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## **Exploring the palliative care ecosystem in Thailand**

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# BMJ Open Quality Exploring the palliative care ecosystem in Thailand: a protocol for a scoping review and bibliometric analysis

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## ABSTRACT

**Introduction** Palliative care is an approach that aims to holistically improve the quality of life, care and death of people living with life-limiting conditions as well as their families. In Thailand, palliative care became one of its national strategies as of 2014. However, the access to as well as the quality of palliative care being delivered still varies across the nation, due to multiple factors spanning multiple levels. Consequently, there is a need to comprehensively understand the current palliative care ecosystem in Thailand. This review aims to explore, map and conceptualise the literature available on the palliative care ecosystem in Thailand, and how the service being delivered influences the quality of life, death and care of people living with life-limiting conditions alongside their families.

**Methods and analysis** This review will consist of two stages. First, a scoping review guided by the Joanna Briggs Institute methodology for scoping reviews will be initially conducted. A systematic literature search using Medical Subject Heading and text words related to palliative care will be performed in PubMed, CINAHL and Thai Citation Index from 2013 to 2023. Grey literature will be searched via alternative sources: Google keyword searching and stakeholders consultation. References of included sources will be handsearched to identify further resources.

The population, concept and context framework is used to frame the inclusion and exclusion criteria. This will be further refined after the initial search, reflecting the iterative nature of a scoping review. Articles will be independently screened by three reviewers. A Microsoft Excel spreadsheet will be used as the data extraction tool. Data will be extracted and presented using a narrative synthesis approach.

Second, included articles from the scoping review will be further analysed and visualised using a bibliometric analysis technique. This stage involves a computational method, including statistical analysis and content analysis of the articles' bibliographic details.

**Ethics and dissemination** This paper describes a protocol for a scoping review and bibliographical analysis. As such, ethical approval was not required. Information relating to the review will be stored with Open Science Framework Registries. The findings of this proposed scoping review will be distributed through a peer-reviewed publication, academic seminars, conferences and patients and public involvement groups.

## INTRODUCTION

Palliative care is a medical approach that improves the quality of life, care and death for people living with life-limiting conditions and their families.<sup>1</sup> Currently, only 14% of the global population receive palliative care; primarily in high-income countries.<sup>1</sup> This limited access to palliative care applies to Thailand, a middle-income country, due to the lack of comprehensive understanding of the palliative care ecosystem in the country.<sup>2</sup> Despite Thai palliative care provisions being categorised by the WHO as level 4a (palliative care at preliminary stage of integration)<sup>3</sup>, access to palliative care continues to be limited due to disjointed healthcare professionals (HCPs) structures, organisational service delivery, alongside variable care provisions across the country.<sup>2</sup> A national survey from tertiary hospitals in Thailand in 2020 showed that 18.7% of inpatients admitted (N=1079) needed palliative care. However, from this, only 17.3% had access to palliative care. The number is lower for people living with dementia (PwD); wherein, only 1.11% get access to palliative care.<sup>2</sup>

Inequitable access to palliative care is particularly problematic since Thailand will become a super-aged society by 2035.<sup>4</sup> By 2050, more than 35% from a population of 67 million will be over 65 years old.<sup>5</sup> This means the incidence of older people living with cancer could increase by 220% as of 2050.<sup>5</sup> For PwD, dementia is the sixth-leading cause of death in Thailand; with 32.83 deaths from dementias per 100 000 population in 2019.<sup>6</sup> The number of PwD is expected to increase from 670 047 in 2019 to 2.4 million in 2050 (257% change),<sup>7</sup> resulting in an increasing burden of care for health services, HCPs and family carers.

The national policy on palliative care was released in 2014, which enhanced the Advance Directives law in 2007.<sup>8</sup> This policy allowed Thais to document their medical care

preferences towards end of life and enabled the implementation of Advance Care Planning (ACP) for people to receive care that reflects their wishes and personal values, demonstrating the core concept of ACP.<sup>8</sup> Moreover, ACP is deemed as one of the 'good death' indicators in the country.<sup>9</sup> As such, HCPs are further encouraged to discuss an ACP with their patients due to this suggestion from the policy level. However, awareness of ACP remains low among the Thai general public and HCPs,<sup>2 8 10</sup> compromising ACP implementation in practice.

