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Palliative Care Needs Of Patients With Chronic Diseases In Family Medicine Settings: A Systematic Review

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Abstract

Background: Patients with chronic diseases such as cardiovascular, renal, respiratory, and oncological conditions frequently experience high symptom burdens and diminished quality of life, underscoring the importance of timely and integrated palliative care. Family medicine and primary care settings are uniquely positioned to address these needs, yet gaps in service delivery persist.

Objective: To systematically review the evidence on the prevalence, characteristics, and outcomes of palliative care needs and interventions for patients with chronic diseases in family medicine or primary care contexts.

Methods: A systematic review was conducted following PRISMA 2020 guidelines. Eligible studies included adults with chronic diseases receiving care in primary care or community settings, published in English between 2010 and 2024. Fifteen studies were included, covering randomized controlled trials, cohort studies, cross-sectional analyses, and mixed-method designs.

Results: Across populations and settings, patients exhibited significant unmet palliative care needs, particularly related to symptom management, psychosocial distress, and functional decline. Interventions such as integrated palliative and disease-specific care models improved quality of life, reduced symptom burden, and, in some cases, decreased hospitalizations. However, not all studies demonstrated reductions in healthcare utilization, and barriers related to provider readiness, service infrastructure, and late referrals were consistently reported.

Conclusion: Integrating palliative care into family medicine pathways offers measurable benefits for patients with chronic diseases. Sustainable implementation will require workforce training, systemic support, and policy frameworks that embed palliative care within chronic disease management strategies.

Keywords Palliative care; Chronic diseases; Family medicine; Primary care; Integrated care; Symptom management; Quality of life; Healthcare utilization; Interdisciplinary care; Systematic review.

Introduction

Chronic diseases such as cardiovascular, respiratory, renal, and neurodegenerative conditions represent the leading causes of morbidity and mortality worldwide, profoundly shaping healthcare needs in aging populations. Unlike acute illnesses, these conditions often involve prolonged trajectories of decline, significant symptom burdens, and complex psychosocial challenges. Palliative care, which addresses quality of life, symptom management, and holistic support, has therefore emerged as an essential complement to chronic disease management in family medicine and primary care settings (Tziraki et al., 2020).

Family physicians are at the frontline of managing chronic illnesses due to their ongoing, long-term relationships with patients and families. Their unique role positions them to identify and address unmet palliative care needs early, rather than waiting until late-stage disease. Integrated community-based palliative care models demonstrate that family medicine can effectively provide continuity of care and improve outcomes when adequately supported with training and resources (Atreya, Patil, & Kumar, 2019).

Despite these opportunities, significant challenges persist. General practitioners often cite barriers such as insufficient time, limited training in end-of-life care, and inadequate communication across sectors, which can hinder timely and effective palliative care delivery (Ramanayake & Dilanka, 2016). These structural limitations not only affect care quality but may also lead to fragmented experiences for patients and families navigating complex chronic illness trajectories.

Primary care providers themselves acknowledge the importance of palliative approaches, but many feel unprepared to implement them fully. For instance, Nowels et al. (2016) found that clinicians in family medicine settings frequently expressed concerns about their preparedness to manage advanced symptoms or engage in advance care planning. Such findings highlight the urgent need for systemic reforms and capacity-building in family medicine to normalize palliative care as a routine aspect of chronic disease management.

Evidence further shows that the adequacy of palliative services in primary care influences satisfaction for both patients and healthcare providers. In a UK-based study, general practitioners and district nurses reported variable satisfaction with out-of-hours palliative care provision, underscoring gaps in service delivery and coordination (Mitchell et al., 2020). These gaps can exacerbate crises and hospital admissions, undermining the continuity and comfort that community-based palliative care aims to provide.

