International Journal of Community Medicine and Public Health
Chalsit P et al. Int J Community Med Public Health. 2026 Apr;13(4):1799-1807
http://www.ijcmph.com
pISSN 2394-6032 | eISSN 2394-6040

DOI: https://dx.doi.org/10.18203/2394-6040.ijcmph20260755

Original Research Article

Prevalence and factors associated with caregiver burden in palliative care in Phra Nakhon Si Ayutthaya Hospital: a cross-sectional study

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Received: 10 February 2026
Accepted: 09 March 2026

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ABSTRACT

Background: Caregiver burden significantly impacts the physical health and quality of life (QoL) of those looking after palliative care patients. Identifying the prevalence and specific determinants of this burden is crucial for developing effective supportive interventions. Objective of the study was to determine the prevalence of caregiver burden and identify factors associated with higher burden levels among primary caregivers of palliative care patients.
Methods: This cross-sectional study was conducted among 190 caregivers at Phra Nakhon Si Ayutthaya Hospital. Data were collected using a two-part structured questionnaire: socio-demographic characteristics of caregivers and patients, and the Thai version of the Zarit burden interview (ZBI) to assess caregiving burden. Participants were categorized into "no-to-mild burden" and "moderate-to-severe burden" groups for comparative analysis.
Results: Of the 190 participants (46 males, 144 females), the prevalence of no-to-mild burden was 86.84%, while 13.16% experienced moderate burden; notably, no cases of severe burden were reported. Statistical analysis revealed that factors significantly associated with increased caregiver burden ($p<0.05$) included caregivers who were married, widowed, or divorced; caregiving duration exceeding 16 hours per day; patients aged under 60 years; and patients with a bachelor's degree or higher.
Conclusions: Although the majority of caregivers reported low burden levels, a significant minority faced moderate distress. Clinical focus should be directed toward high-risk groups, particularly those providing intensive care (>16 hours/day) and those caring for younger or highly educated patients. Implementing support systems, such as caregiver rotation and tailored communication strategies regarding disease progression, is essential to mitigate anxiety and optimize palliative care outcomes.

Keywords: Caregiver burden, Palliative care, Zarit burden interview, Quality of life, Family medicine

INTRODUCTION

Palliative care is an approach that aims to improve the quality of life of patients and their families who are facing life-threatening illnesses, through the prevention and relief of suffering. This includes the management of physical symptoms, psychological distress, social problems, and spiritual concerns, as well as providing care to caregivers to enhance their quality of life.[1]

Globally, in 2011, more than 29 million people died from diseases requiring palliative care. Among adult palliative care patients, the leading causes of death included cardiovascular diseases (38.47%), cancer (34.01%), chronic obstructive pulmonary disease (10.26%), HIV/AIDS (5.71%), diabetes mellitus (4.59%), kidney disease (2.02%), liver cirrhosis (1.70%), and dementia (1.65%).[2]

Numerous international studies have demonstrated that palliative care reduces the length of hospital stay, decreases hospital and intensive care unit readmissions, and improves satisfaction with care among patients and their families.[3] According to the World Health

Organization, approximately 56.8 million people worldwide require palliative care each year; however, only 14% have access to such services.[2] In 2023, national indicator reports showed that 307,160 patients in Thailand received palliative care.[4] At Phra Nakhon Si Ayutthaya Hospital, 654 patients received palliative care services during the same year.[5]

Caregivers are individuals who provide assistance and care to patients, most commonly family members (family caregivers). Based on the level of responsibility, caregivers can be classified as primary caregivers, who provide direct, regular, and continuous care, and secondary caregivers, who provide occasional assistance.[6] Caregiving is a demanding and time-consuming task. In combination with caregiver-related factors such as health problems, financial difficulties, or personal life stressors, caregiving may lead to fatigue and the development of caregiver burden, or even caregiver burnout.[7] Caregivers of palliative care patients are therefore a population at high risk of experiencing caregiver burden, which can adversely affect their health and quality of life, potentially resulting in an inability to continue providing care. When such conditions occur, patients may be at risk of unintentional neglect or abuse.[8]