The ongoing lack of ACP awareness in Thailand might be partly explained by the fact that the concept of ACP originates from the Global North, which emphasises self-determination, autonomy and individualism. These characteristics of ACP are in contrast with the Thai collectivist and family-oriented culture, which requires a person to 'honour' their parents and older people.<sup>9</sup> This Thai cultural practice almost always results in the family's participation in decision-making, largely without the patients' input.<sup>8</sup> Additionally, it is compounded by the conspiracy of silence; wherein, families withhold medical information from patients,<sup>10</sup> resulting in futile life-prolonging treatments and the underuse of ACP.<sup>9</sup> Consequently, more westernised notions of ACP may not fully translate into the Thai context, indicating that an alternative ACP approach is required.<sup>8 11</sup>

Despite ongoing training for HCPs, there remains a lack of the necessary knowledge and skills to support the delivery of palliative care and ACP and enable shared patient involvement in culturally appropriate decision-making.<sup>10 11</sup> This is particularly highlighted for PwD, as suggested by the Thai National Clinical Practice Guideline for Dementia, which recommends that early ACP discussion with PwD and their carers is important,<sup>12</sup> before cognitive and memory decline impedes decision-making. However, this suggestion is not fully implemented due to the lack of dementia knowledge across HCPs and other stakeholders.<sup>13</sup>

At the community level, several grassroot organisations provide various educational and public campaign activities to raise awareness of palliative care and ACPs for the public. However, the appropriateness and quality of such activities are yet to be fully evaluated; thus requiring further scrutiny.<sup>14</sup>

Due to these disjointed, multifactorial barriers that influence ACP implementation in the country, there is an urgent need to comprehensively understand the current palliative care ecosystem of policy, practice and community support. This comprehensive understanding aims to address existing challenges, empower facilitators that influence ACP process which may or may not be culturally appropriate for people living with life-limiting conditions and their family carers. This is to ensure that people living with life-limiting conditions have appropriate access to the palliative care that they are entitled to and consequently have an improved quality of life, care and death throughout their journey.

## STUDY OBJECTIVE

This paper aims to present a protocol for a scoping review and bibliographical analysis of available evidence in relation to the palliative care ecosystem in Thailand. The scoping review aims to examine (1) how palliative care is being delivered and (2) the influence of palliative care over the quality of life, care and death of individuals living with life-limiting conditions.

## METHODS AND ANALYSIS

The review will consist of two stages. First, a scoping review will be used to explore and map existing literature available as, to our knowledge, the palliative care ecosystem in Thailand has yet to be extensively reviewed.<sup>15 16</sup> A scoping review is also deemed appropriate to address the broad objectives of this paper. The scoping review methods used were developed by Joanna Briggs Institute Guidelines<sup>17</sup> to ensure the robustness of the searching process and the analysis. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR)<sup>18</sup> will be used to report the findings of this review.

Second, included articles from the initial scoping review will be further analysed and visualised using the bibliometric analysis technique. The two-step approach consists of statistical analysis and content analysis will be conducted.<sup>19</sup> First, the bibliographical details of the articles, such as author names, publication years and journal names, will be examined through basic descriptive statistical methods. Second, the content analysis will involve conducting a cword network analysis to visualise clusters of terms present in the abstracts across articles to holistically capture the prominent research themes. The most common software used for these techniques are the VoS Viewer and the Bibliometrix package in R.<sup>20</sup>

## Identifying the research question

The population, concept and context framework was used to frame and refine the review questions.<sup>19</sup>

The population is any individuals who receive palliative care as explicitly defined or implied in the included articles. The population is broad—ranging from adults to older people—as it is the intent to explore the trends or the disparities of any empirical studies conducted.

The concept is the type of care the individuals received as well as their actual or perceived quality of life, quality of care and quality of death.

For this review, quality of life may include, but is not limited to, reports of any quality of life measurements and instruments; such as the Patient Health Questionnaire-9 the WHO Quality of Life Instrument, activities of daily living or (disability-adjusted life year), EuroQOL-5 Dimensions questionnaire, Short Form-12 (SF-12) and SF-36.

