


Methods used to identify the prevalence of palliative care needs: An integrative review

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Review Article

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Abstract

Objectives. Early identification of palliative care (PC) needs is crucial to provide appropriate holistic care to patients. The objective of this integrative review is to synthesize the methods used to identify the prevalence of PC needs.

Methods. An integrative review search of the Cumulative Index to Nursing and Allied Health Literature (CINAHL) Plus with full text, ProQuest, Wiley InterScience, ScienceDirect, Scopus, PubMed, and Web of Science with publications from 2010 to 2020 was carried out in English. Empirical studies examining the methods used to determine the prevalence of PC needs were included. The methods of data extraction of the included articles were categorized by data source, study setting, and data collector. Quality appraisal was performed using QualSyst.

Results. Of the 5,410 articles screened, 29 were included in this review. Two articles identified the prevalence of PC needs in a community that was supported by a network of volunteers, while 27 studies considered this at a continent, country, hospital, and/or primary care facility level as represented by physicians, nurses, and researchers.

Significance of results. Various methods have been used to determine the prevalence of PC needs, and the outcomes are valuable for policymakers in developing PC services when allocating resources at the national and community levels. Future research to identify PC needs across health settings, especially primary care facilities, should consider providing PC across a spectrum of care settings.

Introduction

In 2014, the World Health Assembly agreed to integrate palliative care (PC) as a component of the comprehensive care provisions of a health system needed by all citizens. This decision necessitates PC access within the definition of universal health coverage (The Worldwide Hospice Palliative Care Alliance 2014). In addition, the International Association for Hospice and Palliative Care has, through consensus, revised its definition of PC to “the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life” (Radbruch et al. 2020). When PC is considered from an epidemiological perspective, the focus moves away from addressing cancers in response to severe illnesses and chronic conditions with distinct illness trajectories (Gómez-Batiste et al. 2013). Therefore, the concept of PC shifts from being previously an emphasis on the older adult, provided at the end of life and primarily to individuals with cancer, to now a “palliative approach to care,” which starts earlier in the illness trajectory and is not only limited to cancer but providable for people of all ages. A person can begin to receive PC services early on their life-threatening illness to manage their symptoms and improve quality of life.

PC must, therefore, be provided within all health-care settings via the integration of systems, organizations, administrative means, and clinical provisions if patients’ and their families’ quality of life are to be appropriately maintained (Brazil 2018; Radbruch et al. 2020). Zheng et al. (2013) indicated that 25% of patients with cancer, 81% of patients with organ failure, and 80% of patients with frailty/dementia were not identified for PC. This might have led to the limited palliative provisions.

Early identification of people with PC needs is essential if appropriate care is to be offered, which can serve complex needs covering the remaining life of patients, as well as the bereavement of their families (Teike Lüthi et al. 2020). Various methods exist to identify PC needs. These can include setting-based calculations across health-care settings (Fumaneeshoat 2018; Schoenherr et al. 2019), direct measurement (Amblàs-Novellas et al. 2016; Gómez-Batiste et al. 2014, 2012; Teike Lüthi et al. 2020), and estimation (Daya et al. 2017; Murtagh et al. 2014;

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Swarbrick *et al.* 2019). PC needs must be reported in the form of prevalence based on the concept of public health-oriented PC.

In a given population, prevalence can be calculated using several methods. The estimation, in this context, demonstrates the routine use of mortality statistics to estimate population-based PC needs (Higginson 1997; Kane *et al.* 2015; Sleeman *et al.* 2019). Some studies used the International Statistical Classification of Diseases and Related Health Problems-10th Revision (ICD-10) (Etkind *et al.* 2017; Fumaneeshoat 2018; Khalid and Chong 2019; Rosenwax *et al.* 2005). In one study, patients with chronic progressive diseases and a limited life prognosis were considered, and for people with all causes of death, it was estimated that 75% of all deaths lacked PC (Etkind *et al.* 2017). Moreover, the study of Yang *et al.* (Lan Yang SL *et al.* 2020) applied the methods from Murtagh *et al.* (2014) and Gómez-Batiste *et al.* (2014) to project national PC needs.

In addition, some studies have conducted cross-sectional surveys on the prevalence of PC needs (Amblàs-Novellas *et al.* 2016; Daya *et al.* 2017; Gómez-Batiste *et al.* 2013, 2014). However, these studies have utilized different tools, facility approaches, and data collectors. Two systematic reviews and one literature review reported on the screening tools that were employed and the accuracy gained (ElMokhallalati *et al.* 2020; Healthcare Improvement Scotland 2020; Teike Lu Thi *et al.* 2021). However, evidence regarding the methods used to identify PC at the community level is limited. These methods are crucial in different settings and are valuable in designing integrated PC services that enable the achievement of quality outcomes for patients in need of PC. The objective of this integrative review is to synthesize the methods used to identify the prevalence of PC needs.

Methods

Study design

Integrative reviews were conducted to summarize past empirical literature and provide a more comprehensive understanding of the selected topics. This study determined the topics used to identify the prevalence of PC needs. This study was conducted in accordance with the steps of problem formulation and literature search, data evaluation, and data analysis, (Whittemore and Knafel 2005) with presentation of the data in the results section.

Problem formulation and literature search

This step aims to clearly state the topic of interest by listing the variables of interest. The areas of the methods are available through which the prevalence of PC needs is determined as the core concept. An integrative search was performed in the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL) Plus with full text, ProQuest, Wiley InterScience, ScienceDirect, Scopus, PubMed, and Web of Science. The search term keywords included “palliative*,” “hospice*,” “terminal care,” “supportive care,” “end of life care” alongside “prevalence,” “epidemiology,” “how many,” “need*,” “demand,” “method,” “approach,” “procedure,” and “instrument.” Keywords were identified through the titles and abstracts of the articles found via a preliminary search. The indexed terms from the selected databases were identified and included in the search terms for the utilized databases (Table 1). Articles published between 2010 and 2020 were reviewed. This study began in October 2020. We searched the previous 10 years of published articles as 10 years of research was determined to have value cocreation in dealing with this

Table 1. Search terms used in the systematic review by using Medical Subject Headings

To identify	Keywords
Palliative care	palliative*
	hospice*
	terminal care
	supportive care
	end of life care
AND	
Prevalence	prevalence
	epidemiology
	How many
OR	
Need	need*
	demand
OR	
Method	method
	approach
	procedure
	instrument

still emerging concept and clarifying insights into its definition, foundations, drivers, related processes, expected consequences, and measurement (Leclercq *et al.* 2016). The search results were imported into Endnote 7 to enable management. Duplicate references were addressed in the Endnote Library by K.K.

