ORIGINAL ARTICLE

Assessing Palliative Care Needs in Two Rural Communities in Thailand Through a Household Survey

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Background: Community-based palliative care (CBPC) promotes public health and ensures universal access to palliative care. However, identifying patients in need of palliative care within communities remains a challenge.

Objective: To determine the prevalence of the need for palliative care in two rural communities in Thailand based on age and disease status through a household survey.

Materials and Methods: The present study was a cross-sectional study, using purposive sampling, and collaborative effort among the sub-district health promoting hospitals (SDHPHs) of Mae Pa, Tak Province and Mueang Phon, Khon Kaen Province in Thailand. The survey covered eight villages in Mae Pa, which include 2,298 households and eleven villages in Mueang Phon, which include 1,340 households. Trained village health volunteers (VHVs) were given a structured questionnaire to conduct the survey by visiting households. The instrument's validity was confirmed by five experts, with a percentage agreement of 75% to 79.2%. The Fleiss' kappa coefficient was 0.72, with a range of 0.71 to 0.72, with a significant a p-value of less than 0.001. Data was analyzed based on the period prevalence.

Results: In Mae Pa, the palliative care need prevalence was 2.03 per 1,000, among them, 84.62% had non-cancer conditions and 38.46% had neurodegenerative diseases with frailty and dementia. The prevalence was highest, at 93.21%, among the older adults. In Mueang Phon, the prevalence was 2.33 per 1,000, with 54.55% having neurodegenerative diseases with frailty and dementia, and 81.82% having non-cancer conditions. The prevalence was 100% among the older adults.

Conclusion: The results showed that, palliative care need prevalence is highest among individuals with non-cancer conditions and those aged older than 60 years. These findings could help guide the development and provision of palliative care at the community level.

Keywords: Community-based palliative care; Period prevalence; Primary health care; New screening tool

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Aging populations are increasing in many countries, and a significant proportion of older adults suffer from serious chronic illnesses and cancer, increasing the need for supportive and palliative care (PC)(1). In Thailand, the population proportion of those aged over 60 is projected to rise from 19.12% in 2020 to 32.12% by 2040, greater than Asia's average of 13.4%(2). Most older adults have multimorbidity, making them the main group in need of PC(3). PC can be integrated into primary health care and other settings, offering holistic care at home with community support to enhance the quality of life of the patients(4). A report by WHO showed that only 14% of respondents received PC services. The World Health Organization (WHO) works with countries to include PC as a key part of their health systems(5).

A study on advanced cancer patients showed that early palliative care (EPC) improved quality of life and symptom severity, prolongs life, and enhances caregiver satisfaction(6). When EPC is integrated into primary care at diagnosis, it can reduce unexpected, expensive medical interventions, thereby lowering overall healthcare utilization costs. A team-based approach is the most effective model for delivering PC(7). A review article reported that very few studies have identified PC needs in communities by involving

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volunteer workers and health care providers(8). Such studies have been conducted in India, estimating PC needs at 6.1 per 1,000 people in Puducherry, 4.5 per 1,000 in Tamil Nadu, and 2 per 1,000 in Dhanas village, Chandigarh(9,10). Additionally, research using the Supportive and Palliative Care Indicators Tool (SPICT) in rural Nepal and SPICT for All (SPICT-4ALL) in two rural regions in southern India identified PC needs, revealing prevalence rates of 3.04 per 100 and 4.31 per 100, respectively(11). In Thailand, the number of people in need of PC in three tertiary hospitals has been estimated to be 6.05 per 100(12), 7.8 per 100(13), and 18.7 per 100(14). However, there are no studies estimating the need for PC at the community-level in Thailand.