A review of the relevant literature indicates that factors contributing to increased caregiver burden among caregivers of palliative care patients include both caregiver-related and patient-related factors. Caregiver-related factors include the lack of assistance in providing care, while patient-related factors include caring for palliative care patients with non-cancer diagnoses.[9] A study among caregivers of patients with metastatic cancer found that sibling relationships between caregivers and patients, lack of caregiving support, and cancer type were associated with increased caregiver burden.[10] Additionally, a study examining factors associated with caregiver fatigue among family caregivers of patients with terminal cancer reported that providing care for fewer than 8 hours per day, a reduction in caregiving burden, and receiving social support were associated with lower levels of caregiver fatigue.[11]

Previous studies conducted in other countries have examined factors associated with caregiver burden in specific patient populations, such as patients with terminal cancer, Parkinson's disease, and dementia.[12-14] However, studies focusing on caregivers of palliative care patients have mainly investigated caregiver-related factors without concurrently examining patient-related factors.[15] In Thailand, data on the prevalence and factors associated with caregiver burden among caregivers of palliative care patients in urban populations remain limited and insufficient to draw definitive conclusions. Existing studies have been largely restricted to rural populations, such as a study conducted at Kaset Wisai Hospital, Roi Et Province.[9] Given the differing social contexts between rural settings and Phra Nakhon Si Ayutthaya Hospital, which is located in a semi-urban area, this study was undertaken to investigate factors associated with caregiver burden among caregivers of palliative care patients at Phra Nakhon Si Ayutthaya Hospital.

Objectives

Objectives of the study were to determine the prevalence of caregiver burden among caregivers of palliative care patients at Phra Nakhon Si Ayutthaya Hospital, and to identify factors associated with caregiver burden among caregivers of palliative care patients, by comparing caregivers with no to mild burden and those with mild to severe burden.

METHODS

Study design

This study employed a cross-sectional study design.

Study population and sample

A total of 190 caregivers participated in the study. Inclusion criteria were primary caregivers who were currently providing care to palliative care patients, aged 18 years or older, and willing to participate in the study. Exclusion criteria included caregivers of patients with a palliative performance scale (PPS) score greater than 60, caregivers with psychiatric disorders, and caregivers with communication impairments.[16]

Data were collected between August 2024 and January 2025 from caregivers of palliative care patients attending the outpatient palliative care clinic and from inpatient wards at Phra Nakhon Si Ayutthaya Hospital. Participants completed a two-part questionnaire: part 1 collected information on caregiver characteristics and clinical data of the palliative care patients, while part 2 assessed caregiver burden using the Thai version of the Zarit burden interview (ZBI).

Sample size calculation

The sample size was calculated based on data from a pilot study conducted at Phra Nakhon Si Ayutthaya Hospital, which showed a prevalence of mild to moderate caregiver burden of 12.2%. A confidence level of 95% and a margin of error of 5% were applied. The calculation was performed assuming an unlimited population, yielding a required sample size of 165 participants. To account for a potential 15% data loss or incomplete responses, the final sample size was increased to 190 participants.

Data collection

Data used in this study comprised three components. The first component included baseline characteristics of caregivers of palliative care patients, consisting of 11 items: age, sex, marital status, educational level, occupation, income, underlying diseases, relationship to the patient, hours of caregiving per day, total duration of caregiving, and availability of additional caregiving support. The second component included baseline characteristics of the palliative care patients, consisting of five items: age, sex, educational level, palliative diagnosis, and duration since initiation of palliative care. The third component was the assessment of caregiver burden using the 12-item ZBI.

This study aimed to determine the prevalence of caregiver burden and to identify factors associated with caregiver burden among caregivers of palliative care patients at Phra Nakhon Si Ayutthaya Hospital. A systematically developed questionnaire was used to collect data on caregiver characteristics, clinical information of palliative care patients, and caregiver burden assessment (the study floe presented as the Figure 1).

