to be the family members, while more than half (58.6%) of them were offspring and a quarter of them were the spouse of patients with dementia.

Almost half (47.9%) of the caregivers still had other jobs while taking care of their patients (see table 3). A fifth of them (20.7%) reached retirement age, but still had to take care of their patients, because no one else in the household was available to carry out this role. Almost a quarter of them (23.6%) had to quit their job in order

**Table 1** Characteristics of patients with dementia and caregivers

Area	Central		North-Eastern		Southern		Total (%)	
Characteristics	Patients	Caregivers	Patients	Caregivers	Patients	Caregivers	Patients	Caregivers
<b>Gender</b>								
Male	16	15	17	11	19	12	52 (37.1)	38 (27.1)
Female	37	38	24	30	27	34	88 (62.9)	102 (72.9)
Total	53	53	41	41	46	46	140 (100)	140 (100)
<b>Age (years)</b>								
Range	61–100	22–84	60–91	23–84	60–104	30–85	60–104	22–85
Mean	77.6	53.3	77.5	53.9	81.5	54.1	78.9	53.7
SD	10.3	15.2	7.5	14.6	10.1	13.9	9.6	14.5
<b>Health Scheme</b>								
UCS	48	47	36	38	35	33	119 (85)	118 (84.3)
Non-UCS	5	6	5	3	11	13	21 (15)	22 (15.7)
<b>Income (Thai baht)</b>								
0–1000	33	23	10	12	36	4	79 (56.4)	39 (27.9)
1001–5000	20	18	30	14	7	9	57 (40.7)	41 (29.3)
5001–10 000	0	9	1	9	3	13	4 (2.9)	31 (22.1)
10001–20 000	0	2	0	4	0	15	4 (2.9)	21 (15)
20001 and over	0	1	0	2	0	5	0 (0)	8 (5.7)

UCS, universal coverage scheme.

to take care of their patients. Some of them had severe health conditions causing them to quit their jobs but still had to take care of their patients. One had been laid-off, and a few had never worked before becoming a caregiver.

To identify factors associated with dependency levels (by ADL/IADL) among people who had dementia, many factors were taken to consideration (see [table 4](#)). The mean age of the elderly was statistically different between each level of their dependency (ANOVA  $F(2,137)=7.77$ ,  $p<0.00$ ). The dependency level also had significant associations with the severity of illness ( $\chi^2(4)=105.38$ ,  $p<0.00$ ); with the chance of hospitalisation of the elderly patient with dementia ( $X^2(2)=6.46$ ,  $p<0.04$ ); also the frequency of hospitalisation of elderly patient with dementia (Kruskal-Wallis test  $\chi^2(2)=7.96$ ,  $p<0.01$ ).

Focusing on the household per capita income as socioeconomic status, 48.6% of them were the poorest, 35.7% were poor and only 15.7% had a monthly income of 20001 baht and above. [Table 5](#) presents the factors associated with the level of household income. The income level was significantly associated with dementia severity ( $\chi^2(4)=10.53$ ,  $p<0.03$ ), the health benefit coverage of the elderly with dementia ( $X^2(4)=12.74$ ,  $p<0.01$ ) and the chance of hospitalisation of the elderly with dementia ( $X^2(2)=7.09$ ,  $p<0.03$ ).

## DISCUSSION

The main findings of our study provide insight into the issue of the current circumstances of caregivers, patients

and formal-informal care in the Thai rural community. The discussions of this study are as follows:

The first concern on informal caregivers is their sandwich generation. More than half of caregivers were the adult children of patients with dementia, and most of these caregivers also had their own offspring. The multi-generational household means that the caregiver could be caught between the needs of the elderly patient and the needs of their own children.<sup>42</sup> The caregivers are mostly people of working age.<sup>43</sup> The sandwich generation caregivers have many problems and concerns such as financial difficulties, physical and mental wellness, legal and management issues, and mental health issues.<sup>42 44 45</sup>

The next concern is the pattern of an unhealthy lifestyle due to caregiving responsibilities. Despite the absence of statistical significance between the level of dependency and the caregiver's sleep hours per day in this study, one in seven caregivers (13.6%) reported that they had unhealthy sleep patterns (less than 6 hours sleep per day). Among these caregivers with low sleep levels, 21.1% of elderly patients with dementia were less dependent, 36.8% partially dependent and 42.1% totally dependent on their caregivers. The finding in [table 4](#) found that the first quartile of the caregiver's hours of sleep was lowest at the partially dependent stage as 6 hours per day. In these circumstances, the caregivers had the lowest numbers of hours of sleep as these patients with dementia were the most active and could exhibit psychotic symptoms before declining to the stage of severe dementia.<sup>46</sup> Khoo *et al*<sup>47</sup>