Four investigators (N.K., K.K., O.K., and S.M.) independently screened the titles and abstracts of the searched articles. The inclusion criteria were that each article must have been peer-reviewed, written in English, published between 2010 and 2020, have a primary outcome pertaining to the prevalence of PC needs, and include prospective and/or retrospective cohort studies, case-control studies, and cross-sectional studies. Review articles and studies published as chapters in a book along with opinion/editorial/conference publications were excluded. Articles whose full text could not be accessed were excluded. Finally, studies that included non-PC patients or that focused on populations with specific symptoms or syndromes (e.g., patients with pain, depression, or delirium) were excluded. Disagreements in the screening process were resolved through discussions and consultations with a third researcher (R.T.). The excluded studies and the main reasons for exclusion were recorded in a separate database.

Data evaluation

The identified research articles were assessed using QualSyst software. The checklist for assessing the quality of quantitative studies consists of 14 items, with scoring being measured in relation to the degree to which specific criteria are met (“yes” = 2, “partial” = 1, and “no” = 0). Items not applicable to a particular study design are marked “n/a” and excluded from the calculated summary score. A summary score is calculated for each paper by summing the total score obtained across all relevant items and then by dividing the total possible score [i.e., 28 – (number of “n/a” × 2)] (Leanne *et al.*

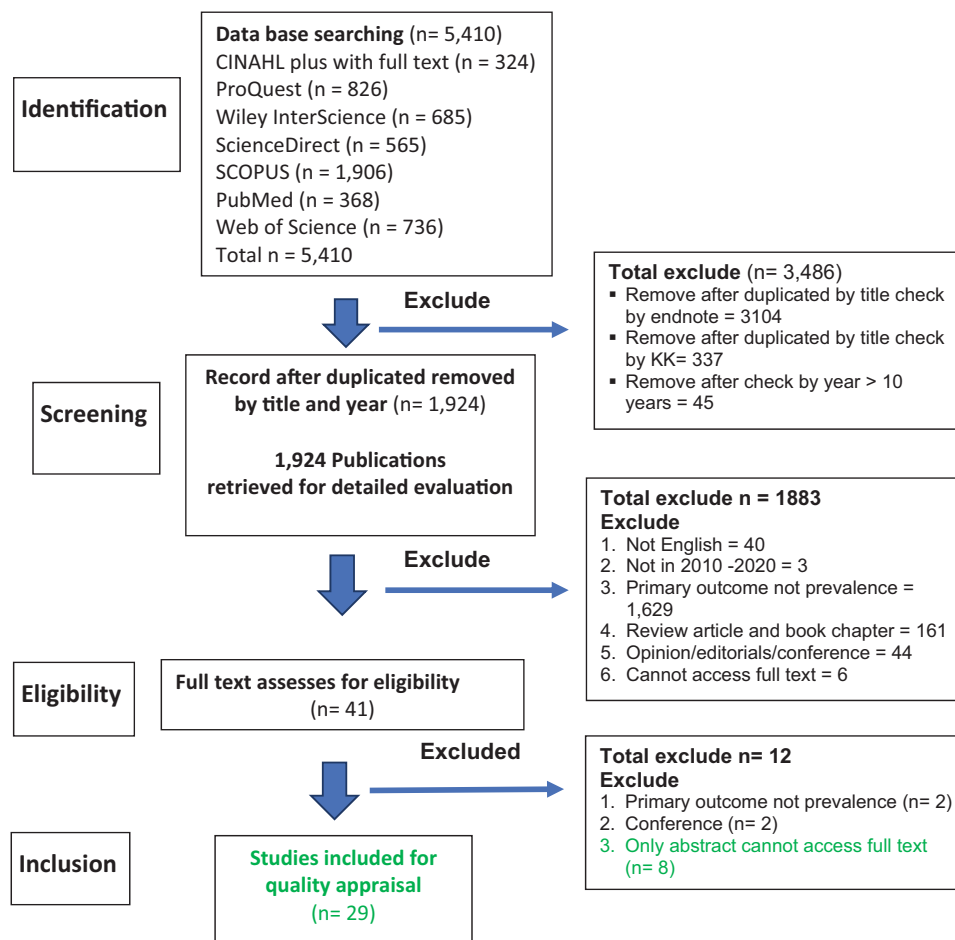


Figure 1. PRISMA flow diagram of the study selection.

2004). The assessment was completed independently by 4 investigators (N.K., K.K., O.K., and S.M.). The scores obtained were compared and discussed to reach a consensus.

A standardized system, with scores ranging from 0 to 2, was used to assess all aspects of an article's research quality. The total possible scores (28 for quantitative studies and 20 for qualitative studies) were then converted to a standardized score of 1. A QualSyst cutoff score of 0.55 was chosen to capture 75% of the articles considered, thereby ensuring that valuable data were included. Following this quality scoring, the final selection of articles was reviewed by the authors, thereby guaranteeing that each article's inclusion was based on its originality and relevance. The inter-rater agreement for the overall scale range of each article ranged 0.86–1, with the discrepancies in the overall scores having ranged 0.02–0.10.

Data analysis

Data were simplified using the 2 methods of primary and secondary data collection to identify PC needs. The data were displayed in the format of a table to show the connection with the topic. The data of this study were extracted to accomplish the aim of determining the methods available to identify the prevalence of PC needs. The table designed was populated to denote each article's author, year of publication, country of focus, objective, data collection methods, subgroup of the setting, approach (e.g. facility,

hospital, primary care, and/or community level), and data collector. The authors (N.K., K.K., O.K., and S.M.) extracted the data and R.T. reviewed the data. A narrative synthesis was conducted. Subsequently, the findings of this study are presented. The data were verified in the results section, including methods, setting, and tools and data sources of data collection regarding PC prevalence.

