

# Barriers and Facilitators of Early Palliative Care in the Trajectory of People Living with Chronic Condition: A Mini Review Using Socio-ecological Framework to Inform Public Health Strategy

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**Abstract:** The increasing incidence of chronic conditions on a global scale requires a comprehensive approach to palliative care, which is recognized as an essential element of the continuum of care for people with life-threatening conditions. It has been argued that the integration of early palliative care for people with chronic conditions is beneficial. Nevertheless, barriers to integrating early palliative care have been extensively not reviewed. This review aimed to explore the barriers and facilitators of integrating early palliative care for people living with chronic conditions, employing a socio-ecological framework to provide a critical understanding of the influencing factors at multiple levels. The method was a mini review. This review emphasizes the complex and diverse factors that either hinder or facilitate progress in four areas: individual (such as gaps in knowledge and emotional reactions), interpersonal (such as support from family caregiver), healthcare professionals and policy (such as barriers in education, guidelines, and collaboration among professionals), and community (such as societal knowledge and attitudes). Each level presents unique challenges and opportunities for enhancing early palliative care integration, from addressing misconceptions and fears at the individual level, to fostering supportive policies and community awareness. In conclusion, the effective management of early palliative care requires a comprehensive strategy that spans various dimensions, including educational initiatives, policy adjustments, and active involvements of the community. Healthcare systems are supposed to enhance the integration of early palliative care into the trajectory of chronic conditions and enhance the quality of life of affected persons and their families by recognizing and addressing the socio-ecological elements involved.

**Keywords:** barrier, early palliative care, facilitator, people living with chronic condition

## Introduction

The prevalence of chronic conditions and life-limiting illnesses is increasing due to the aging and expanding global population.<sup>1</sup> At the global level, the incidence of chronic illnesses that impose limitations on life, including cardiovascular diseases, cancer, respiratory diseases, and diabetes, has exceeded that of infectious diseases, establishing them as the primary cause of mortality among adults.<sup>2</sup> According to the Lancet Commission on palliative care and pain reduction, over 61 million peoples suffer from chronic health issues each year, which might greatly benefit from palliative care.<sup>3</sup> These conditions encompassed dementia, cancer, cardiovascular diseases, liver cirrhosis, chronic obstructive pulmonary disease, diabetes, HIV/AIDS, kidney failure, multiple sclerosis, and Parkinson's disease.<sup>4</sup> The prominence of palliative

care as part of the trajectory of care for people with chronic conditions in global healthcare is expected to grow as an essential part of the global response on increasing the rising prevalence of chronic illness and its early availability during the trajectory of a disease.<sup>3,5-7</sup>

Palliative care is a holistic approach to address the needs of patients across all age groups facing substantial distress as a result of illness or injury. This distress impacts all aspects of well-being, including physical, social, spiritual, and emotional dimensions.<sup>8</sup> This type of care involves a healthcare collaboration to reduce symptoms such as the pain and anxiety of people with serious, life-threatening illnesses. The World Health Organization (WHO) acknowledges palliative care as advantageous for patients with both malignant and non-malignant illnesses.<sup>9</sup> Palliative care aims to alleviate distress and enhance the overall well-being of patients and their family caregivers.

In recent years the term “early palliative care” was initiated earlier in the illness trajectory and not limited to the very advanced and terminal stages of the illness.<sup>10</sup> Early palliative care is administered in conjunction with disease modifying treatment such as chemotherapy, heart failure treatment, and renal replacement.<sup>10-12</sup> While the 2002 WHO definition highlighted the need for early intervention to enhance quality of life, conclusive evidence supporting this care model did not arise until nearly ten years later.<sup>13</sup> Several studies reported that patients who received early specialized palliative care exhibited enhanced symptoms, quality of life, survival rate, and satisfaction with care compared to those who received conventional care.<sup>14-16</sup>

However, there is a significant deficiency in the literature regarding early palliative care for patients with chronic conditions. Despite supporting data for the advantages of including palliative care at an early stage of the disease, there is still a significant gap between the desired integration of these services and existing healthcare practices. This gap can be attributed to several factors, including a limited understanding among healthcare practitioners regarding the optimal time for initiating palliative care and variations in referral procedures.<sup>17</sup> Furthermore, the timely provision of palliative services is a barrier to societal and patient-related challenges, including the prevailing misunderstanding that palliative care is synonymous with end-of-life care.<sup>17</sup> In order to thoroughly explore barriers or facilitator factors in the provision of early palliative care, it is imperative to have a full understanding of the many challenges in integrating early palliative care into the trajectory of care for chronic life-limited diseases. Therefore, this review aimed to explore the barriers to and facilitators of integrating early palliative care using a socio-ecological framework.