Quality of care may include any measured care from instruments and perceived quality of care from patients

and family carers, such as the Palliative Outcome Scale or Zarit caregiver burden scale.

Quality of death is rather subjective; hence, this is more challenging to report and capture. To our knowledge, there is no validated instrument that measures the quality of death in the country to date. To that end, for this review, relevant tools that have been used in other Asian countries will be explored; namely the Good Death Inventory, the Good Death Scale and two versions of the Quality of Dying and Death Questionnaires.<sup>21</sup> Additionally, the aim is to capture the perceived quality of death that was reported in the included articles and examine what is the discourse around the concept of a ‘good death’ in Thailand. The initiation rate of ACP along with the completion rate of Advance Directives will also be looked at, as they are used as one of the good death indicators in Thailand.

The context is any care setting in Thailand; namely community and primary care, long-term care facilities, acute hospitals and palliative care specialist units.

The primary review question is: ‘what evidence is available around the palliative care ecosystem in Thailand?’ The review subquestions are as follows:

- ▶ How does the palliative care available influence the quality of life, care and death of people living with life-limiting conditions and their families?
- ▶ How does the initiation or ACP influence the quality of life, care and death of people living with life-limiting conditions and their families?
- ▶ What are the facilitators and barriers that influence the quality of life, care and death of people living with life-limiting conditions and their families?

- ▶ What are the gaps in evidence that can be proposed for future studies that will enhance the palliative care service and delivery in Thailand?

### Identifying relevant studies

These databases will be searched: PubMed, CINAHL and the Thai Citation Index (TCI). The search will focus on articles published between 2013 and 2023, to ensure that findings are up to date. The initial search will be conducted on PubMed and the search strategies will be subsequently refined for other databases. Reference lists of included studies will also be screened. The search strategy was developed in consultation with an academic librarian in April 2023. It is expected that the proposed search terms may be refined as the extent of literature is explored, especially in the TCI database where most articles are published in Thai.

Grey literature will be searched via alternative sources; such as Google keyword search, Google Scholar and other relevant resources, as suggested from stakeholders consultation.

### Study selection

Studies will be considered for inclusion if they relate to palliative care delivery and its influence on quality of life, care and death of adults living with life-limiting conditions in any healthcare setting (see [table 1](#)).

The search will consist of these search terms:  
 ‘palliative’ OR ‘end-of-life’ OR ‘end of life’ OR ‘terminal’ OR ‘hospice’ OR ‘long-term’ OR ‘incurable’  
 AND  
 ‘adult’ OR ‘patient’ OR ‘hospice’ OR ‘terminally ill’  
 AND

**Table 1** Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Population	<ul style="list-style-type: none"> <li>▶ Individuals living with any conditions and receive any implicitly or explicitly stated palliative care</li> <li>▶ Age &gt;18</li> </ul>	<ul style="list-style-type: none"> <li>▶ Individuals who do not receive any implicitly or explicitly stated palliative care</li> <li>▶ Children (age &lt;18)</li> </ul>
Concept	Any studies discussing individuals’: <ul style="list-style-type: none"> <li>▶ Quality of life</li> <li>▶ Quality of care</li> <li>▶ Quality of death</li> </ul>	Any studies discussing and other topics beyond the: <ul style="list-style-type: none"> <li>▶ Quality of life</li> <li>▶ Quality of care</li> <li>▶ Quality of death</li> </ul>
Context	<ul style="list-style-type: none"> <li>▶ Any healthcare settings such as:</li> <li>▶ Community and primary care</li> <li>▶ Long-term care facilities</li> <li>▶ Acute hospitals</li> <li>▶ Palliative care specialists units</li> </ul>	<ul style="list-style-type: none"> <li>▶ Articles that discuss paediatric palliative care in any settings</li> </ul>
Type of evidence sources	<ul style="list-style-type: none"> <li>▶ Articles published between 2013 and 2023</li> <li>▶ Articles published in English or Thai</li> <li>▶ Empirical studies of any design (quantitative, qualitative, mixed method)</li> <li>▶ Reviews</li> <li>▶ Grey literature</li> </ul>	<ul style="list-style-type: none"> <li>▶ Articles published before 2013</li> <li>▶ Articles published in other languages apart from English or Thai</li> </ul>



'facilitate' OR 'increase' OR 'improve' OR 'enable' OR 'support' OR 'barrier' OR 'hinder' OR 'inhibit' OR 'restrict' OR 'reduce' OR 'decrease'

AND

'quality of life' OR 'quality of care' OR 'quality of death' OR 'advance care plan' OR 'advance care planning' OR 'advance directive' OR 'living will' OR 'concordance' OR 'discuss'.