The demand for palliative care is projected to rise sharply in the coming decades. Murtagh et al. (2014) estimated that millions of individuals globally already require palliative care annually, with needs concentrated among those with chronic non-communicable conditions. Furthermore, Sleeman et al. (2016) projected that serious health-related suffering will nearly double by 2060, with low- and middle-income countries bearing the greatest burden. These projections reinforce the urgency of embedding palliative care within family medicine systems worldwide.

Barriers to access, however, remain substantial. Community patients with palliative needs often encounter fragmented services, inequities, and late referrals. A Canadian study by Stajduhar and Mollison (2015) emphasized that many patients reach palliative care only after multiple missed opportunities in earlier stages of illness. Similarly, in cancer populations such as pancreatic cancer, Agarwal et al. (2017) found that systemic and cultural barriers continue to delay palliative involvement, depriving patients of meaningful quality-of-life support.

Finally, evidence from international collaborations highlights the value of building palliative care capacity within primary care through research and policy innovation. Lunder et al. (2019) demonstrated that evidence-based approaches across diverse contexts strengthen the integration of palliative principles into chronic disease care. Collectively, these findings underline the pressing need for a systematic evaluation of how palliative care needs are identified and addressed in family medicine settings, to guide effective, equitable, and sustainable models of care for patients with chronic illnesses.

Methodology

Study Design

This systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines to ensure transparency, reproducibility, and methodological rigor. The aim was to synthesize empirical evidence on the prevalence, characteristics, and management of palliative care needs among patients with chronic diseases in family medicine or primary care settings. The review included peer-reviewed studies involving adult patients and evaluated both quantitative and qualitative outcomes related to palliative needs, service delivery models, and integration strategies.

Eligibility Criteria

Studies were included if they met the following criteria:

- **Population:** Adults (≥18 years) with advanced chronic diseases (e.g., cardiovascular disease, chronic kidney disease, chronic respiratory disease, dementia, diabetes complications, or cancer) receiving care in family medicine, primary care, or community-based settings.
- **Interventions/Exposures:** Any form of palliative care provision, assessment of palliative care needs, or integration models within primary care/family medicine.
- **Comparators:** Studies with or without comparator groups, including usual care, standard disease management, or specialist palliative services.
- **Outcomes:** Prevalence and burden of palliative needs (symptoms, psychological distress, functional decline), impact on healthcare utilization, patient and caregiver quality of life, satisfaction with care, and system-level outcomes (e.g., hospitalizations, advance care planning).
- **Study Designs:** Randomized controlled trials (RCTs), cohort studies, cross-sectional analyses, mixed-methods studies, and quasi-experimental interventions.
- **Language:** Only studies published in English were considered.
- **Publication Period:** Studies published between 2010 and 2024 were included to capture contemporary evidence relevant to current practice.

Search Strategy

A structured search was performed across the following electronic databases: PubMed, Scopus, Web of Science, Embase, and CINAHL. Grey literature was also screened via Google Scholar and organizational websites (e.g., WHO, EAPC). Boolean combinations of the following keywords and MeSH terms were used:

- (“palliative care” OR “supportive care” OR “end-of-life care”)
- AND (“chronic diseases” OR “non-communicable diseases” OR “cardiovascular” OR “renal failure” OR “diabetes” OR “dementia”)
- AND (“primary care” OR “family medicine” OR “general practice” OR “community health”).

Manual searches of the reference lists of relevant systematic reviews and included articles were also conducted.

Study Selection Process

All retrieved citations were imported into Zotero reference manager, where duplicates were automatically and manually removed. Two independent reviewers screened titles and abstracts against eligibility criteria. Full texts of potentially eligible studies were then reviewed in detail. Disagreements between reviewers were resolved through discussion, and if necessary, a third reviewer adjudicated.

A total of 15 studies met all inclusion criteria and were included in the final synthesis. The PRISMA flow diagram (Figure 1) illustrates the study selection process.