The social ecological model is a comprehensive framework that conceptualizes health as influenced by a wide range of factors. The model posits that health is shaped by dynamic interactions between individuals, their groups, or communities, and their physical, social, and political environments.<sup>18,19</sup> The social ecological model offers a comprehensive framework for understanding the multifaceted interplay of factors that influence health outcomes. This model posits that health is affected by multiple levels of influence encompassing individual behaviors, interpersonal relationships, community environments, and broader societal policies. This model facilitates a holistic approach to address health issues.

## Data Source, Search, and Extraction

This was performed using a mini-review. A mini-review is a concise literature review that addresses a specific clinical question by summarizing and critically appraising the most relevant studies, using explicit inclusion criteria and a reproducible search strategy.<sup>20</sup> Unlike full systematic reviews, which aim to synthesize all valid evidence on a subject, mini-reviews apply arbitrary limits to the scope of the search, making the volume of material manageable within limited resources.<sup>20</sup> Relevant articles were searched using PubMed, Scopus, and Cochrane Library. The Boolean operator, which included: “Palliative Care” OR “supportive care” AND “Early palliative” OR “Early Intervention” OR “Early Stage” AND “barriers” AND “facilitators”. Inclusion criteria included articles of this review that specifically investigated barrier and facilitator factors of early palliative care for chronic conditions faced by patients and/or their caregivers and published in peer-reviewed journals in English. The exclusion criteria were studies focused solely on end-of-life care, review studies, non-peer-reviewed sources, and non-English publications. The reviews were manually extracted using table extraction and synthesized through thematic analysis. The review strictly identified the factors influencing early palliative care based on the included studies. Recommendations to address these barriers and facilitators were synthesized by the authors using additional literature to provide a strategy for improvement.

## Barrier and Facilitator of Integrating Early Palliative Care

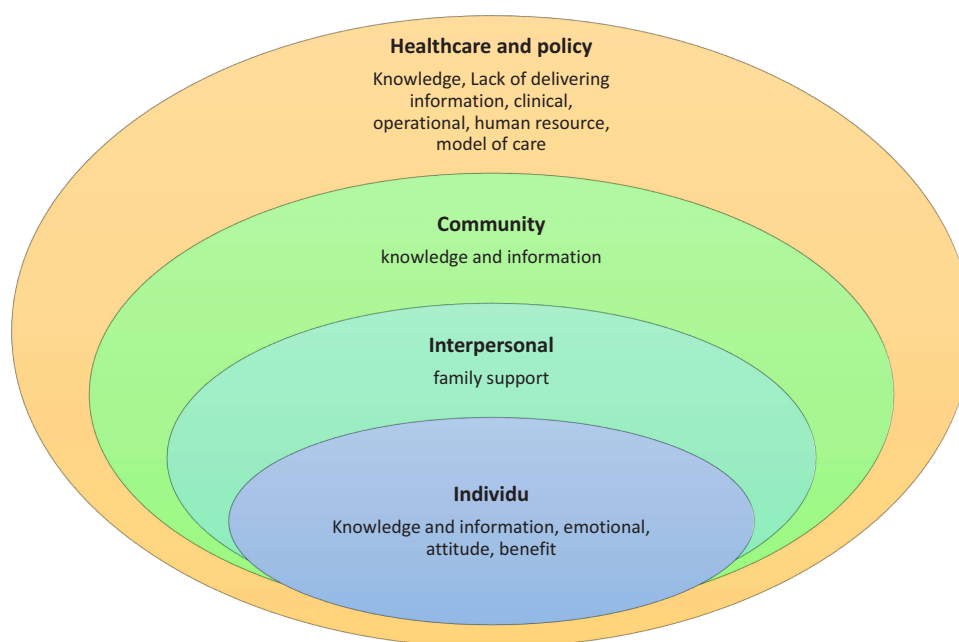
This review provides an overview of the structure and extent of the categories, subthemes, and themes that explore barriers and facilitators of early palliative care in patients with chronic conditions. This review discusses various barriers and facilitators that influence the integration of early palliative care in patients with chronic conditions. The analysis was organized into four interrelated levels: community, healthcare professionals, policy, and individuals (see [Figure 1](#) and [Table 1](#)).

