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Defining "early palliative care" for adults diagnosed with a life-limiting illness: a scoping review

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Abstract

Background Palliative care is for people suffering from life-limiting illnesses that focuses on providing relief from symptoms and stress of illness. Previous studies have demonstrated that specialist palliative care consultation delivered earlier in the disease process can enhance patients' quality of life, reduce their symptom burden, reduce use of hospital-based acute care services and extend their survival. However, various definitions exist for the term early palliative care (EPC).

Objective To investigate how EPC has been defined in the literature for adults with life- limiting illnesses.

Methods This review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) extension for Scoping Reviews guidelines and follows the Joanna Briggs Institution methodology for scoping reviews. The literature search was conducted using MEDLINE (Ovid), CINAHL (EBSCO), Embase (Ovid), PsycINFO (Ovid), Web of Science Core Collection, Ovid Cochrane Library, and ProQuest (Health and Medicine and Sociology Collections). All articles retrieved were screened by three independent reviewers.

Results 153 articles met the inclusion criteria between 2008 and 2024. Five categories of definitions for EPC were created to organize definitions: (1) time-based (e.g. time from advanced cancer diagnosis to EPC initiation); (2) prognosis-based (e.g. prognosis or the 'surprise question'); (3) location-based (e.g. access point within the healthcare system such as outpatient setting); (4) treatment-based (e.g. physician's judgement or prior to specific therapies); and (5) symptom-based (e.g. using symptom intensity questionnaires). Many studies included patients with cancer ($n=103$), with the most common definition category being time-based ($n=53$). Amongst studies focusing on multiple or non-cancer diagnoses ($n=50$), the most common definition category was symptom-based ($n=16$).

Conclusion Our findings provide a useful reference point for those seeking to understand the scope and breadth of existing EPC definitions in cancer and non-cancer illnesses and contemplate their application within clinical practice.

Keywords Early palliative care, Life-limiting illness, Cancer, Chronic illness, scoping review.

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Background

Modern palliative care is an approach to care for people suffering from life-limiting illnesses that focuses on improving quality of life through the prevention and relief of physical, psychosocial and spiritual suffering through early identification, thorough assessment and symptom-focused treatment [1]. Previous randomized control trials in the cancer population have demonstrated that specialist palliative care consultation delivered earlier in the disease process can enhance patients' health-related quality of life and reduce symptom intensity [2], improve mood, decrease use of hospital-based acute care services at the end of life and extend their survival [3]. The World Heath Organization recognizes early palliative care as an effective method to reduce unnecessary hospital admissions and the use of health services. However, they state there is still a global need to for adequate national policies, programmes, resources, and training within the palliative care community [4].

The concept of early palliative care (EPC) gained momentum after Temel and colleagues conducted a prospective randomized controlled trial (RCT) of patients ($n = 151$) with non-small-cell lung cancer who received either early specialist palliative care consultation (within 8 weeks of diagnosis of advanced cancer, integrated with standard oncologic care), or standard oncologic care alone with referral to palliative care as needed in the ambulatory care setting [3]. Patients receiving EPC met with a member of the palliative team (board-certified palliative care physicians or advanced-practice nurse) within three weeks of enrollment. Patients were then seen monthly until death with the option of additional visits if needed. During these visits, patients physical and psychosocial symptoms were carefully assessed and time was spent establishing goals of care. Patients who received EPC reported better quality of life, fewer depressive symptoms, received fewer aggressive end-of-life interventions, and actually lived longer. This trial was the first to conduct a systematic identification of appropriate patients for EPC while incorporating patient reported outcomes.

Subsequent trials have reported varying success replicating Temel et al.'s (2010) findings. Haun and colleagues conducted a systematic review of seven randomised and cluster-randomised controlled trials ($n = 1\ 614$ participants) to compare effects of EPC interventions (delivered by specialist palliative care teams) versus standard oncology care on health-related quality of life, depression, symptom burden and survival among adults diagnosed with advanced cancer [2]. They found that compared with standard cancer care alone, patients exposed to EPC has significantly improved health-related quality of life (SMD 0.27, 95% confidence interval (CI) 0.15 to 0.38) than among control participants. There were no differences in survival, depressive symptoms and a small effect was noted for lower symptom intensity in the EPC group compared with the control group (SMD − 0.23, 95% CI -0.35 to -0.10). The authors speculated that inconsistencies in EPC definitions used, varying implementation practices, and differing needs within different patient populations were a contributor to non-significant results [2].