Results

The search yielded 5,410 articles, of which 3,441 were removed following the elimination of duplicate titles using Endnote (K.K.). Furthermore, 45 articles were removed after discovering that they were published more than 10 years ago. According to the inclusion and exclusion criteria, 1,895 articles were excluded and 29 studies were eligible, and they were included for quality appraisal (Fig. 1). In terms of the quality of the paper was reported inter-rater agreement for overall scale 0.86–1.

Nineteen articles were published within the last 5 years (2016–2020). Of these, 8 studies were carried out in England, Wales, and Ireland (Etkind et al. 2017; Fraser et al. 2020; Gardiner et al. 2013a, 2013b; Kane et al. 2015; May et al. 2019; Murtagh et al. 2014; Ryan et al. 2013). The other regions studied included India (Daya et al. 2017; Elayaperumal et al. 2018), Spain (Gómez-Batiste et al. 2013, 2014), Columbia (Calvache et al. 2020; Hua et al. 2014), Germany (Engeser et al. 2020; Scholten et al. 2016), and Belgium (Hermans et al. 2017; Maetens et al. 2019) – with 2 articles

for each country. One article addressed Japan, Australia, Thailand, Senegal, the United States, South Africa, Nepal, France, and Cyprus (Aristodemou and Speck 2017; Bowers *et al.* 2020; Creutzfeldt *et al.* 2015; Hamano *et al.* 2018; Hamdi *et al.* 2018; Molin *et al.* 2019; Niekerk and Raubenheimer 2014; Swarbrick *et al.* 2019; Wirasorn *et al.* 2016). In addition, the estimated prevalence in the worldwide, European, and non-European populations was also found in a study (Connor *et al.* 2017; Morin *et al.* 2017).

Methods of data collection as to PC prevalence

The methods used to gather information fall between the primary and secondary data collection approaches. Thirteen studies were undertaken via the collection of primary data, whereby various tools and data collection methods utilized were supported by a network of volunteers in 2 studies and by trained health-care professionals in 11 studies. The remaining 16 studies were undertaken via the collection of secondary data, as analyzed and interpreted primary data utilized recorded hospital data and national statistics. Therefore, PC needs were calculated by the researcher(s). One study employing secondary data reported a global estimate (Connor *et al.* 2017), while one study reported an estimate for 12 European and non-European countries (Morin *et al.* 2017).

Setting of data collection as to PC prevalence

Regarding the data collected on PC needs prevalence, 13 studies undertook primary data collection, while 16 studies produced an estimation. Two of the 13 primary data collection studies emphasized community-collected data for all populations of the considered households, while 11 pertained to data derived from hospitals and primary care facilities. Of these 11 studies, 7 collected data in the context of a hospital and 3 collected data in the context of a general practitioner clinic (as a primary care facility) in Japan (Hamano *et al.* 2018), primary care centers, a district general hospital, social health centers, nursing homes in Spain (Gómez-Batiste *et al.* 2014, 2012), and a nursing home in Belgium (Hermans *et al.* 2017). One study was conducted at a hospital and primary care facility (as offered primary care, social health, and nursing home services) (Gómez-Batiste *et al.* 2012). For the secondary data collection studies, 2 studies pertained to a hospital (Hua *et al.* 2014; Wirasorn *et al.* 2016) and 14 studies reported on demographics at the population and country levels (Aristodemou and Speck 2017; Bowers *et al.* 2020; Calvache *et al.* 2020; Connor *et al.* 2017; Engeser *et al.* 2020; Etkind *et al.* 2017; Fraser *et al.* 2020; Kane *et al.* 2015; Maetens *et al.* 2019; May *et al.* 2019; Morin *et al.* 2017; Murtagh *et al.* 2014; Scholten *et al.* 2016; Swarbrick *et al.* 2019).

Tools and data sources of the data collection as to PC prevalence

In primary data collection studies to determine the prevalence of PC needs at a community level, 2 examples were undertaken in India by a trained team of medical social workers, medical interns, nursing students, postgraduates, and faculty from the department with the support of a network of volunteers in the villages (Daya *et al.* 2017; Elayaperumal *et al.* 2018). The study of NECPAL (from Necesidades Paliativas in Spanish [Palliative Needs]) can identify patients in need of PC in both primary and secondary care facilities, as recorded by trained doctors and nurses (Daya *et al.* 2017; Gómez-Batiste *et al.* 2014, 2012). The other instruments available are the Supportive and Palliative Care Indicators Tool (SPICITTM),

the Palliative Outcome Scale (POS), surprise questions, admission characteristics, and examined outcomes, the Sheffield Profile for Assessment and Referral to Care (SPARC), Gold Standards Framework (GSF), and PALLIA-10 (Table 2) (Creutzfeldt *et al.* 2015; Gardiner *et al.* 2013a, 2013a; Hamano *et al.* 2018; Hamdi *et al.* 2018; Hermans *et al.* 2017; Molin *et al.* 2019; Niekerk and Raubenheimer 2014; Ryan *et al.* 2013).

In contrast, estimations given as to the prevalence of PC needs via the use of secondary data sources employ data that is already collected by investigator and organizations, wherein emphasis is given to the population and/or country level. The data sources used here depend on the health data of each country that may comprise administrative health data by calendar year, the ICD-10 code relating to life-limiting conditions eligible for PC, World Health Organization (WHO) mortality data from the Global Health Estimates: Causes of Death 2000–2011, UNAIDS data on HIV prevalence, United Nations population data by country (for ages 0–19) and year, World Bank country population estimates for 2010, national inpatient hospital data, hospital episode statistics as to the admitted patient care, Office for National Statistics mortality data, and death certificates. Calculations through population-based methods as to estimating PC needs can be derived from (1) age- and sex-specific proportions of deaths from defined chronic progressive illnesses, (2) multiplying the number of people dying from a particular condition by the percentage of pain prevalence for the condition, (3) projected mortality data, combined with projected population data and observed individual-level data from a prospective longitudinal study on aging, (4) Higginson, (5) Rosenwax, (6) Gómez-Batiste, and (7) Murtagh (Aristodemou and Speck 2017; Bowers *et al.* 2020; Calvache *et al.* 2020; Connor *et al.* 2017; Engeser *et al.* 2020; Etkind *et al.* 2017; Fraser *et al.* 2020; Hua *et al.* 2014; Kane *et al.* 2015; Maetens *et al.* 2019; May *et al.* 2019; Morin *et al.* 2017; Murtagh *et al.* 2014; Scholten *et al.* 2016; Swarbrick *et al.* 2019; Wirasorn *et al.* 2016). The studies were grouped according to their author/year/country, objective, and data collection methods (Table 3).