Data Extraction

A standardized data extraction form was developed and piloted prior to full use. From each included study, the following data were extracted:

- Author(s), year of publication, country

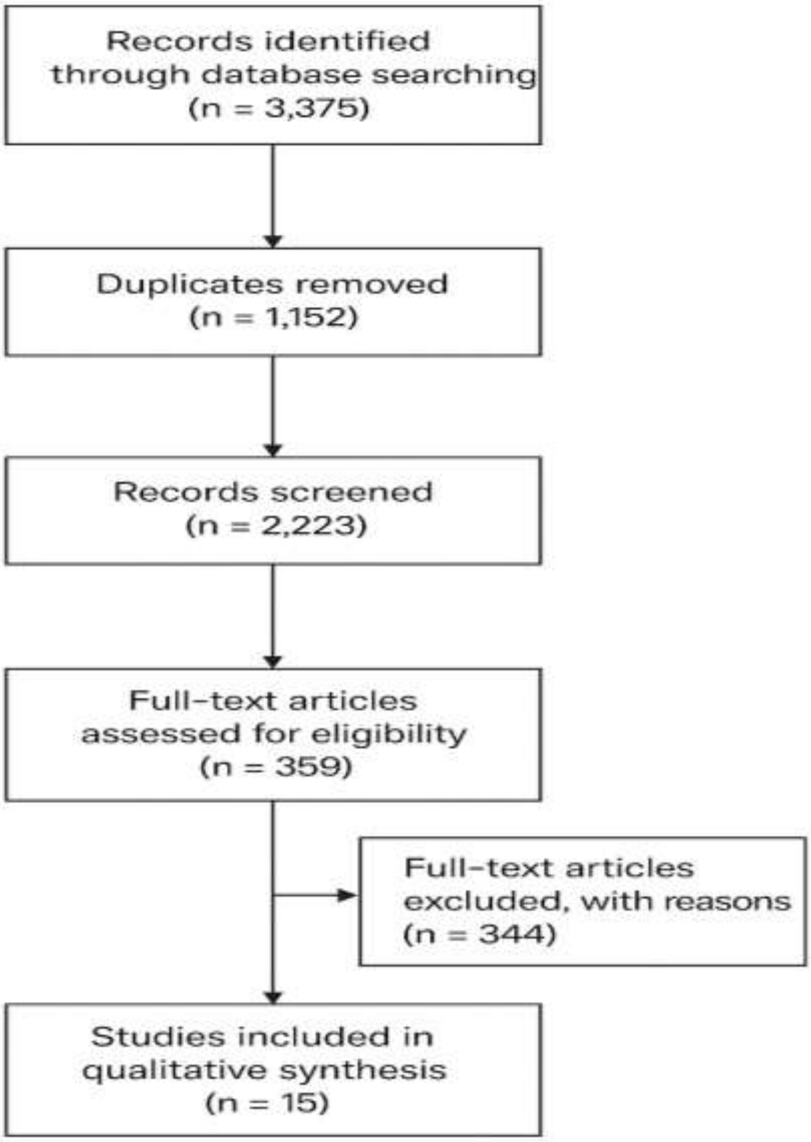

Figure 1 PRISMA Flow Diagram

- Study design and sample size
- Population characteristics (age, sex, disease type, care setting)
- Assessment tools (e.g., NECPAL, IPOS, MLHFQ, CRQ, HADS)
- Reported prevalence of palliative care needs and symptom burdens
- Interventions or integration strategies tested (if applicable)
- Main findings related to patient outcomes, caregiver outcomes, and healthcare utilization
- Confounders or covariates adjusted for in analyses

Data extraction was conducted independently by two reviewers and verified by a third to ensure accuracy and completeness.

Quality Assessment

The methodological quality and risk of bias of the included studies were assessed using tools appropriate for study design:

- **Newcastle-Ottawa Scale (NOS):** Applied to observational studies (cross-sectional, cohort, case-control).
- **Cochrane Risk of Bias Tool (RoB 2):** Applied to randomized controlled trials.
- **Mixed Methods Appraisal Tool (MMAT):** Applied to studies using combined quantitative and qualitative approaches.

