

**Identifying core domains to assess the ‘quality of death’:
A scoping review**

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Figure 1: PRISM flow diagram of scoping review results

Table 1: Number of articles included in the review by study characteristic

Figure 2: Overview of domains identified through scoping review

Table 2: List of identified domains and sub-domains

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Abstract

Context: There is growing recognition of the value to patients, families, society, and health systems in providing healthcare, including end-of-life care, that is consistent with both patient preferences and clinical guidelines.

Objectives: Identify the core domains and subdomains that can be used to evaluate the performance of end-of-life care within and across health systems.

Methods: PubMed/MEDLINE (NCBI), PsycINFO (ProQuest), and CINAHL (EBSCO) databases were searched for peer-reviewed journal articles published prior to February 22, 2020. The SPIDER tool was used to determine search terms. *A priori* criteria were followed with independent review to identify relevant articles.

Results: 309 eligible articles were identified out of 2728 discrete results. The articles represent perspectives from the broader health system (11), patients (70), family and informal caregivers (65), healthcare professionals (43), multiple viewpoints (110), and others (10). The most common condition of focus was cancer (103) and the majority (245) of the studies concentrated on high-income country contexts. The review identified 5 domains and 11 sub-domains focused on structural factors relevant to end-of-life care at the broader health system level, and 2 domains and 22 sub-domains focused on experiential aspects of end-of-life care from the patient and family perspectives. The structural health system domains were: 1) stewardship and governance, 2) resource generation, 3) financing and financial protection, 4) service provision, and 5) access to care. The experiential domains were: 1) quality of care, and 2) quality of communication.

Conclusion: The review affirms the need for a people-centered approach to managing the delicate process and period of accepting and preparing for the end of life. The identified structural and experiential factors pertinent to the ‘quality of death’ will prove invaluable for future efforts aimed to quantify health system performance in the end-of-life period.

Key Message

End-of-life care is a core component of universal health coverage, and quality end-of-life care is a valued health goal of patients and families. Efforts to improve health system performance must incorporate relevant indicators to track and compare progress across systems and over time.

Key words: *end-of-life care; quality of care; universal health coverage; serious health-related suffering; palliative care*

1. Introduction

The end-of-life (EoL) period – the timeframe after diagnosis of a life-limiting illness and “preceding an individual’s natural death from a process that is unlikely to be arrested by medical care”¹ through bereavement – is a critical, but often overlooked, component of the care continuum. During this period, commonly the last 6-12 months of life,¹ avoidable suffering often occurs; in 2015, an estimated 25.5 million people experienced serious health-related suffering at the EoL.^{2,3} Yet, this is only one area of concern of current end of life care. Through appropriate access to quality end-of-life care (EoLC), a recognized component of universal health coverage, many other concerns could largely be eliminated.²⁻⁴

People-centered care, a cornerstone of high-quality health systems and of efforts to secure universal health coverage globally, is premised on meeting individual patient needs and those of informal caregivers (referred henceforth as caregivers) across the life course.⁵⁻⁷ A ‘good death’, to the extent that such a concept exists, could be defined as one where efforts are made to achieve what patients and caregivers’ value at EoL. Eliciting these preferences and documenting the core domains associated with a ‘good death’ is thus tantamount to ensuring a high-quality EoL experience.

Prior literature reviews, including systematic reviews and meta-analyses, have examined key components of the ‘quality of death’.⁸⁻¹² However, previous reviews have not explicitly focused on comprehensively identifying domains of ‘quality of death’ important to multiple stakeholders such as caregivers, community members, healthcare providers, and the broader health system. Further, there has been a lack of attention given to issues that are important across stakeholders and which are critical to improving health system performance on EoLC. That is the focus of this review. The review is guided by the three most cited dimensions of health system performance – accessibility, affordability, and quality.^{13,14} Quality is broadly defined to include foundations, processes, and outcomes of care.^{6,7,15,16} The focus of the review is to identify factors that can be influenced by the health system to improve the ‘quality of death’. Thus, our review was limited to those databases and articles where such information is most likely to be published. This contrasts with the larger societal perspective which would require a broader interdisciplinary query from fields such as sociology, anthropology, and others and that could include a much broader set of domains.

This review serves as the first step toward producing the Quality of Death and Dying Index 2021, a composite metric to assess health system performance on EoLC across countries, and in informing development of relevant indicators. Future studies can similarly identify relevant indicators within and across these domains and weigh their importance to patients and caregivers overall and for specific subpopulations of interest (e.g., women, minoritized communities) to comprehensively evaluate EoL health system performance from a person-centered perspective. The findings of this review are equally relevant during public health emergencies, as is currently occurring with the COVID-19 pandemic, when access to and quality of EoLC can quickly diminish in the absence of explicit prioritization by health systems.¹⁷

2. Methods

A scoping review was conducted to systematically map and synthesize knowledge within the exploratory area of ‘quality of death’ and to identify core concepts, evidence types, and related gaps within this area using a health systems lens.¹⁸ As compared to systematic and integrative reviews, the purpose of this review was not to examine experimental studies to evaluate their effectiveness nor to develop a theory or hypotheses based on review of experimental and non-

experimental studies,¹⁹ but to provide a narrative synthesis of core issues within the broader scope of EoLC.

Prior to conducting this review PROSPERO and the Cochrane Library of Systematic Reviews were searched, and an informal PubMed search was performed to ensure that this scoping review did not duplicate prior efforts. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) was referenced in the protocol (WebAppendix 1, pg. 2-9) to ensure that the suggested reporting items were included with the corresponding checklist (WebAppendix 2, pg. 10-12).^{20,21} The definition of EoLC applied in the review draws from the existing consensus-based definition of palliative care.²²

2.1 Search strategy and selection criteria

The SPIDER tool, used in reviews of qualitative and mixed methods research studies as a framework to organize and conduct concept mapping of the review question,²³ was applied to identify relevant search terms (WebAppendix 1, pg. 3-5). The SPIDER tool was selected for its greater specificity than the alternate PICO tool, developed for quantitative reviews.²³ Peer-reviewed articles indexed in three databases – PubMed/MEDLINE (NCBI), PsycINFO (ProQuest) and CINAHL (EBSCO) – were searched as these serve as repositories of a wide range of literature covering biomedical and life sciences, behavioral science and mental health, as well as related content from the nursing and allied health professions. The review did not have any restrictions on date, geography, or age group but was limited to peer-reviewed journal articles available in full text and published in English. The search was implemented on February 22, 2020.

Results were screened based on *a priori* eligibility criteria (WebAppendix 1, pg. 6-7) on the types of studies, participants, outcomes, and publications to be included. Only non-experimental studies explicitly focused on the EoL period, regardless of reference to palliative care, were included. The review focused on extracting information from any study that aimed to define and/or measure the construct of ‘quality of death’ and/or to document information on concepts relevant to ‘quality of death’. This included studies that conducted one or more of the following – 1) systems level analyses of core aspects of EoLC and/or 2) examination of patient, caregiver, and/or community member experiences, preferences, views, attitudes, and perceptions of healthcare services at the EoL. Studies, including systematic reviews and meta-analyses, eligible for inclusion were those that provided qualitative and/or quantitative information through primary or secondary data on relevant EoLC domains. Both primary and secondary sources were included to ensure capture of the range – breadth and depth – of evidence and to address any inadvertent gaps in the search. Outcome measures were those in the broad health system performance domains of access, affordability, and the various dimensions of quality.^{5-7,15}

2.2 Screening strategy

Prior to commencing, a brief calibration exercise was conducted to test consistency in application of the outlined criteria. Two independent reviewers²⁴ (AB and LEO) evaluated the titles and abstracts following the eligibility criteria. A third reviewer (JLC) reconciled differences in selection. Two independent reviewers (JLC and LEO) reviewed the full text articles, and a third reviewer (AB) conducted a verification review of all full text articles, identified inconsistencies and reconciled differences between the two independent reviewers.