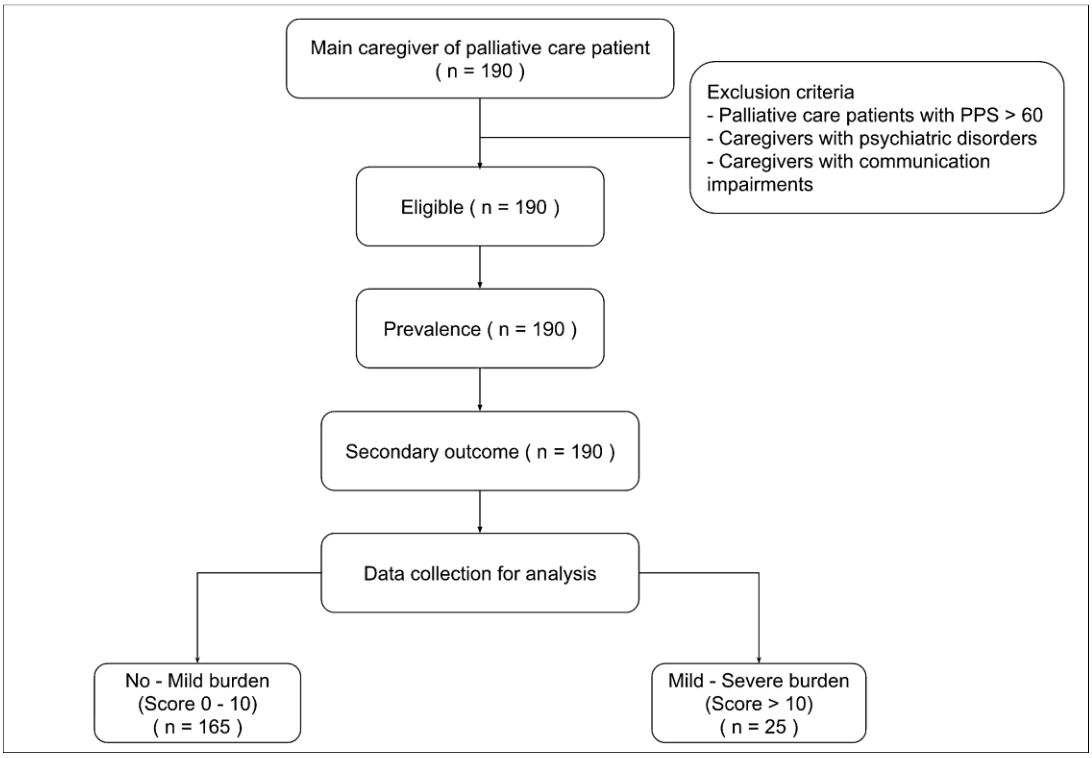

Figure 1: The presentation of the study flow.

Statistical analysis

Data were analyzed using STATA statistical software. Descriptive statistics were used to summarize participant characteristics, presented as percentages, means, and standard deviations. Differences between groups were analyzed using multivariable logistic regression analysis. Marginal odds ratios and 95% confidence intervals were subsequently calculated using the standardization method with predictive margins.

Ethical considerations

All participants were provided with detailed information about the study and gave written informed consent prior to participation. No personal identifiers were recorded; participants were assigned running numbers instead of names. Participation was voluntary, and participants could refuse to participate or withdraw from the study at any time without any impact on their medical care or rights to standard services. Data were securely stored in a password-protected computer system accessible only to the principal investigator. All data will be permanently deleted from the hard drive at least one year after publication of the study. This study was approved by the Human Research Ethics Committee of Phra Nakhon Si Ayutthaya Hospital on 28 August 2024 (Research Project No. 0140/2567).