Many people suffering from non-cancer chronic illnesses such as heart failure, liver failure, dementia, chronic obstructive pulmonary disease (COPD), and human immunodeficiency virus (HIV) also experience similar health-related physical, psychological, social and existential suffering but there are limited studies examining the efficacy of specialist EPC consultation in these groups [5–9]. This may be due to variable illness trajectories within and between people with these chronic life-limiting illnesses [10].

Since EPC is an emerging concept of interest, further concept clarification is needed to allow for study replication, solidification of the evidence base and enhanced clinical care. Studies examining EPC have used varying definitions and there is limited consistency between them. While palliative care can be provided at any time during the illness trajectory, from diagnosis to death and simultaneously with curative or disease-focused treatments, what is considered to be the most advantageous disease-specific timing, setting and/or transition points in the illness for the delivery of EPC is still under much debate [11]. This has caused challenges in implementing EPC in routine practice, despite best practice recommendations to implement palliative care earlier in not only cancer but other diseases including heart failure, and respiratory diseases [12–14]. The purpose of this review is to investigate how EPC has been defined in the literature for adults with life-limiting illnesses. The question has been designed to be broad and examine a variety of operational and conceptual definitions to better understand the concept of EPC.

Review question

How is early palliative care (EPC) defined for adults diagnosed with a life-limiting illness?

Methods

This scoping review was follows the JBI methodology for scoping reviews and is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews (PRISMAScR) guideline [15, 16]. For additional details on methods, search strategy and data extraction techniques please refer to our published study protocol [17, 18].

Search strategy

All articles that provided a novel EPC intervention or examined EPC in a different patient population among adult participants (aged 18 years and over), diagnosed with a life-limiting illness were examined for inclusion in this review. We considered a definition as novel if it introduced new concepts, components, or approaches to early palliative care that were not previously identified in the existing literature. This could include innovative aspects such as unique criteria for patient inclusion, new timing or triggers for initiating care, distinctive interdisciplinary team roles or patient populations. Articles that discussed, or made a suggestion on when EPC should be initiated (whether quite broad such as at the time of diagnosis [19]) or much more detailed (such as stage III/IV cancer with significant symptom burden identified using a standardized questionnaire like the Edmonton Symptom Assessment Scale [20]) were considered an EPC definition and included in this review. Literature from all countries and healthcare settings were included if published in English. A three-step search strategy was used: initial search, reference list screening and grey literature search. The literature search strategy was developed in collaboration with a librarian scientist (ARW) and designed to locate both published studies and grey literature using Ovid MedLine, CINAHL (Ebsco), Ovid Embase, Ovid PsycInfo, Web of Science Core Collection, Ovid Cochrane Library, and Proquest Dissertations. The original search identified articles between database inception (1946) to April 28, 2020, and an updated search was completed on January 16th, 2024. A separate grey literature search was completed using ProQuest, CADTH, Google, and SUMSearch. Please see appendix 1 for exact wording and search strategy. Studies that are reviews of original studies, conference proceedings, opinion pieces, and those that cite definitions from other published sources were excluded.

Study/Source of evidence selection

Titles and abstracts were uploaded into Covidence© software, duplicates removed, and then screened by three independent reviewers to assess eligibility based on above inclusion criteria.

Data extraction

Data was extracted for key study characteristics by three independent reviewers using a modified template for scoping reviews [16]. Study title, authors, journal, volume, issue, and pages were exported from Covidence into an excel worksheet and additional data was manually added based on the objectives of the scoping review. Additional data included: study design, study population (primary life-limiting illness studied), inclusion criteria for EPC intervention, how authors describe or define EPC, and implementation strategies for EPC. An iterative process was used, including a pilot phase (data from 10 studies were extracted and assessed for congruency between investigators) [21]. Once congruency was established, remaining articles were extracted by three independent reviewers (CK, EM, JF). Discrepancies between reviewers were resolved through discussion and consensus. Results were collated, then uploaded into EndNote X7 (Clarivate Analytics, PA, USA). Methodological quality of studies was not appraised.