2.3 Data management and charting

All articles derived from the previously described search were downloaded and managed in Endnote X9, including for purposes of independent and blinded review. Article duplicates were removed. A standardized data charting form documented the following: 1) contextual and methodological study characteristics including focus country/countries, objectives, data type (e.g., primary, secondary), data collection method (qualitative, quantitative or mixed), perspective (e.g., patient caregiver, provider, general public), sample size, condition(s) of focus (if any), population group (e.g., adult, children), study setting (e.g., hospital, nursing home, community-based care, homecare), instruments or metrics used or developed, specifying if validated or not, and study limitations; and 2) identified domains and sub-domains and rationale on relevance to the construct of 'quality of death.' Narrative analysis was conducted to identify structural and thematic patterns following an iterative process of constant comparison of charted information from selected articles, periodic discussion, and updates to charting. This was done to ensure that domains and sub-domains, particularly their detailed explanations, emerged from the literature and represented thematic saturation. Moreover, the health systems functions framework¹⁴ and frameworks of quality of care,^{5-7,15} including quality of palliative and end-of-life care,^{8,12,25} were referenced. While these did not determine domains, they served as a reference point on thematic patterns once data charting and synthesis of findings was completed.

2.4 Managing risk of bias

The potential for bias is recognized given the multitude of interpretations of the construct of 'quality of death.' The possibility of subjective interpretation and bias in the study was limited by independent and dual review with reconciliation through a third independent reviewer of all search results, full-text review, and data charting. Grey literature was not included and could result in bias. However, key concepts from this broad literature are likely to also appear in the published works.

3. Results

3.1 Overview of search results

The search yielded 2728 discrete articles from PubMed/MEDLINE, PsycINFO, and CINHL (PRISMA flowchart; Figure 1). Based on duplicate removal, and abstract, title and full-text review, 309 articles were selected for inclusion. Full text of one article could not be retrieved to assess for inclusion.

3.2 Characteristics of included studies

Study characteristics of the 309 articles in the review are presented in Table 1. Majority of the studies (n=257) used primary data pertinent to at least one relevant EoLC domain followed by 50 reviews or metaanalyses. The primary perspectives ranged from patients (n=70), caregivers (n=65), health care providers (HCPs) (n=43), broader health system (n=11), multiple (n=110), and other (n=10). 'Other' studies, captured the general public's perspective on what they believe is important for better 'quality of death' from a health systems lens. These classifications denote the primary lens of the article, however, many studies that focus on the patient, caregiver, or provider perspectives also offer information on the broader health system or community perspectives. The largest proportion of studies examined multiple perspectives, including from the health system and community level. Notably, a third (n=104) of the studies focused on cancer and only 14 focused on specific sub-populations of interest (e.g., women, minoritized

communities, indigenous populations, or lesbian, gay, bisexual, and transgender individuals). The majority (n=245) provided data from only high-income countries (HICs), while 38 articles included low- and middle-income country (LMIC) data. The number of relevant articles has steadily increased since 2007, with the most relevant articles being published in 2018 and 2019, the last full year covered by the review.

3.3 Domains and sub-domains of identified in included studies

The scoping review identified 7 domains and 33 sub-domains (Table 2, further details in WebAppendix 3, pg. 13-24). These identify relevant parameters of ‘a good death’ and can be used to guide EoLC reform (Panel 1). The 7 identified domains, reported in turn, relate to the system structure to provide EoLC (5 domains) – stewardship and governance, resource generation, financing and financial protection, service provision, and access to care – and patient and caregiver experiences of EoLC (2 domains) – quality of care and quality of communication. The systemic and experiential domains are expected to impact realization of a ‘quality of death’ alongside effecting clinical and population health outcomes related to health at the EoL (Figure 2). Panels present in-depth analysis of cross cutting issues that intersect multiple domains. WebAppendix 3 and 4 list the full list of references for each domain and sub-domain (pg. 13-24) and the entire review bibliography (pg. 25-41).

Panel 1: Defining and preparing for a ‘good death’

What constitutes a ‘good death’ is an ongoing debate, and presumably, the characterization of it is of curiosity and concern to all humans given death’s universality. While the notion of a ‘good death’ is personal and contextually driven, there are common features that have been cited in studies conducted around the world. These cut across the experiential domains of quality of care and quality of communication, and corresponding sub-domains. General definitions of a ‘good death’ and preparing for it can, to the extent possible, inform the design and reform of EoLC to deliver on the ‘quality of death.’

Studies report a ‘good death’ to be a peaceful and dignified death,^{26,27} with special emphasis on protecting the elder’s dignity.²⁸ A ‘good death’ is reported to be one with readiness for death, presence (e.g. family and loved ones at bedside) and sense of community, time to say goodbye, having had clear information on treatment options presented at the EoL, in one’s sleep and quietly, without pain and suffering, anxiety or depression, devoid of an overwhelming or drawn out process and with preferred death rituals performed.^{26,27} A specific wish is to not feel shortness of breath or a drowning sensation at the moment of death.²⁶ Further, not being a burden to family, maintaining autonomy, having positive final days, shielding others from grief, and being able to make care decisions through to the final days before death were stable preferences of most patients at EoL.^{29,30} These factors have a linkage to impact on health-related quality of life (HrQoL). Patients may want to avoid unwanted life prolonging interventions,^{29,31-33} as evidenced by the negative impact of EoL hospitalizations and ICU on HrQoL,³⁴ and in certain cases, request for assisted dying.³⁵ For pediatric patients, the need for acknowledgement of their childhood and related needs in EoLC, such as the opportunity to play, were noted.³⁶

EoL preparedness, requires acceptance of death as an impending reality. Hence, EoL preparedness corresponds to tasks, processes, and actions necessary to reach closure and the acceptance of loss as inevitable.^{27,37} Related preferences differ due to various factors – clinical

(e.g., cognitive and functional status), personal (e.g., awareness of prognosis), social/cultural (e.g., perceived burden on others), emotional (e.g., existential anguish), spiritual (e.g., support from faith community), and financial (e.g., costs of care, financial security).³⁸ Patients and families prefer to know what to expect in terms of the physical condition as death nears to prepare for it and identify a proxy for decision-making.³⁹ For patients, preparedness relates to completing life tasks and unfinished business, including organizing affairs⁴⁰ (e.g., financial, legal, and funeral arrangements), family coordination (e.g., towards ensuring that family is secure after death),⁴¹ and to be treated as a ‘whole person’ by others.^{31,42} Patient preferences vary on whether or not they want to know when death is imminent.^{43,44} For caregivers, EoL preparation also involves having time to process information emotionally (affective preparedness), to finish important tasks (behavioral preparedness)⁴⁵ with potential to ease the transition into bereavement,⁴⁶ and to learn how to manage fluctuating situations.⁴⁷ Further, both patients and caregivers rank patient’s desire not to be a burden to their family, and to have family presence at time of death and in general to be important for death preparation.⁴⁸ Healthcare providers can play a critical role in facilitating acceptance of and preparation for death.⁴⁹