**Table 2** Characteristics of dementia caregivers

	Caregivers (n=140)			
	North-			
Area	Central	Eastern	Southern	Total
Educational status				
Primary level and lower	44	28	23	95 (67.9%)
Secondary level	6	9	9	24 (17.1%)
Bachelor level and higher	3	4	14	21 (15%)
Employment status				
Employed	27	15	24	66 (47.1%)
Unemployed	26	26	22	74 (52.9%)
Health conditions				
No medications prescribed	37	20	23	80 (57.1%)
Had medication prescribed	16	21	23	60 (42.9%)
Caregivers' offspring				
Had offspring	41	34	37	112 (80%)
No offspring	12	7	9	28 (20%)
Relationship with patient				
Offspring	30	22	30	82 (58.6%)
Spouse	15	11	9	35 (25%)
Sibling	1	1	2	4 (2.9%)
Others	7	7	5	19 (13.6%)
Living conditions				
Lived with patient	41	38	40	119 (85%)
Lived in their household	12	3	6	21 (15%)
Support to caregivers				
No support to caregivers	29	20	21	70 (50%)
Had one secondary caregiver	14	14	13	41 (29.3%)
Had more than one secondary caregiver	10	7	12	29 (20.7%)
Hired respite care services	3	2	5	10 (7.1%)

n, number of participants.

also found that caregiver distress was found the most in cases of moderate dementia. The present study also found higher-income households had significantly shorter caregiver's sleep hours (see [table 5](#)), as the higher-income households had greater demand for informal care and greater capacity to support the living issues. The higher-income households delivered more dementia service activities to their elderly, hence reduced caregivers' hours of sleep. During data collection in the present study, the researcher (NNC) observed that the higher-income households also had greater concerns on privacy matters and ignored community support provided by the informal

**Table 3** Reasons to be the informal caregiver for the elderly with dementia (n=140)

Reason to be the informal caregiver	N (%)
No other people to care for the elderly with dementia but can still be working	67 (47.9)
Reached the age of retirement	29 (20.7)
No other people to care for the elderly with dementia and quit the job	33 (23.6)
Suffering from own health conditions	6 (4.3)
Had been laid-off	1 (0.7)
Never worked	3 (2.1)
Desired to early retired	1 (0.7)
Total	140 (100)

caregivers while the lower-income households used more of the community support, such as ADL caring services.

Interestingly, the present study found that families with lower incomes are inflicted with the less severe cases of dementia, instead of the higher-income households who face a lower risk of cognitive impairment as the studies conducted in urban areas in the Western countries such as by Fotenos *et al.*<sup>49</sup> and Wee *et al.*<sup>48</sup> Studies were conducted in restricted financial resources but with high piety value. Like in the present study, it was discovered that most high-income households delivered more assistance services with low emotional support for their parents<sup>49-51</sup> but the low-income households that provided more emotional support with less material assistance<sup>52</sup> had slowed down cognitive impairment.<sup>53</sup> The present study suggested further research on whether the opportunity to delay the stages of dementia severity (as found in the high-income group) may be lost if the Thailand dementia care plan did not address the dementia care literacy issue. The benefits would be for all households, rural or urban communities, and higher-income or lower-income households.

While the less severe cases were found more in the lower-income households, higher rates of hospitalisations were found in the lower-income households as shown in [table 5](#). Most of the low-income households' hospitalisations were covered by the UCS and they might see hospitalisation as the option for respite care with no out-of-pocket expenses compared with the higher-income households who could afford the private respite care option.

Despite the high hospitalisation rate of low-income households, the average hospitalisation rate that the present study found at 11.4% (16/140) was comparable with the findings of Liu *et al.*<sup>54</sup> who studied elderly patients with chronic diseases who live in rural areas with low access to healthcare services. The low admission rate found in the present study implies that the ambulatory health services for the patients with dementia at subdistrict health promoting hospitals in rural areas in Thailand were of good quality with a very low co-payment for both ambulatory and hospitalisation services and not a strict gatekeeping rule for hospitalisation. Bodenheimer

