Defining and quantifying population-level need for children's palliative care: findings from a rapid scoping review

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Abstract

Background The number of children who require palliative care has been estimated to be as high as 21 million globally. Delivering effective children's palliative care (CPC) services requires accurate population-level information on current and future CPC need, but quantifying need is hampered by challenges in defining the population in need, and by limited available data. The objective of this paper is to summarise how population-level CPC need is defined, and quantified, in the literature.

Methods Scoping review performed in line with Joanna Briggs Institute methodology for scoping reviews and PRISMA-ScR guidelines. Six online databases (CINAHL, Cochrane Library, EMBASE, Medline, PsycINFO, and Web of Science), and grey literature, were searched. Inclusion criteria: literature published in English; 2008–2023 (Oct); including children aged 0–19 years; focused on defining and/or quantifying population-level need for palliative care.

Results Three thousand five hundred seventy-eight titles and abstracts initially reviewed, of which, 176 full-text studies were assessed for eligibility. Overall, 51 met the inclusion criteria for this scoping review. No universal agreement identified on how CPC need was defined in population-level policy and planning discussions. In practice, four key definitions of CPC need were found to be commonly applied in quantifying population-level need: (1) ACT/RCPCH (Association for Children with Life-Threatening or Terminal Conditions and their Families, and the Royal College of Paediatrics and Child Health) groups; (2) The 'Directory' of Life-Limiting Conditions; (3) 'List of Life-Limiting Conditions'; and (4) 'Complex Chronic Conditions'. In most cases, variations in data availability drove the methods used to quantify population-level CPC need and only a small proportion of articles incorporated measures of complexity of CPC need.

Conclusion Overall, greater consistency in how CPC need is defined for policy and planning at a population-level is important, but with sufficient flexibility to allow for regional variations in epidemiology, demographics, and service availability. Improvements in routine data collection of a wide range of care complexity factors could facilitate estimation of population-level CPC need and ensure greater alignment with how need for CPC is defined at the individual-level in the clinical setting.

Keywords Palliative care, Children, Need, Eligibility criteria, Life-limiting conditions, Life-threatening conditions

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Background

Children's palliative care (CPC) is defined as *"an active and total approach to care, from the point of diagnosis or recognition throughout the child's life, death and beyond."* ([1]: pg.9) CPC has been described as a 'thread' that runs through children's lives, often alongside other treatments, focusing on enhancing quality of life for children and supporting their families, including management of distressing symptoms, provision of short breaks, and care through death and bereavement [1]. There are distinct levels of CPC including the delivery of a palliative approach by all healthcare providers, general palliative care delivered by specialists of a given disease with training in palliative care, and specialist CPC delivered by experts in CPC [2]. There are important differences between adult and children's palliative care [3] involving very different timescales: CPC (ideally) begins when illness is diagnosed and may be needed for just a few days, or could extend over many years [4]. The potential benefits of CPC include improvements in symptom control and quality of life for children and their parents [2], potential reductions in hospitalisations, and increases in the likelihood that the preferred place of death is achieved [5].

The number of children (aged 0–19 years) who need palliative care has been estimated to be as high as 21 million globally with the majority (>97%) of them living in low to middle-income countries [3, 6]. However, internationally, access to CPC lags "far behind" that of adult palliative care services ([3]: pg.16) and there are still many countries where CPC is insufficient or unavailable [3, 4]. Adequate provision of CPC services requires accurate information on the number of children who need palliative care, now and in the future, but quantifying need is hampered by challenges in defining the population in need [3, 7–9] and by limited available data [2, 4, 10].

Defining CPC eligibility criteria is complicated because the range of health conditions that could make paediatric patients potentially eligible for palliative care is broad and heterogeneous [9]. In addition, CPC eligibility is determined not just by diagnosis but by different 'care complexity' factors that also need to be taken into account, including the extent and nature of clinical, psychological, social, organisational, spiritual and ethical problems faced by the child and family ([9]: pg.2). Moreover, the population of children with palliative care needs is changing due to ongoing advancements in medicine and technology which have simultaneously reduced neonatal and paediatric mortality and increased survival of paediatric patients with increasing health and care needs [4, 9, 11–13]. For example, many children with neurological conditions are living longer, with rising use of complex medical technologies (e.g., long-term home ventilation,

gastrostomy tubes) [4]. However, context is important here, with much of the work on CPC eligibility being carried out in well-resourced settings [14] where the profile of needs may be different to that in lower and middle-income countries.

Clear CPC eligibility criteria are important in both clinical and organisational/planning settings [9]. In the clinical context, individual-level needs are assessed against referral criteria and a decision is taken on whether or when to refer a child to palliative care, together with decisions on the nature and complexity of the palliative need (e.g., general, specialist) [15, 16]. A recently published scoping review categorised the different types of criteria used in clinical settings to initiate a CPC referral, the most common being disease-related, symptom-related and communication-related criteria [15]. A small selection of screening tools were also identified. Overall, the review highlighted broad variations in CPC referral practices across clinical settings and geographic regions. The authors underlined the need to formally evaluate existing criteria (e.g., robust clinical trials, prospective cohort studies) to establish evidence-based CPC referral practices [15].

In the organisational/planning context, policymakers and service planners focus on how CPC is resourced, organised, and delivered to serve the child population in need of palliative care, and rely on population-level (e.g., global, national, regional) estimates of the total number of eligible children to assist current and future planning [10, 12].

The primary aim of this paper is to examine how population-level CPC need is defined and quantified internationally, using a rapid scoping review of the literature. In keeping with the goals of a scoping review to describe and map the literature in a specific field [17], this review documents the most frequently used definitions of CPC need within a broad range of articles focused on population-level CPC need. This includes international policy statements and standards as well as general/conceptual discussions (Category 1), and applied research estimating population-level CPC need (Category 2). The review also examines and categorises the variations in data and methods used to quantify CPC need.

Methodology

Design/method

This review was performed in line with the Joanna Briggs Institute (JBI) methodology for scoping reviews [18]. Scoping review findings are presented following the Preferred Reporting Items for Systematic Reviews (PRISMA-ScR) recommendations [19]. The study protocol is registered in the Open Science Foundation database [20].

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The overall aim was to describe how CPC need is defined, and quantified, in a population-level policy and planning context. Specific review questions included:

- Category 1 – Defining CPC Need (Policy/Concepts): How is CPC need defined in international policy statements/standards and general CPC conceptual discussions?
- Category 2 – Defining & Quantifying CPC Need (Applied): Within the applied literature on estimating population-level CPC need, how is CPC need defined in these studies, and what data and methods are used to quantify need?

Search terms

Selection of the search terms and eligibility criteria were guided by the PCC (Population, Concept and Context) framework [18]. A list of potential key words and index terms included standard search terms used in other scoping reviews (Table 1). A research librarian with expertise

Table 1 Example search conducted in Web of Science, Topic Field

	Search Terms
Population	(adolescen* OR baby OR babies OR boy* OR child* OR "early birth*" OR girl* OR infant* OR juvenile* OR learner* OR "low birth weight*" OR minor* OR neonat* OR newborn* OR "new born*" OR pediatric* OR paediatric* OR perinatal OR premature OR preterm OR "pre term" OR pupil* OR schoolboy* OR schoolgirl* OR student* OR teen* OR young* OR youth)
AND Context NEAR/15 Concept	(("dying" OR (complex NEAR/2 need*) OR ((hospice OR palliative OR terminal*) NEAR/2 (care OR disease* OR ill*)) OR ((life) NEAR/2 (limiting OR "end of" OR shorten* OR incompatible OR threaten*))) NEAR/15 (categor* OR classif* OR concept* OR eligibil* OR epidemiol* OR estimat* OR incidence* OR prevalen* OR quantif* OR quantity OR terminol* OR ((defin*) NEAR/2 need*)))

in systematic and scoping reviews supported the development of the search strategy.

Data sources

The search was undertaken between July and October in 2023. Systematic electronic searches of the following academic databases were conducted: CINAHL, Cochrane Library, EMBASE, Medline, PsycINFO, and Web of Science. Searches for grey literature (e.g., reports, conference proceedings and policy documents) were also undertaken. This involved identifying key global leaders in advancing children's palliative care including the World Health Organization, European Association of Palliative Care, and Together for Short Lives (TfSL, based in the UK, one of the first countries to establish CPC as a distinct speciality) [21, 22]. An initial search of their websites was undertaken with a view to identifying relevant literature. The search was supplemented with citation searches on included studies.

Eligibility criteria

Literature that met the inclusion criteria described in Table 2 were included. A timeframe of 15 + years (2008 to October of 2023) was adopted to capture the different ways of defining and quantifying population-level CPC need that would be of current and practical relevance and to increase the efficiency of the search.