EoL preparedness also pertains to autonomy and empowerment. For patients, it is being able to set and achieve goals, being able to have a choice and to make decisions for oneself.⁵⁰ For caregivers, it includes being able to practice patient advocacy and for parents of pediatrics patients, have ‘competencies for dealing with the child’ to provide normality and security for them.⁵¹ EoL preparedness preferences on place of care and preferred place of death incorporate setting-related wishes of each patient whether descriptive (e.g. ‘one’s favorite place’⁵² or a calm environment^{52,53}) or designated choice (e.g. home,⁵⁴ hospice,⁵⁵ or hospital⁵⁶). Priority considerations applied in assessing a place of death include, the ability to provide pain and overall symptom control, safety,⁵⁷ patient living conditions and arrangements, social support level, level of burden imposed on caregivers, meeting of specific personal needs, and familiarity of location.^{57,58} Safety perceptions are also linked with familiarity.⁵⁷ There is variability across each factor influencing preferences. Further, it is important to acknowledge that preferences can and do vary over the course of EoLC.⁵⁹

3.3.1 Domain 1: Stewardship and governance

Domain 1 – *stewardship and governance* – was defined as the coordinating and management of functions that are precursors to improving EoLC within the health system.¹⁴ Findings were subdivided into 3 sub-domains. Sub-domain 1, *priority-setting and strategic planning of EoLC system*, highlights the importance of EoLC prioritization, including policymaking, resource allocation, and coordination, particularly on structural and institutional aspects.⁶⁰⁻⁶⁵ This includes adoption and implementation of National Palliative Care Plans to address different facets of EoLC.⁶⁶

Sub-domain 2, *laws, regulations, and standards*, focuses on the regulatory framework, including laws, regulations, and rules establishing standards of EoLC around quality, safety, and efficacy.^{61,66-68} This could include provider authorizations to prescribe controlled medicines⁶⁶ and safeguards for assisted dying,³⁵ and accreditation guidelines and enforcement.^{69,70}

Sub-domain 3, *public awareness and death education*, focuses on barriers that may limit the health system’s capacity to deliver EoLC, including leading up to and at death (for patient and caregivers), and beyond death (for caregivers).^{71,72} Public discourse and community

engagement on the ‘value of death’, for example, can promote open dialogue, break down stereotypes, and thus improve the EoL experience for patients.⁷³ Death education can inform the citizenry on ways to meet personal preferences at EoL while understanding that diverse values on dying and death exist within any society.^{72,74-76} Health systems have a role to play in advancing public awareness and education on EoLC through, for example, dissemination of appropriate resources and information.

3.3.2 Domain 2: Resource generation

Domain 2 – *resource generation* – pertains to human, physical, and knowledge inputs necessary to effectively realize health system goals, including EoL goals.¹⁴ Findings were summarized into 5 sub-domains. Sub-domain 1, *training of competent and multidisciplinary care teams*, identified the need for all cadres of health workers to obtain standardized palliative care (PC) and EoLC-specific competency-based^{31,34} training to strengthen the hospital culture on and meet patient and family needs related to dying and death.⁷⁷ Cited competencies include: 1) ability to provide compassionate and comfort care,⁷⁸⁻⁸⁰ 2) to promote death preparation and provide death education,⁷¹ 3) effectively and openly communicate sensitive, accurate, and culturally appropriate information (e.g., on bad news, truth disclosure) in a timely manner,^{30,34,40,81-85} 4) effectively prescribe opioids for symptom control,^{71,86} 5) comprehension of legal and ethical aspects at EoL,^{78,87} and 6) provide facility-based, community-based and home-based EoLC given varying preferences.⁸⁸⁻⁹⁰ Shared training of PC staff and non-PC staff (e.g., social workers, clergy) was recommended to promote holistic care.⁹¹

Sub-domain 2, *HCP staffing, benefits, compensation, and access to essential resources*, encapsulates broader human resource concerns. These include, not only issues related to compensation, but educational and practical tools to enhance sensitivity of HCPs to vulnerability of family caregivers during the EoL period and to bolster the health workforce in delivering EoLC.^{83,92-96}

Sub-domain 3, *HCP-centered support*, captures the challenges HCPs face in providing care for terminal patients and caregivers, often without adequate training.^{97,98} Specifically, the need to balance moral and emotional distress with professional duty to fulfill their prescribed role and ability to meet it.^{30,98-101} Relevant resources and adequate time to address the impact of death on HCPs at personal and professional levels, including on their HrQoL, were reported as being overlooked.^{78,96,101,102} Peer and professional support networks and services (e.g., multidisciplinary meetings on psychosocial issues) were suggested interventions.^{34,84,89}

Sub-domain 4, *environment*, pertains to the EoLC built environment. This includes factors related to physical environment (e.g., infrastructure related both in terms of equipment and to create a private, personalized, and comfortable space such as a single room with a window and less visible technology),^{49,53,64,103-109} organizational environment (e.g., healthcare setting and design characteristics that promote familiarity and openness),^{69,76,110} and social environment (e.g., environmental facilitation of social interactions that allow closeness to others such as with regular caregiver visits, stimulating activities that are ‘positive distractions’, and activities of daily living including the practice of spirituality).^{108,109,111,112} These resource elements account for the influence of environment on facilities functioning, including safety.^{103,108,113}

Sub-domain 5, *knowledge and evidence for policy and practice*, is premised on the collection and utilization of accurate patient-centered data,¹¹⁴ alongside other health system performance indicators, and development of applicable metrics that capture local needs.^{61,66,115}

This includes the presence of a robust information system to monitor and evaluate quantifiable aims of EoLC system functioning and systematic research to improve EoL delivery.^{66,115,116}

3.3.3 Domain 3: Financing and financial protection

Domain 3 – *financing and financial protection* – was defined as the need for measures to manage healthcare costs and avert catastrophic health expenditure linked with impoverishment.¹⁴

Findings were sorted into 2 sub-domains. Sub-domain 1, *financial distress and fragility*, encapsulates the direct and indirect costs of EoLC and the ability to pay for it.^{60,117,118} Direct costs encompass expenses for healthcare services, medicines, and other healthcare needs including professional caregivers at home.^{104,119-123} Cost of traditional healers and alternative or complimentary therapies was noted in some cases,^{120,124} as were differences in costs in urban versus rural contexts.¹²⁵ Indirect costs include transportation costs, income loss due to caregiving responsibilities, costs for funeral and burial services, and other legal and financial preparation costs.^{38,43,104,120,121,126} Out-of-pocket costs and lost earnings can result in financial loss and fragility which can be long-term and hamper financial well-being,^{29,38,117,118,121,124,125} and can increase patient’s self-perceived burden to others.¹²⁷

Sub-domain 2, *EoLC financing and affordability of care*, encompasses putting the financial mechanisms (e.g., health insurance for agreed provisions by the health system), particularly public financing of EoLC, in place to ensure that the financial ability to pay is not a barrier to EoLC.^{60,61,66,104,110,120,128} The need for allocated funding to improve drug supply,⁹⁴ provide spiritual care¹²⁹ and for educational activities to raise public awareness⁷² was noted. Financial assistance through cost-effective and targeted schemes can reduce the financial burden and distress on patients and families due to direct and indirect costs.^{43,61,64,68,76,114,120,130-132} Assistance to access financial resources was especially noted by studies focused on indigenous communities.^{120,133}