RESULTS

Demographic characteristics

A total of 190 caregivers participated in the study. Of these, 144 were female (75.8%) and 46 were male (24.2%). One hundred and twenty-two caregivers (64.2%) were younger than 60 years, while 68 (35.8%) were aged 60 years or older. Most caregivers were married, widowed, or divorced (n=139, 73.2%). The majority had an educational level below a bachelor's degree (n=171, 90%). One hundred and twenty-six caregivers (66.3%) were employed, while 64 (33.7%) were unemployed. Monthly income exceeded 10,000 THB for 162 caregivers (85.3%), while 28 (14.7%) earned less than 10,000 THB per month. Underlying diseases were reported by 105 caregivers (55.3%). Regarding the relationship with patients, 186 caregivers (97.9%) were spouses, children, or other relatives, and 4 caregivers (2.1%) were parents of the patients. The duration of caregiving per day was 1–16 hours for 114 caregivers (60.0%) and more than 16 hours for 76 caregivers (40.0%). The total duration of caregiving was 1–180 days for 153 caregivers (80.5%) and more than 180 days for 37 caregivers (19.5%). Most caregivers had additional caregiving support (n=123, 64.7%). Among the palliative care patients, 93 were male (48.9%) and 97 were female (51.1%). The majority were aged 60 years or older (n=135, 71.1%). Most patients had an educational level below a bachelor's degree (n=181, 95.3%). The primary palliative diagnoses included cancer in 92 patients (48.4%) and non-cancer conditions in 98 patients (51.6%). The duration since initiation of palliative care was 1–180 days for 168 patients (88.4%) and more than 180 days for 22 patients (11.6%) (Table 1).

Levels of caregiver burden assessed by the Zarit burden interview (ZBI)-Thai

The caregivers demonstrated varying levels of caregiver burden as assessed by the Thai version of the ZBI. One hundred and sixty-five participants (86.84%) reported no to mild caregiver burden (score 0–10), while 25 participants (13.16%) reported mild to moderate caregiver burden (score 11–20). No participants reported severe caregiver burden (score >20) as the Table 2.

Results of multivariable logistic regression analysis of factors associated with caregiver burden

Multivariable logistic regression analysis identified four factors significantly associated with caregiver burden among caregivers of palliative care patients (p<0.05). Regarding caregiver-related factors, single caregivers had a significantly different likelihood of experiencing caregiver burden compared with those who were married, widowed, or divorced (marginal OR=0.29; 95% CI=0.08–1.03; p=0.049). Caregivers who provided care for more than 16 hours per day were significantly more likely to experience caregiver burden (marginal OR=2.63; 95% CI=1.15–6.01; p=0.023). For patient-related factors, caring for patients aged 60 years or older was significantly associated with caregiver burden compared with caring for patients younger than 60 years (marginal OR=0.30; 95% CI=0.11–0.81; p=0.014). In addition, caregivers of patients with an educational level below a bachelor's degree had a significantly different likelihood of experiencing caregiver burden compared with those caring for patients with a bachelor's degree or higher (marginal OR=0.27; 95% CI=0.08–0.93; p=0.044) as follow by the Table 3.

Table 1: Demographic characteristics of caregivers and palliative care patients.

Variables	N (%)
Caregiver factors	
Gender	
Male	46 (24.2)
Female	144 (75.8)
Age (years)	
<60	122 (64.2)
≥60	68 (35.8)
Marital status	
Married/divorced/widowed	139 (73.2)
Single	51 (26.8)
Education level	
≥Bachelor	19 (10)
<Bachelor	171 (90)
Occupation	
Employed	126 (66.3)
Unemployed	64 (33.7)
Income per month (baht)	
>10,000	162 (85.3)
≤10,000	28 (14.7)
Underlying disease	
No	85 (44.7)
Yes	105 (55.3)
Relationship	
Spouse/child/others	186 (97.9)
Parent	4 (2.1)
Duration of caregiving per day (hours)	
1-16	114 (60)
>16	76 (40)

Continued.