The study population of the included articles included family caregivers and patients with carcinoma, cancer, and chronic obstructive pulmonary disease (COPD). Articles involving participants from Italy, Canada, Germany, the USA, and Belgium were published between 2016 and 2023. These studies focused on the barriers and facilitators of early palliative care in oncology and chronic obstructive pulmonary disease (COPD).

### Individual Factor

Exploring individual characteristics reveals a multifaceted interaction between information, emotional reactions, attitudes, and perceived advantages, which may hinder or facilitate early involvement in palliative care. There is a prevalent misunderstanding that combines early palliative care with end-of-life care, which barriers early involvement.<sup>21</sup> Nevertheless, it has been suggested that the distinction between early and late palliative care may contribute to enhanced awareness and recognition.<sup>21</sup> The presence of a clear understanding of the significance and advantages of palliative care has been recognized as a facilitator.<sup>17,21</sup> The significant disparity in understanding and widespread misunderstandings regarding palliative care highlights the need for educational programs customized for the general public and specific patient populations. These measures have the potential to provide understanding of the extent and advantages of palliative care, thereby differentiating it from end-of-life care. Addressing worries and rectifying misconceptions can cultivate a more receptive mindset toward early palliative care.<sup>17,21</sup>

The presence of fear and avoidance responses was identified as a common barrier leading to feelings of isolation among family caregivers in their caring responsibilities.<sup>21,22</sup> Emotional barriers such as dread and the sense of isolation experienced in caregiving underscore the imperative requirement for extensive support systems. According to Preisler et al<sup>22</sup> and Bandiero et al<sup>21</sup> these systems need to do more than just give patients and their family information. They also need to offer emotional and psychosocial support so that people can make good decisions regarding palliative care and the complicated nature of their chronic conditions.



**Figure 1** Barriers and facilitators of early palliative care. Data from these studies.<sup>17,21–24</sup>

**Table 1** Barrier and Facilitator of Early Palliative Care

Level	Theme	Category	Study
Individual	Knowledge and Information	B: Lack of knowledge about palliative care	Bandieri et al (2023) <sup>21</sup>
		B: Misconception about early palliative care with end-of-life care	Bandieri et al (2023) <sup>21</sup>
		F: Awareness difference between early and late palliative care	Bandieri et al (2023) <sup>21</sup>
		F: Palliative care meaning and benefit	Hannon et al (2016); <sup>17</sup> Bandieri et al (2023) <sup>21</sup>
	Emotional	B: Fear and avoid reaction	Bandieri et al (2023) <sup>21</sup>
		B: Being alone in taking care	Preisler et al (2018) <sup>22</sup>
	Attitude	B: Lack of treatment adherence	Iyer et al (2020) <sup>23</sup>
		B: Patient readiness	Dhollander et al (2018) <sup>24</sup>
	Benefit	B: Lack of perceived benefits due to minimal symptom reporting by the patients	Hannon et al (2016) <sup>21</sup>
	Interpersonal	Family support	F: Involving a family caregiver
Healthcare professionals and policy	Education	B: Misconception of palliative care and end-of-life care	Iyer et al (2020); <sup>23</sup> Bandieri et al (2023) <sup>21</sup>
		B: Lack of HCP team knowledge of oncology	Dhollander et al (2018); <sup>24</sup> Bandieri et al (2023) <sup>21</sup>
		B: Lack of HCP team knowledge of on referral procedures	Dhollander et al (2018) <sup>24</sup>
		B: Lack of interprofessional collaboration	Dhollander et al (2018) <sup>24</sup>
		F: Train specialist doctor in primary care	Iyer et al (2020) <sup>23</sup>
		F: Clearly define palliative care	Iyer et al (2020) <sup>23</sup>
	Lack of delivering information	B: Inadequate delivery of procedure information	Preisler et al (2018) <sup>22</sup>
		B: Inadequate delivery of diagnosis and treatment information	Preisler et al (2018) <sup>22</sup>
	Clinician barrier	B: Unclear timing	Iyer et al (2020) <sup>23</sup>
		B: Fear of giving opioids for symptom management	Iyer et al (2020) <sup>23</sup>
		B: Complex management with exacerbation and complex symptom	Iyer et al (2020) <sup>23</sup>
		F: Consensus on referral criteria	Iyer et al (2020) <sup>23</sup>
	Operational	B: Limited time available for in-clinic palliative care provision	Iyer et al (2020) <sup>23</sup>
		B: Reimburse	Iyer et al (2020) <sup>23</sup>
		B: Lack of financial resource	Dhollander et al (2018) <sup>24</sup>
	Human resources	B: Workforce shortage	Iyer et al (2020) <sup>23</sup>
		F: Increase the number of palliative care provider	Iyer et al (2020) <sup>23</sup>
	Model of care	F: Increase multidisciplinary healthcare that provides palliative care	Iyer et al (2020) <sup>23</sup>
		F: Develop a delivery care model of palliative care	Iyer et al (2020) <sup>23</sup>
	Community	Knowledge and Information	B: Social perception of palliative care
B: Lack of social information			Bandieri et al (2023) <sup>21</sup>