Synthesis of results

Studies were grouped by the type of disease studied, a summarized description of the study design, and EPC category. Additional information included the number of participants, mean age, and percentage of male participants. During data analysis themes in the extracted definitions were identified based on intervention approaches and principles of practice. Common elements were identified and used to group definitions into categories. We then summarized the frequency and distribution of categories, compared definitions across studies, identifying variations and commonalities and analyzed trends over time. Themes that emerged in definitions included: (1) time-based (e.g. time from advanced cancer diagnosis to EPC initiation); (2) prognosis-based (e.g. prognosis or the 'surprise question'); (3) location-based (e.g. access point within the healthcare system such as outpatient setting); (4) treatment-based (e.g. physician's judgement or prior to specific therapies); and (5) symptom-based (e.g. using symptom intensity questionnaires such as the Edmonton Symptom Assessment Scale (ESAS)).

Results

A total of 1 620 titles and abstracts were identified and additional 18 articles were identified through citation searching and grey literature search. After duplicates were removed, 1 149 articles remained and were screened by title and abstract. Of these, 562 were sought for retrieval, 528 full texts were reviewed for relevance and153 studies met the inclusion criteria and were included for narrative analysis. Please refer to Fig. 1 for PRISMA flow diagram.

Characteristics of included studies

Included studies were grouped based on year of publication, country (based on lead author), design, disease(s) studied (i.e. type of cancer, multiple diagnoses and non-cancer illnesses) and definition category. For full study characteristics table see Appendix 2. Studies that examined EPC in more than one primary life limiting illness were considered 'multiple diseases' (e.g., Cancer and/or Dementia and/or COPD and/or Sepsis) [22].