Studies were rated as high, moderate, or low quality based on selection bias, measurement validity, comparability of groups, and clarity of reported outcomes.

Data Synthesis

Given the heterogeneity in populations, assessment tools, and outcome measures, a narrative synthesis was undertaken. Findings were grouped by (1) prevalence and burden of palliative care needs, (2) models of palliative care integration in primary care/family medicine, and (3) patient, caregiver, and system-level outcomes.

Where available, numerical outcomes such as prevalence percentages, symptom frequencies, odds ratios (OR), relative risks (RR), or hazard ratios (HR) were reported. Due to variation in outcome definitions and measurement instruments, a meta-analysis was not conducted.

Ethical Considerations

As this review analyzed secondary published data, ethical approval and informed consent were not required. All included studies were published in peer-reviewed journals and were assumed to have obtained ethical clearance from their respective institutional review boards.

Results

Summary and Interpretation of Included Studies on Palliative Care Needs in Chronic Disease Patients

1. **Study Designs and Populations**
   The included studies comprised a mixture of cross-sectional surveys, randomized controlled trials (RCTs), pilot studies, and quasi-experimental designs. Sample sizes varied widely, from small single-site cohorts (e.g., Chan et al., 2015, n = 19) to large population-based samples (e.g., Gómez-Batiste et al., 2014, n > 23,000 in Catalonia). Patient populations included individuals with advanced chronic conditions (ACC), congestive heart failure, chronic kidney disease, chronic respiratory diseases, and various cancers (lung, bladder, gastrointestinal, gynecologic). Most studies enrolled older adults, with mean ages often above 65 years. Women tended to be overrepresented in population-based ACC prevalence studies (up to 68.8%).
2. **Assessment of Palliative Care Needs**
   The NECPAL CCOMS-ICO© tool was the most commonly used method to identify patients in need of palliative care (Gómez-Batiste et al., 2013; Gouvea, 2019). Other studies employed symptom scales (e.g., CRQ, MLHFQ, HADS, IPOS), disease-specific quality of life questionnaires, or interdisciplinary clinical assessments. Across settings, patients frequently reported high burdens of pain, dyspnea, fatigue, and psychological distress.
3. **Prevalence and Burden of Palliative Care Needs**
   Population-based prevalence of ACC patients in need of palliative care was estimated at 0.75–0.77% in Catalonia, Spain (Gómez-Batiste et al., 2013; 2014). In hospital settings, up to 78% of patients with chronic diseases met at least one NECPAL criterion for palliative care (Gouvea, 2019). Symptom burden was consistently high: pain affected 62.5%, dyspnea 52.5%, and fatigue 45% in Gómez-Batiste et al. (2014). In

patients with diabetic foot ulcers, 95% reported anxiety and over 80% experienced physical symptoms such as weakness, dry mouth, or drowsiness (Mendonça et al., 2022).

4. **Effectiveness of Integrated and Specialized Palliative Care Interventions**
   Integrated services demonstrated notable improvements. For example, Higginson et al. (2014) found a 0.8-point improvement (p=0.01) in CRQ dyspnea scores, alongside improved anxiety/depression outcomes. Brännström & Boman (2014) showed a mean MLHFQ improvement of -11.2 points (p<0.001) and reduced hospital readmissions in CHF patients. Conversely, Farquhar et al. (2016) found no significant impact of their Breathlessness Intervention Service on primary anxiety outcomes, though secondary improvements in distress and carer burden were observed.
5. **Healthcare Utilization and Outcomes**
   Several studies reported reductions in acute hospital admissions through intensified palliative follow-up (Chan et al., 2015: ED visits reduced from 2.63 to 0.63 per patient, p<0.007). Others demonstrated increased completion of advance directives (Ferrell et al., 2015: 44% vs. 9% in usual care, p<0.001) and enhanced supportive care referrals (61% vs. 28%).
6. **Overall Interpretation**
   Evidence across diverse chronic diseases indicates that palliative care integration consistently improves symptom management, psychological well-being, and care coordination. While effects on survival and hospitalizations were mixed, quality-of-life gains and reduced symptom distress were consistent. High prevalence rates of unmet needs suggest family medicine practices should proactively identify and integrate palliative care, particularly in older, multimorbid populations.