3.3.4 Domain 4: Service provision

Domain 4 – *service provision* – was defined as the management and delivery of personal and non-personal health services.¹⁴ Findings were grouped into 4 sub-domains. Sub-domain 1, *availability of facility-based, home-based and community-based EoLC*, encompasses the availability of safe EoLC services and medicines across geographic locations (facility, home, community) and levels of care (primary, secondary, tertiary) with related linkages.^{30,54,64,88,90,134-145}

Sub-domain 2, *administration of symptom management*, is the enabling of providers and facilities to administer symptom control to alleviate physical, psychological, social, and spiritual suffering, and provide comfort care following appropriate guidelines and protocols.^{34,36,68,69,87,92,103,116,122,131,146-157} Sub-domain 3, *care integration*, is coordinated care through intersectoral cooperation between facilities and levels of care (especially primary and secondary), particularly through a functioning referral system, and interpersonal collaboration between HCPs.^{61,64,70,73,156,158,159} Noted features of integration were existence of care protocols and pathways,^{142,156,159,160} multidisciplinary approach to service provision to respond to multidimensional needs with informed care, information exchange between HCPs on diagnosis, treatment and prognosis,^{123,132,139,140} consideration of the financial aspects of care,^{130,148} and assessment of provider-centered factors contributing to integration.¹⁶¹

Sub-domain 4, *responsiveness*, focuses on the organization and delivery of care to offer timely, active, attentive, secure, and technically and culturally competent care that is patient-

centered, and generates confidence in the health system.^{63,105,149,162-165} In the EoL context, it incorporates early PC consultation and specialist support when necessary,^{166,167} discussion and understanding of patient and family experience and needs, as well as respecting and honoring of patient’s and family’s values, goals, preferences (e.g., use/avoidance of artificial prolongation of life) and decisions for medical and other care.^{33,36,38,42,135,155,168} It involves anticipating and providing necessary support based on recognition of heterogeneity in need,¹⁶⁹ particularly when the patient is actively dying,^{34,147,155,170} considering special needs (e.g., children or elderly, acknowledgment of patient’s childhood and ‘biographical uncertainty’),^{28,36,56,171,172} facilitating acceptance of death,⁸⁴ acknowledging time as important,¹⁷³ accounting for practical patient needs to maintain daily routines,¹⁷³⁻¹⁷⁵ and preserving and protecting of dignity.^{28,80,93,176} It also includes familial aspects such as valuing the caregivers’ expert knowledge of the patient,^{69,177} and ensuring shared decision-making to the degree preferred on patient care with advanced care planning (e.g., ability to issue advance directives).^{41,175,178}

3.3.5 Domain 5: Access to care

Domain 5 – *access to care* – captures experiential aspects of access, such as to address the core dimensions of serious health suffering – physical, psychological, social, and spiritual – and to address structural components of access.^{14,15} Findings were categorized into 8 sub-domains. Sub-domain 1, *access to medicines*, specifically captures opioid consumption at the country level to alleviate the burden of serious health-related suffering and secure a reliable and timely supply of Palliat Meds, such as morphine, at the patient level.^{65,92,104} This requires addressing regulatory and prescription barriers,⁶¹ a common pitfall in supply chain management of opioid medications.^{30,92} Access to physical and psychological care extend beyond access to medicines.

Sub-domain 2, *access to physical care*, pertains to professional management of physical symptoms and related distress such as pain^{53,69,106,130,135,174,179-182} while sub-domain 3, *access to psychological care*, is the guarantee of the same for psychological symptoms and related distress.^{53,101,106,116,135,183} Physical care includes the neglected area of oral care due to high prevalence of dental conditions at EoL and as oral health was expressed as important to quality of life.^{184,185} Psychological care incorporates access to counselling services,^{30,68,131} including to cope with the fear of dying and death,¹⁸⁶ and considers psychological changes of patients and caregivers as they adjust and adapt to life altering experiences.⁷¹ Further, it includes emergent issues at EoL – death-related stigma and family reconciliation and closure before death of a loved one.¹³¹ Sub-domain 4, *access to spiritual care*, for those who wish, is professional management of spiritual distress and to achieve spiritual well-being at the EoL, which has a positive association with QoL at the EoL.^{187,188} Spiritual care is reported to promote a sense of ‘wholeness’,¹⁸⁰ the opportunity to go beyond the physical,¹⁸⁹ primarily to find meaning and purpose (e.g., for some closeness to and a connection with God or a higher being),⁷⁴ and the performance of last rites during the dying process.³³ It can offer coping mechanisms such as hope to manage spiritual distress in the face of loss,¹⁹⁰ aid in honoring family values, help preserve dignity, and generally contribute to death preparation.⁹³ Integrating access to clergy or chaplain was reported to provide comfort and healing for spirit maintenance.^{111,191}

Sub-domain 5, *access to social care*, is for professional management of social distress by social care specialists or social workers that facilitate support and access to resources.^{30,170,192} It is interconnected with psychological suffering and contributes to addressing psychosocial needs.¹⁹³ Perceived social support is reported to be significantly associated with resilience, which can have protective effects on emotional distress.¹⁹⁴ Sub-domain 6, *access to bereavement care*

for grief management, is for the facilitation of expressing and managing grief through both acknowledgement of suffering and anguish experienced by family/caregivers, and provision of targeted planning and services.^{45,115,195,196} It encompasses structured guidance to address grief or ‘living loss’¹⁷¹ over the dying process (before and after the patient’s death) such as support for psychological and emotional trauma related to anticipatory grief¹⁹⁷ and mourning (e.g., depression), meeting cultural and/or religious rituals that influence grief,^{26,183} and to attend to family needs overall. It includes assistance with management of the body and funeral arrangements,^{58,131} and convening of grief support groups and providing bereavement follow-up.⁹⁷ Such care has contributed to cognitive, affective, and behavioral preparedness (tailored to individual) for death and bereavement, and to averting or reducing complicated grief.¹⁹⁷

Sub-domain 7, *access to care navigation*, is related to navigational services that can help steer patients and caregivers through the complexity of any health system, including on logistical support, clear procedures to access resources and services, and assistance with issues such as identification of the right facility or skilled facility placement.^{80,119,130,177,198} Sub-domain 8, *equity in access*, pertains to access to care without discrimination, addressing factors that exacerbate structural inequities in access and accounting for underlying social disadvantages.^{63,73,164,199} LMICs populations were reported to experience inequities across access domains,^{104,115,118,121,200} and similar concerns, including around substandard care,²⁰¹ exist among minoritized populations.^{73,164,199} These structural inequities have resulted in mistrust of the health system among marginalized and minoritized communities.^{164,201} Findings recommend that EoLC programs and policies not be built only around a ‘normative’ palliative-patient population type given significant barriers to access if patients do not fit the defined parameters of what is considered ‘normative’ in that context.⁶³ Past discrimination (e.g., as experienced by minoritized groups and LGBTQ+ community) by health and legal systems is also reported to have made the health system untrustworthy.^{164,201}