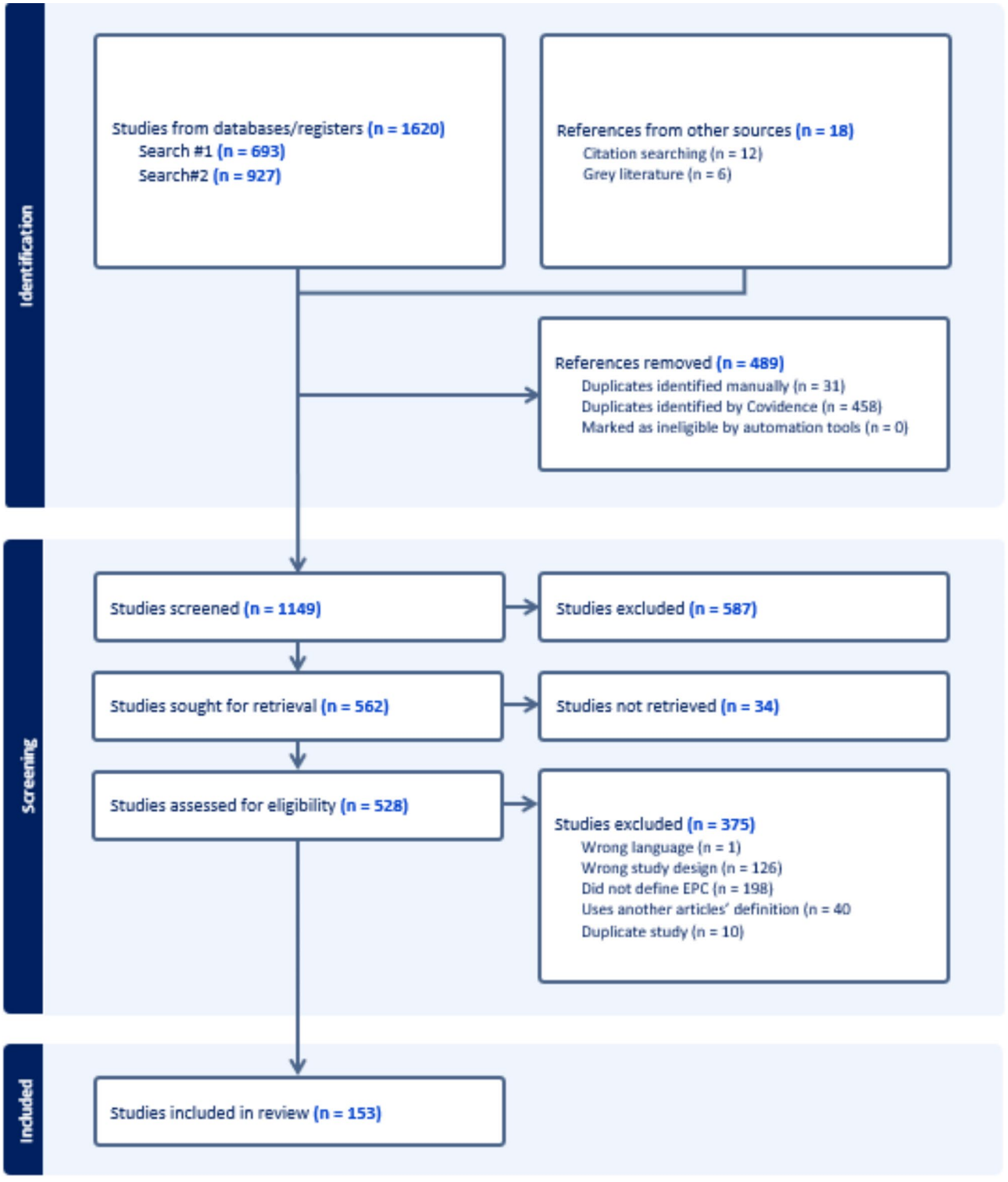

Fig. 1 PRISMA flow chart for identified records

Studies were grouped into categories that emerged from EPC criteria used to describe EPC which included: (1) time-based; (2) prognosis-based; (3) location-based; (4) treatment-based; (5) symptom-based. See Appendix 3 for a comprehensive list of definitions, organized by disease and definition category. Although some definitions had elements from multiple categories, a primary theme was selected for each definition based on which criteria

was stated first or had more prominence; for example, where EPC was defined as specialist palliative interventions after being admitted to acute care with advanced stage of disease with first palliative care consult occurring within three days [22, 23], this could be considered time or location-based but was sorted into location-based category.

One hundred and three of the included studies examined EPC in cancer populations. Table 1 provides a visual depiction of types of primary cancers studied and definition category assigned to each study based on criteria most stressed within the definition ($n = 103$).

EPC definitions in Cancer

Time-based definitions (Cancer)

Most EPC operational definitions described among patients with cancer were time-based (e.g. time from advanced cancer diagnosis to EPC initiation, $n = 38$ or timing of EPC initiation before death, $n = 11$). Most of these definitions align with and often cite the seminal article published by Temel et al. (2010). In these studies ($n = 17$) patients were enrolled if diagnosed with advanced cancer within the previous 6–8 weeks; some required an Eastern Cooperative Oncology Group (ECOG) performance status of 0, 1, or 2 [3, 12, 24–38]. More recently authors looked at timing of EPC within six weeks of initiation of palliative systemic treatment [39]. The remaining studies and guidelines either broadly stated that EPC should be initiated at the time of diagnosis of an advanced or incurable cancer or recommended that it be initiated within specific timeframes: from 2 weeks to one year after diagnosis ($n = 21$) [40–60]. EPC interventions varied between unstructured needs-based care to standardized EPC consultations. Retrospective studies described EPC as specialist palliative care initiated within a certain timeframe such as more than three months before death [61–66], or 6–12 months before death [67].

Table 1 Frequencies of EPC categories used in cancer populations

Primary Cancer	Disease based	Location based	Symptom based	Time based	Treatment based
Gastrointestinal				2	
Genitourinary	1				
Gynecological				1	
Glioblastoma			1	1	
Mesothelioma				1	
Breast				1	1
Head & Neck		1		1	1
Hematologic	2		3	3	2
Lung	3	2	1	10	
Lymphoma				1	
Mixed primary	12	6	7	30	2
Myeloma			1		
Ovarian		1			
Pancreatic	1			2	
Penile	1				
Solid Tumour					1
Grand Total	**20**	**10**	**13**	**53**	**7**

Prognosis-based definitions (Cancer)

In 18 studies, prognosis-based indicators were used to distinguish EPC initiation among cancer patients. Seven studies used staging criteria (stages III/IV) to identify patients eligible to receive EPC services [19, 68–73]. Four authors used prognosis of 6–24 months, as determined by the physician, as the operational definition of appropriateness for EPC initiation [74–77]. Tanzi and colleagues (2020) initiated EPC in patients with a prognosis of greater than one month once patients were on their last active treatment. In four articles, the 'surprise question' (would the physician be surprised if this patient dies in the next year?) was used to determine appropriateness for EPC intervention [78–81] New models using large datasets to estimate overall survival have recently been suggested with an EPC consultation being considered for those with an overall survival estimated to be 6–12 months [82, 83].