Papers were excluded if they failed to meet the inclusion criteria (e.g., did not directly address the review objectives/wrong context), had insufficient detail on the key concepts, were outside the timeframe, focused on an adult population only or where data on children could not be disaggregated, focused on individual-level need in a clinical setting, where only the abstract was available, or multiple papers reported on findings from the same study in which case, the latest article was included. Final search results were exported into Covidence© which facilitates both the efficient screening of papers and the removal of duplicates. Two independent reviewers (SS) and (TD) examined the titles and abstracts for relevance against the inclusion criteria. Selected publications underwent

Table 2 Inclusion criteria

Inclusion criteria

o Peer-reviewed articles or grey literature sources including quantitative, qualitative and mixed methods studies, study protocols, discussion/conceptual papers, and international policy documents/standards

o Published in English from 2008 to (Oct) 2023

o Children and young people aged 0–19 years

o Definition and/or quantification (with methods and data described) of population-level need for palliative care

o Children's palliative care context (including key terms used in children's palliative care (CPC) context, e.g., life-limiting conditions, life-threatening conditions, complex chronic conditions, end-of-life, dying, etc.)

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full-text review for relevance (SS and TD). If a discrepancy was identified, a third reviewer (JB) reviewed the paper alongside the pre-specified inclusion criteria and subsequent agreement to include/exclude was made via consensus. Study quality was not reviewed as per scoping review guidelines [18].

Extraction and analysis

A data extraction tool was customised and piloted based on JBI's 'template source of evidence details, characteristics and results extraction instrument' [18]. Two authors (SS and TD) undertook data extraction, each reviewing all of the 51 included articles, and extracting the relevant information into the data extraction tool. A comparative appraisal of the extracted information was facilitated in Covidence©, ensuring consistent extraction of data. The final data extraction tool included the following study descriptives: author(s), year, setting (country/multi-country/global), study aims, study population (age range), and key findings.

The tool also included key study characteristics of specific relevance for the scoping review:

– Study focus. Articles were categorised according to the two core review questions, i.e., Category 1 (Defining CPC need – policy/concepts) referring to policy statements/standards and general conceptual discussions; and Category 2 (Defining and quantifying CPC need – applied) referring to applied research estimating population-level CPC need.
– Within the applied literature (Category 2), we extracted key methodological characteristics outlined in standard reporting requirements for applied observational studies (e.g., STROBE, RECORD [23, 24]) including: variables (level of palliative care, definition of CPC need), estimation methods (proportion/number of deaths with CPC needs, prevalence of CPC needs, other) and core data sources (i.e., data, such as mortality, or other clinical data used to define CPC need – note that additional data used as denominators in incidence/prevalence calculations, such as national population data, were not extracted).

Results

Study selection

The literature search produced 5,572 records from electronic database searches including an additional 9 documents from grey literature sources (Fig. 1 PRISMA-ScR flowchart). Following the removal of duplicates ($n=1,994$), 3,578 titles and abstracts were reviewed and 3,402 were deemed to be irrelevant. 176 full-text studies were assessed for eligibility. Overall, 51 met the inclusion criteria for this scoping review. Reasons for exclusion included studies that were not directly addressing the review objectives ($n=87$), insufficient detail on key concepts ($n=11$), wrong context ($n=8$), unable to source at this time ($n=7$), adult population only ($n=3$), unable to disaggregate data for children ($n=3$), and study more recently described ($n=6$).

Study characteristics

Table 3 presents descriptive information on the study characteristics. Of the 51 included papers, the majority ($n=47$, 92%) were published between 2013 and 2023. Thirteen studies adopted a multi-country, European or global perspective [1–4, 6, 14, 25–31], 10 studies were conducted in either Canada, the USA, or South America [32–41], 22 studies were undertaken in Europe, of which 14 were UK-based [7, 8, 11, 12, 42–51], and other European countries included Belgium, France, Germany, Ireland, and Italy [9, 52–58]. Six papers focused on population cohorts in Asia (China, Malaysia, South Korea), Australia, and Africa (Uganda, South Africa) [10, 21, 59–62].

Of the 51 included papers, 13 articles defined or discussed population-level need for CPC from an international policy, planning, or conceptual discussion perspective (category 1). Thirty-eight articles were applied studies, defining CPC need as well as describing the data and methods used to quantify population-level need for CPC (category 2).

The majority of articles focused on children and young people ($n=37$). A small number of articles focused on the perinatal/neonatal population ($n=5$). In this paper, the term 'child' refers to infants, children and young people unless otherwise specified.

The extracted material from each article (i.e., study descriptives, study focus, applied methodological characteristics, etc.) is presented in Table 4.

Category (1) defining CPC need - policy/concepts

The review included 13 international policy statements/standards and general conceptual discussions on CPC need, of which two referred to both adults and children [6, 26], 11 focused specifically on children [1–4, 9, 14, 27, 29, 35, 36, 39].

Policy statements/standards

The 'Global Atlas of Palliative Care' defined need for palliative care for adults and children in terms of the concept of 'serious health-related suffering'. The concept was introduced by the Lancet Commission on Global Access to Palliative Care and Pain Relief [63] which outlined 20 diagnostic groups and a range of symptoms needing palliative care [6]. A review of standards and norms for palliative care by the European Association of Palliative Care
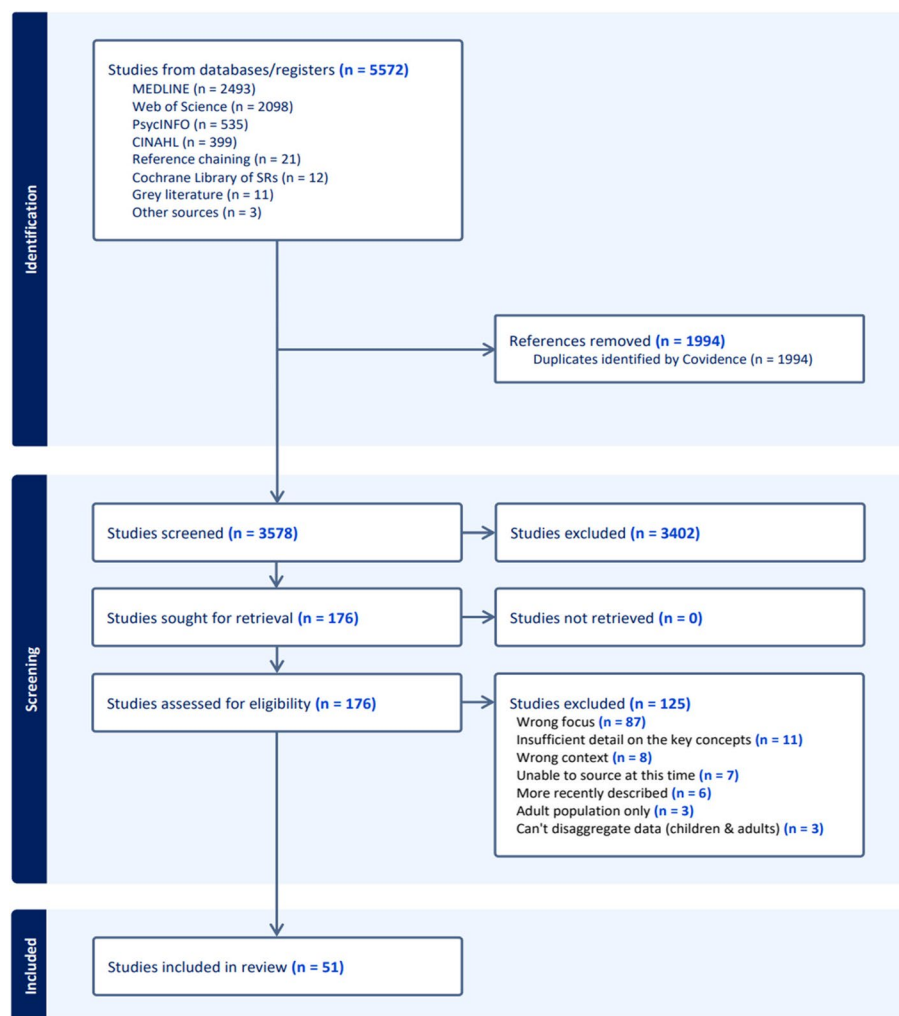
Fig. 1 PRISMA diagram results

(EAPC) stated that palliative care should be available to all adults and children with life-threatening diseases (not defined) and highlighted concerns about the use of the emerging concept of serious health-related suffering to describe the objectives of palliative care [26].

The five international palliative care standards and policy statements that were focused on children all drew on key concepts outlined in A Guide to Children's Palliative Care, by the UK-based charity, Together for Short Lives (TfSL) [1]. In the Guide, CPC need was defined in terms of having a life-threatening condition (for which curative treatment may be feasible but may fail) or life-limiting condition (for which there is no reasonable hope of cure). These conditions were categorised into four groups describing disease progression (Table 5). The groups were first proposed by the Association for Children with Life-threatening or Terminal Conditions and their Families, and the Royal College of Paediatrics and Child Health

(ACT/RCPCH) in the first edition of the Guide in 1997. This review included the 2018 (4th edition) Guide which noted that aside from diagnosis, other factors (e.g., spectrum of disease, severity of disease, complications, needs of the individual child and family) should be accounted for when determining CPC need [1].

The WHO outlined groups of populations and conditions that generate a CPC need [3]. Population groups were defined in terms of disease progression categories which overlap with the ACT/RCPCH groups (Table 5), and condition groups including malignancies, conditions discovered in the perinatal period, injuries, serious infections, genetic conditions, malnutrition, and pain.