The situation of PC at the primary care level in Thailand revealed a structured approach. Primary care services are provided to patients in their catchment areas, through collaboration with contracting units of primary care with community or provincial hospitals. Furthermore, long-term care (LTC) funds that deliver both LTC and PC services are provided through individualized care plans according to the target population, considering factors such as age, for over 60 years, degree of frailty, and level of dependence on activities of daily living (ADL) as assessed by care managers and caregivers. Moreover, village health volunteers (VHVs) and paid caregivers trained for home visits by health professionals provide PC(15-17). In Thailand, PC access in resource-limited settings has improved through the LTC scheme, which assesses individuals based on their ADL scores, categorizing them into active, homebound, and bedridden groups. This often leads to misinterpretation of PC as solely end-of-life care(18). The caregivers under the LTC scheme are VHVs who receive 70 hours of training to screen ADL and provide care to patients enrolled in the LTC scheme. Owing to the strength of volunteers and LTC resources, the identification of PC needs by volunteers serves as the basis for developing community-based palliative care (CBPC). Therefore, the present study was conducted based on the resources of the community. The present study is significant in its findings and can be used to plan and develop CBPC for improving the quality of life of people in the community.

Objective

The present study aimed to estimate the prevalence of PC needs in primary care based on age and disease status in rural areas.

Materials and Methods

Setting

The present study was a descriptive cross-sectional study conducted in two primary care facilities in Mae Pa Subdistrict in Mae Sot District, Tak Province, and Mueang Phon Subdistrict in Phon District, Khon Kaen Province, which have approximate populations of 10,073 and 5,371 people, respectively. These areas were selected based on discussions with a PC doctor, considering 1) the presence of family physicians supervising PC services at community hospitals, 2) the availability of an outpatient department for PC at a community hospital, 3) the existence of a CBPC team linking primary and secondary care in collaboration with local organizations, and 4) the willingness to participate in the project.

The PC process in the two areas operated as hospital-based PC, which included data recording, home visits, and caring for dependent individuals within the LTC fund. However, currently, no screening was conducted by trained community volunteers specifically for PC needs. Having data from such screenings, confirmed by a doctor, would facilitate earlier PC for patients in need. This would create a stronger link between CBPC and the hospital.

Study population

All the residents of the selected areas were included in the present study. Visitors to these areas were excluded from the study.

Data collection

The data collection process consisted of two steps, developing the validity and reliability of the instrument, training VHVs, conducting a pilot test, and meeting the research and PC teams. The second step involved the collection of field practice data.

Development of the validity and reliability instrument

The research team developed a PC needs screening tool by reviewing chronic illnesses and clinical indicators from literature and chart reviews. Meetings were held twice until consensus was reached. Five experts in PC, including two specialists, one family physician, and two nurses, confirmed the face validity. The questionnaire included instructions on greeting the household and explaining the purpose of the visit, followed by two screening questions. If both screening questions, 1 and 2, received a ‘no’ answer, the interview ended. For any other conditions, the interview was continued to discuss the second section on assessed symptoms lasting over six months within the past year, covering conditions such as cancer, heart problems, lung problems, liver problems, kidney problems, nervous system with age-related conditions such as dementia and Parkinson's disease, and stroke. Individuals with any one of these conditions were identified as requiring PC. The item content validity index (I-CVI) was then assessed by five experts who were different from those involved in face validity to ensure the adequacy of the items in reflecting the measured content domain. This panel comprised two family physicians, two PC nurses, and one academic from a university. The participants were asked to rate each of the clinical indicators in terms of clarity and relevance on a four-point Likert scale with 1=not relevant, 2=somewhat relevant, 3=quite relevant, and 4=highly relevant, and the I-CVI was set as a priority at 0.80, which was acceptable. The average I-CVI score for this instrument was 0.98.

Sixty VHVs were invited for a six-hour training program consisting of three parts, lectures on the definition and characteristics of PC, training on screening tools, and case studies for identifying patients in need of PC. A minimum score of 80% was required to be recruited for the present study. The pilot test was designed with Phra That sub-district health promoting hospital (SDHPH), which was selected because of its similarity to the population characteristics and geographic location of the facility. Family physicians identify households with and without a need for PC. Trained VHVs, nurses, and family physicians visited the same households to assess patients in need of PC. The inter-rater reliability between these three different raters for each clinical indicator of the same patient was assessed. The percentage agreement and Fleiss' kappa coefficient were calculated considering chance agreement(19). A percentage agreement of 75% to 90% indicated an acceptable level of agreement(20). A Fleiss' kappa coefficient greater than 0.61 indicated substantial agreement, which is 0.61 to 0.80, and values between 0.81 and 1.00 indicated almost perfect agreement(21). It was important to present both the percentage agreement and Fleiss' kappa coefficient to demonstrate the consistency of agreement(22). The percentage agreement of this instrument varied from 75% to 79.2%. The Fleiss' kappa categorical coefficient was 0.72, with a range of 0.71 to 0.72, and a p-value of less than 0.001.