3.3.6 Domain 6: Quality of care

Domain 6 – *quality of care* – was defined as effective and efficient healthcare services meeting both guidelines and standards as well as being people-centered (i.e., considering preferences of patients and caregivers).⁵⁻⁷ Findings were classified into 9 sub-domains. Sub-domain 1, *safety*, notes the importance of a culture of safety and maintenance of patient safety through use of established standards of care to avert potential harms.^{67,69,103,108,113,202,203} Safety is also of concern in determining preferred place of care,^{54,58} harms related to unmanaged symptom management, lack of medication reviews and use of unnecessary or incorrect medications,¹⁴⁸ environmental harms related to physical environment and harms linked with care transitions (e.g., related to discharges and transfers).¹⁰³ Safety aligns with trust generation²⁰⁴ and is impacted by prior knowledge of a hospital or other healthcare facility and corresponding experience of care by patient and caregiver.^{29,57}

Sub-domain 2, *appropriateness of care*, is defined as people-centered of care (interconnected with related concepts of patient-centered, family-centered, and person-centered care) that is holistic and tailored to individual needs with care priorities established through consultation, generating a sense of security.^{52,130,157,205,206} Such care is technically competent^{80,148,149,199} and is expected to anticipate and meet patient needs, as well as preferences, wishes, beliefs, and goals of care (including around preferred place of care, preferred place of death, and preferred death parameters near death and at the event of death)^{53,57,58,74,80,155,157,168,177,207} while also accounting for related considerations for

caregivers.^{52,95,208} This is especially true for when the patient is actively dying.¹⁷⁰ Culturally sensitive consultation is expected and can help mediate conflicting priorities between cultural preferences and medical soundness.^{85,106,164,209,210} Moreover, appropriateness of care is achieved through consideration of patient and family perspectives on care,⁸⁷ safety,^{29,203} confidentiality,¹⁵³ and privacy of care (e.g., not dying in an open ward), especially when approaching death to allow for farewells.^{36,83,109,211}

Sub-domain 3, *coordination and continuity of care and support across phases, stages, and transitions in EoLC*, is defined as coordinated and continuous EoLC without excessive administrative procedures and following standard PC guidelines.^{73,212} This includes support across various phases, stages, and transitions of the EoLC pathway that address death-related vulnerability and avoid medical abandonment or isolation.^{29,151,158} Continuity can be divided into: 1) relational or personal continuity in terms of HCPs (e.g., general practitioners, formal caregivers) to establish relationships and have a ‘trusted helper’;²¹³⁻²¹⁵ 2) informational continuity in addressing informational needs (e.g., after referral) and through coordination and transfer of knowledge between providers and institutions responsible for care (e.g., reporting of symptoms in the electronic patient file);^{174,213-215} 3) management continuity between care stages and with a coordinated discharge plan when relevant (e.g., transition from facility-based to home-based care, setting up related needs such as delivery of extra equipment);^{107,151,216} and 4) organizational continuity in care during and after hours to ensure uninterrupted service provision, professional support (e.g., between secondary care, acute and community settings) and therapeutics, especially for patients with complex needs.^{107,155,212-214,217}

Sub-domain 4, *alleviation of serious health-related suffering and promoting health-related quality of life or HrQoL*, encompass both the critical concern of patients and caregivers to alleviate pain and other forms of distress that can be ameliorated with palliative and EoLC. Review results indicate that patients, caregivers and HCPs all equate HrQoL at EOL to well-being in its various dimensions (physical, psychological, functional, emotional, social, environmental, spiritual), including related health outcomes, life satisfaction (e.g., meaning and sense of purpose, life fulfillment), and engagement with life and work activities.^{52,94} HrQoL is closely linked with sub-domain 5, *life continuity*, which is defined as preservation of identity, personhood and ‘continuity of self’;²¹⁸ as well as autonomy and independence to maintain life pursuits, albeit potentially altered.²¹⁹ Life continuity refers to the transition from everyday life prior to a death prognosis to post-prognosis care in a manner that establishes a new normalcy with activities of daily life. It is also connected to awareness of impending death and its acceptance.^{43,80} Panel 2 examines life continuity in the context of transitioning and accompaniment through EoLC and the role of hope.

Panel 2: Transitioning and accompaniment through EoLC: life continuity and hope

The EoL period is defined by various stages and transitions that serve as reference points for patients and families alike in the process of understanding, accepting, and coping with the uncertainty and permanency of death. Life continuity and hope have been identified as sources of comfort and security across these reference points.^{23,220} The phases and transitions of EoLC require accompaniment and opportunities for life continuity and hope. Findings on these are presented in turn.

Two key transitions between distinct phases of EoLC were reported – transition from (acute) curative treatment to the early palliative phase, also referred to as EoL or terminal care period for progressive disease with expected survival of months or less, and transition from early to late palliative phase or ‘actively dying’ with expected survival of days or hours when symptom distress, functional dependence, anxiety, and depressive symptoms are increased.^{1,158} The various timeframes in EoLC and the dying trajectory can signify changes in needs, goals, preferences (e.g., preferred place of death), and decision-making expected across and within the transitions, including on care management, need for pain relief, needs of loved ones, including family caregivers, and anticipatory guidance.^{1,59,147} During these changes, patients repeatedly report fear of abandonment by and isolation from family, society, HCPs and the health system.^{29,163,221-223} This has been especially concerning in light of COVID19.

Over these phases and transitions, maintaining life continuity contribute to patient resilience and preserving dignity.²³ Patients indicate social relations and ‘belongingness’ through the opportunity to be with friends and family (including chosen family,^{164,202} an expressed concern of LGBTQ+ community), as an opportunity for ‘living while dying.’¹⁶⁵ Moreover, living life to the fullest can be translated to engaging in fulfilling activities, being able to give to others, having privacy, and maintaining pleasure are valued and which together are reported to contribute to patient resilience and preserving dignity.²³ For caregivers, the avoidance of life being on hold,⁸⁰ maintenance of work and family bonds, existence of meaning and purpose in life during the dying trajectory and after with the ability to move on, and gratitude were reported features of life continuity.^{171,224}

Hope, as a process and as an outcome, can improve coping, reduce existential distress, and address related fears.²²⁰ Studies report hope in relation to disease prognosis and progression, the desire to be pain and symptom-free, to be in the preferred care setting,²²⁵ to strengthen familial ties, to be focused on whatever is after death, and to create a ‘living legacy’ that can be left behind.²²⁶ Further, it is clear that hope changes occur with changes in condition.²²⁷ Two identified categories of hope were reported – ‘particularized hope’, which is cure-oriented, enhances avoidance of death, and can lead to false hope, and ‘generalized hope’, which is focused on fostering a good death, death acceptance, and truthfulness around death.²²⁷

Hope was reported to have an association with past or future gains (e.g., physical improvement or spending time with significant others)²²⁸ and information sharing, particularly truthful information.⁹⁶ Conversely, hopelessness can be correlated with previous life losses, including health-related losses, loss of livelihood and income, loss of a family member, or the despair of future loss and particularly the loss of the future itself.⁹⁹ Greater resilience was significantly associated with lower hopelessness. Loss of hope is considered a barrier to beginning EoL discussions, including to provide information on prognosis.⁹⁶ Hope levels have been found to increase with age, and be lower among women than men.²²⁹