Location-based definitions (Cancer)

Five studies considered EPC as care delivered in outpatient or homecare settings, the rationale for this was that outpatient care is generally provided earlier in the disease process, before the onset of overly burdensome symptoms [84–88]. In five articles, authors examined specialist palliative care consultation within the hospital setting for advanced cancer patients, where initiation of palliative services with 2–3 days of admission to an acute care hospital was considered EPC [89–93].

Treatment-based definitions (Cancer)

Treatment-based criteria used to define the initiation of EPC was less common. In two studies, authors used physician's judgment to determine when to initiate EPC after providing education to enhance awareness and optimize their referral-based practices. Greater awareness led to increased consults [94, 95]. Five authors defined EPC as care initiated prior to a definitive therapy such as a hematopoietic stem cell transplant or palliative intent first-line chemotherapy [96–100].

Symptom-based definitions (Cancer)

In 13 articles, authors used symptom-based indicators to define initiation of EPC; five of which described EPC interventions after patients exhibited disease or treatment related symptoms or felt distress [20, 101–104]; symptoms were assessed using routinely collected

likert-type scales to assess severity of symptoms. (e.g. ESAS) [101]. In the remaining eight articles, authors described trigger-based criteria for EPC initiation which combined an increased symptom burden, measured by specific questionnaires (e.g. The European Organization for Research and Treatment of Cancer quality of life questionnaire [EORTC QLQ-C30]) and/or increased tertiary services such as frequent emergency department visits combined with advanced disease stage (such as stage III/IV cancer) [105–112].

EPC definitions used for studying multiple diagnoses and Non-cancer diseases

Twenty-three of the included studies examined EPC interventions among patients with multiple diagnoses. Multiple diagnoses include studies that discuss the initiation of EPC among those with one or more of the following diseases: cancer, heart failure, respiratory diseases, sepsis, frailty, organ failure and neurodegenerative diseases. Some authors used specific criteria for each disease such as advanced disease stage (e.g. heart failure with a score of 2–4 using the New York Heart Association (NYHA) Functional Classification, or a score of 1–4 on the Global Initiative for Chronic Obstructive Lung Disease Scale (GOLD)) [9]. In other cases, authors did not differentiate between diseases but used other criteria to define initiation of EPC such as palliative care delivered more than 60 days before death [113]. Table 2 provides frequencies of types of diseases studied when multiple diseases were examined as well as other non-cancer diseases using a single EPC intervention ($n = 50$).

Time/location-based definitions (multiple diagnoses)

In four retrospective studies, authors defined EPC as initiation within a specific time frame before death; for example, EPC was considered specialist consultation more than three months before death [113–116]. Six authors defined EPC as specialist palliative intervention initiated within 24–78 h of being admitted to an acute care hospital for: advanced stage of cancer, dementia, cardiovascular, COPD, sepsis or other diseases [22, 117]; frailty [23]; heart failure, cirrhosis, COPD, cardiovascular, frailty, dementia, renal, HIV, or cancer patients [118]; and ICU patients [119, 120].

Table 2 Frequencies of EPC categories used in multiple diagnoses and non-cancer diseases

Primary Illness	Disease based	Location based	Symptom based	Time based	Treatment based
COPD	2		3	1	
Dementia			1		
End-Stage Liver Disease	1			1	1
Heart Failure	2		3		
HIV	2	1		1	
Organ transplant patients					2
Trauma patients		1			
Multiple/Mixed	3	6	9	5	
Respiratory			1	2	
Sepsis		1			
Stroke		1			
Grand Total	**10**	**10**	**17**	**10**	**3**

Prognosis-based definitions (multiple diagnoses)

Beernaert et al. (2016) explored EPC needs in cancer, COPD, heart failure and dementia patients separately using standardized tools to identify disease stage and need for EPC. For example, authors used the NYHA Functional Classification for heart failure and considered patients with a score of 2–4 [9]. While other authors used a prognosis of less than a year among cancer, heart failure, COPD, neurodegenerative and other life-limiting illnesses to initiate EPC [121, 122].