After the pilot test, the item wording was improved to enhance clarity and comprehension. For example, 'Termination of the treatment' was revised to 'The doctor advised that it is incurable and to stop treatment', 'Ascites' was adjusted to 'Abdominal swelling due to abnormal enlargement of the abdomen', and 'End-stage renal disease' was modified to 'Patients with end-stage renal failure who decline hospital-based or peritoneal dialysis and continue to receive symptomatic treatment'. These revisions were made to make the language easier to understand for lay people. The present study included all household members; therefore, selection bias was minimized. Misclassification bias, which referred to incorrect classification of participants regarding the condition of interest, was addressed by using trained volunteers who passed a post-training exam with a minimum score of 80%.

Field practice data collection

Sociodemographic information including age, gender, perceived diagnosis, and total number of inhabitants in each household was collected. The questionnaire instructions included the greeting when entering the household and how to explain the purpose of the visit. The first section of the questionnaire included two screening questions, 1) Is there anyone in the household who is severely ill or unable to work and needs to stay at home? 2) Is there anyone in the household with any of the following diseases: cancer, heart disease, lung disease, liver disease, kidney disease, neurological disorders/frailty/dementia, or stroke? The two screening questions must yield a positive response on one or both items for the interview to continue. The participants were asked if they had experienced the abovementioned diseases for more than six months within the past year. Then, the volunteer proceeded to the next page of the questionnaire. If the answer was 'no' to both screening questions, the interview ended.

Data analysis

Statistical analyses were conducted using SPSS Statistics, version 17.0 (SPSS Inc., Chicago, IL, USA). Sociodemographic data were presented as numbers and percentages. The main outcome was the number of people in need of PC per 1,000 people.

Ethical approval

The present study was conducted in accordance with the Helsinki declaration. The study was approved by the Human Research Ethics Committee of Naresuan University (COA No. 112/2022). Prior to data collection, access to the field was obtained with permission from the provincial health office, community hospital, district health office, and local administrative organization. Written informed consent was obtained from all participants.

Results

Period prevalence per 1,000

Among the 2,298 individuals surveyed in the Mae Pa Subdistrict, 13 required PC, resulting in a period prevalence of 2.03 per 1,000 people. In the Mueang Phon Subdistrict, among the 1,340 surveyed individuals, 11 required PC for a period prevalence of 2.23 per 1,000 (Table 1).

Table 2 illustrates the demographic characteristics of individuals requiring PC in the Mae Pa and Mueang Phon subdistricts. In the Mae Pa Subdistrict, a high proportion of the patients were female, at 53.85%, over 60 years of age, at 92.31%, had a primary education level and no formal education for 76.92%, engaged in agriculture, for 38.46%, had experienced illness for 12 to 18 months or more than 19 months, for 61.54%, lived in households with more than three members, for 69.23%, and had health insurance under the universal healthcare scheme for 84.62%. In the Mueang Phon Subdistrict, a significant majority were female, at 54.56%, had a primary education level or no formal education for 90.91%, engaged in agriculture for 72.73%, had experienced illness for 7 to 12 months for 54.55%, lived in households with more than three members for 90.91%, and all respondents were over 60 years of age and had health insurance under the universal healthcare scheme.

The most common disease conditions requiring PC identified in the present study in the Mae Pa and Mueang Phon subdistricts are shown in Table 3. In the Mae Pa Subdistrict, the most common conditions requiring PC were neurological diseases and dementia for 38.46%, followed by cancer and lung disease, each accounting for 15.38% of cases. Only 7.69% of the patients requiring PC had heart, liver, kidney, or cerebrovascular diseases. A greater proportion (84.62%) of PC needs were observed among non-cancer patients than among cancer patients. In the Mueang Phon Subdistrict, the most common conditions requiring PC were neurological diseases and dementia for 54.55%, followed by heart disease for 27.27%, and cancer for 18.18%. Only 9.09% of patients needing PC had kidney disease. A considerable proportion (81.82%) of patients needing PC, were non-cancer patients compared to those with cancer.