**Abbreviations:** B, Barrier; F, Facilitator; HCP, Healthcare professional.

Iyer et al<sup>23</sup> and Dhollander et al<sup>24</sup> have identified non-adherence to treatment and lack of readiness to adopt palliative care as individual barriers. The absence of perceived advantages, particularly in symptom management, was seen as a barrier.<sup>17</sup> The patient's perspective toward treatment and care. The results pertaining to attitudes, such as non-adherence to treatment and insufficient preparedness for palliative care, indicate that the implementation of individualized communication strategies and patient education is crucial. Implementing such an approach could make it easier for treatment goals to be consistent with patients' values and preferences, making treatment more acceptable, and encouraging adherence.<sup>23,24</sup> It is necessary to use a two-pronged strategy to compensate for the lack of perceived benefits. As part of this approach, patients learn more about how to deal with their symptoms and the benefits of palliative care. It is also important to emphasize patient-centered care tailored to each person's values and preferences.<sup>17</sup>

## Interpersonal Factor

The participation of family caregivers is important to enable patients to seek early palliative care services.<sup>23</sup> The importance of family support in early palliative care underlines the need for effective family involvement approaches. This strategy helps people with palliative care progress and recognizes the role of caregivers in facilitating palliative care access and involvement.<sup>25</sup> Family caregivers need knowledge and resources to navigate the healthcare system. Educational campaigns for caregivers can explain palliative care's difficulties, benefits, and differences from end-of-life care, reducing resistance and encouraging early involvement.<sup>26</sup> In family-centered care, healthcare practitioners must actively involve family caregivers in treatment.<sup>27,28</sup> These methods can ensure complete care planning and decision-making that considers patient and family choices. Moreover, collaboration can help to integrate palliative care into a patient's comprehensive treatment plan. Support networks help to reduce emotional and physical strain in family care.

## Community Factor

Engagement in palliative care is significantly influenced by societal perceptions and transmission of information at the community level. One significant barrier in the field of palliative care is social perception, which is frequently stigmatized or misunderstood by the community.<sup>24</sup> Moreover, a widespread lack of social knowledge on palliative care intensifies this problem, which lead to a significant segment of the population being uninformed or misunderstanding the essence and advantages of palliative care.<sup>21</sup> The combination of these elements together influences the community-level context, which can either barrier or facilitate patients' and families' choices to pursue early palliative care treatments.<sup>27,28</sup> To tackle the difficulties at the community level, it is essential to adopt a strategy that focuses on changing societal attitudes and improving the spread of information regarding palliative care. The stigma and misunderstandings associated with palliative care within the community underscore the need for public education campaigns and community involvement.<sup>13,15</sup> Efforts should be directed toward elucidating that the concept of palliative care should not be associated only with end-of-life care. Instead, efforts should be made to explain what it means and how it can improve the health of people with chronic conditions and their families.<sup>6,7</sup> Effective techniques for expanding understanding and acceptance of palliative care include actively involving community leaders, utilizing social media platforms, and integrating palliative care education into public health programs.<sup>17,22</sup> In addition, the establishment of easily accessible resources and information channels that offer precise and reliable information regarding palliative care services has the potential to empower communities, promote well-informed decision-making, and ultimately foster increased involvement with palliative care during the initial phases of chronic conditions management.<sup>4</sup>

## Healthcare Professionals and Policy Factor

The domains of healthcare professionals and policy were combined to reflect the inherent interconnectedness between professional practices and policy frameworks in the context of early palliative care integration. In practice, healthcare professionals operate within the constraints and guidance of existing policies, and policy changes can directly impact clinical practice.

The complex interplay of educational barriers, knowledge gaps, and cooperation challenges within the healthcare professionals and policy domain greatly influences the early integration of palliative care for people with chronic conditions.<sup>21-24</sup> The presence of misconceptions among healthcare professionals, who mistakenly associate palliative

care exclusively with end-of-life situations, and a significant lack of awareness within healthcare teams regarding cancer and referral procedures. These barriers are worsened by the insufficiency of interprofessional collaboration, a critical factor in the comprehensive administration of palliative care.<sup>23</sup> Moreover, implementation of early palliative care in patients with COPD is challenging due to its unpredictable illness trajectory,<sup>23</sup> unlike the more predictable progression seen in many cancers. This unpredictability makes it difficult to determine the optimal timing for palliative care initiation, as patients with COPD may experience sudden exacerbations and fluctuations in their condition. In contrast, the trajectory of many cancers follows a more predictable path, allowing for earlier and more planned integration of palliative care services.