Symptom-based definitions (multiple diagnoses)

Six articles used trigger-based criteria; four of which considered EPC for inpatients. In three articles, authors examined EPC in ICU patients with triggers including advanced disease stages (e.g. stage IV cancer, multi-organ failure, class III or IV heart failure), tertiary service use (e.g. >1 hospital or ICU admission within three months), and failure to thrive (e.g. prolonged mechanical ventilation) [123–125], in the remaining article, authors developed and tested a trigger based pathway in the ED [126]. Similarly, a tool was developed for primary care physicians to initiate EPC in heart failure, COPD, and cancer patients using advanced disease stage, tertiary service use, and worsening symptoms [127]. Gomez-Batiste et al. (2017) created a standardized tool to identify patients with multiple chronic conditions in need of palliative care services using a tool called the NECesidades Paliativas (NECPAL). It uses prognosis (i.e. the surprise question), symptoms (refractory symptoms using the ESAS), and disease stage e.g. NYHA stage III or IV heart failure, or renal failure with a GFR < 15 to trigger initiation of EPC [128]. Johnston et al. (2018) completed a mixed methods study looking to evaluate a home care palliative care model with an early palliative referral before burdening symptoms for cancer, cardiac, respiratory, dementia/frailty, neurologic and other conditions [129]. Chidiac et al. (2018) completed a review highlighting the various definitions and defined EPC as, "specialist palliative care interventions delivered earlier in the course of illness and before the onset of burdening symptoms, using an integrated model of care" [130 p.231].

EPC in other non-cancer diseases

In the remaining 27 studies, authors examined EPC initiation in single, non-cancer diseases including: heart

failure ($n=5$), HIV ($n=4$), COPD ($n=6$), respiratory disease ($n=3$), liver disease ($n=3$), organ transplantation ($n=2$), dementia ($n=1$), trauma ($n=1$), stroke ($n=1$), and septic patients ($n=1$).

Time/location-based definitions (non-cancer diseases)

Time-based definitions were less common in non-cancer diseases. Barnes et al. (2019) defined EPC as specialist palliative care services initiated 30 days prior to death among patients with end-stage liver disease [131]. Lindell et al. (2018, 2021) recommended EPC at the time of diagnosis of interstitial pulmonary fibrosis while Iyer et al. (2019) suggested a broader definition of EPC which integrated planning, emotional, spiritual and social support along with chronic disease management at the time of diagnosis of COPD [132, 133]. Three authors focused on EPC initiation for inpatient units with EPC being delivered within a specified timeframe of admission (1–4 days) in trauma [134], Stroke [135], and Septic [136] patients. For those with HIV, time-based initiation of EPC was discussed in two articles [8, 137], and in one article the emphasis was place solely on location, where EPC was defined as palliative care initiated to HIV patients in the outpatient setting [138].

Prognosis-based definitions (non-cancer diseases)

A large portion ($n=8$) of definitions in non-cancer diseases are prognosis-based and use advanced disease stage as their primary criteria for EPC. Within the HIV population, one author suggested that EPC should be defined by clinical criteria, specifically a CD4 T-cell in the 300–400 cells/mL [139]. Webel and colleagues (2019) defined EPC as care initiated early in the disease trajectory for HIV patients [8]. When examining the role of EPC among patients with COPD, authors based their definition on advanced disease stage (stage III or IV based on the GOLD criteria) [5, 140]. Similarly, among people with heart failure, disease stage was the operational definition for when EPC should be initiated (AHA Stage C/D or NYHA Class III/IV) [141, 142]. The surprise question was used as a prognostic indicator and primary criteria for EPC among patients with end-stage liver disease [143].

Treatment-based definitions (non-cancer diseases)

All treatment-based definitions were related to rescue therapies, specifically palliative care that is delivered pre-organ transplant (for liver, lung, and heart transplant patients) [6, 144, 145].

Symptom-based definitions (non-cancer diseases)

Most studies examining EPC in non-cancer populations used symptom-based definitions compared to cancer populations (34% vs. 13%). In one study, authors examined EPC in patients with dementia using a trigger-based tool called the Gold Standard Framework Proactive Identification Guidance tool which combines the surprise question, client choice and need, with clinical indicators such as advanced disease stage and decreased function [146]. Similarly in the COPD population, authors used a trigger-based method which included advanced disease stage (GOLD III or IV) plus one or more of the following clinical indicators: oxygen dependence, frequent hospitalization, refractory dyspnea, recent intubation, and/or recent weight loss [147, 148].