**Table 4** Factors associated with the dependency level (n=140)

	Dementia elderly with less dependent (n=32)	Dementia elderly with partially dependent (n=51)	Dementia elderly with totally dependent (n=57)	Test	P
Age (years) mean (range)	75.09 (60-100)	77.24 (60-104)	82.40 (65-98)	7.77†	0.00*
Gender				0.56‡	0.75
Male n (%)	11 (34.38)	21 (41.18)	20 (35.09)		
Female n (%)	21 (65.63)	30 (58.82)	37 (64.91)		
Dementia severity				105.38‡	0.00*
Mild n (%)	28 (87.5)	21 (41.18)	2 (2.51)		
Moderate n (%)	4 (12.50)	26 (50.98)	11 (19.30)		
Severe n (%)	0 (0)	4 (7.84)	44 (77.19)		
Dementia elderly's health coverage scheme n (%)				3.65‡	0.72
Universal coverage scheme	29 (90.63)	43 (84.31)	47 (82.46)		
Social security	0 (0)	1 (1.96)	0 (0)		
Civil servant medical benefit	2 (6.25)	6 (11.76)	9 (15.79)		
Others	1 (3.13)	1 (1.96)	1 (1.75)		
Caregiver's health coverage scheme n (%)	45 (22.17)	88 (43.35)	70 (34.48)	3.26‡	0.78
Universal coverage scheme	26 (81.25)	46 (90.20)	46 (80.70)		
Social security	2 (6.25)	2 (3.92)	3 (5.26)		
Civil servant medical benefit	2 (6.25)	2 (3.92)	6 (10.53)		
Others	2 (6.25)	1 (1.96)	2 (3.51)		
Number of informal caregivers median (Q1-Q3)	1 (0-2)	2 (1-2)	2 (1-3)	5.0§	0.08
Caregiver's sleep hours per day (hours) median (Q1-Q3)	7.5 (6.25-9)	8 (6-9)	7.5 (6.5-8.5)	0.89§	0.64
Whether dementia elderly had hospitalisation				6.46‡	0.04*
Yes n (%)	3 (9.38)	2 (3.92)	11 (19.30)		
No n (%)	29 (90.63)	49 (96.08)	46 (80.70)		
Whether the caregiver had hospitalisation				4.95‡	0.08
Yes n (%)	2 (6.25)	2 (3.92)	9 (15.79)		
No n (%)	30 (93.75)	49 (96.08)	48 (84.21)		
Dementia elderly's number of times of hospitalisations median (Q1-Q4)	0 (0-5)	0 (0-6)	0 (0-17)	7.96§	0.01*

Continued

**Table 4** Continued

Caregiver's number of times of hospitalisations median (Q1-Q4)	0 (0-4)	0 (0-3)	0 (0-30)	3.58§	0.17
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\*P&lt;0.05.

†ANOVA.

‡ $\chi^2$ .

§Kruskal-Wallis test.

ANOVA, analysis of variance.

*et al*<sup>55</sup> argued that the primary care system should focus more on the coordination of care than the gatekeeper role. Moreover, the health literacy assessment towards utilisation of health services has to be considered for impending changes in the health systems, as the equity objective of the universal health coverage should reach all populations.<sup>56</sup>

There is a need for informal and formal care coordination. The present study found that the informal caregiver played the significant role of informal care on the elderly with dementia as all of the patients were living in a rural community with their relatives while health professionals provided formal support for both the elderly and the caregiver. Tuppin *et al*<sup>16</sup> agreed that informal

**Table 5** Factors associated with the level of household income (n=140)

	Income 6500 baht and lower per month (n=68)	Income 6501–20,000 baht per month (n=50)	Income 20 001 and higher per month (n=22)	Test	P
Dementia severity				10.53†	0.03*
Mild n (%)	31 (45.59)	17 (34)	3 (13.64)		
Moderate n (%)	20 (29.41)	15 (30)	6 (27.27)		
Severe n (%)	17 (25)	18 (36)	13 (59.09)		
Dementia elderly's health coverage n (%)				18.51†	0.01*
Universal coverage scheme	64 (94.12)	40 (80)	15 (68.18)		
Social security	1 (1.47)	0 (0)	0 (0)		
Civil servant medical benefit	3 (4.41)	7 (14)	7 (31.82)		
Others	0 (0)	3 (6)	0 (0)		
Number of informal caregivers median (Q1-Q3)	1 (0-2)	2 (1-3)	2 (1-2)	4.70‡	0.1
Caregiver's sleep hours per day (hours) median (Q1-Q3)	8 (7-9)	7.5 (6-9)	7 (6-7.5)	8.01†	0.02*
Whether dementia elderly had hospitalisation				7.10†	0.03*
Yes n (%)	12 (17.65)	1 (2)	3 (13.64)		
No n (%)	56 (82.35)	49 (98)	19 (86.36)		
Dementia elderly's number of times of hospitalisations					
median (Q1-Q4)	0 (0-17)	0 (0-6)	0 (0-6)	2.35‡	0.31

\*P&lt;0.05.