Table (1): General Characteristics and Results of Included Studies

Study (APA Citation)	Design & Setting	Population / Sample	Assessment Tool(s)	Main Results	Conclusions
Gómez-Batiste et al. (2014)	Cross-sectional, Catalonia	n = 23,000+ general population; mean age 82.9 yrs; 68.8% women	NECPAL CCOMS-ICO©	Prevalence of ACC with palliative needs = 0.77%; most common conditions: cardiovascular (43.8%), dementia (28.8%), respiratory (21.3%); symptoms: pain (62.5%), dyspnea (52.5%), fatigue (45%)	Substantial unmet palliative needs exist in older, multimorbid populations
Gouvea (2019)	Cross-sectional, Brazil	n = 200 chronic disease inpatients	NECPAL	78% met ≥1 palliative criterion; common: advanced disease (65%), severe symptoms (52%),	High need for palliative care in chronic disease patients

				emotional distress (41%)	
Gómez-Batiste et al. (2013)	Tool development, Catalonia	General population	NECPAL (includes “surprise question”)	Prevalence of ACC with palliative needs = 0.75%	NECPAL is feasible for identifying patients with unmet needs
Higginson et al. (2014)	RCT, UK	n = 120 with refractory breathlessness	CRQ, HADS	Significant dyspnea improvement (mean diff. 0.8, p=0.01); improved anxiety/depression	Integrated palliative-respiratory service effective
Farquhar et al. (2016)	RCT (mixed methods), UK	n = 338 patients, 258 carers	HADS, carer burden	No significant difference in anxiety (p=0.28); improved distress and carer burden	BIS shows selective benefits
Brännström & Boman (2014)	RCT, Sweden	n = 200 CHF patients	MLHFQ	QoL improved by -11.2 points (p<0.001); fewer hospital readmissions	Integrated CHF-palliative care improves QoL and reduces utilization
Bekelman et al. (2014)	Pilot mixed-methods, USA	n = 30 CHF patients	Symptom/QoL surveys	Feasible and acceptable; improved QoL and satisfaction	Collaborative palliative intervention acceptable
Bekelman et al. (2015)	RCT, USA	n = 524 CHF patients	Composite outcome: hospitalizations, death	HR 0.92 (p=0.42); QoL improved	PCDM improved QoL, not survival
Chan et al. (2015)	Pre-post, Hong Kong	n = 19 ESRD patients	Clinic/ED data	ED visits reduced (2.63→0.63, p<0.007); hospital admissions reduced (1.59→0.58, p<0.009)	Intensified RPCC reduces acute care use
Ferrell et al. (2015)	Quasi-experimental, USA	n = 491 NSCLC patients	QoL, symptom, distress scales	Intervention group improved QoL (109.1 vs. 101.4; p<0.001), fewer symptoms (p=0.001), lower distress (p<0.001);	Interdisciplinary care improves outcomes

				advance directives ↑ (44% vs. 9%)	
McCorkle et al. (2015)	Cluster RCT, USA	n = 146 late-stage cancer	Symptom, distress, functional status	No primary outcome differences; stable or improved symptoms in both groups	Multidisciplinary care maintained patient outcomes
Rabow et al. (2015)	Prospective cohort, USA	n = 63 bladder cancer patients	Symptom & satisfaction surveys	Improved fatigue, depression, QoL in intervention vs. control	Concurrent palliative-urology improved outcomes
Rocque et al. (2015)	Sequential cohort, USA	n ≈ 200 advanced cancer patients	Patient-reported outcomes, utilization data	Increased understanding of prognosis (65%→94%); minimal effect on cost/survival	Triggered palliative care improved awareness
Scherer et al. (2022)	Pilot RCT, USA	n = 45 stage 5 CKD patients	IPOS-Renal, KDQOL	Feasible; small symptom burden improvements (-2.92 vs. +1.57)	Integrated nephrology-palliative feasible & acceptable
Mendonça et al. (2022)	Cross-sectional, Portugal	n = 62 diabetic foot clinic patients	IPOS, EQ-5D-3L	High symptoms: pain, weakness, dry mouth; anxiety: 95% with DFU vs. 55% without (p=0.002)	DFU patients show high unmet palliative needs