Discussion

Prevalence is an epidemiological measure that represents the proportion of a given population affected by a certain condition (Fletcher *et al.* 2014). The present research focuses on the prevalence of PC needs and knowledge, which are needed to reflect the importance of such services being provided under Human Right to Health. Prevalence estimates are also important for health-related decision-making and such outcomes must correspond with national policies, programs, resources, and PC-related training for health professionals, volunteers, and families (World Health Organization 2021). This conclusion is consistent with previous research, which has indicated that the identification of PC patients can help health-care providers assess the need to develop a care plan (Amblàs-Novellas *et al.* 2016).

The methods of collecting data on the prevalence of PC needs, with the use of primary and secondary data sources, depend on the objective of each study. Primary data are collected to address a specific problem at hand using the fit that best responds to that problem. By contrast, secondary data are collected for purposes other than the problem at hand (Hox and Boeije 2005). The present study was supported by primary data collected regarding the prevalence of PC needs, produced in community, hospital, and primary care facility contexts, in an effort to provide appropriate PC services that respond to the needs faced. For example, at the community

Table 2. Evidence of the primary data collection according to author/year/country, objective, methodological characteristics, and result of the included studies

Author/year/country	Objective	Study design	Study setting	Study tool	Study population and sample size	Data collector	Result
Gómez-Batiste et al. (2012), Spain	To development of the NECPAL tool to identify patients in need of PC and initial implementation of the NECPAL Program in the region	Quantitative and qualitative for data collection	Hospital and primary care: Primary care services, acute bed hospitals, social health centers, and nursing homes	The NECPAL	<ul style="list-style-type: none"> - Quantitative = 1,064 - Qualitative = 2 focus groups of 8 health-care professionals 	Health-care professionals (doctors and nurses)	<ul style="list-style-type: none"> - Surprise question: 1.45% of the total population and 7.71% of the population aged over 65 - NECPAL: 1.33% of the total population and 7.00% of the population aged over 65
Gardiner et al. (2013b), The United Kingdom	To explore the extent of PC need in the acute hospital setting To explore agreement between different sources in the identification of patients with PC need	Cross sectional survey	Two UK acute hospitals	GSF	<ul style="list-style-type: none"> - 1,359 patients are in patient population - 524 patients completed dataset 	The researcher	<ul style="list-style-type: none"> - Medical staff identified 15.5% of patients as having PC needs - Nursing staff 17.4% of patients as having PC needs - Patient self-report of 83.2% of PC needs
Ryan et al. (2013), The United Kingdom	To explore the extent of burden in 2 large UK hospitals, focusing upon those patients who meet PC criteria To explore the use of palliative services and identify the most significant clinical diagnostic and demographic factors that determine physical and psychological burden	Prospective survey (census) of inpatients	Hospital	The SPARC. The GSF	514 patients	The researcher	The sample who met PC criteria ($n = 185$) = $[(185 \times 100) / 514 = 36\%]$
Gardiner et al. (2013a), The United Kingdom	To describe the profile of older hospital inpatients (≥ 85 years) To explore the prevalence and nature of PC needs among this group	Cross-sectional survey	Two UK hospital	GSF prognostic indicator criteria and questionnaires comprising a range of demographic and health measures, including preferences for place of cares	<ul style="list-style-type: none"> - 1,359 inpatients were eligible for inclusion in the survey. - The total eligible patient population, 654 patients agreed to participate 	The researcher with a clinical background in medicine or nursing	<ul style="list-style-type: none"> - 40% of the older patients were identified as having PC needs according to GSF criteria. - 16.7% of frailty was the most common indicator of PC need
Gómez-Batiste et al. (2014), Spain	To determine, by direct measurement the prevalence of people in need of PC among advanced chronically ill patients in a whole geographic population	Cross-sectional, population-based study	Primary care centers and 1 district general hospital, 1 social health center, and 4 nursing homes serving the patients	The NECPAL	<ul style="list-style-type: none"> - 1,064 chronically ill 	Health-care professionals (doctor and nurse)	Prevalence by SQ = $[(841 \times 100) / 51,595] = 1.6\%$

(Continued)

Table 2. (Continued.)

Author/year/ country	Objective	Study design	Study setting	Study tool	Study population and sample size	Data collector	Result
Niekerk and Raubenheimer (2014), South Africa	To assess the need for PC among inpatients occupying acute beds in the public sector hospitals of the Cape Town Metropole	Cross-sectional	Hospital	The UK GSF Prognostic Indicator Guidance and adapted for the South Africa with surprise question	1,443 hospital inpatients were surveyed	The researcher	16.6% were found to have an active life-limiting disease
Creutzfeldt et al. (2015), The United States	To explore the prevalence and type of potential PC consultation triggers in neuroICUs	Retrospective cohort study	NeuroICUs	A published PC trigger protocols in a medical ICU	1268 patients who admission to 2 neuroICUs	The researcher	200 patients (15.8%) met one or more triggers for PC consultation
Hermans et al. (2017), Belgium	To describe PC needs and symptoms of older adults anticipated to be in the last year of their life in Flemish nursing homes (Belgium) and to evaluate whether these needs differ between residents with and without dementia	Cross-sectional study	Setting: nursing home residents Tool Data collector Prevalence report after excluding residents aged younger than 65 years	The Palliative Care Outcome Scale and surprise question	1,635 nursing home residents	Multidisciplinary team consisted of nurses, certified nursing assistants, psychologists, physiotherapists, quality coordinators, directors, and/or medical directors	109 nursing home residents anticipated to be in the last year of life = [(109 × 100)/1635 = 6.67 ≈ 7%]
Daya et al. (2017), Puducherry, India	To estimate the prevalence of need of PC in an urban area of Puducherry	Cross-sectional study	Community	Three questions are as follows 1. Is there anyone in your family who is bedridden? 2. Is there anyone in your family who is unable to go to work because of a physical illness? 3. Is there anyone in your family who is not well and needs help to look after his/her activity of daily living?	3,554	A trained team of medical social workers, medical interns, nursing students, postgraduates, and faculty from the department with the support of people who are likely to be interested in helping in the villages	Period prevalence = [(22 × 1,000)/3,554] = 6.1/1,000
Hamano et al. (2018), Japan	To explore the prevalence and characteristics of family practice patients who need PC approach as determined using SPIC TM (April 2015) in Japan	Cross-sectional study	17 clinics with 22 GPs in Japan	The Japanese version of SPIC TM (SPIC TM -J) Supportive and Palliative Care Indicators	87 patients	Health-care professionals (doctors)	Eight patients are identified as needing PC approach = [(8 × 100)/87] = 9.2%
Hamdi et al. (2018), Senegal	To assess the capacity and need for PC in Senegal	A multicomponent assessment of availability and demand for PC	Two tertiary and 2 regional hospitals	POS on a 5-point Likert scale	167	Doctor	Nearly half (44.4%) of all inpatients (n = 167) had an active life-limiting illness