The International Standards for Paediatric Palliative Care (Global Overview – PPC Standards 2021, GO-PPaCS) set out general and specific factors in defining CPC need [2]. At the general level, it was agreed that children with life-threatening, life-limiting, or terminal

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Table 3 Study characteristics (*n* = 51)

Characteristic	n	%
Year of publication		
2018–2023[a]	31	61
2013–2017	16	31
2008–2012	4	8
Country		
Multi-country/ global	13	25
Africa (Uganda/S. Africa)	1	2
Australia	1	2
Belgium	1	2
Cambodia	1	2
Canada	1	2
China	1	2
Germany	2	4
Ireland	1	2
Italy	4	8
Malaysia	1	2
Mexico	1	2
South Korea	1	2
United Kingdom	14	27
United States	8	15
Journal discipline		
Medical/Nursing	31	61
Multi-disciplinary	11	22
Grey literature	9	17
Study focus		
1) Defining CPC need – policy/concepts (Category 1)	13	25
2) Defining & quantifying CPC need— applied (Category 2)	38	75
Study population		
Infants only	5	10
Children and young people	37	72
Children and adults	9	18

Source: Rapid scoping review – included full-texts (*n* = 51)

[a] October 2023

illness may need CPC. Life-threatening/life-limiting were defined as per the TfSL guide and terminal was defined as a condition where death becomes inevitable in children with life-limiting or life-threatening illnesses. Specifically, conditions eligible for CPC were classified into five categories describing disease progression, the first four of which were adopted from the 'ACT/RCPCH' groups (Table 5) and the fifth referred to perinatal/neonatal conditions. These standards also stated that diagnosis is not the only important factor and that the complexity of each child and family's needs are important to consider. The standards further stated that 'complex chronic conditions' (CCCs) should also be considered, a concept developed by Feudtner et al. (discussed below) [32]. The need for standardisation of eligibility criteria was emphasised and a list of 'red flag' eligibility criteria were described including diagnosis of a life-limiting/life-threatening condition, serious episodes of hospitalisations, use of invasive medical devices, conditions that cause difficulties in pain/symptom management, complex psychosocial and spiritual needs, and difficulties in making significant decisions. The GO-PPaCS were endorsed in the 2022 European Charter on Palliative Care for Children and Young People ([29] pg.2). A recent blueprint for CPC also described CPC need in terms of the ACT/RCPCH groups [27].

Conceptual discussions

Six review papers discussed key CPC concepts including how CPC need is defined [4, 9, 14, 35, 36, 39]. Spicer et al. [36] outlined an agreed set/lexicon of CPC terminology for use in Canada where CPC need was defined in terms of 'Life-threatening conditions' [36]. Life-threatening conditions were defined as encompassing life-limiting or life-shortening conditions, and were described in terms of the ACT/RCPCH groups. It was further explained that life-threatening conditions (as per this lexicon) are frequently complex chronic conditions with significant impact on the child/family [36]. Similarly, an overview of core issues in CPC for medical practitioners described CPC need both in terms of complex chronic conditions and the ACT/RCPCH groups [39].

The remaining four of these papers were published within the last 5 years and provide recent perspective on developments in CPC eligibility discussions [4, 9, 35]. Macauley [35] discussed the origins, and drawbacks, of the term 'life-limiting', highlighting its disproportionate use in children's, compared with adults', palliative care literature. Macauley [35] noted that the term life-limiting could expand the reach of palliative care by encompassing both shortened life and/or burden of disease but pointed out several problems with the term, including its lack of specificity. Jankovic et al. [9] undertook consensus discussions with experts in the field to identify well-defined CPC eligibility criteria that could be implemented in both clinical and organisational/healthcare planning contexts. The authors provided general guidelines for defining incurability in paediatric cancer and non-cancer patients, and outlined other parameters that should be accounted for (i.e., child and family personal and social factors), subsequently cited in the GO-PPaCS [2, 9]. Fraser et al. [4] and Downing et al. [14] discussed advances and challenges in CPC access and research, including challenges associated with defining the eligible population. Fraser et al. [4] highlighted drawbacks of recent approaches that combine adult and children's palliative care, citing the difference of opinion at the

Table 4 Summary of extract data from included papers (n = 51)

STUDY DESCRIPTIVES (n = 51)					KEY STUDY CHARACTERISTICS: Study focus (n = 51)		KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n = 38)			
Author(s) & Year	Setting (country/ multicountry/ global)	Study aims	Study population (age range)	Key findings	CATEGORY 1(n=13) Defining CPC need - policy/concepts	CATEGORY 2(n=38)Defining & quantifying CPC need - applied	Level of palliative care	Definition of CPC need	Estimation methods	Core data source
Alotaibi et al. (2023)	Multi-country (Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, United Arab Emirates)	To estimate the number of children living with life-threatening illness requiring CPC.	0-14 years	First known study to highlight the unmet need for CPC in these countries. Study limitations: relying on secondary data sources; prevalence of CPC need based on mortality data likely to be under-estimated.		✓	General & specialist palliative care	ACT/RCPCH	Prevalence	Mortality data
Amarri et al. (2021)	Italy	To investigate the prevalence of children with medical complexities eligible for a local palliative care network & draw comparisons with international data.	1-19 years	Observed a lower prevalence of children with medical complexity relative to other published European studies (e.g, possibly because of use of older, less accurate eligibility criteria, variations in understanding of PC from health-care professionals involved, etc.)		✓	General or palliative care approach	ACT/RCPCH	Prevalence	Clinical chart data
Benini et al. (2010)	Italy	To estimate the proportion of hospitalisations with life-limiting or life-threatening diagnoses amongst children in Italy.	0-17 years	First detailed picture of the numbers of life-limiting/ life-threatening conditions in paediatric patients in Italy.		✓	Not specified/ unclear	Miscellaneous definitions	Prevalence	Hospital inpatient data

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Table 4 (continued)

STUDY DESCRIPTIVES (n = 51)				KEY STUDY CHARACTERISTICS: Study focus (n = 51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n = 38)			
					General & specialist palliative care	Multiple definitions	Prevalence	Specific research datasets
Benini et al. (2021)	Italy	To estimate prevalence of general and specialised CPC need in Italy and compare this to the number of adults requiring PC.	0–18 years	Estimates of 34–54 children per 100,000 inhabitants of any age in need of PC in Italy with an estimated 18 children per 100,000 inhabitants in need of specialised CPC. While a greater number of adult patients require PC, the journey of a CPC patient can last for several years.	✔	✔		
Benini et al. (2022)	Global	To update the PPC standards (2007) under the GO-PPaCS (Global Overview of PPC Standards) Project including definition of CPC, eligibility criteria & extent of CPC need.	0–18 years	Eligibility for CPC aligned to ACT/TfSL categories with a 5th category added (unborn/neonates). Diagnosis and complexity of CPC need should be taken into account (e.g., freq. of hospitalisation; intensity of medical intervention; family needs). Challenges to quantifying CPC need include lack of data homogeneity, diverse data collection methods, & heterogeneity of eligibility criteria.	✔			

Table 4 (continued)

STUDY DESCRIPTIVES (n = 51)				KEY STUDY CHARACTERISTICS: Study focus (n = 51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n = 38)			
Bösch et al. (2018) Bösch et al. (2018) Bösch et al. (2018) Bösch et al. (2018)	Germany	To examine children's palliative care need in a University Paediatric Tertiary Care Centre.	0-18 yrs	✓	Found variations in paediatricians' vs. CPC experts' classification of patient subgroups (acute, chronic, life-threatening disease or life-limiting disease) that may be explained by the lack of a robust system for defining CPC need. Diagnoses are not sufficient and must be supplemented with information on complexity of need.	Specialist palliative care	Directory	Prevalence	Clinical chart data
Boss et al. (2018)	US	To quantify the proportion of hospital admissions defined as 'complex chronically ill' where children's palliative care could be beneficial.	<10 years	✓	Children with complex chronic illnesses can have frequent and lengthy hospitalisations and medical complexity that could benefit from children's palliative care.	General & specialist palliative care	Miscellaneous definitions	Prevalence	Hospital inpatient data

Table 4 (continued)

STUDY DESCRIPTIVES (n=51)					KEY STUDY CHARACTERISTICS: Study focus (n=51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n=38)			
	Country	Aim	Age	Findings					
Bowers et al. (2020)	Australia	To estimate the prevalence of children and young people aged 0-21 years with LLCs living in Queensland.	0-21 years	Prevalence of children and young people with LLCs increased from 35.2 per 10 000 population in 2011 to 43.2 per 10 000 population in 2016. Large proportion of children with LLCs die within first month of life. Highlighted potential under-estimation due to limitations of data sources & differences in coding practices.	✓	Not specified/unclear	Directory	Prevalence	Linked datasets
Cardenas-Turanzas et al. (2015)	Mexico	To assess the need for CPC for children dying from CCCs in Mexico and to examine characteristics of children with/without CCCs.	1-17 years	Study found 41% of deaths of children were associated with CCCs and that 80% of these may have benefited from CPC.	✓	Not specified/unclear	CCCs	Incidence	Mortality data
Celiker et al. (2017)	Cambodia	To describe the establishment of CPC in a hospital setting in Cambodia and to quantify CPC need.	Child	Approx. 60% of patient beds in the hospital were occupied by children who would potentially benefit from CPC.	✓	Not specified/unclear	Miscellaneous definitions	Prevalence	Hospital inpatient data
Connor et al. (2013)	Mutli-country (South Africa, Kenya, Zimbabwe)	To estimate the need for CPC and availability of CPC services in Zimbabwe, South Africa and Kenya.	0-19 years	Findings highlighted very large gaps between need for and provision of specialised CPC services in these three countries.	✓	General & specialist palliative care	Miscellaneous definitions	Prevalence	Mortality data