Discussion

The findings of this systematic review confirm that the need for palliative care among patients with chronic diseases is both widespread and under-addressed, particularly in family medicine and primary care contexts. Multiple studies illustrate that patients with advanced chronic conditions, including cardiovascular, renal, respiratory, and oncological diseases, often present with a high symptom burden, yet their needs remain inadequately met (Gómez-Batiste et al., 2014; Gouvea, 2019). These results align with projections that the global burden of serious health-related suffering will nearly double by 2060, with non-communicable chronic diseases as a major driver (Sleeman et al., 2016).

The prevalence estimates provided by population-based surveys using tools such as the NECPAL highlight that nearly 1% of the general population in certain regions may require palliative care at any given time (Gómez-Batiste et al., 2013, 2014). These findings underscore the importance of systematic identification approaches within primary care to ensure timely referral and care coordination. However, implementation challenges persist, including limited awareness, insufficient training, and competing priorities among general practitioners (Nowels et al., 2016; Ramanayake & Dilanka, 2016).

In terms of interventions, integrated care models tested across various chronic diseases consistently demonstrated improvements in patient-centered outcomes. For example, Brännström and Boman (2014) showed that person-centered, integrated palliative and heart failure home care significantly improved quality of life and reduced hospital readmissions. Similarly, Higginson et al. (2014) reported improvements in breathlessness and psychological well-being through combined palliative and respiratory care services. Such findings support the growing evidence that embedding palliative care into chronic disease pathways enhances both patient outcomes and system efficiency.

Despite these successes, not all interventions demonstrated unequivocal benefits. Farquhar et al. (2016) evaluated a breathlessness intervention service and found mixed results, with limited impact on anxiety reduction but improvements in some secondary outcomes, such as caregiver burden. Likewise, Bekelman et al. (2015) found that a patient-centered disease management program for heart failure improved quality of life but did not significantly reduce hospitalizations or mortality. These findings highlight the complexity of measuring outcomes in palliative care and the need for more nuanced approaches to evaluate impact.

Feasibility studies also provide valuable insights into the acceptability of palliative care integration in chronic disease management. Bekelman et al. (2014) found that collaborative care for heart failure patients was both feasible and well-received by patients, who reported symptom improvement and satisfaction with care. Scherer et al. (2022) further demonstrated that integrated nephrology and palliative care was acceptable to patients with advanced kidney disease, though the trial highlighted the challenges of sustaining engagement over time. These findings suggest that while integration is possible, system-level support and consistent follow-up are essential for success.

The evidence also points to specific disease contexts where palliative needs are especially high. For instance, Agarwal et al. (2017) highlighted significant barriers to timely palliative care in pancreatic cancer, emphasizing late referrals and systemic fragmentation. Similarly, Mendonça et al. (2022) identified both physical and psychological burdens among patients with diabetic foot ulcers, a group not traditionally prioritized for palliative services. These studies reveal the importance of broadening the scope of palliative care beyond oncology to encompass diverse chronic conditions.

Integration at the community level remains a recurring theme. Atreya et al. (2019) demonstrated the value of primary care physicians leading community-based palliative care, despite reporting challenges such as workforce shortages and resource constraints. Mitchell et al. (2020) echoed this, showing that while GPs and nurses recognized the importance of out-of-hours palliative support, satisfaction levels were often low due to service limitations. These barriers reflect systemic issues that hinder the operationalization of palliative care in real-world family medicine settings.