Variables	N (%)
Duration of caregiving (day)	
1-180	153 (80.5)
>180	37 (19.5)
Secondary caregiver	
No	67 (35.3)
Yes	123 (64.7)
Patient factors	
Gender	
Male	93 (48.9)
Female	97 (51.1)
Age (years)	
<60	55 (28.9)
≥60	135 (71.1)
Education level	
≥Bachelor	9 (4.7)
<Bachelor	181 (95.3)
Palliative care disease	
Cancer	92 (48.4)
Non-cancer	98 (51.6)
Duration of palliative care (day)	
1-180	168 (88.4)
>180	22 (11.6)

Table 2: Levels of caregiver burden assessed by the Zarit burden interview (ZBI)-Thai (n=190).

Level of burden	N (%)
No-mild burden (score 0-10)	165 (86.84)
Mild-moderate burden (score 11-20)	25 (13.16)
Severe burden (score >20)	0 (0)

Mean=5.037, SD=4.400, min=0, max=20

Table 3: Multivariable logistic regression analysis of factors associated with caregiver burden among caregivers of palliative care patients.

Variables	Crude OR	95% CI	P value	Marginal OR	95% CI	P value (model)
Caregiver factors						
Gender: female	0.8	0.31-2.05	0.636	0.71	0.29-1.73	0.452
Age ≥60 (years)	0.52	0.20-1.38	0.193	0.71	0.24-2.15	0.539
Marital status: single	0.33	0.10-1.16	0.085	0.29	0.08-1.03	0.049*
Education level: <bachelor	2.94	0.37-23.04	0.305	3.85	0.44-34.00	0.203
Unemployed	0.92	0.37-2.25	0.848	1.02	0.42-2.47	0.964
Income per month (≤10,000 baht)	2.05	0.74-5.70	0.168	1.99	0.75-5.30	0.181
Have underlying disease	0.86	0.37-2.00	0.725	0.77	0.32-1.81	0.544
Relationship: parent	2.25	0.22-22.52	0.49	1.58	0.19-13.45	0.683
Duration of caregiving (>16 hour per day)	2.56	1.08-6.05	0.032*	2.63	1.15-6.01	0.023*
Duration of caregiving (>180 days)	1.04	0.36-2.98	0.943	1.21	0.41-3.59	0.732
No secondary caregiver	0.68	0.27-1.72	0.417	0.5	0.21-1.22	0.131
Patient factors						
Gender: female	0.4	0.16-0.98	0.046*	0.54	0.22-1.30	0.16
Age ≥60 (years)	0.17	0.07-0.42	<0.001*	0.3	0.11-0.81	0.014*
Education level: <bachelor	0.16	0.04-0.66	0.011*	0.27	0.08-0.93	0.044*
Palliative care disease: non-cancer	0.48	0.20-1.15	0.099	0.72	0.32-1.64	0.432
Duration of palliative care >180 days	1.05	0.29-3.84	0.944	1.08	0.27-4.35	0.916

*Significant level at 0.05

DISCUSSION

This study examined the prevalence of caregiver burden and associated factors among caregivers of palliative care patients at Phra Nakhon Si Ayutthaya Hospital. The findings showed that most caregivers experienced no to mild caregiver burden (score 0–10) (86.84%), while 13.16% experienced mild to moderate burden (score 11–20), and no caregivers reported severe burden (score >20). These findings are consistent with a study conducted at Maharaj Nakorn Chiang Mai Hospital, which reported that 76.47% of caregivers of palliative care patients did not experience caregiver burden.[17] Similarly, a study conducted in a tertiary hospital in central Thailand found that caregivers of terminal cancer patients predominantly experienced low levels of caregiver burden.[18] In addition, the results are consistent with previous studies conducted in India, where 76.4% of caregivers of elderly patients with cancer reported no caregiver burden, and in Argentina, where more than half of caregivers of palliative care patients experienced no to mild caregiver burden.[19,20] These findings may be explained by the support provided by hospital palliative care teams, including appropriate symptom management, guidance on home-based patient care, and accessible communication channels for consultation with healthcare professionals. Such support may reduce caregiver anxiety and enhance coping capacity, resulting in lower levels of perceived caregiver burden.