(Continued)

Table 2. (Continued.)

Author/year/ country	Objective	Study design	Study setting	Study tool	Study population and sample size	Data collector	Result
Elayaperumal et al. (2018), Rural Tamil Nadu, India	To assess the need for PC and its determinants in the villages under the Urban Health Training Centre (UHTC), Villupuram, and to know their sociodemographic characteristics and morbidity profile	Cross-sectional study	Community	Three questions are as follows: 1. Is there anyone in your family who is bedridden? 2. Is there anyone in your family who is unable to go to work because of a physical illness? 3. Is there anyone in your family who is not well and needs help to look after his/her activity of daily living?	7,493	A trained team of medical social work- ers, medical interns, nursing students, postgraduates, and faculty from the department with the support of people who are likely to be interested in helping in the villages	Period preva- lence = $[(34 \times 1,000)/$ $7,493] = 4.5/1,000$
Molin et al. (2019), France	To explore the use of the PALLIA-10 questionnaire and its related score in a popu- lation of advanced cancer patients	Prospective multicentric study	Hospital conventional medicine or in radio- therapy departments in 18 of the 20 French comprehensive cancer centers	The PALLIA-10 questionnaire	840	The researcher	687 (82%) palliative patients

Table 3. Evidence of the secondary data collection according to author/year/country, objective, methodological characteristics, and result of the included studies

Author/year/ country	Objective	Study design	Study setting	Data sources	Study population and sample size	Data collector	Result
Hua <i>et al.</i> (2014), Columbia University Medical Center	To estimate the prevalence of ICU admissions who met criteria for PC consultation using different sets of triggers	Retrospective cohort study	Hospital	Data came from Project IMPACT (Cerner Corporation, Kansas City, MO), a database of ICU admissions for the years 2001–2008	385,770 admissions to 179 ICUs	Researcher	Overall, 53,124 (13.8%) ICU admissions met one or more primary triggers for PC consultation
Murtagh <i>et al.</i> (2014), England	To refine existing methods of estimating population-based need for PC and to compare these methods to better inform their use	Refinement of existing population-based methods, based on the views of an expert panel, and application/comparison of existing and refined approaches in an example dataset	Population level	Secondary data of IDC 10th, data warehouse for England provided by all National Health Service (NHS) hospitals and for NHS hospital patients treated elsewhere Two linked datasets (Death registrations and HES) as combined in the linked ONS/HES mortality dataset Calculation of population-based methods to estimate PC need: (a) Higginson; (b) Rosenwax; (c) Gomez-Batiste; (d) Murtagh (methods developed in this article)	National population data from England as an example to standardize the setting and data for comparison. In England, approximately 470,000 people die each year	Researcher	A minimum of 63.03% (95% confidence. All deaths in England, January 2006–December 2008, using linked mortality and hospital episode data interval = 62.95% – 63.11%) of all deaths needing PC, with lower and upper mid-range estimates between 69.10% (95% confidence interval = 69.02% – 69.17%) and 81.87% (95% confidence interval = 81.81% – 81.93%)
Kane <i>et al.</i> (2015), Ireland	To estimate the potential population with generalist and/or specialist PC needs in Ireland using routine mortality data inclusive of nonmalignant conditions To consider the quality of Irish data available for this population-based estimate	Murtagh <i>et al.</i> was used to give a population-based PC needs estimate	Population level	Data source used Routine mortality data (2007–2011) International Statistical Classification of Diseases and Related Health Problems – 10th Revision codes Calculation by the method of Murtagh <i>et al.</i> to estimate a population-based PC need	The population death during the period 2007–2011, there were 141,807 deaths	Researcher	- Eighty percent were from conditions recognized as having associated PC needs
Scholten <i>et al.</i> (2016), Germany	To estimate the size of the German population that may benefit from PC	Three (Rosenwax's minimal and maximal estimations and Murtagh's adapted version) of the existing methods to estimate the number of people who are possibly in need of PC	Population level	Data source used German death registration data were analyzed and contrasted with international results. The data include all death cases in 2013 in Germany Calculation by a population-based methods (Rosenwax and Murtagh)	A total of 893,825 people died in Germany in 2013	Researcher	- The estimation, based on Murtagh's refined method, results in 78.0% of death cases potentially being eligible for PC - Based on the Murtagh Method, in the age category between 30 and 39 years, a potential demand for PC can be found for 40.4% of all deaths occurring in this age category, with this number increasing to 80.3% in the age bracket of 80 years and over

(Continued)

Table 3. (Continued.)