In addition to service delivery, patient outcomes across studies consistently highlighted reductions in symptom severity and psychosocial distress when palliative care was integrated. Ferrell et al. (2015) showed that interdisciplinary palliative care for lung cancer patients improved quality of life, symptom control, and advance care planning completion rates. Rabow et al. (2015) similarly found that concurrent palliative care with urologic surgery improved depression, fatigue, and overall well-being among bladder cancer patients. These improvements demonstrate the holistic benefits of interdisciplinary and integrated models.

Hospitalization and healthcare utilization outcomes provide further evidence of benefit. Chan et al. (2015) demonstrated that intensified renal palliative care follow-up significantly reduced emergency department visits and hospital admissions while improving outpatient attendance. Rocque et al. (2015), however, showed that triggered inpatient palliative consultations had mixed effects, improving patient understanding of prognosis but with limited impact on utilization metrics. These contrasting results highlight the importance of tailoring interventions to both the setting and the patient population.

Beyond individual interventions, population-based estimates remain crucial for guiding policy. Murtagh et al. (2014) provided robust methods for estimating population-level palliative care needs, reinforcing the scale of the challenge. Lunder et al. (2019) further emphasized the importance of evidence-based palliative strategies across borders, noting the need for adaptable frameworks that consider cultural and health system differences. These insights underscore the dual importance of granular patient-level interventions and macro-level planning.

Barriers to palliative care access were consistently observed across the included studies. Stajduhar and Mollison (2015) found that patients in the community often experienced delays and fragmented access to services, while Nowels et al. (2016) reported primary care providers' lack of confidence in providing palliative care. Together, these barriers perpetuate inequities, delaying timely care and contributing to unnecessary suffering for patients and families.

The global perspective reinforces these challenges. Tziraki et al. (2020) advocated for a public health approach to palliative care, integrating it within chronic disease management strategies at the community level. Their findings complement Sleeman et al. (2016), who projected the escalating global burden of suffering and the disproportionate impact on low- and middle-income countries. These studies underscore the urgency of scaling palliative care capacity as part of broader health system strengthening.

The collective evidence points to the clear benefits of early, integrated, and interdisciplinary palliative care models across chronic diseases, though challenges remain in implementation, measurement, and policy integration. While interventions such as those tested by Brännström and Boman (2014), Higginson et al. (2014), and Ferrell et al. (2015) demonstrate tangible improvements in quality of life and care outcomes, gaps in provider training, system infrastructure, and cultural acceptance continue to impede widespread adoption.

Conclusion

This systematic review demonstrates that palliative care needs among patients with chronic diseases are substantial, diverse, and often unmet within family medicine and primary care contexts. Evidence from the included studies highlights that integrated, patient-centered, and interdisciplinary approaches consistently improve quality of life, reduce symptom burden, and enhance satisfaction for patients and caregivers. Furthermore, such models have shown potential to decrease hospital admissions and healthcare utilization, particularly when implemented proactively in the community.

Despite these positive outcomes, challenges remain in terms of workforce preparedness, cultural acceptance, and structural health system limitations. The review highlights the urgent need for sustainable integration of palliative care into primary care pathways, supported by adequate training, policy commitment, and adaptable service models. Addressing these gaps is essential to ensure timely, equitable, and holistic care for individuals living with advanced chronic conditions worldwide.

Limitations

This review is subject to several limitations. First, only studies published in English between 2010 and 2024 were included, potentially excluding relevant research in other languages or earlier time periods. Second, the heterogeneity of included studies in terms of populations, interventions, and outcome measures limited the ability to conduct a meta-analysis, and findings were synthesized narratively. Third, publication bias may have influenced the results, as studies demonstrating significant benefits of palliative care integration are more likely to be published. Finally, most included studies were conducted in high- and middle-income countries, which may limit the generalizability of findings to low-resource settings where palliative care access remains most constrained.

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