Sub-domain 6, *dignity*, defined as being respected as a human being with worth and personal integrity who is afforded humanized care.⁴² Dignity is relevant for both patients and caregivers.^{36,162} Lack of symptom control, especially pain, the presence of existential distress, certain models of care provision, and particular healthcare settings and designs serve as threats to patient dignity and are reported to be a component of dignified care.⁸⁶ Dignity is reported to be impacted by self-identity (e.g., loss of self-worth), social factors (e.g., fear of vulnerability,

changes to social identity), autonomy (e.g., not having control over the process of dying or self-determination),²¹⁸ and functionality (e.g., loss of control over body).²³⁰ Sub-domain 7, *empowerment*, was defined as the ability to self-determine, control, and know how to undertake self-care or provide care for a loved one.^{61,230} It is influenced by autonomy, power relations and dynamics,²³¹ and access to ‘informational power.’^{29,169}

Sub-domain 8, *hope*, is defined as “an active, dynamic state of existential coping among patients with life-threatening disease.”²²⁰ Hope is maintenance of a sense of security amidst uncertainty^{52,232} and a connection with the future,^{50,203,233} and linked to preparedness and spirituality,¹⁸¹ which for the health system is linked to access to spiritual care.⁸⁰ While much of the reviewed literature focused on patient hope,^{50,225,233,234} hope was also cited as a factor in reducing caregiver vulnerability and protecting them against burnout.⁹⁵

Sub-domain 9, *caregiver-centered support to manage caregiver burden*, pertains to the extensive informal caregiving burden faced by family members in supporting patients (Panel 3). This burden can be reduced through formalized and professional support, including both training for informal caregivers and professional home-based caregiving, which is integrated into the referral system.^{40,235,236} The former is especially needed in rural areas where professional services are limited.¹⁴³ Caregiver support can address the complex (e.g., managing medical regimens) and continuous nature of care as well as the caregiver burden itself.^{95,208}

Panel 3: Caregiving: from demands to interventions

Caregiving requires a balance between the burden of care and the capacity to cope with it, both of which impact the vulnerability of the caregiver, including in areas of distress and suffering,⁹⁵ and their HrQoL.^{52,80,108,237}

Caregivers provide extensive support to patients, from adhering to clinical recommendation and supporting the continuation of patient’s activities of daily life to providing emotional support, mediation, advocacy and decision-making based on resourcing information and assistance, and management of finances.¹³³ Caregivers are responsible for knowing what to do, when, and how, while addressing competing elements of care.¹³³

Caregivers need a support system that can help them cope with stress, anxiety, dread, guilt, unpredictability of care, specific incidents or episodes, frightening or anguishing elements of care, regain control of life and balance caregiving responsibilities, provide normalcy and hope, and increase satisfaction with caregiving role.^{159,208} Support systems can help affirm the moving aspects of care, provide an opportunity for self-reflection, personal development and benefit-finding, opportunities to discuss PC, avoid feelings of powerlessness, address moral distress and promote caregiver confidence, and strengthen cooperation with other caregivers.¹⁰¹ The unavoidable caregiver burden on family and loved ones can also be eased by “networks and relations of support”²³⁸ that help reduce caregiver vulnerability⁹⁵ and address caregiver suffering that may relate to loneliness of care or overburden of caregiving.²³⁶ This can be particularly helpful for working caregivers¹²⁸ and the unique reported needs of parents experiencing the loss of a child.^{47,239,240} Support systems also have the potential to break down certain social boundaries and raise awareness around dying and death.²⁰⁸

3.3.7 Domain 7: Quality of communication

Domain 7 – *quality of communication* – focused on the interactional aspects of healthcare and the exchanging of relevant information in a manner that enhances patient-centeredness.^{7,15} Findings were organized into 2 sub-domains. Sub-domain 1, *effective interpersonal interactions and relations*, refers to relational and social aspects of care.²⁰⁴ It is HCP, social worker, spiritual caregiver interactions and relations with patient and families that demonstrate respect, empathy, compassion, kindness, a warm and genuinely concerned attitude as evidenced by verbal and non-verbal (e.g. actions and body language) communication,^{105,224,241-244} emotional awareness and honesty.^{221,245} These promote the development of a ‘good relationship,’ approachability of HCPs, trust and a sense of security.^{33,52,53,203} Moreover, patients and caregivers seek interactions that demonstrate respect for them as people.^{33,52} Noted examples were attentiveness, taking the time to make care team and patient introductions, integrating the family in the care process,²⁴⁶ reflecting cultural competency,^{209,210} responding to questions,¹⁶⁵ and clarifying and legitimizing patient and caregiver requests.^{214,242}

Sub-domain 2, *effective communication*, centers around the substantive delivery of information in a timely manner (by phase and time point) with sensitivity and through discussions with patients and families, using clear, consistent, comprehensive, timely, accurate and reliable communication (related to cognitive preparedness) at a suitable pace,^{45,192,200} capturing both the demands of effective and affective – pertaining to the expression of emotions – communication.^{149,244,247} Communication is necessary on values, preferences, aims of care, fears, concerns, and uncertainties.^{247,248} Effective communication encompasses active information sharing with patients and caregivers to understand EoLC,^{69,237,247,249} including the role of PC and hospice care as part of the care continuum,⁸¹ and notification of death and cause of death.²⁴¹ Communication was in general reported as the most unmet need.¹⁷⁴ In the case of children, information on measures taken to save the child’s life and maintain their mental state before dying, including about what to do at time of death and after death, were noted as important for parents, alongside other communication needs specific to the death of a child.^{240,241}

Effective communication also incorporates timely, frequent, and standardized assessment of needs and associated support,²¹² including on the types of distress experienced to allow for early and accurate identification of PC patients,¹⁶⁷ symptom management and related information,^{247,250} recognition of decline,³⁷ determination of readiness to engage in EoL discussions.^{225,232} Moreover, initiation and routinization of difficult EoL conversations to share information and facilitate informed decision-making (e.g., advanced care planning and directives, anticipatory guidance) is considered the duty of HCPs and a key information need of relatives.^{89,251-253} Informed EoL conversations and decisions are associated with less aggressive acute or intensive care, shorter hospital stays, greater hospice use and higher likelihood of death outside the hospital, and less costly EoLC.²⁵⁴

4. Discussion

This scoping review provides an extensive list of the domains and sub-domains identified as pertinent to the delivery of better EoLC through a health systems lens. The integrated results linking health systems level structure and individual level experience can substantially contribute to ongoing efforts to examine the design and performance of EoLC systems. The overarching theme of the 7 domains identified is the promotion of security and confidence⁴⁰ to cope with death-related vulnerability and the need for various types of support to address the complexity of dying and death. The stark uncertainty of death and the need for specialized caregiving that is

sensitive to and responsive of this is a unique concern during the EoL period as compared to non-EoL stages of care. It is reflected in the heightened concern across various domains at the EoL around avoidance of suffering related to isolation and medical abandonment (Panel 2).^{29,163,221-223}

The health system has a critical role in the ongoing facilitation of and involvement in core actions that address suffering at the EoL, including from clinical management of symptoms to resources for management of existential distress of facing life’s end and addressing related emotional, psychological, and social impact. As such, the present review highlights the need to shift EoLC from merely focusing on treatment of biological aspects of disease to a holistic biopsychosocial-spiritual model of care that seeks to alleviate serious health-related suffering across its dimensions (physical, psychological, social, and spiritual) to realize a ‘good death’.^{2,22,255} Moreover, it emphasizes the functional and foundational role of accessibility to and quality of information exchange in ensuring quality of care across all care sub-domains. This resulted in separation of quality of communication as a distinct domain from quality of care. Thus, providing room to capture cultural nuances in communication practices, alongside consideration of heterogeneity in patient preferences overall.