Table 1. Period prevalence

	Maepa Subdistrict	Muang Phon Subdistrict
Number of households	2,298	1,340
Total population in households	6,419	4,726
People in need of palliative care	13	11
Period prevalence per 1,000	2.03	2.33

Table 2. Demographic characteristics of people who need palliative care

Demographic characteristics	People who need palliative care in Maepa Subdistrict (n=13); n (%)	People who need palliative care in Muang Phon Subdistrict (n=11); n (%)
Sex		
Male	6 (46.15)	5 (45.44)
Female	7 (53.85)	6 (54.56)
Age (years)		
≤15	0 (0.00)	0 (0.00)
16 to 59	1 (7.69)	0 (0.00)
≥60	12 (92.31)	11 (100)
Education status		
Illiterate and primary school	10 (76.92)	10 (90.91)
Middle school	3 (23.08)	1 (9.09)
Occupation		
Agriculture	5 (38.46)	8 (72.73)
Merchant	3 (23.09)	2 (18.18)
Housewife	2 (15.38)	0 (0.00)
Employee	1 (7.69)	0 (0.00)
Non-occupation	2 (15.38)	1 (9.09)
Perceived of illness (months)		
≤6	2 (15.38)	2 (18.18)
7 to 12	3 (23.09)	6 (54.55)
13 to 18	4 (30.77)	3 (27.27)
≥19	4 (30.77)	0 (0.00)
Member of household living (person)		
≤2	4 (30.77)	1 (9.09)
≥3	9 (69.23)	10 (90.91)
Health insurance		
Universal health coverage	11 (84.62)	11 (100)
Civil servant medical benefit scheme	1 (7.69)	0 (0.00)
Social security scheme	1 (7.69)	0 (0.00)

Discussion

The present study was conducted with the support of trained VHVs who used a validated tool for identifying PC needs in communities. This tool is similar to those used in the previous studies(9,10) conducted in Puducherry, Tamil Nadu, India. VHVs are people in the community who are trained and contribute their time and efforts to support community-based activities in response to

Table 3. Disease condition of people requiring palliative care

Disease condition	Maepa Subdistrict; n (%)			Muang Phon Subdistrict; n (%)		
	Male	Female	Total	Male	Female	Total
Disease						
Cancer	2 (15.38)		2 (15.39)	2 (18.18)	0 (0.00)	2 (18.18)
Heart disease		1 (7.69)	1 (7.69)	1 (9.09)	2 (18.18)	3 (27.27)
Lung disease		2 (15.38)	2 (15.39)	0 (0.00)	0 (0.00)	0 (0.00)
Liver disease	1 (7.69)		1 (7.69)	0 (0.00)	0 (0.00)	0 (0.00)
Kidney disease		1 (7.69)	1 (7.69)	0 (0.00)	1 (9.09)	1 (9.09)
Neuro disease with frailty and dementia	2 (15.38)	3 (23.08)	5 (38.46)	2 (18.18)	3 (27.27)	5 (45.45)
Stroke	1 (7.69)		1 (7.69)	0 (0.00)	0 (0.00)	0 (0.00)
Total	6 (46.15)	7 (53.85)	13 (100)	5 (45.45)	6 (54.55)	11 (100)
Disease category						
Cancer	0 (0.00)	2 (15.38)	2 (15.38)	2 (18.18)	0 (0.00)	2 (18.18)
Non cancer	6 (46.15)	5 (38.46)	11 (84.62)	3 (27.27)	6 (54.55)	9 (81.82)
Total	6 (46.15)	7 (53.85)	13 (100)	5 (45.45)	6 (54.55)	11 (100)

health issues in rural areas(23). Consequently, if they understood the definition of PC and had a positive attitude, they will be familiar with their community's cultural perspectives and can assist healthcare providers in promoting awareness of PC within the community. The present study trained the VHVs for six hours, requiring a minimum of 80% in a post test. Each VHV assessed the needs of 5 to 15 households. Similar to findings in India(24), community factors such as caste, poverty, and illiteracy challenge the implementation and sustainability of CBPC.