Author/year/ country	Objective	Study design	Study setting	Data sources	Study population and sample size	Data collector	Result
Wirasorn et al. (2016), Thailand	To get a perspective on the elderly cancer situation in Northeast Thailand	n/a	Hospital-based Population of Elderly Cancer Cases in Northeastern	A recorded data of all cancer cases treated in the hospital of Khon Kaen Cancer Registry Department since 1987, Deaths obtained from the civil registration database	Case definitions: All new cancer cases aged ≥65 years reg- istered in Srinarangin Hospital between January 1, 1993, and December 31, 2012, were included in this study	Researcher	Elderly patients accounted for 31.6% of all cancer patients and new cancer cases in the older age group increased 46% from the first to second decades
Connor et al. (2017), Global estimate of the worldwide	To create an accurate global estimate of the worldwide need for chil- dren's palliative care (CPC) based on a representa- tive sample of countries from all regions of the world and all World Bank income groups	A Cross-sectional analysis	- Country level - Estimating the need for CPC at the national level in a sam- ple of countries reported as the country-level prevalence data were used from secondary data sources	Data source used: (1) country-level prevalence data from the Institute for Health Metrics and Evaluation at the University of Washington; (2) WHO mortality data from the Global Health Estimates: Causes of Death 2000–2011; (3) UNAIDS data on HIV prevalence in the target countries; (4) UN population data by country for ages 0–19 by year; and (5) country population estimates for 2010 from World Bank	- Estimate the world- wide need for CPC based on a repre- sentative sample of countries from all regions of the world and all World Bank income groups - This study intended that the sample of countries should be greater than 50% of the world's population	Researcher	120 per 10,000 children in Zimbabwe 20 per 10,000 in the United Kingdom Overall, among the over 21 million with conditions that will benefit annually from a PC approach, more than 8 million need specialized CPC worldwide
Etkind et al. (2017), England and Wales	To estimate future pop- ulation PC need in 2 high-income countries	Secondary analysis: projections of PC need estimates	A population based at country level	Data source used Mortality statistics for England and Wales from 2006 to 2014 Use previous diagnosis-based approaches, the author calculated age- and sex-specific proportions of deaths from defined chronic progressive illnesses to estimate the prevalence of PC need in the population Modeled PC need up to 2040	Population time period of 2006–2014	Researcher	If age- and sex-specific pro- portions with PC needs remain the same as in 2014, the number of peo- ple requiring PC will grow by 25.0% (from 375,398 to 469,305 people/year) However, if the upward trend observed from 2006–2014 continues, the increase will be of 42.4% (161,842 more people/year, total 537,240)

(Continued)

Table 3. (Continued.)

Author/year/ country	Objective	Study design	Study setting	Data sources	Study population and sample size	Data collector	Result
Morin et al. (2017), 14 countries: Belgium, Canada, Czech Republic, England, France, Hungary, Italy, Mexico, the Netherlands, New Zealand, Spain (Andalusia), South Korea, the United States, and Wales, across 12 European and non-European countries	To estimate the proportion of decedents potentially in need of PC across 12 European and non-European countries	Cross-sectional study	Population level	Date certificate data calculation the causes of death used to apply 3 estimation methods developed by Rosenwax et al., the French National Observatory on End-of-Life Care, and Murtagh et al., respectively	4,908,114	Researcher	- Overall, the proportion of decedents who died from a disease that may indicate a need for PC ranged from 38.4% (Rosenwax et al.'s minimal estimate) to 74.0% according to Murtagh et al.'s refined minimal estimate The methods developed by the ONFV provided an intermediate estimate of 63.6% of the total population
Aristodemou and Speck (2017), Cyprus	To assess the PC service needs in Cyprus using routine mortality data, and this was achieved by (a) analysis of mortality death registration statistics making inferences to PC needs and (b) reviewing existing PC service provision in Cyprus	A population-based estimate of PC needs	Country level	Data derived from death registrations from January 2011 to December 2013 were analyzed using specific International Classification of Diseases and Related Health Problems–10th Revision codes	People whose death and record in death registrations from January 2011 to December 2013	Researcher	Out of the 5,500 people on average dying in Cyprus annually, a minimum of 2,634 and a maximum of 3,927 could benefit from a PC service
Maetens et al. (2019), Belgium	To investigate time trends in the use and timing of initiating palliative home care support (PHCS)	An observational study	Population level	Data source used: Population databases linked with health claims data for the entire population living at home that died of diseases indicative of PC needs in Belgium between 2010 and 2015 The data used involved 8 administrative databases, linked at an individual level using a unique identifier by a third party that is responsible for data protection and linkage in Belgium The linked data included person-level reimbursed health care use in the last 2 years of life For all health care data, using ICD-10 codification	230,704	Researcher	Palliative home care support increased from 31.7% to 34.9% between 2010 and 2015

(Continued)

Table 3. (Continued.)

Author/year/ country	Objective	Study design	Study setting	Data sources	Study population and sample size	Data collector	Result
Swarbrick et al. (2019), Nepal	To generate a quantified estimate of the projected need for PC in Nepal	n/a The method for estimating the number of people requiring PC is based on multiplying the number of people dying from a particular condition by the PPP for the condition	Country level	- Data source used: The percentage pain prevalence (PPP) for the condition. The number of deaths for each condition for Nepal was taken from the WHO Global Health Estimates (GHE) for deaths by country dataset of the WHO Health Statistics and Information Systems - Calculation by multiplying the number of people dying from a particular condition by the PPP for the condition. Data were also extrapolated to create estimates of the need for palliative care per 100,000 of the national population, based on the national population in 2012	The national population, based on the national population in 2012	Researcher	- Total death 84, 659 Total PC need 58,727 = 69.37%
May et al. (2019), Ireland	To estimate PC needs in Ireland from 2016 to 2046	Secondary research study of already-collected data	- Country level	- Data source used - Secondary research study of already-collected data - In Analysis 1, used routinely accessible statutory data in Ireland on recorded deaths 2007–2015 and projected mortality 2016–2046 - In Analyses 2 and 3, retained projected mortality data, and combined these with projected population data 2016–2046 and observed individual-level data from a prospective longitudinal study on aging	People whose death and recorded deaths between 2007 and 2015 in Ireland	The researcher	- In 2016, the number of people dying annually from a disease indicating PC need was estimated as 22,806, and the number of people aged 50+ with a relevant diagnosis was estimated as 290,185. Equivalent estimates for 2,046 are 40,355 and 548,105, increases of 84% and 89%, respectively
Bowers et al. (2020), Queensland, Australia	To estimate the prevalence of life-limiting conditions for children and young people aged 0–21 years living in Queensland, Australia	An observational study using linked administrative health data from the 2011 and 2016 calendar years	Country level	- Data source used: Using linked administrative health data from the 2011 and 2016 calendar years was performed for all individuals with an International Statistical Classification of Diseases and Related Health Problems 10th Revision Australian Modification code relating to a life-limiting condition eligible for PC recorded against an admission to a public or private hospital and health service provider in Queensland or against a cause or underlying cause of death in the Queensland Registrar General Deaths	4,529	Researcher	The overall prevalence of life-limiting conditions per 10,000 population increased from 35.2 (95% confidence interval (CI) 34.2–36.2) in 2011 to 43.2 (95% CI 42.1–44.4) in 2016

(Continued)

Table 3. (Continued.)