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Table 4 (continued)

STUDY DESCRIPTIVES (n = 51)				KEY STUDY CHARACTERISTICS (n = 51)	KEY STUDY CHARACTERISTICS: Study focus	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n = 38)			
						Not specified/unclear	Miscellaneous definitions	Prevalence	Mortality data
Connor et al. (2017)	Global	To provide a global estimate of the need for CPC.	0-19 years	More than 21 million children annually worldwide were found to need palliative care. Quantifying CPC need using mortality data may underestimate need. Using pain as an indicator of need for CPC ignores potential for other troubling symptoms.	✓	Not specified/unclear	Miscellaneous definitions	Prevalence	Mortality data
Downing et al. (2018)	Global	To examine the development and challenges to providing CPC specifically in resource-poor countries.	Adult & child	Provides a global overview of CPC and highlighted challenges to CPC development.	✓				
Etkind et al. (2017)	UK (England and Wales)	To estimate the numbers and proportions of people (including children) at end-of-life stage who may benefit from palliative care, and project estimate of PC need up to 2040.	Adult & child	Different methods used to measure population PC needs e.g, patient diagnoses, symptom prevalence, and population surveys. Estimated that between 25% and 47% more people may need palliative care by 2040 in England and Wales.	✓	General & specialist palliative care	Multiple definitions	Incidence	Mortality data

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Table 4 (continued)

STUDY DESCRIPTIVES (n = 51)				KEY STUDY CHARACTERISTICS: Study focus (n = 51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n = 38)		
European Association for Palliative Care (EAPC, 2022)	Global		EAPC Charter describes standards for CPC regarding rights of children and their families; expected standards of care; and standards and principles of care that should be provided in all European countries.	0 - 18 years	Need for palliative care based on presence of a LLC/LTC.	✓	
Feudtner et al. (2014)	US		To update the original (version 1) CCC classification system to reflect update from ICD-9 to ICD-10 codes and to compare performance of version 1 versus version 2 CCC system.	Child	Modified CCC classification system (CCC version 2) includes premature & neonatal conditions and an added domain of complexity i.e., IT dependence and transplantation status. When compared, CCC version 2 identified more children with CCCs. Concluded that health status/ disease trajectories are complex & therefore, any classification system needs to be flexible & adaptable for research/service development purposes.	✓	Not specified/ unclear	CCCs Prevalence	Hospital inpatient data

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Table 4 (continued)

STUDY DESCRIPTIVES (*n*=51)				KEY STUDY CHARACTERISTICS: Study focus (*n*=51)	KEY STUDY CHARACTERISTICS:Applied articles quantifying CPC need (*n*=38)			
Fraser et al. (2012)	UK (England)	To estimate the prevalence of life-limiting conditions among children and young people in England.	0-19 years	Developed a list of ICD-10 codes to identify children with LLCs. Applied list to hospital inpatient data & combined with population data to estimate prevalence. Prevalence increased steadily over the previous 10 years and higher for (i) specific ethnic populations and (ii) in the most deprived areas.	✓	Specialist palliative care	List of LLCs	Prevalence	Linked datasets
Fraser et al. (2014)	UK (England)	To describe prevalence of LLCs in children and young adults and to inform planning future palliative care service provision.	0-40 years	Palliative care services aimed at children and young adults need to take account of the diagnostic and demographic breakdown of this population in order to develop efficient and equitable services.	✓	Not specified/unclear	List of LLCs	Prevalence	Linked datasets

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Table 4 (continued)

STUDY DESCRIPTIVES (*n* = 51)			KEY STUDY CHARACTERISTICS: Study focus (*n* = 51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (*n* = 38)			
				Not specified/ unclear	List of LLCs	Prevalence	Linked datasets
Fraser et al. (2021)	UK (England)	To estimate current and future prevalence of children with a LLC in England up to 2030 and to inform planning of CPC services.To estimate current and future prevalence of children with a LLC in England up to 2030 and to inform planning of CPC services.To estimate current and future prevalence of children with a LLC in England up to 2030 and to inform planning of CPC services.	0-19 years	Prevalence of children with a LLC highest in those aged < 1 years. Differences observed between England versus Scotland for the same period. Quantifying CPC need must go beyond diagnosis and capture complexity of need.	✓		
Fraser et al. (2020)	European	To describe some of the key challenges and advancements in CPC.	Child	Not all serious illness in childhood is encompassed by the terms LLCs/ LTCs. Highlighted medical/IT advancements & increased survival times.	✓		

Table 4 (continued)

STUDY DESCRIPTIVES (n = 51)				KEY STUDY CHARACTERISTICS: Study focus (n = 51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n = 38)			
Fraser et al. (2023)	UK (Wales)	To update the prevalence of children with a LLC living in Wales and assess the complexity of this population to information to service planning and delivery.	Child & young adult	Assessed trends in the number and prevalence of children living with LLCs in Wales. Quantified proportion of these children as stable/unstable/deteriorating or dying. Study also assesed complexity of need (e.g. severity of symptoms, intensity of medical intervention, resource utilisation).	✓	General & specialist palliative care	List of LLCs	Prevalence	Linked datasets
Friedel et al. (2019)	Belgium	To examine the number of children & adolescents living with a CCC and referrals to CPC liaison teams.	0-19 years	Found a small proportion of children with a CCC who were admitted to hospital were referred on to CPC. Highlighted issues in using mortality versus routine health data to estimate CPC need.	✓	General palliative care	CCCs	Prevalence	Hospital inpatient data

Table 4 (continued)

STUDY DESCRIPTIVES (n = 51)					KEY STUDY CHARACTERISTICS (n = 51)	KEY STUDY CHARACTERISTICS: Study focus	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n = 38)			
							General & specialist palliative care	Perinatal	Prevalence	
Garten et al. (2018)	Germany	<1 years	To examine the prevalence and characteristics of neonates with LLCs/LTCs who may be defined as "comfort care patients".	"Comfort care" defined as care without curative intent versus palliative care (i.e., care with or without curative intent). Highlighted issues using ICD-10 codes to estimate prevalence of children with comfort care needs (e.g., codes being too broad/ not capturing all potential diseases).		✓	Perinatal		Prevalence	Clinical chart data
Guttmann et al. (2022)	US	<1 years	To define neonatal serious illness as a key concept in defining who needs CPC.	Conceptual definition of 'neonatal serious illness' developed: (i) carries a high risk of short term mortality OR lifelong medical complexity with probable shortened lifespan, (ii) may involve substantial prognostic uncertainty that complicates medical decision-making, and (iii) significantly impacts the patient and family's life now or in the future with strain related to treatments and care."		✓	Perinatal			Hospital inpatient data

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Table 4 (continued)

STUDY DESCRIPTIVES (n=51)				KEY STUDY CHARACTERISTICS: Study focus (n=51)		KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n=38)			
Hain et al. (2013)	UK (Wales)	To develop and pilot a directory of life-limiting diagnoses in children that map onto the ACT/RCPCH trajectory types and may be used for secondary analysis of epidemiological data.	0-19 years	✓	Developed a Directory of LLCs which is conceptually linked to ACT/TfSL categories and based on a list of diagnoses.	General & specialist palliative care	Directory	Incidence	Mortality data
Harnden et al. (2023)	UK	To quantify the number of patients in the Neonatal Intensive Care Unit (NICU) with potential need for perinatal PC by mapping diagnoses & clinical characteristics onto British Association of Perinatal Medicine's (BAPM) categories.	<1 years	✓	Just over 2% (c. 2,000 infants) of neonatal admissions meet BAPM palliative care categories annually. Mapping diagnoses to pre-defined categories may not capture all potential conditions. Differences in concepts and terminologies pose challenges to quantifying PC need.	Not specified/unclear	Perinatal	Prevalence	Specific research datasets
Jacinto et al. (2015)	Uganda	To quantify the proportion of adult & child patients admitted to a large tertiary referral hospital in Uganda with a previously diagnosed life-limiting disease, and therefore eligible for palliative care.	Adult & child	✓	Prevalence of LLCs in the hospital was high with nearly 20% of patients aged <18 years. Study highlights need for hospital-based palliative care teams.	General palliative care	Miscellaneous definitions	Prevalence	Clinical chart data

Table 4 (continued)