Other articles used advanced disease with the presence of disease or treatment related symptoms which aligns with the American Thoracic society guidelines for palliative care for patients with respiratory diseases as early as diagnosis if disease or treatment related symptoms are present [14, 149, 150]. This definition was also found within the heart failure population [13, 151, 152].

Discussion

In this scoping review we synthesized existing operational and conceptual definitions of the term EPC among studies of adults with all cancer and non-cancer life-limiting illnesses. Our findings build upon previous work by creating a repository of available definitions for cancer and non-cancer illnesses and identify key differences between patient populations. It is evident that investigation of EPC increased after 2014. With number of publications rising from 1 to 5 per year to 10–20. EPC was first primarily discussed in relation to patients with cancer, with 18 studies being published between 2008 and 2014 and then expanded, incorporating more mixed and non-cancers populations between 2015 and 2023. See Fig. 2 for a breakdown of when studies were published by diseases studied.

Definitions have also evolved over time: from prognosis-based (e.g., using the surprise question to estimate prognosis within the year), to timing-based from advanced diagnosis to EPC and more recently needs- or symptom-based (particularly in the non-cancer population). It is also evident that many studies based their definition of EPC on the landmark randomized control trial by Temel and colleagues (2010) which was considered time-based as the emphasis was placed on initiation of EPC within 8 weeks of diagnosis of metastatic lung cancer which many studies chose to replicate. However, this study also had elements of location and symptom-based definitions as they initiated EPC in an out-patient clinic in ambulatory patients. This highlights the complexity of reaching consensus with this term. Other studies have attempted to replicate the effectiveness of this EPC intervention using different elements of this primary definition, with varied success, indicating a need for clearer understanding of what constitutes EPC. In non-cancer

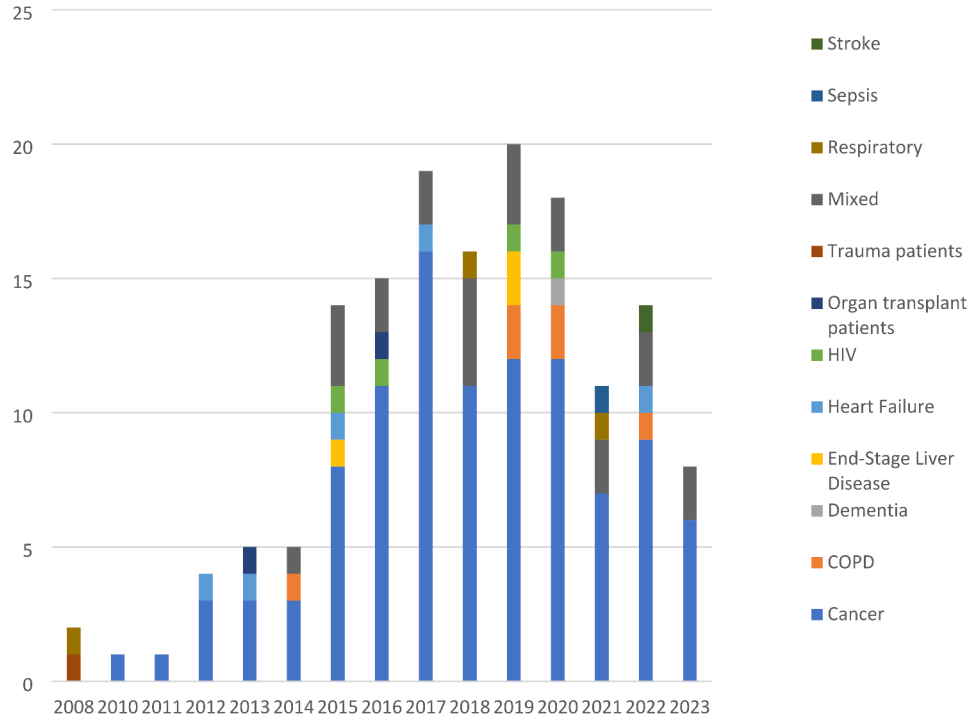

Fig. 2 Number of reports published by year and disease

diseases, most definitions are based on advanced disease stage or a symptom and/or trigger-based tool without a specific time window in which EPC should be initiated. Based on number of articles published with similar definitions in the cancer population there is more consensus and clarity surrounding definitions of EPC in people with cancer versus non-cancer diagnoses. This may be related to cancers more predictable illness trajectory which uses staging of disease and expected survival [10]. More clarity is needed when determining what constitutes EPC in non-cancer populations.