EndNote reference management software will be used to facilitate the process.

We will follow the suggestion from the Joanna Briggs Institute. That is, the screening and selection process will be piloted on a random sample of 25 articles to ensure consistency.

During this stage, three reviewers will independently screen these 25 articles and decide whether to include or exclude these articles for the analysis. Any disagreement will be discussed during team meetings and email communications. The screening process will commence once at least 75% agreement or greater is achieved. After that, articles will be randomly and evenly split between three reviewers. The titles and abstracts of the searched articles will be independently reviewed and have record decisions on a form. Any disagreements will be resolved via discussion. Further disagreement will be discussed with the fourth author. After the initial screening of titles and abstracts, the three reviewers will read the full papers and consider whether to include the articles or not. Reasons for exclusion will be recorded. PRISMA-ScR checklist will be used to report the process and findings.<sup>18</sup>

### Charting the data

Three authors will read the articles independently and record data extraction in a charting form. Data extracted will include:

Authors; year of publication; format of paper; aim of study; study design; methodological orientation; theoretical framework used; data collection methods; sample size; facilitators that influence the quality of life, care and death; barriers that influence the quality of life, care and death; reported outcomes of quality of life, care and death; strengths of the study; limitations of the study; recommendations from authors.

The charting process is iterative; hence, the charting form will be updated from time to time.<sup>19</sup> Quality assessment will not be performed, as the aim is to comprehensively capture the currently available evidence, without excluding any articles due to its quality. It is also not recommended as a part of the scoping review methodology.<sup>17</sup>

### Collating, summarising and reporting the results

Due to the anticipated heterogeneity of the available evidence, a narrative summary will be provided. Summaries of all papers will be presented in a table format. Findings will be grouped and relate back to the subreview questions in this review.

### Dissemination

Information relating to the review will be stored with Open Science Framework Registries. Findings of this proposed scoping review will be distributed through a peer-reviewed publication, academic seminars and conferences, patients and public involvement (PPI) group.

### Patient and public involvement

The Thai PPI group consists of one representative from the breast cancer survivor support group, one health service and palliative care policy-maker and one palliative care physician. All were initially consulted for the relevancy of this review; they agreed with the aim of the review. Emerging findings will be presented to the PPI group, which will subsequently be disseminated back to multiple level stakeholders (people with lived experience, policy-makers and HCPs who work within the primary and tertiary care settings). The PPI group will also be consulted for additional relevant resources of this review. The discussion and suggestions from the PPI process will be synthesised as a part of the final findings.

### DISCUSSION

This review aims to comprehensively explore, map and conceptualise the palliative care ecosystem in Thailand, and how it influences the quality of life, death and care of individuals living with life-limiting conditions. This comprehensive understanding of the palliative care ecosystem in Thailand has become more important due to the ageing population of Thailand as well as increasingly complex needs and multiple comorbidities that people have. We anticipate that this review will offer more insights to the palliative care situation in the country, and subsequently offers evidence-informed recommendations that will lead to improved palliative care delivery. Findings of this review will be disseminated to wider audiences via the authors' existing academic and clinical network. Additional knowledge dissemination channels include networks from PPI group which consist of breast cancer survivors, their families, palliative care HCPs, academic sectors, researchers and palliative care policy-makers. Findings from the review should enable us to gain a better understanding of the palliative care service and delivery in Thailand as well as how to improve the quality of life, care and death of individuals receiving palliative care.

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**Contributors** Conceptualisation: TP. Data curation: TP. Formal analysis : TP, KA, SS and SV. Investigation: TP. Methodology: TP and SV. Project administration: TP. Software: SV. Supervision: TP. Validation: SV. Visualisation: SV. Writing—original Draft : TP, KA, SS and SV. Writing—review and Editing: TP, KA, SS and SV.

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