STUDY DESCRIPTIVES (n=51)					KEY STUDY CHARACTERISTICS: Study focus (n=51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n=38)			
Jankovic et al. (2019)	Italy	To identify well-defined CPC eligibility criteria that can be easily implemented in clinical, organisational, and healthcare planning contexts.	Child (age not specified)	Paper acknowledges heterogeneity of illnesses that may be eligible for CPC. Diagnosis alone is not enough and complexity of care should also be a factor in assessment of CPC need (e.g., diagnosis of incurability, and wider child/family needs).	✓				
Jarvis et al. (2017)	Scotland	To identify the number of children and young people with LLCs/LTCs in Scotland, their clinical stage, and risk factors for instability.	0-25 years	Clinical stages were defined using objective measure of healthcare use. Children aged <1 yr more likely to be categorised as unstable, deteriorating or dying.	✓	Specialist palliative care	List of LLCs	Prevalence	Linked datasets

Table 4 (continued)

STUDY DESCRIPTIVES (n=51)					KEY STUDY CHARACTERISTICS: Study focus (n=51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n=38)			
						Not specified/unclear	List of LLCs	Prevalence	Linked datasets
Jarvis et al. (2018)	UK (England and Scotland)	To assist planning of CPC services, this study compares routine inpatient data and death records as means of identifying LLCs in children and young people. To assist planning of CPC services, this study compares routine inpatient data and death records as means of identifying LLCs in children and young people. To assist planning of CPC services, this study compares routine inpatient data and death records as means of identifying LLCs in children and young people.	0-19 years; >19 years	Study identified increasing prevalence of children and young people with LLCs in Scotland. Mortality data found to be less reliable in terms of estimating prevalence of LLCs compared to hospital inpatient data.	✓	Not specified/unclear	List of LLCs	Prevalence	Linked datasets
Khalid et al. (2019)	Malaysia	To estimate the number of children dying in hospital in Malaysia with palliative care needs.	0-18 years	Study found that over 44% of children who died in hospitals had a LLC.	✓	General palliative care	Directory	Incidence	Mortality data
Kim et al. (2020)	South Korea	To examine the prevalence of children and young people with LLCs, patterns of healthcare use, and associated costs at end of life.	0-24 years	CPC in South Korea is in the very early stages of development. Prevalence of LLCs highest among sample aged < 1 year.	✓	Not specified/unclear	Multiple definitions	Prevalence	Specific research datasets

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Table 4 (continued)

STUDY DESCRIPTIVES (*n* = 51)			KEY STUDY CHARACTERISTICS: Study focus (*n* = 51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (*n* = 38)			
Lindley et al. (2019)	US	To examine prevalance of CCCs (version 1) in a national sample of infant decedents aged <1 year.	<1 years	Less than half (41.87%) of infant decedents had a CCC classification. The CCC classification system may be contributing to the exclusion of infants who are not generally classified with a CCC (e.g., prem/low birthweight) from end-of-life/palliative care research studies.	✓	Not specified/unclear	CCCs	Incidence	Mortality data
Lindley et al. (2020)	US	To compare version 1 and 2 of the CCC classification systems using a sample of infant decedents aged <1 year.	<1 years	More infants counted when using the modified (updated) CCC classification system. Ultimately, research using CCC system will generate data for end-of-lifeservice improvements. Further research needed to evaluate the performance of the two systems, e.g. in prospectively identifying infants with LLCs.	✓	Not specified/unclear	CCCs	Incidence	Mortality data

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Table 4 (continued)

STUDY DESCRIPTIVES (n = 51)					KEY STUDY CHARACTERISTICS: Study focus (n = 51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n = 38)			
						Not specified/ unclear	List of LLCs	Prevalence	Specific research datasets
Ling et al. (2015)	Ireland	0-17 years	To estimate the number of children with LLCs in Ireland to inform service provision and workforce planning in CPC in Ireland.To estimate the number of children with LLCs in Ireland to inform service provision and workforce planning in CPC in Ireland.	Published letter on behalf of the Health Service Executive National Development Committee for Children's Palliative Care. No national database of the number of children in Ireland living with LLCs. Drew on UK prevalence figures to estimate number of children with LLCs at a population level.	✓				
Lu et al. (2020)	China	0-19 years	To estimate number of children in need of end-of life palliative care at a national level.	Focused on end-of-life CPC needs using mortality data. Of 131,400 deaths aged 0-19 in 2017, an estimated 90,600 children in China could potentially benefit from end-of-life paediatric palliative care.	✓	Not specified/ unclear	Miscellaneous definitions	Incidence	Mortality data
Macauley (2019)	US	Child (age not specified)	Explores pros & cons of using various terms in the field of palliative care, with a focus on CPC.	The term 'life-limiting' has been used disproportionately in paediatric palliative and hospice care literature but there are differing interpretations of the term and it is not always broadly applicable.	✓				

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Table 4 (continued)

STUDY DESCRIPTIVES (*n* = 51)			KEY STUDY CHARACTERISTICS (*n* = 51)	KEY STUDY CHARACTERISTICS: Study focus	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (*n* = 38)		
Moody et al. (2011)	US	Child (age not specified)	Review of CPC including epidemiology, special communication concerns, decision-making, ethical and legal considerations, symptom assessment, etc. to improve service provision.	Addressed some of the factors to consider in provision of CPC. Provides a broad estimate of the number of children amenable to CPC. Draws on earlier research which refers to ACT/ TfSL categories to define CPC need. Applied Feudtner's CCC system to quantify need and ACT/ TfSL categories to describe who is eligible.	✓		
Murtagh et al. (2014)	UK (England)	Adult & child	To refine existing methods for estimating population-based needs for palliative care and compare the results from the different methods.	Study refined existing methods for quantifying need & compared these using different combinations of mortality data, symptom prevalence, disease prevalence and/ or linked hospital data. Showed a significant increase from 37% to 63% of all deaths which may need palliative care.	✓	General & specialist palliative care	Multiple definitions	Prevalence	Linked datasets

Table 4 (continued)

STUDY DESCRIPTIVES (n = 51)					KEY STUDY CHARACTERISTICS: Study focus (n = 51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n = 38)			
						Not specified/ unclear	List of LLCs	Prevalence	Linked datasets
Norman et al. (2014)	UK (England)	To analyse time trends in prevalence amongst children and young people by deprivation using alternative measures of deprivation & examine increasing survival.	0-19 years	Prevalence rate of 32 per 10,000 children and young people living with LLCs in England with variations in prevalence by age, area deprivation and ethnic group. Increasing prevalence of LLCs associated with falling mortality rates.	✓		List of LLCs	Prevalence	Linked datasets
Noyes et al. (2013)	UK (Wales)	Integration of available evidence and use of new methodological epidemiological work to contribute to population-needs assessment and costing/ commissioning methodology in children's palliative care.	0-19 years	Difficulty establishing number of children with CPC need due to inconsistent use of terminology (i.e. life-limiting versus life-threatening) and heterogeneity of CPC needs. Applied 3 population prevalence estimation methods to determine prevalence of children with LLCs and number and diagnoses of children and young people dying each year from life-limiting illnesses.	✓	General & specialist palliative care	Multiple definitions	Prevalence	Specific research datasets

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Table 4 (continued)

STUDY DESCRIPTIVES (n=51)				KEY STUDY CHARACTERISTICS (n=51)	KEY STUDY CHARACTERISTICS: Study focus (n=51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n=38)			
Payne et al. (2022)	Global	To revise the recommendations on standards and norms for palliative care in Europe.	Adult & child	Most recommendations on standards and norms for palliative care in Europe remained unchanged since 2009, with 13 new recommendations relating to emerging specialisms (including neonatal palliative care, geriatric and dementia services) and service improvements.	✓				
Public Health Scotland (2020)	UK (Scotland)	To report the demographics and phase of illness of children across Scotland with life-shortening conditions (CHiSP3 study).	0–21 years	Reports on prevalence (using ICD-10 codes), demographic characteristics and phase of illness of children with life-shortening conditions (LSCs) living in Scotland. Number of children living with a LSC has increased from 92 per 10,000 (2009/10) to 130 per 10,000 (2018/19).	✓	Not specified/unclear	List of LLCs	Prevalence	Specific research datasets
Randall et al. (2011)	US	To estimate the prevalence of children with LTCs cared for in the military health system.	< 24 years	Developed a definition of LTCs based on the ACT/TfSI disease trajectories. Reported 0.15% of children with LTCs.	✓	General or palliative care approach	ACT/RCPCH	Prevalence	Hospital inpatient data

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Table 4 (continued)

STUDY DESCRIPTIVES (n = 51)			KEY STUDY CHARACTERISTICS: Study focus (n = 51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (n = 38)
Roland et al. (2022)	Global	Policy report describing a vision (or 'blueprint') for children's palliative care in the future. Involved 51 CPC leaders across 27 countries and six continents.	Child (not specified)	✓ Highlights best practice in terms of CPC developments and service provision. Defines CPC need in terms of LLCs using ACT categories. Of the estimated 21m children with LLCs and LTCs globally, around 8m require specialist children's palliative care at any one time. 90% of the estimated 8m children in need of specialist CPC globally never receive it.