This review has various limitations. Quality of included studies was not appraised, as is common with systematic and increasingly with scoping reviews, and grey and non-English literature was not included. The latter could result in limited incorporation of culturally diverse reflections on dying and death, as well as missing perspectives. Understanding societal values and belief systems, and the underlying cultural nuances that inform them, was not the focus of this review. However, we recognize that these factors are critically important and that societies may weigh each identified domain and sub-domain differently. Indeed, a query of how cultural factors inform EoLC perspectives would constitute a review of its own and would require a much broader review of the literature.

The possibility of missing specific articles that may be relevant to the review area is acknowledged, particularly given the wide scope of the review and the inclusion of studies that explicitly focus on the EoL period, not palliative care overall. However, the review reached saturation in themes and concepts based on the high degree of repeated information across studies. Yet, as the review was conducted in the early days of the pandemic, it captures domains from published literature prior to the COVID-19 pandemic. Moreover, while the methods employed have been carefully detailed for transparency and replicability, reproduction of the scoping review may be affected by the multidimensional nature of the search and screening process, as well as potential biases of reviewers during the screening process. Despite these limitations, this review contributes to a growing body of literature on the key domains that encompass EOL care from the health systems lens. It affirms the already acknowledged need for a people-centered approach to managing the delicate process and period of accepting and preparing for one’s death or the death of a loved one through irreversible physical, psychological, social, and spiritual changes. The review has shown the scant published research on the ‘quality of death’ in LMIC settings and within the context of improving the quality of care at the systems level.

The identified domains can add value to patients, families, and society through recognition of the unparalleled challenges and circumstances that emerge during the EoL period and translation into meaningful change in the design, delivery, and assessment of EoLC at the systems level. They can serve as a marker for tracking progress in both policy translation and implementation. Specifically, measurement of health system performance at the EoL can be

informed by domains reflecting health system functions (stewardship/governance, resource generation, financing, and service provision), and goals (access to care, improved health, responsiveness, financial protection, and equity), and in terms of patient and caregiver preferences for care. The identified domains and sub-domains provide a patient-centered and EoLC-specific lens to address the challenges of death vulnerability, which can be accordingly integrated into health system performance improvement and universal health coverage efforts. The development of robust indicators corresponding to the domains identified in this review can be used for quantifying health system performance both within and across countries and can further appraise progress made in the design and delivery of EoLC. It is acknowledged that while structural and experiential factors were captured in the domains identified and they reflect both process and outcome elements, there continue to be data limitations and measurement challenges in some of these areas. Reiteration of their importance can motivate innovative techniques to quantify performance in these domains and to assess the complex journey that EoL patients face.

The review identifies important areas for future research. This includes specifically targeted EoLC for children, refugees, LGBTQ+ communities, groups minoritized based on gender and sexual identify, and individuals with disabilities who likely have specific needs for EoLC that can be further mapped, and related domains weighted in metrics development. Moreover, current literature on the EoL period has a notable focus on cancer and ongoing research on non-malignant conditions may contribute to additions and/or changes to the identified domains and broader conceptual framing. Future research can also take a more nuanced view to differentiate ‘quality of death’ considerations for individuals with acute or chronic conditions.

Authors' Contributions

EAF, AB, and RS conceptualized the research goals and aims of the study. AB conceived the scoping review, and led and implemented all aspects of the investigation, including methodological design, analysis, and write-up. EAF advised the scoping review and made critical contributions. EAF and RS obtained funding for the study and advised alignment of the review within the broader Quality of Death and Dying Index study. AB searched the articles. AB, JLC, and LEO retrieved and screened titles and abstracts, reviewed the full text of selected articles, and conducted the data extraction. AB wrote the first draft of the manuscript as well as led and undertook all subsequent substantive manuscript revisions. EAF revised the draft manuscript and contributed to subsequent iterations. LEO and JLC also contributed to revisions. All authors contributed to various aspects of content discussions, provided inputs, and reviewed the final manuscript.

Disclosure/Conflict of Interest Statement

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Figure 1: PRISMA flow diagram of scoping review results

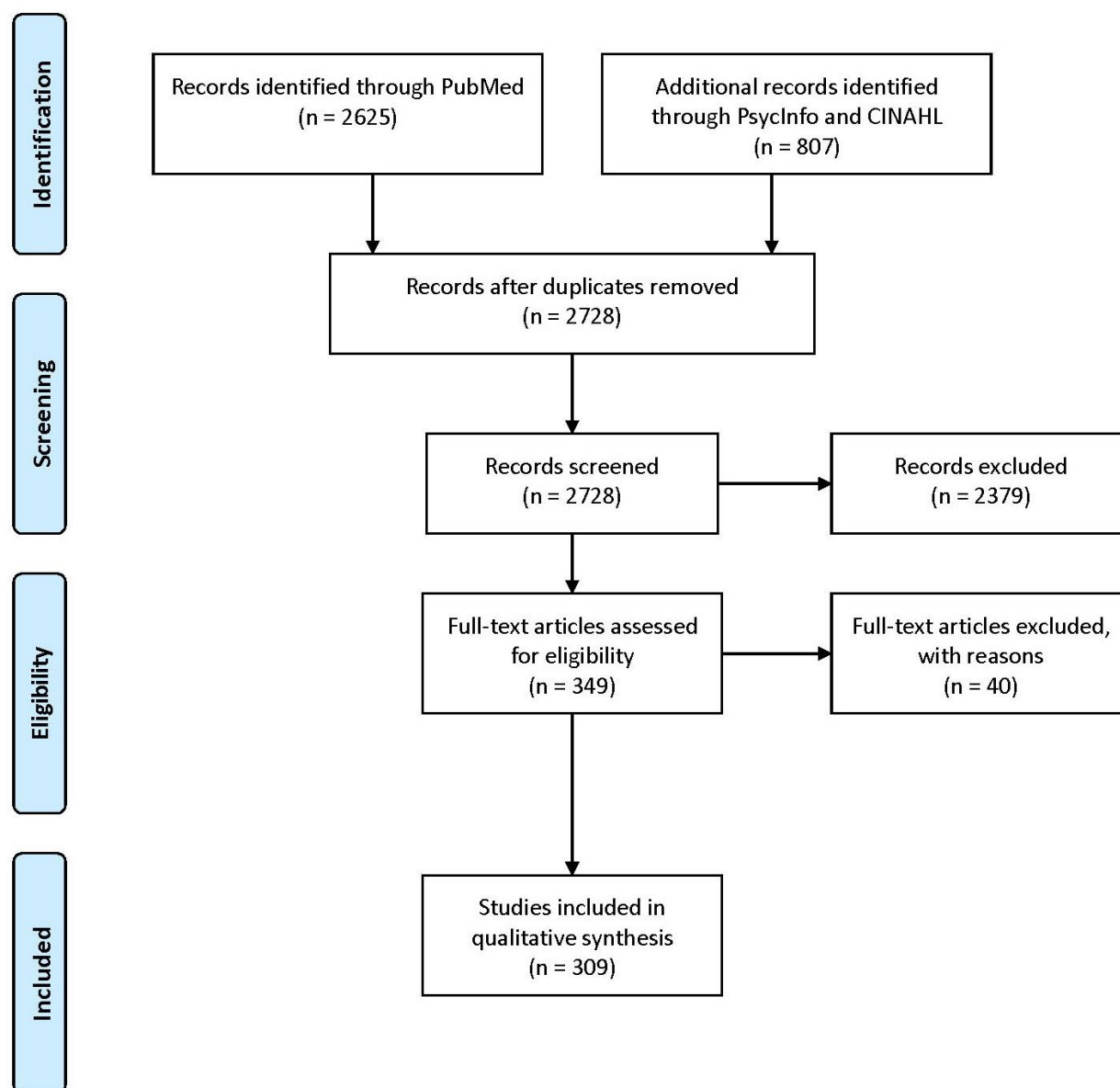


Table 1: Number of articles included in the review by study characteristic

Data Type		Condition(s) of Focus	
Primary	253 (82%)	Cancer	104 (34%)
Secondary	3 (<1%)	Cardiovascular Disease	2 (<1%)
Review/Meta-Analysis	51 (17%)	Cerebrovascular Disease	1 (<1%)