Author/year/ country	Objective	Study design	Study setting	Data sources	Study population and sample size	Data collector	Result
Fraser <i>et al.</i> (2020), England	To estimate the current prevalence of children with a life-limiting condition and to model future prevalence of this population	Observational study	A population-based approach utilizing ethnic-specific population projections was used to estimate future prevalence	- Data source used: Using national inpatient hospital data of all children aged 0–19 years with a life-limiting condition diagnostic code recorded in Hospital Episodes Statistics data in England from 2000/01 to 2017/18 Hospital Episode Statistics Admitted Patient Care (HES) were linked to the Office for National Statistics (ONS) mortality data	4,543,386 hospital episodes for 359,634 individuals	Researcher	The prevalence of children with a life-limiting condition rose from 26.7 per 10,000 (95% CI 26.5–27.0) in 2001/02 to 66.4 per 10,000 (95% CI: 66.0–66.8) in 2017/18
Calvache <i>et al.</i> (2020), Colombia	To provide an estimate of the need of PC services in Colombia and compare these needs with the current available offer	Cross-sectional study	Country level	- Data source used Using death certificate-based study of individuals deceased above 18 years in Colombia between 2012 and 2016 Data from death certificates provided by National Administrative Department of Statistics of Colombia (DANE) Chronic conditions for which PC is required were identified from the main cause of death using ICD-10 codes	People who were recorded of mortality statistics for the Colombia for the period 2012–2016	Researcher	Prevalence = 2.3/1,000 in 2012 and increase to be 2.6/1,000 in 2016
Engeser <i>et al.</i> (2020), Germany	To assess whether the provision of specialist home palliative care (SHPC) for outpatients increased the likelihood of patients dying at home	An Observational Study	Country level	- Data source used Secondary data of PC patients who were identified using the ICD-10 code Z51.5 or the assigned medical billing code of the German fee schedule Patients receiving care from an SHPC team were identified using the billing codes 01425 or 01426	Data were collected in 2015 from a German statutory health insurance company covering 3.872 million people	Researcher	Using data from 2015 compiled from a large German statutory health insurance company (AOK Baden-Wuerttemberg) which insures 3.87 million people, it found that 3,535 patients diagnosed with advanced cancer as having PC needs 669 (18.9%) of these were referred to a specialist home care team. Of these, 302 (45.1%) were referred to a PC team on the day they were diagnosed, but 367 (54.9%) were referred only at a later point in time

level, such information will contribute to the training of volunteers, families, local organizations, and health-care professionals in accordance with their respective roles and responsibilities. The prevalence of PC needs identified at each level can be used to design PC delivery, such as community-based (CBPC), hospital-based, or primary care facility-based PC (such as that offered in hospices or nursing homes). The model produced for each PC level corresponds to numerous interdisciplinary and discrete tasks and activities associated with the delivery of PC. This is reflected in the work of Bhavsar et al. (2017), who focused on CBPC. This study reported that physicians spent 94% of their time on tasks related to patient care and 1% on administrative tasks. In contrast, nurse practitioners and registered nurses spent 82% and 53% of their time on patient-related tasks and 2% and 37% on administrative tasks, respectively.

For the primary data collected at the hospital level, this study reported 7 studies relevant to hospital-based PC services proposed by the WHO. This concept covers services provided via an outpatient PC clinic, PC consultation service for hospital inpatients, PC day-care service, inpatient PC unit, and PC outreach/home care provision. Several types of staff are required to provide these services including doctors, nurses, auxiliary/palliative nurse aides, and pharmacists. In addition, psychologists or counselors, social workers, and volunteers should be involved. Hospital-based PC also facilitates discussion on the values, diagnosis, prognosis, and agreements of patients alongside the goals of the care offered (World Health Organization 2016). Moreover, Paramanandam et al. (2020) found that collaboration between a hospital's PC team and CBPC results in high-quality transitions across care settings and a reduction in acute care utilization.

Through primary data collection at the primary care facility level, this study reported on 3 studies undertaken in (1) general practitioner clinics in Japan (Hamano et al. 2018), (2) primary care centers and 1 district general hospital, 1 social health center, and 4 nursing homes in Spain (Gómez-Batiste et al. 2012), and (3) a nursing home in Belgium (Hermans et al. 2017). These primary care facilities serve the needs of older adults in countries having the highest proportion (28.2% of the total population aged over 65 years): 28.0% in Japan, 19.1% in Spain, and 18.7% in Belgium (Population Reference Bureau 2021). The context of the increasing older adult populations invokes the need for residential care homes and/or assisted living facilities. The identification of PC needs for these older adults living in these facilities and accessing other provisions is important in the early phase (Galiana and Haseltine 2019). However, the need for PC is not restricted to older adults; yet, this demographic requires greater access to PC than other groups (Daya et al. 2017; Elayaperumal et al. 2018). This is consistent with the general regime and practice of geriatric PC (Goldhirsch et al. 2014). In line with the concept of home-based PC, CBPC and aging within the community encourage the provision of PC (Galiana and Haseltine 2019) in places other than hospitals.

For the primary data collection undertaken at the community level, this study reported on 2 studies relevant to the CBPC as proposed by the WHO. This concept holds that CBPC should be offered at primary care facilities (such as community health centers, sub-district health promoting hospitals, and nursing homes) and should involve people in the community as witnesses of the facilitation of PC assessments, planning, implementation, resource mobilization, and collaboration with local health authorities. This approach shall allow community organizations to play a role in establishing PC services in their community and for these efforts

to be integrated into the wider health system (World Health Organization 2016). The involvement of volunteers in assessing PC needs within a community must arise alongside a system designed to enable assessment tools to be used, and the roles and responsibilities of PC teams should be clarified based on the concept of intersectoral collaboration and the appropriate training of relevant teams. Additionally, one study developed a tool to identify PC needs in both primary care facilities and hospital settings (Gómez-Batiste et al. 2012).