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Table 4 (continued)

STUDY DESCRIPTIVES (*n* = 51)			KEY STUDY CHARACTERISTICS: Study focus (*n* = 51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (*n* = 38)			
				Not specified/ unclear	Miscellaneous definitions	Incidence	Mortality data
Sleeman et al. (2019)	Global	To project the future global burden of serious health-related suffering requiring palliative care until 2060, and to identify the world regions, age groups, and health conditions for which suffering and palliative care need are expected to rise the most.	Adult & child	Combined WHO global mortality data with estimates of symptom prevalence in 20 conditions. The proportion of people (including children) dying with serious health-related suffering will increase from 45% (26m) of all deaths in 2016 to 47% (48m) in 2060. Most rapid increases will occur in low income countries (LICs), among people >70 years and those with dementia.	✓			

Table 4 (continued)

STUDY DESCRIPTIVES (*n* = 51)		Study focus	Age	KEY STUDY CHARACTERISTICS (*n* = 51)	KEY STUDY CHARACTERISTICS: Study focus (*n* = 38)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need			
						Not specified/ unclear	ACT/RCPCH	Prevalence	Specific research datasets
Spicer et al. (2015)	Canada	To establish a shared vocabulary (list of terms) for use in the field of CPC in Canada.To establish a shared vocabulary (list of terms) for use in the field of CPC in Canada.	0-19 years	Agreed a set of terminology for use by clinicians & researchers in Canada relating to CPC (including 18 terms of importance in the CPC literature). Provides a broad definition of CPC and the population it serves (i.e., children with chronic, complex & LTCs) where preference is to use 'life-threatening' as an umbrella term to encompass ACT/TfSL categories.	✓					
Together for Short Lives (2013)	UK	To determine whether CPC services were meeting child and family needs in the UK (West Midlands region) by analysing a minimum dataset from PC services.	0-30 years (80% of sample aged 1 - 18 years)	21 service centres (National Health Service (NHS) & non-NHS) participated in the study. CPC defined in terms of LLCs. Key recommendations regarding service improvements, better understanding of local population needs and future research.		✓	Not specified/ unclear	ACT/RCPCH	Prevalence	Specific research datasets

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Table 4 (continued)

STUDY DESCRIPTIVES (*n* = 51)			KEY STUDY CHARACTERISTICS (*n* = 51)	KEY STUDY CHARACTERISTICS: Study focus (*n* = 38)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (*n* = 38)
Together for Short Lives (2018)	UK	A guide to children's palliative care in the UK.	Neonates, children & young people	Defines CPC, LLCs & LTCs. Recognises need for palliative care is not only based on a definitive diagnosis but also on complexity of need, severity of symptoms, and other child & family needs. Prevalence of children living with LLCs is rising.	Prevalence data
World Health Organization (2018)	Multi country	Global report on CPC to inform service planning, implementation and managing CPC.	0-19 years	21 million children and adolescents (0-19 years) need CPC worldwide. Provided a broad definition of PC, including CPC. Identified CPC need as those with LLCs based on ACT/RCPCH categories and/or those presenting with specific conditions that might not be life-threatening but may generate a CPC need (e.g., perinatal conditions, injuries - head trauma, burns, exposure to violence, serious infections).	

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Table 4 (continued)

STUDY DESCRIPTIVES (*n* = 51)			KEY STUDY CHARACTERISTICS: Study focus (*n* = 51)	KEY STUDY CHARACTERISTICS: Applied articles quantifying CPC need (*n* = 38)
Worldwide Palliative Care Alliance (2020)	Multi country	Global Atlas of Palliative Care - to examine the status of palliative care worldwide including estimating the number of people with a life-threatening illness who need palliative care.	Adult & child — Estimated global total number of children (0-19 years) in need of CPC in 2017 is almost 4 million (7% of the total global PC needs) with the majority of children living in the African & Southeast Asian regions. CPC need defined based on presence of specific disease groups (e.g., premature birth, injury, poisonings) and conditions differed between HICs vs. LMICs.	✓

Notes: ACT/RCPCH (Association for Children's Palliative Care/ Royal College of Paediatrics and Child Health) also described as ACT/TfSL (Together for Short Lives) CPC (children's palliative care)Directory (Hain's Directory of Life-Limiting Conditions) HICs (high income countries) IHME (Institute for Health Metrics and Evaluation) LTCs (life-threatening conditions) LLCs (life-limiting conditions) List of LLCs (life-limiting conditions; from Fraser and colleagues) LMICs (low and middle-income countries) PC (palliative care) UNAIDS (The Joint United Nations Programme on HIV/AIDS) WHO (World Health Organization)

Table 5 Defining CPC need – policy statements/standards

Source	Group	Description
ACT/RCPCH (Together for Short Lives) [1]	(1) Life-threatening conditions for which curative treatment may be feasible but can fail (2) Conditions where premature death is inevitable (3) Progressive conditions without curative treatment options (4) Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death	These groups aim to capture a wide range of conditions that may benefit from CPC support/intervention A fifth category was added to these in the GO-PPaCS to capture peri/neonatal conditions [2].
Global Atlas of Palliative Care [6]	Serious health-related suffering	Identified 20 diagnostic groups and a list of symptoms needing palliative care
EAPC [26]	All adults and children with life-threatening diseases	Diseases not defined
WHO [3]	(1) Children with acute/chronic life-threatening conditions that may or may not be cured (2) Children with progressive non-curable life-threatening conditions (3) Children with severe neurologic conditions that may cause deterioration and death (4) Neonates severely premature or with severe congenital abnormalities (5) Family of fetus/child who dies unexpectedly	Similar in wording to the ACT/RCPCH (TfSL)[a] groups of LLCs
Pediatric Complex Chronic Conditions (CCC) classification system [32]	'Any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or 1 organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center.'	The original CCC (version 1) was developed in 2000 and included a list of diagnoses based on ICD-9-CM.[b] The CCC (version 2) was later expanded to include a new neonatal category as well as an assessment of complexity captured via technology dependence or organ transplantation [32].

[a] ACT merged with Children's Hospices UK to form Together for Short Lives in 2012

[b] ICD-9-CM (International Classification of Diseases version 9 Clinical Modification)

international level about the new definition of palliative care developed by the International Association of Hospice and Palliative Care that draws on the Lancet Commission concept of serious health-related suffering [64].

Category (2) defining & quantifying CPC need – applied
The review included 38 articles undertaking applied research estimating population-level CPC need. The following sections describe the core definitions of population-level CPC need adopted, noting if/where complexity of need was addressed, and the estimation methods and data sources applied in the studies. (Core methodological characteristics of the applied articles are summarised in Additional File 1.)

Definitions of CPC need in applied literature
Three articles focused on developing a detailed list of diagnoses/conditions that would be considered eligible for CPC, on the understanding that proper planning of services requires detailed information on the population of children who need the services, which in turn requires detailed diagnostic criteria [7, 32, 42]. In each case, the list of diagnoses were coded according to the International Classification of Diseases (ICD10), although

different versions were used [65]. A further 16 papers applied or modified these lists to estimate population-level need for CPC to inform service planning [12, 33, 34, 41, 43, 45–49, 55–58, 61, 62]. Nine additional papers compared multiple definitions or adopted study specific definitions [8, 21, 30, 40, 44, 50–52, 54]. Four papers focused on perinatal/neonatal palliative care [11, 33, 34, 56]. A final eight papers used unclear or miscellaneous definitions to quantify CPC need [10, 25, 28, 31, 38, 53, 59, 60].

– Specified Lists of Diagnoses

Feudtner et al. [32] developed a list of complex chronic conditions (CCCs) (in ICD10-CM and ICD10-PM codes) which refer to 'any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or 1 organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center') ([32]: pg.2). This was a revision of an earlier list [66] and includes > 1,000 diagnoses in 10 CCC categories (cardiovascular, respiratory, neuromuscular, renal, gastrointestinal, haematologic

or immunologic, metabolic, other congenital or genetic, malignancy, and perinatal) and incorporates a 'domain of complexity' referring to dependence on medical technology, and a domain for post-transplant related conditions ([32]: pg.3). The authors note that no single classification system is perfect given the multidimensional nature of the needs of children with complex conditions, and recommend that any system should be transparent and adaptable to each research question [32]. Feudtner et al. [32] compared both versions of the CCCs list in hospital datasets and showed that version 2 classified more patients as having CCCs than did version 1 (with some exceptions). One article in this review used the CCCs list to assess the need for end-of-life CPC in Mexico [41], while another article examined the prevalence of CCCs amongst children in hospital in Belgium and the extent to which children with a CCC were being referred for palliative care [57]. In both studies, CCCs were defined as per version 1, which included diagnoses only and did not include the 'domain of complexity' as per version 2 [32, 66]. Lindley et al. [33, 34] examined life-limiting illness amongst neonatal deaths, applying (and comparing) both versions of the CCCs list.

Hain et al. 2013 [7] developed a 'Directory' of life-limiting conditions by mapping the four ACT/RCPCH groups onto diagnoses (in ICD10 codes) of patients admitted to palliative care services in the UK. The final version of the Directory included 376 diagnostic labels, and the Directory was piloted through an examination of the proportion of deaths with life-limiting conditions in Wales between 2002 and 2007. Similar to Feudtner et al. [32], the authors highlighted the need to update the list as new diagnoses become apparent. Hain et al. [7] also suggested revisiting the underlying ACT/RCPCH groups where additional conditions could potentially be added where palliative care can play an important role (e.g., traffic injuries) [7]. Three studies in this review estimated need for CPC using the Directory to define need including: an examination of CPC need in a German hospital (with additional assessment of complexity of need in terms of higher needs for medical devices, medications, and nursing care) [55]; an estimate of the number of children dying in hospital in Malaysia with palliative care needs (using the Directory as well as expert opinion to identify life-limiting conditions) [61]; an estimate of the regional prevalence of life-limiting conditions among children in Queensland, Australia [62] .