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Other	2 (<1%)	Chronic Kidney Disease	2 (<1%)
		Dementia	6 (2%)
		Other Neurological Conditions	2 (<1%)
		HIV/AIDS	2 (<1%)
		Liver Disease	2 (<1%)
		Chronic Obstructive Pulmonary Disease	5 (2%)
		Multiple	183 (59%)

Study Method		Geographic Location	
Quantitative	70 (23%)	HICs only	245 (79%)
Qualitative	196 (63%)	LMICs only	38 (12%)
Mixed	41 (13%)	<i>Low-income only</i>	3 (1%)
Not Applicable	2 (<1%)	<i>Lower-middle income only</i>	12 (4%)
		<i>Upper-middle income only</i>	22 (7%)
		Global	11 (4%)
		Not specified	15 (5%)

Perspective		Population Age Group	
Patient	70 (23%)	Adult	228 (74%)
Family/Caregiver	65 (21%)	Children/Young People	16 (5%)
Healthcare Professional	43 (14%)	Elderly	20 (6%)
System	11 (4%)	Multiple	45 (15%)
Multiple	110 (36%)	Population Groups	
Other	10 (3%)	Women	1 (<1%)
		Indigenous	4 (1%)
		LGBTQ+	1 (<1%)
		Minoritized communities	8 (3%)
		Parents of terminal children	12 (4%)
		Mixed/general population	283 (92%)

Study Sample Size (n)			
Primary/Secondary/Other		Reviews	
<50	138 (45%)	<10 Articles	4 (1%)
50-99	38 (12%)	11-25 Articles	18 (6%)
100-249	38 (12%)	26-50 Articles	13 (4%)
250-499	18 (6%)	>50 Articles	12 (4%)
500-999	7 (2%)		
>1000	18 (6%)		
Not Reported	1 (<1%)		

Not Applicable	4 (1%)
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Figure 2: Overview of domains identified through scoping review

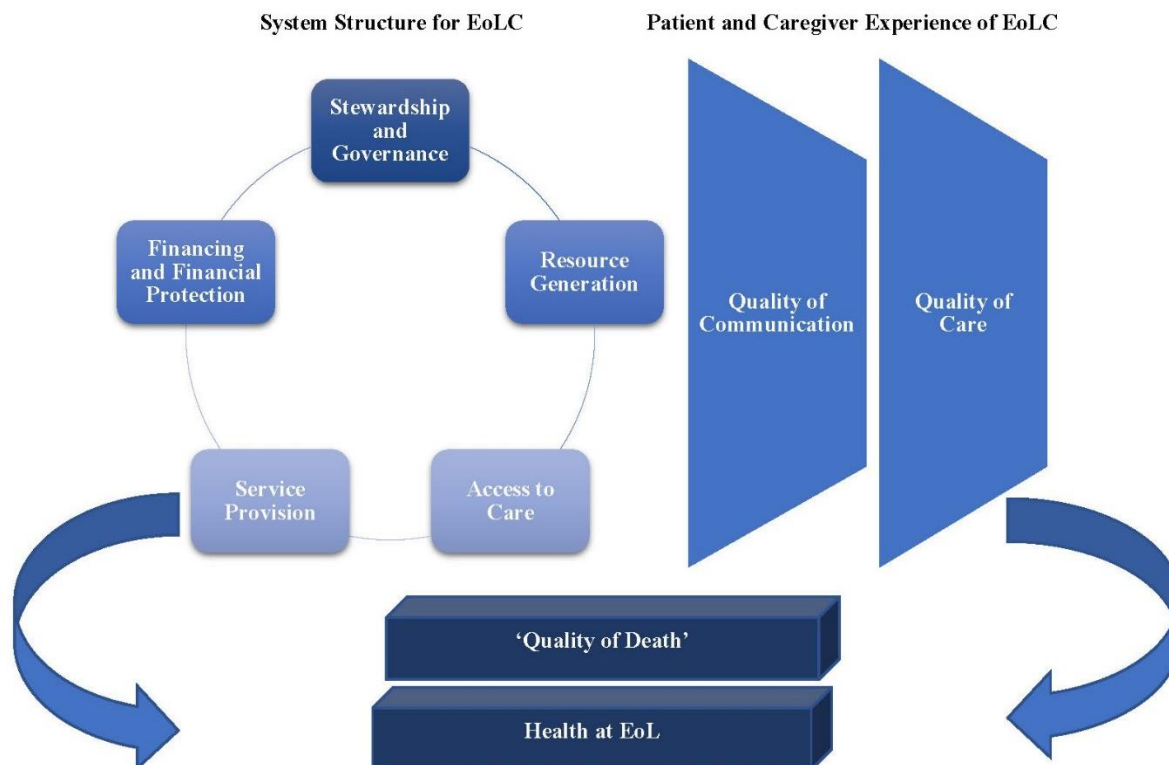


Table 2: List of identified domains and sub-domains

Domain	Sub-Domain(s)
1. Stewardship and Governance	<ol style="list-style-type: none"> 1. Priority-setting and strategic planning of EoLC system 2. Laws, regulations, and standards 3. Public awareness and death education

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2. Resource Generation (human, physical, and knowledge)	<ol style="list-style-type: none"> 1. Training (of competent and multidisciplinary care teams) 2. HCP staffing, benefits, compensation, and access to essential resources 3. HCP-centered support 4. Environment 5. Knowledge and evidence for policy and practice
3. Financing and Financial Protection	<ol style="list-style-type: none"> 1. Financial distress and fragility 2. EoLC financing and affordability of care
4. Service Provision	<ol style="list-style-type: none"> 1. Availability of facility-based, home-based, and community-based EoLC 2. Administration of symptom management 3. Care integration 4. Responsiveness
5. Access to Care	<ol style="list-style-type: none"> 1. Access to medicines 2. Access to physical care 3. Access to psychological care 4. Access to spiritual care 5. Access to social care 6. Access to bereavement care for grief management 7. Access to care navigation 8. Equity in access
6. Quality of Care	<ol style="list-style-type: none"> 1. Safety 2. Appropriateness (of care) 3. Coordination and continuity of care and support across phases/stages/transitions in EoLC 4. Health-related quality of life and alleviation of serious health-related suffering 5. Life continuity 6. Dignity 7. Empowerment 8. Hope 9. Caregiver-centered support (to manage caregiver burden)
7. Quality of Communication (within system and with patients/caregivers)	<ol style="list-style-type: none"> 1. Effective interpersonal interactions and relations 2. Effective communication