When examining factors associated with mild to severe caregiver burden among caregivers of palliative care patients, four factors were found to be statistically significant (p<0.05). These included caregiver-related factors—marital status and hours of caregiving per day—and patient-related factors—age and educational level.

This study found that single caregivers were less likely to experience caregiver burden compared with those who were married, widowed, or divorced, with a marginal odds ratio of 0.29 (95% CI: 0.08–1.03; p=0.049). This finding is consistent with previous studies in Thailand among caregivers of older adults, which reported higher caregiving stress among caregivers who were married, widowed, or divorced compared with those who were single.[21] Other studies have similarly shown that married caregivers experience greater caregiver fatigue and burden.[22] In addition, single caregivers have been reported to have significantly higher levels of well-being than married caregivers, as married caregivers often have overlapping roles and responsibilities in caring for other family members, which increases their caregiving burden.[23]

These findings are also consistent with international studies examining caregiver burden among caregivers of psychiatric patients, which found that married caregivers experienced significantly higher levels of severe caregiver burden than single caregivers (OR=1.65, p=0.028).[24] Furthermore, marital status has been identified as a significant factor associated with higher caregiver burden and greater financial strain compared with single caregivers.[25] This may be explained by the fact that caregiving for palliative care patients requires substantial physical and emotional effort. Caregivers who are married, widowed, or divorced often carry additional roles and responsibilities as spouses or parents, which may contribute to higher levels of perceived caregiver burden compared with single caregivers.

The duration of daily caregiving was significantly associated with caregiver burden. Caregivers who provided care for more than 16 hours per day were significantly more likely to experience caregiver burden, with a marginal odds ratio of 2.63 (95% CI: 1.15–6.01; p=0.023). This finding is consistent with previous studies in Thailand among caregivers of patients with schizophrenia, which reported that caregiving for 9–12 hours per day increased caregiver burden by 30.29 times.[26] International studies have similarly demonstrated that providing care for an average of 20.62 hours per day was associated with increased caregiver burden, and that caregivers who spent the entire day providing care experienced significantly higher levels of moderate to severe caregiver burden (p=0.034).[27,28]

In addition, qualitative research exploring caregiver experiences in memory clinics reported that continuous caregiving for 24 hours without adequate rest resulted in both physical and psychological exhaustion.[29] Other studies have shown that caregiving for more than 14 hours per day was associated with at least a twofold increase in caregiver burden compared with caregiving for fewer than 14 hours per day.[30] This may be explained by the fact that caregivers who devote most of their day to patient care have limited time for rest, self-care, social interaction, or stress-relieving activities, leading to physical and emotional exhaustion, which in turn contributes to increased caregiver burden.

Patient age was significantly associated with caregiver burden. Caring for palliative care patients aged 60 years or older was identified as a protective factor, with caregivers being significantly less likely to experience mild to severe caregiver burden compared with those caring for patients younger than 60 years (marginal OR=0.30; 95% CI=0.11–0.81; p=0.014). This finding is consistent with previous studies in Thailand among caregivers of terminally ill patients, which reported that older patient age significantly reduced caregiver burden (OR=0.30) compared with younger patients.[31] Other studies have also found that caregivers of older patients experienced lower levels of stress and caregiver burden than those caring for younger patients, as caregiving for older individuals is often perceived as a more natural life course event. In addition, older patients are more likely to receive support from extended family members, which may help reduce caregiver burden.[32] These findings are further supported by international studies in palliative care populations, which identified younger patient age as a risk factor for severe caregiver burden.[33] Caregivers of younger patients often experience overlapping responsibilities, such as income generation and childcare, resulting in significantly higher caregiving burden compared with caregivers of older patients.[34] This may be explained by the perception that serious illness in younger patients is unexpected and difficult to accept, leaving caregivers less prepared to adapt. Furthermore, younger patients are often primary income earners and have parental responsibilities; when illness occurs, caregivers must assume these roles while simultaneously providing care, leading to increased physical, emotional, and psychosocial burden.