Fraser et al. 2012 [42] developed a list of life-limiting conditions (in ICD10 codes), labelled here as the 'LLCs List', combining two sources of information: Hain's Dictionary and a list of diagnoses for children accepted for care at a UK hospice. The authors used the term life-limiting to encompass life-threatening conditions and both

terms were defined from the TfSL Guide [1]. Each diagnosis on the combined list was assessed as to whether most children with the diagnosis were life-limited/life-threatened; and if most subdiagnoses within the ICD10 code were life-limiting/life-threatening. The final list of 777 4-digit ICD10 codes included any diagnosis that fulfilled those two criteria, and all malignant oncology codes. In the same article, Fraser et al. [42] applied the LLCs List (plus the ICD10 code for palliative care to include persons without a firm diagnosis) to estimate the prevalence of life-limiting conditions amongst children in England. In subsequent work, Fraser and colleagues used the LLCs List (or modified versions, such as examining subsets of the list) to examine detailed trends (by time, age, deprivation, ethnicity) in the prevalence of LLCs amongst children in England [12, 46, 49]. Jarvis & Fraser [47] applied a refined version of the LLCs List to estimate the number children with LLCs in England and Scotland, comparing findings from alternative data sources. In a more recent phase of analysis, Fraser and colleagues [43, 45, 48] have explored in more depth how to capture the complexity of need (e.g., clinical instability, medical complexity) within national estimates (Scotland, Wales) of the prevalence of LLCs amongst children. Drawing on the work by Fraser and colleagues, Ling et al. [58] applied estimates of LLC prevalence from England (based on the LLCs List) to Irish population data to estimate need for CPC in Ireland.

– Multiple definitions

Five applied articles compared alternative definitions of CPC need including the Directory, the LLCs List, and other definitions used in the adult palliative care literature (e.g., rule of thumb type estimates, such as a given % of deaths) [8, 21, 44, 50, 54].

Four of those studies applied alternative population prevalence methods from the literature (some of which captured complexity in terms of symptom prevalence) to local data (e.g., mortality data) to estimate need for palliative care for children, or for adults and children [8, 21, 44, 50]. For example, one article applied both the Directory and the List of LLCs to estimate national prevalence of LLCs in South Korea (categorising the diagnoses according to the CCC classification system).

One study applied alternative estimates of prevalence of need (based on different definitions of CPC need) from the literature to population data to estimate national (Italy) level of CPC need [54]. Most of the prevalence estimates adopted in the study did not take complexity into account (i.e., diagnoses only, or rules-of-thumb), with the exception of one estimate which incorporated estimates of pain prevalence.

– ACT/RCPCH definitions

Four studies quantified CPC need using the ACT/RCPCH groups to guide the definition of need although detailed lists of diagnoses were not provided [30, 40, 51, 52]. For example, Alotaibi et al. [30] estimated CPC need across 6 countries (Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, United Arab Emirates) defining need in terms of life-threatening illness (categorised by ACT/RCPCH groups, but not listed).

– Miscellaneous definitions

One article estimated the proportion of deaths with serious health-related suffering (i.e., from the Lancet Commission [63]) to examine global need for palliative care (adults and children), drawing on a list of diagnoses combined with empirical evidence on physical and psychological suffering for different diseases [28]. Two multi-country studies examined the prevalence of a predefined list of diseases (based on analysis by the WHO for the 2014 version of the Global Atlas) as well as pain prevalence to estimate the CPC need [25, 67].

Five additional studies quantified CPC need using study-specific definitions, or unclear definitions (i.e., detailed lists of inclusion criteria not provided), of CPC need [10, 38, 53, 59, 60]. Lu et al. [10] estimated the number of children in need of end-of life care at a national level (China). Need for end-of-life palliative care was defined in terms of deaths from any medically-related illness with no additional adjustment for complexity of need. Benini et al. [53] examined the proportion of hospitalisations with life-limiting or life-threatening diagnoses amongst children in Italy (drawing on a list of diagnoses developed in an earlier study by the same authors [68]). Jacinto et al. [59] examined the proportion of hospital admissions (adults and children) with 'active life-limiting disease', defined as any disease that is progressive, incurable and likely to be terminal, and thereby designated as appropriate for palliative care referral ([59]: pg.197). Boss et al. [38] examined the proportion of hospital admissions 'chronically critically ill' where children's palliative care could be beneficial, drawing on diagnostic as well as information on prolonged/repeated hospitalisations, technology dependence, and multiorgan dysfunction ([38]: pg.1832). Celiker et al. [60] estimated CPC need within one hospital (Cambodia), defining need in terms of having a chronic, progressive, debilitating, or life-limiting illness drawing on diagnostic and other details on infection and intensive-care use.

– Defining perinatal/neonatal need for palliative care

Perinatal palliative care has been defined as *"[an] approach to health care services that addresses the needs of the fetus [sic] and parents beginning at the time of diagnosis, and extending through the birth, through the death of the infant and, and into the bereavement period"* ([69]: pg.367). Three papers examined and highlighted challenges in applying existing CPC diagnostic lists (e.g., CCCs list, the LLCs List) to the perinatal/neonatal population [33, 34, 56]. A fourth paper established a detailed list of 60 + antenatal/postnatal conditions that would be considered eligible for palliative care, consistent with guidelines set out by the British Association of Perinatal Medicine (BAPM) [11]. A fifth paper described the need for neonatal palliative care in terms of 'neonatal serious illness', defined as carrying a high risk of short term mortality, may involve prognostic uncertainty, and substantially impacts on the patient's and family's life [37].

Data and estimation methods in applied literature

Two broad estimation approaches were identified in the applied articles: an incidence approach, focusing on the proportion or number of deaths with end-of-life care needs, or an approach involving estimation of the prevalence of CPC needs (however defined) over a longer disease trajectory. Measuring prevalence of CPC need requires data on children living with illness such as disease prevalence, hospital admission or other healthcare utilisation data.

The following describes these two approaches as applied in the literature, outlining the methods used and the core data types.

– Incidence of end-of-life care needs & mortality data

Eight studies relied on mortality data to estimate CPC need. Four studies examined the number of children with end-of-life care needs at a national level (China, England, Malaysia, Mexico, Wales) using national mortality data [7, 10, 44], or hospital inpatient data (deaths only) [41, 61]. Sleeman et al [28] used mortality data to estimate the proportion of global deaths (adults and children) with serious health-related suffering. Two studies examined the proportion of neonatal deaths with life-limiting illness using hospital inpatient data (deaths only) [33, 34].

– Prevalence approach & mortality data

Three studies combined disease prevalence data and mortality data from the Institute of Health Metrics and Evaluation (US) to estimate prevalence of CPC need [25, 30, 67].

– Prevalence approach & clinical chart data

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Four studies used clinical chart data to estimate the proportion of hospital inpatients with CPC needs (variously defined). Three out of the four examined CPC needs within one ward/hospital [55, 56, 59], and the fourth retrospectively surveyed chart data to estimate prevalence of CPC needs in one region [52]. Two of these studies supplemented clinical chart data with hospital inpatient administrative data [55, 56].

– Prevalence approach & hospital inpatient data

Six studies examined hospital inpatient administrative data (e.g., demographic details, diagnoses, procedures, length of stay, discharge destination, etc.) to estimate population prevalence of CPC needs [40], or the number/proportion of children in one/multiple hospitals with CPC needs [32, 38, 53, 57, 60]. One of these studies analysed both hospital outpatient and inpatient data to examine CPC needs [40].

– Prevalence approach & linked datasets

Ten studies used linked datasets to quantify CPC need [12, 42, 43, 45–50, 62]. Of these, four studies used linked hospital inpatient and mortality data to quantify national/regional prevalence estimates of CPC need [12, 47, 50, 62], one of which examined alternative data sources and demonstrated that estimating prevalence using death records only underestimates CPC need [47].

Fraser and colleagues linked hospital admission data with geographic and deprivation data to examine national (England) prevalence of CPC need by area and deprivation factors [42, 46, 49]. In three more recent studies of national prevalence of CPC need (Scotland, Wales), Fraser and colleagues linked hospital admission and mortality data with additional data sources (e.g., paediatric intensive care, outpatient, general practice, prescribing data) intending to capture more information about complexity of need [43, 45, 48].

– Prevalence approach & specific research datasets

Six studies used miscellaneous datasets and methods to quantify CPC need [8, 11, 21, 51, 54, 58]. Kim et al. [21] analysed national health insurance claims data, incorporating inpatient, outpatient, and emergency department utilisation, to estimate the national prevalence of life-limiting conditions in South Korea. Harnden et al. [11] examined the National Neonatal Research database to estimate the proportion of neonatal admissions with palliative care needs in England and Wales. A study by TfSL used a minimum dataset from palliative care providers to examine the prevalence of CPC in specific regions [51]. Three studies

applied estimates of CPC prevalence from the literature to population data to estimate national/regional level of CPC need (Ireland, Italy, North Wales) [8, 54, 58].