As with many innovative models, barriers exist that must still be overcome before EPC is broadly accepted and implemented. These barriers include ongoing stigma and lack of resources. The term palliative care still holds negative connotations for patients, family members, and physicians alike [153]. This often directly effects referral practices and physicians have reported feeling apprehensive to refer a patient to palliative care and due to fear of overwhelming the patient, not wanting to abandon them, or seeing a palliative care referral as an admission of failure [154]. For those who have overcome the stigma and have attempted to adopt earlier referral practices, they are faced with further road-blocks due to lack of resources and availability of palliative care practitioners [155]. Availability of resources can often be a rate-limiting step in healthcare which is why it is so crucial to understand the key elements and processes of EPC that derive the most benefits for patients. Reaching a consensus and how EPC should be defined is an important step in streamlining this process.

While there is sound clinical evidence to introduce palliative care earlier, inconsistencies in how palliative care is defined and standards for reporting palliative care are still cited as significant limitations to EPC delivery [156]. These differences are highlighted within this scoping review, particularly when we delve into the many different ways EPC is being defined. While several authors examined EPC in outpatient ambulatory clinics, others studied more acute areas including Intensive Care Units (ICU). This is presents unique challenges when examining interventions and outcomes as ICU patients have significant differences in their illness trajectory compared to those living in the community.

Ideally, this field will move towards creating consensus-based, practice-focused definitions of EPC which will incorporate details from each definition category (time, prognosis, location, treatment and symptom-based information) for specific life-limiting illnesses. However, in the short-term, we urge those investigating and delivering EPC to provide specific contextual information about timing of their EPC intervention, location of where it was delivered, prognosis for the patient, symptom level and treatment plan in their protocols. This will advance scientific investigation of the concept by improving accuracy and clarity, build palliative care research capacity through improved data standardization and outcomes assessment and allow for future national and international

comparisons providing more standardized implementation approaches enabling broader access. With clearer EPC definitions for specific life-limiting illnesses, we will also be able to investigate disparities in access to EPC among equity deserving groups.

Future research could engage practice experts in a consensus process with palliative care specialists, internal medicine experts, nurses, health care decision makers, patients, and family members [157]. This will require clinicians to consider whether existing definitions align with their current practices and may be appropriate for their population of interest. As this field expands, there is a need to incorporate opinions and expertise from clinicians familiar with various disease trajectories and incorporate their knowledge.

Limitations

This review presents an overview of the definitions of EPC currently found in academic and grey literature. The authors acknowledge that an alternate term for EPC, supportive care, has gained popularity in the literature in recent years to minimize the stigma surrounding its end-of-life component. Based on our selected search strategy, we do not believe this will impact our results. This study also did not investigate the duration or dose of EPC exposure or how definitions align with models of care delivery. An *integrated care model*, where oncologists refer patients to specialist palliative care teams early in the disease trajectory seems to be preferred when initiating EPC. Davis et al. (2015) identified that despite variations in definitions of how and when EPC is delivered, for patients to realize the benefits, EPC should include a multidisciplinary team with the patient receiving these services for at least 3–4 months, indicating that duration of care is important when considering EPC [158]. To ensure broad inclusion of studies, no assessment of validity or reliability was used in assessment of included articles. In addition, our search was limited to definitions used in adults, definitions for the pediatric population may differ. Finally, studies exploring EPC in other languages were not identified since only studies published in English and within a specific timeframe were captured. This limits the international scope of our findings.

Conclusion

Significant variation between definitions used for EPC are illustrated in this review. The review identifies key elements of EPC definitions that will aid future scientific investigation of the concept, help optimize uptake by clearly defining referral criteria, and assist clinical decision makers to advocate for broader access and more standardized implementation. Our findings provide a useful reference point for those seeking to understand the scope and breadth of existing EPC definitions in cancer and non-cancer illnesses and contemplate their application to future research and clinical practice.

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

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A.R.W. completed the literature search. C.K., J.F., and E.M. screened, selected, and extracted data from articles for review. C.K. and C.L.G. wrote the main manuscript text. C.K., A.R.W., E.M., C.L.G., T.H., J.T., C.E.G. reviewed and provided edits to the manuscript.

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Data availability
Not applicable.

Declarations

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Not required.

Consent for publication
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Competing interests
The authors of this scoping review report they have no conflicts of interest to declare.

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