The patient's level of education was associated with caregiver burden. Patients who had an educational level lower than a bachelor's degree were a protective factor, resulting in caregivers experiencing a lower caregiving burden compared with caregivers of patients who had a bachelor's degree or higher, with statistical significance (marginal OR=0.27; 95% CI=0.08–0.93; p=0.044). This finding is consistent with the previous study by Boontip et al conducted among caregivers of patients with chronic diseases, which found that higher educational levels were associated with higher expectations regarding the quality of care.[35] If caregivers are unable to provide care that meets the patients' expectations, this may lead to pressure and accumulated stress in caregiving. This is also consistent with studies among caregivers of palliative care patients, which found that patients with higher educational levels tend to have higher expectations for care and require in-depth information regarding disease and treatment, resulting in more complex caregiving, communication, and information management, and consequently higher levels of stress and caregiver burden.[33] In addition, research in health psychology has shown that patients with higher educational levels tend to have higher health literacy; however, when disease progression worsens, these patients are more aware of functional decline, which may lead to depression or anxiety.[36] These emotional states can be directly transmitted to caregivers, placing caregivers of palliative care patients with higher educational levels at greater risk of experiencing a higher caregiving burden than those caring for patients with lower educational levels.

The strengths of this study include its conduct in a semi-urban setting and the inclusion of a heterogeneous palliative care population, comprising both cancer and non-cancer patients. Factors related to both caregivers and the palliative care patients they cared for were analyzed for their association with caregiver burden. The prevalence results showed that the majority of caregivers (86.84%) experienced no to mild burden (no–mild burden), and none experienced severe burden. This reflects the presence of an effective palliative care team capable of providing comprehensive patient care and adequate support for caregivers. The limitations of this study include an imbalanced distribution between caregivers with no–mild burden and those with mild–severe burden, as well as the assessment of caregiver burden at only a single time point, which may have underestimated the true level of burden. This may be because caregivers were not yet comfortable expressing their feelings, felt reluctant to disclose their burden out of consideration for the palliative care team, or perceived that reporting a sense of burden might imply inadequate caregiving on their part.

CONCLUSION

A total of 190 participants were included in the study, comprising 46 males and 144 females. The results showed that caregivers of palliative care patients experienced caregiver burden at the no–mild burden level in 86.84% and at the mild–moderate burden level in 13.16%, with no participants experiencing severe burden. Factors significantly associated with mild–severe caregiver burden ($p<0.05$) included caregivers who were married, widowed, or divorced; caregiving duration of more than 16 hours per day; caring for patients younger than 60 years; and caring for patients with a bachelor's degree or higher education level.

Recommendations

The findings indicate that care provided by the palliative care team results in most caregivers experiencing a low level of caregiver burden. However, caregiver burden should still be closely monitored, with ongoing assessment particularly among high-risk groups, including caregivers who are married, widowed, or divorced, and those caring for patients younger than 60 years. Support systems and caregiver rotation should be arranged to reduce prolonged continuous caregiving exceeding 16 hours per day. In addition, information regarding the disease and treatment approaches should be communicated in a manner appropriate to the patient's knowledge and educational level to promote shared understanding and reduce anxiety. These measures may help prevent and reduce caregiver burden among caregivers of palliative care patients.

Increasing the sample size to enhance the statistical power of multivariable logistic regression analysis, as well as conducting repeated assessments of caregiver burden over time, may encourage caregivers to express their feelings more openly and help prevent underestimation of the true level of caregiver burden.

ACKNOWLEDGEMENTS

The authors would like to express their sincere gratitude to the family medicine physicians of the Department of Social Medicine, Phra Nakhon Si Ayutthaya Hospital, for their guidance throughout the research process. They would also like to thank all caregivers of palliative care patients who willingly participated in this study.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Chalsit P, Phithakwongrojn K, Bosittipichet T, Leesri T. Prevalence and factors associated with caregiver burden in palliative care in Phra Nakhon Si Ayutthaya Hospital: a cross-sectional study. Int J Community Med Public Health 2026;13:1799-807.