Discussion

Overview

This rapid scoping review has shown that there is no universal agreement on how CPC need is defined in population-level planning, although there are four key definitions of CPC need that have been commonly applied in quantifying population-level need. To a large extent data availability drives the methods used to estimate population-level CPC need and only a small proportion of articles incorporated measures of complexity of need. The following outlines key lessons from the findings, highlighting important issues to take into account in future work clarifying key concepts and methods when defining and quantifying population-level need for CPC.

Key lessons

No universally agreed definition of CPC need

The findings describe multiple ways of defining population-level CPC need (e.g., broad disease trajectories, lists of life-limiting/life-threatening conditions, lists of complex chronic conditions, serious health-related suffering, active life-limiting disease, chronically critically ill, etc.) highlighting the absence of a universally agreed definition in the literature.

Within policies that focused on CPC only, there was common reference to the ACT/RCPCH disease trajectories [1, 70], although the most recent global standards for CPC (GO-PPaCS [2]) expanded beyond the original four disease groups, adding a fifth relating to perinatal/neonatal conditions. The GO-PPaCS standards also acknowledged the need for greater standardisation in eligibility criteria and highlighted the importance of considering complexity of need. The standards themselves were complex, adopting more than one set of eligibility criteria including the (modified) ACT/RCPCH groups; complex chronic conditions; as well as the 'red flag' criteria developed by Jankovic et al. [9]. Challenges in defining need for CPC were also confirmed in the discussion/review literature, citing the inconsistent and varied use of key terms (life-limiting, life-threatening, life-shortening, etc.) as well as challenges due to ongoing changes in the population of children that could benefit from palliative care. The concentration of work to define and quantify need for CPC in higher income countries is also notable in this review. For example, over half of the applied articles in this review were undertaken in the UK and US. Further consideration is needed of regional variations in palliative care needs, particularly in relation to differing disease profiles observed across low-, middle- and high-income countries [3, 6, 14, 30]. Thus, although consistency in

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defining CPC need is important, future work on defining population-level need for CPC needs to be flexible so as to allow for international variations in epidemiology, demographics and service availability.

Four common definitions of CPC need in applied literature

Despite the overall inconsistency in defining CPC need, the applied work on quantifying CPC need was dominated by a small number of specific definitions. Almost 60% of the applied articles used one of four definitions of CPC need, namely the ACT/RCPCH groups (11%), CCCs (14%), the Directory (11%), and the List of LLCs (24%), and additional articles applied one or more of these definitions where multiple definitions were adopted or compared. Both the Directory and the List of LLCs are conceptually linked with the ACT/RCPCH groups thereby highlighting the prominent place occupied by these disease trajectories in describing the life-limiting/life-threatening conditions considered eligible for CPC. The groups themselves have not changed since they were first published in 1997 [71] but additional groups have been proposed [2, 7, 14]. There is work underway to revise the groups [72] although the focus is on defining need in the clinical setting, in the UK, rather than on population-level planning.

The two most detailed lists, CCCs (> 1000 diagnoses and > 1,600 procedures), and the List of LLCs (777 + diagnoses), together accounted for 38% of the applied articles included in this review. While both were initially developed using mortality data, our results found notable differences in where and how these lists have since been applied (Additional File 1), yet no article included in this review undertook a detailed direct comparison of these two applied definitions of CPC need. Thus, there is scope for further research to compare and contrast these, and other lists (e.g., serious health-related suffering). The proposed analysis could examine the rationale for the application of one list over another or develop a refined/combined list leading to more systematic, internationally comparable methods for defining CPC need.

Data requirements when quantifying CPC need

In the majority of the applied studies, the estimation method was driven by data availability, and 47% of articles cited challenges with data limitations in this field. This is particularly relevant for LMICs where the challenge will be greater in resource-constrained settings. Nearly a third of the applied articles used data on deaths only, which restricted the analytic focus to end-of-life care. This has been acknowledged to be particularly problematic for quantifying palliative care need amongst children (relative to adults), where the trajectory of palliative care needs may extend for several years [50] depending

on the child's condition and circumstances. Relying on mortality data to estimate CPC need risks under-estimating the number of children who could benefit from palliative care [30, 41, 44]. To facilitate proper resourcing, planning and delivery of CPC, analysts need access to population-level data on children living with life-limiting illnesses (however defined) so as to capture needs over the full trajectory of illness and not just at the end of life.

Defining complexity of need – those with and without specified diagnoses

Complexity of need was directly measured in 35% of the applied articles, but with varying degrees of detail. Methods included national estimates of pain or symptom prevalence, small-scale studies of detailed clinical chart data, examination of procedure codes to identify technology dependence (i.e., using the CCCs list), or use of linked datasets including mortality, healthcare utilisation and prescribing data to provide richer information on care needs. Most of these studies focused on examining complexity of needs within a given cohort of children deemed eligible for palliative care based on specified diagnoses. However, fewer studies addressed a second source of complexity, namely the challenge of capturing palliative care eligibility amongst cases where there was no diagnosis, or where the need for palliative care was based not on diagnosis but on a combination of factors such as the care complexity factors as described by Jankovic et al. ([9]: pg.2). Access to richer population-level data on care needs and social and family circumstances (e.g., including parental mental health) is an important challenge for this field to capture both sources of complexity. Future work is needed on conceptualising complexity in children's palliative care and identifying data that can inform those conceptions.

Need for greater alignment between clinical and planning settings

The need for greater alignment in CPC eligibility criteria between the clinical and organisational/planning settings has also been highlighted in the literature [9, 37]. For example, Guttmann et al. noted that having a research/planning definition of CPC need with no relevance to a clinical context is likely to have "very limited utility' ([37]: pg.1659). As highlighted in the scoping review by Carney et al. [15], clinical referral practices are varied and thus greater consistency is needed both within, and between the clinical and organisational/planning settings. Carney et al. [15] noted that disease- and symptom-related criteria were the dominant sources of information used in the majority of clinical referral practices in their rapid scoping review, with less focus on child and family psychosocial and emotional support. At the minimum, future

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work is needed to enhance access to population-level information on symptoms as well as diagnosis to facilitate greater alignment between the two settings.

However, improvements in routine data collection on a wider range of complexity of need factors could greatly assist both individual-level referral practices and population-level planning, and their alignment. As outlined by Noyes et al., data collection for CPC is complicated by the fact that the data need to be of precise and practical use "about service needs that are often subjective and individual" ([8]: pg.2). Thus, it is important for service providers and planners to consider all the evidence, from both individual-level clinical referral practices (as reviewed by Carney et al. [15]), and population-level planning (as reviewed here), on different options for data collection to capture CPC needs.

Level of palliative care not often specified

In more than 50% of the applied articles, it was not clear if the aim was to quantify need for all/some levels of palliative care (i.e., general, specialist, etc.) (see Additional File 1). Greater clarity is needed on the different data requirements for quantifying need for general versus specialist palliative care.

Limitations

This scoping review was restricted to English language articles which limited the size of the review. However, the focus on English gave a reasonable estimate of the scope of the literature in this field particularly given that the UK was one of the first places to develop CPC as a distinct specialty [21, 22]. A protocol for a scoping review focusing on use of administrative data to quantify CPC need in several non-English articles could further supplement the findings in this review [73].

In reviewing the full texts, three types of articles were identified, namely those that directly addressed the scoping review questions on defining or quantifying population-level need for children's palliative care, articles where a definition of need could be indirectly deduced from the content (e.g., analysis of a sample of patients considered eligible for children's palliative care) ($n=7$) [74–80], and articles which analysed characteristics of patient samples already in receipt of children's palliative care ($n=3$) [81–83]. While we only included the first type of papers in this review, the latter two types of papers could also be examined for insight into how need for children's palliative care is defined in the general literature.

The quality of articles was not assessed, as is typical for a scoping review. While details on setting, variables, data and estimation methods could be reported for most of the articles in this review, there were some for which the definitions, data, and/or methods were unclear. Future reviews in this field could examine more closely the quality of the methods used to quantify need for CPC.

Conclusions

This review scoped 51 articles including international policies and standards, discussion/review articles, and applied literature to examine how population-level need for CPC is defined and quantified. Overall, greater consistency in how CPC need is defined in population-level planning is important, but with sufficient flexibility to allow for regional variations in epidemiology, demographics, and service availability. Improvements in routine data collection of a wide range of care complexity factors could facilitate estimation of population-level CPC need and ensure greater alignment with how need for CPC is defined at the individual-level in the clinical setting.

Abbreviations

CPC	Children's Palliative Care
LLCs	Life-Limiting Conditions
CCCs	Complex Chronic Conditions
ACT/ RCPCH	Association for Children with Life-threatening or Terminal Conditions and their Families, and the Royal College of Paediatrics and Child Health
TfSL	Together for Short Lives
WHO	World Health Organization

Supplementary Information

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> Supplementary Material 1.

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