When considering the data collectors of the primary data studies considered here, it was found that 11 studies were undertaken in relation to primary and secondary care facilities by trained health-care professionals (e.g., doctors and nurses). This reflects how PC, in this setting, is provided by trained staff at primary care facilities and hospitals. However, collaboration among health-care professionals working in community hospitals at the district level occurs through the production of discharge plans by health-care professionals operating at the primary care level. Therefore, volunteers working in communities are required. Khongsrichay et al. (2020) indicated that an obstacle faced by nurses working at the primary care level is the lack of knowledge development in PC. Thus, greater training of health-care professionals in PC is needed if PC provisions are to be comprehensively integrated into health-care systems. Furthermore, it was found that 2 studies utilizing primary data were carried out by trained volunteers with this activity being in concordance with CBPC, whereby people in a community are involved in such assessment processes (World Health Organization 2016). Data collected by trained volunteers will be the input of primary care facilities, whereas the latter will design PC services. In other words, through primary health care enacted alongside community participation, appropriate technology that is compatible with *local*, cultural, and economic conditions can emerge. Simultaneously, responsive tools and processes can be maintained and operationally controlled by the local population, while intersectoral collaboration in the community should be strengthened. The information derived from and contributed by each community shall therein be culturally and demographically responsive and will acknowledge the resources available therein, thereby providing solutions that are community-centered and advocating the continuity of care across all levels (Calvache et al. 2020)

The secondary data approach used to estimate the prevalence of PC needs has mostly been undertaken at the country or continent level (Aristodemou and Speck 2017; Bowers et al. 2020; Calvache et al. 2020; Connor et al. 2017; Engeser et al. 2020; Etkind et al. 2017; Fraser et al. 2020; Kane et al. 2015; Maetens et al. 2019; May et al. 2019; Morin et al. 2017; Murtagh et al. 2014; Scholten et al. 2016; Swarbrick et al. 2019). Information on the overall prevalence of people with PC needs can, therefore, be positioned to determine a country's PC-related policy, resource/funding allocation, and workforce training (among both professionals and lay people). Additionally, secondary data sources derived from hospitals can pinpoint the prevalence of PC needs (Hua et al. 2014; Wirasorn et al. 2016). To understand the trends of PC needs, from which processes can manifest and appropriate methods are developed through which PC needs within hospitals are determined, the accessibility of PC must be comprehended. Furthermore, secondary data (or routine data), including those derived from death registries, hospital activity records, primary care data, and specialist PC registers, are widely underutilized. The benefits of secondary data pertain to this existing information and are often formatted on a population basis. The combination of existing data pertaining to given areas, services, and demographics may be vital in

contributing to a comprehensive understanding of the current context of such health care and where improvements may be made or are required. Patient-centered outcome measures are increasingly seen as the gold standard for measuring quality of care; therefore, person-level data must be collected uniformly over time. On the other hand, the use of secondary data encounters a number of challenges, including varying quality of the data, associated safety and ethical issues, lack of linkage with other information, and non-specificity of PC and end-of-life care needs (Davies *et al.* 2016).

Data collected on PC needs prevalence via different means allows population-based estimations at national or continent levels to emerge through which determination can be given as to implementing responsive policies and resource allocation. In this sense, primary data sources from primary, secondary, and tertiary care facilities can be used to improve PC services and determine policy and resource management at the facility level. Primary data from community-level sources can be facilitated by primary care facilities to improve their services by using a network of community PC volunteers and working together with health-care providers in the community, such as providing information on population illness in the community (Daya *et al.* 2017; Elayaperumal *et al.* 2018) and caring and spiritual supporters of PC patients. The diversity of methods used to identify PC needs is crucial for the comprehensive assessment and treatment of pain and other physical, psychosocial, and/or spiritual problems (World Health Organization 2016). The PC needs must be identified to manage resources such as those of health-care professionals (in terms of the extent and quality of their training), volunteers, medical equipment, information, and pertinent networks. The methods of determining PC needs in a given context will vary depending on whether the given PC program is designed to be community-, facility- (primary care facility and hospital), or country-based. This will impact PC assessment, planning, implementation, and evaluation processes designed and operated.

Strengths and limitations of the present study

The strengths of this study pertain to its focus on addressing the methods used to identify the prevalence of PC needs. The integrative review method that was employed has set out stringent inclusion and exclusion criteria enacted by 2 researchers and was then independently reviewed. When disagreement arose regarding the inclusion or exclusion of an article, justification and discussion were raised in collaboration until a consensus was reached. This process was designed to minimize potential bias. Furthermore, a comprehensive evaluation has been given to the methods used to identify the prevalence of PC needs via various levels of coverage (e.g. continental, country, facility, and community). However, the present integrative review had several limitations. First, in addressing the prevalence of PC needs presented in each context and the economic disparities across populations, generalization needs to be considered. Second, language bias must be acknowledged as only papers published in English were included in this integrative review.

Implications for further research

This study suggests that most of the research undertaken with secondary data sources (12 studies) pertains to the country level, whereas research undertaken with primary and secondary data (12 studies) pertains to hospital-level data. The determination of PC needs at the community level was found in only 2 studies. Thus,

there is a need to enhance the provision of PC within communities, integrate this effort with national health systems, and strengthen collaboration between health sectors, local organizations, and the people sector. Moreover, the prevalence of PC needs should be reported across all levels of care, including community, primary, secondary, and tertiary care, in order to design integrated PC.

Conclusions

This integrative review revealed that there are several methods through which data can be collected regarding the prevalence of PC needs, including primary and secondary data collection. The benefits of each method correspond to their respective purposes of utilization (e.g., policy development or practice improvement). Here, data on the prevalence of PC needs can be collected at continental, country, facility (primary care facility and/or hospital), and community levels. The tools and data sources accessible in this context demonstrate the involvement of trained health-care providers, researchers, and support from trained volunteers. The prevalence of PC needs was recorded as the population proportion (i.e. per 100 and 1,000). A bottom-up approach is used to understand the prevalence of PC needs spanning both the community level and primary care facilities. Thus, there is a need to develop CBPC services designed to be integrated with national health systems.

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Competing interests. The authors declare that they have no competing interests.

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