The present study developed a screening tool comprising ten general questions and 22 clinical indicators for seven chronic illnesses. It was similar to the tool used in a recent study(11) conducted in two health centers in southern India, called the SPICT-4ALL, which consisted of two parts, general information and data on eight chronic illnesses with 22 clinical indicators, with illness over three months identified as chronic. However, the data in the abovementioned Indian study were collected by a trained eight-member survey team, including faculty, postgraduates, and medical interns, whereas the data in the present study were collected by trained VHVs. The present study approach of data collection aligned with CBPC outlined by the WHO(25). In Thailand, VHVs are locals who volunteer their time to support rural community health activities. They work with networks and engage in community-based activities to address disasters and health concerns. They serve as a crucial link between community members and healthcare providers, promoting a public health approach at the community level(26). This is consistent with the WHO Public Health Model for Palliative Care and highlights the need for community implementation frameworks. Integrating PC requires resources such as guidelines to help clinicians identify, assess, and plan care for eligible patients while fostering community participation in CBPC(27). This approach, aligned with a previous study(28) that stated that the screening of PC needs will facilitate early access.

The current study reported that the number of patients who required PC was 2.03 and 2.33 per 1,000 people in Mae Pa and Mueang Phon, respectively. This aligns with the previous studies(9,10,29) that estimated PC needs in communities of Chandigarh, Tamil Nadu, and Puducherry at 2, 4.5, and 6 per 1,000 people, respectively. Furthermore, a systematic review and meta-analysis of PC needs in India reported a prevalence of 6.21 per 1,000 people. In terms of region, it was revealed that the prevalence in the southern region was 10.83 per 1,000, while it was 2.24 per 1,000 in the northern region(30). These prevalence rates differ from those reported in two previous studies of Thaha Municipality, Nepal and Udupi District, India(11,31), which reported rates of 30.44 and 43.12 per 1,000 people, respectively. Both studies employed assessment tools, namely, the SPICT and the SPICT-4ALL. The SPICT and SPICT-4ALL include seven general indicators, eight chronic illnesses, and 22 clinical indicators. When assessing neurological conditions alongside geriatric diseases, dementia, and cerebrovascular diseases, a criterion of two or more symptoms indicates the need for PC (+PC need). However, the present study sets a criterion of three or more symptoms for neurological conditions combined with geriatric diseases and dementia, potentially impacting the identification of +PC needs compared to the previous studies utilizing the SPICT and SPICT-4ALL. Variations in regional prevalence result from differences in age, education, and awareness of PC services. Community-based assessments are essential for workforce planning, quality, and PC.

When analyzing patients needing PC by age, the authors found the prevalence rates of 92.31% and 100% for those aged 60 and older, in Mae Pa and Mueang Phon, respectively. This aligns with findings from the previous studies(9-11,31), which reported prevalence rates of 73.5%, 64.77%, 60.61%, and 59.09%, of Rural Tamil Nadu, India, Udupi District, India, Thaha Municipality, Nepal, and Puducherry, India respectively, in older adults. In particular, a study in rural Tamil Nadu, India(10) found that the need for PC was 28 times higher among older adults than among those aged 15 to 59 years. In the present study, Mae Pa had an older adult population share of 15.92%, indicating an aging society, whereas in Mueang Phon had 22.49%, also indicating an aged society. The Worldwide Palliative Care Alliance(5) highlights the necessity of PC for patients with chronic conditions, such as HIV/AIDS and heart failure, as the growing elderly population increases the prevalence of geriatric diseases and dementia requiring these services.

In Mae Pa, 38.46% of patients needing PC had neurological conditions combined with geriatric diseases, particularly dementia, whereas 84.62% had non-cancer issues. In Mueang Phon, 54.55% of the patients had neurological and geriatric conditions, and 81.82% were not related to cancer. These findings align with those of a previous study in Puducherry, India(9), which indicated that 41% of those requiring PC were older adults and 95.45% had non-cancer diseases. Similarly, a previous study(10) reported that 41.2% of patients requiring PC were older adults without cancer. These results emphasize the need to prioritize PC for chronic conditions such as HIV/AIDS and heart failure, as highlighted by the Worldwide Palliative Care Alliance(5).