† $\chi^2$ .

‡Kruskal-Wallis test.

ANOVA, analysis of variance.



care complemented formal care, and most patients with dementia relied on informal care. Formal care played an essential role in supporting and guiding efficient informal care as Bremer *et al*<sup>57</sup> found that proper informal care-giving led to lower healthcare spending. Nonetheless, the informal sector needs proper health literacy from the formal sector<sup>58</sup> and the two systems have to support each other along the way for the best dementia care planning and the management of elderly patients with dementia. The present study found that more than half of the caregivers were unemployed and the caregivers with good health literacy could improve informal dementia care in Thailand. Payment incentives could improve the quality of informal care, as noted in a study by Conrad and Perry.<sup>59</sup>

Implications for policymakers were that they should consider designing both formal and informal care plans in accordance with caregivers' social constraints and their patients' dependency. The multitasked responsibilities, especially in the lowest socioeconomic group found in the present study suggested that the policymakers when improving dementia care in Thailand, should consider informal care for elderly Thai patients and promote it as the dominant pattern of dementia care as the informal caregivers are the principal human resources for dementia care and services in the current circumstances.

### Limitations and generalisability: the community is more significant than the household

This study is probably the first to explore the burden of dementia in rural communities in Thailand. Furthermore, the present study was undertaken in the villages to contribute to the development of the national LTC policy in Thailand.

Of the population of elderly patients with dementia in the present study, 22% of them were non-responders because caregivers were absent or patients simply lacked caregivers. Most of these non-responders were in the severe level of dementia and in urgent need of sufficient care. The underestimated situations of the present study should be investigated further.

Moreover, the present study investigated circumstances in Community Comprehensive Dementia Care.<sup>34</sup> Cautions on implications of the findings should be acknowledged. First, as most of the areas of Thailand still lacked a comprehensive dementia care plan, the situations of dementia households might not be the same as these selected areas. Second, different managements of the local governments having different laws<sup>60</sup> does affect the availability of social services for the elderly with dementia in households. Third, each area in the present study had different geographical and climate issues affecting the population, occupation and income. For example, households in the southern region located in the tropical forest area participating in rubber and coconut agriculture, had a higher income as compared with households in other regions.

Thailand had a strong and highly admired piety value; the strong piety value contributes to the strong belief in Thai society to ostracise those who neglect their sick and elderly. A recent study stated that 'in the moral aspect, the individuals should be responsible for their dependent elderly. If they neglect their duty, they should be penalised with some allegations'.<sup>61</sup> As it is unacceptable in Thai society, the government shelter home for older persons does not have a popular official name. Another study conducted in the community-based setting revealed that there were many elderly with chronic diseases living in the elderly shelter setting, with no health personnel to take care of.<sup>62</sup> The present study did not include samples in any older persons' home since there was no such home located in the investigation areas. This study included only the elderly with dementia who had caregivers to give the data.

Even if dementia is an unpreventable and incurable illness<sup>2</sup> it should be noted that formal health and social sectors in the Thai community had the potential to encourage everyone to practise cognitive skills before anyone in the community is afflicted with dementia.<sup>34 63</sup>

### CONCLUSION

The formal health sectors are well established in Thailand, but the informal care circumstances, especially in dementia care, portray a different story. The informal caregivers are the principal human resources for dementia care and services in rural areas; policymakers should consider informal care for the Thai elderly with dementia and promote it as the dominant pattern of dementia care in Thailand. Although, there were factors associated with the dependency levels of the elderly patients with dementia, age, dementia severity, hospitalisations and the frequency of hospitalisations of the elderly had significant associations with the level of dependency. Also, dementia severity, the health benefit scheme of elderly patients with dementia, the caregiver's sleep hours per day and hospitalisation of the patients with dementia had significant associations with their income status. Dementia caregivers in Thailand were mostly family members of patients with dementia, and they are faced with multiple responsibilities.

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**Data availability statement** Data are available upon reasonable request. Individual data from the survey may be shared under the restricted condition of not exposing confidentiality of the study participants.

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