When considering chronic diseases, specifically heart, lung, and liver diseases, the prevalence in Mae Pa Subdistrict and Mueang Phon Subdistrict were 38.46% and 30.76%, respectively. Non-cancer patients often suffer more from insomnia, fatigue, and impaired quality of life than cancer patients, highlighting a critical need for PC(32). The literature in England and Wales indicated that hospices were the place of death for 1.2% of non-cancer patients (4,503 patients), while this figure was 16.5% (24,925) for those with cancer(33). Due to the disease trajectory, PC for patients with chronic organ failure is needed to improve the quality of life of patients with advanced chronic organ failure. WHO(34) recommends that early delivery of PC reduces unnecessary hospital admissions and the use of health services.

The present research aimed to estimate the prevalence of PC needs in primary care, specifically considering age and disease status in rural areas. The recommendations from this research can be practically applied. The present study involved developing a tool and method to screen patients in the community who require PC services. These screenings were then confirmed by doctors at the community hospital. Once confirmed, this data should be mapped against patient lists from the LTC fund and PC patients at the hospital's outpatient department. For new patients, advance care planning should be initiated. This ensures that patients who need PC services can access PC services early, and it fosters collaboration with trained community volunteers in PC.

This study aimed to identify patients in the community who need PC, categorizing them by disease and age. The goal was to use this information to plan EPC interventions for these patients. The results revealed that the prevalence of PC needs was highest among individuals with non-cancer conditions. Therefore, future research should compare the community prevalence found with the prevalence of both cancer and non-cancer illnesses in the area. The present study serves as a crucial starting point for collecting prevalence data on PC needs in the community, categorized by disease and age.

The present study is important because it assessed community PC needs by trained volunteers who used a screening tool to identify patients. Then the patients were confirmed by doctors from the community hospital. In addition, it focused on facilities with established PC for doctors, nurses, and pharmacists in SDHPHs and community hospitals, where they supervise the allied health provider in providing PC, along with volunteers. Nonetheless, the findings can be generalized to similar nationwide settings. In future studies, enhancing the user-friendliness of this screening tool through trained volunteers is recommended.

Conclusion

The PC service systems in both areas share common features, which are 1) the staffed by medical professionals, pharmacists, and nurses dedicated to PC, 2) outpatient services are offered once a week, 3) SDHPHs have nurses and applied Thai traditional medicine practitioners, 4) the district health system provide a LTC fund, and 5) local volunteers work with this fund. All professionals and volunteers involved were trained in PC. The prevalence was highest among individuals with non-cancer conditions and those older than 60 years. These results will inform the development of CBPC operated by trained VHVs, with confirmation from the PC team. This strategy is tailored for rural areas. Furthermore, the study focused on facilities with a PC team from community hospitals that collaborated with SDHPHs and local communities to enhance the role of CBPC.

What is already known about this topic?

1. CBPC services are provided by health professionals and community health workers or volunteers.

2. Screening and early identification of PC needs enable the development of advanced care plans through shared decision-making with patients, families, and caregivers, ensuring timely access to appropriate end-of-life and PC services.

3. Few existing instruments demonstrate sound psychometric properties to identify PC needs in community.

What does this study add?

1. This study provides an instrument for assessing PC needs in rural communities of Thailand through a household survey with the acceptable of validity and reliability.

2. Trained volunteers have the capacity to conduct screening for PC needs, and the results need to be confirmed by physicians at the community hospital.

3. The prevalence rates in Mae Pa and Mueang Phon were 2.03 and 2.33 per 1,000, respectively. Most of the PC patients had non-cancer conditions and were older adults.

Authors' contributions

NK contributed to the study's conception and design. KK and SM reviewed the literature. NK, KK, RT, and AR performed data collection and material preparation. OK and KK carried out the data analysis. KK and interpreted the results and RT confirmed the results. NK wrote the first draft of the manuscript. KK prepared the tables and figures. All authors (NK, KK, OK, SM, RT, and AR) read and approved of the final version.

Availability of data and materials

Data supporting the findings of this study can be obtained from the corresponding author upon reasonable request. Permission should be obtained by informing the Secretary of the Naresuan University Research Ethics Committee, who will coordinate with the lead author to provide additional information.

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Conflicts of interest

The authors declare that they have no conflict of interests.

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