Nevertheless, certain factors that could potentially enhance the process have been recognized, such as the need to provide training to experts in primary care and the establishment of a precise definition of palliative care within healthcare regulations.<sup>23</sup> It is essential to incorporate these components in order to effectively navigate the complexities of integrating palliative care. However, the palliative care approach calls on training for all health care professionals and providers across primary care (not just primary care experts) and across all other specialty areas, also across cancer and non-cancer illnesses.<sup>29</sup> This highlights the urgent need for educational reform, policy modifications, and improved collaborative approaches among healthcare professionals to create a favorable setting for the timely and efficient provision of palliative care services.<sup>13,15</sup> Palliative care education continues to be a critical approach to addressing the needs of patients with palliative care requirements. Curriculum gaps and learning requirements associated with palliative care have been identified throughout the learning cycle of healthcare professionals, including undergraduate and postgraduate training, as well as continuing education for clinicians in practice.<sup>30</sup>

## Comparison of Barriers and Facilitators in Early Palliative Care versus Palliative and End-of-Life Care in General

This review highlights that the major barrier to the provision of early palliative care is misconceptions among healthcare professionals, patients, and their family caregivers, who mistakenly associate palliative care exclusively with end-of-life situations. Since early palliative care is provided during the early phase of the disease trajectory when symptoms are minimal, the absence of perceived benefits, particularly in symptom management, has been a major barrier.<sup>17</sup> Previous reviews, in the context of palliative care in general, have highlighted that Lack of capacity, practical issues including multidisciplinary collaboration, culture, and communication or discussions about patients' and their family caregivers' values, wishes, and needs are major barriers.<sup>31–33</sup> Several review concluded that barriers for palliative clinicians are related to several factors, including prognostic uncertainty or disease trajectory, the risk of taking away hope, inadequate education or lack of competence, emotional discomfort for patients and their family caregivers, lack of clinical guidelines, uncertainty about responsibilities and roles, and precondition of communications (such as insufficient time and privacy).<sup>31,33</sup> The findings of previous reviews align with those of the present review, which also underscores concerns within the healthcare professional and policy scope.

The barriers to palliative care at the policy level, in the context of palliative care in general, highlight the presence of pragmatic care and funding uncertainty. Palliative care service fragmentation is the most barrier in providing quality, person centered care for patients with a life limiting illness in Australia.<sup>34</sup> Additionally, International sources of long-term support, such as multinational and bilateral donor organizations, require formal cooperation with governments as a political requirement.<sup>35</sup> The allocation of external financing to NGOs relies on the government's willingness to allocate funds to NGOs.<sup>35</sup> Palliative care organizations face limited opportunities to directly receive support from international funding agencies because NGOs primarily prioritize advocating for palliative care as a human right, whereas funding agencies are more likely towards economic matters rather than human rights.<sup>36,37</sup>

This present review highlights major factors that facilitate improving the provision of early palliative care, including a clear understanding of the significance and advantages of palliative care, an involved family caregiver, referral guidelines, an increased number of palliative care providers, training and education, and interprofessional collaboration. The previous review that reviewed at how palliative care is usually given has a lot in common with this result. The previous review regarding facilitator factors in provision in palliative care, in a regular context, included increasing

community comfort in discussing death and dying, community understanding about palliative care, and upskilling health and social care providers to improve timely initiation of palliative care. The facilitator factors included previous experience, good relationships, communication and information provision, person-centered care, improved advance care planning, predictability of the disease trajectory, and demographics (eg, young age and high literacy).<sup>31–33</sup>

## Implication for Public Health Strategy

Patients with chronic life-limiting conditions have complex needs that emerge at different stages of their illness.<sup>38</sup> They often receive care from various healthcare sectors, including hospitals, residential facilities, and home care.<sup>38</sup> Effective care for these patients necessitates integrating palliative care principles into all care settings, regardless of whether specialized palliative services are available.<sup>38</sup> This integration, known as a “palliative approach”, involves incorporating patient- and family-centered care focused on quality of life into the treatment provided across different healthcare sectors throughout the illness trajectory.<sup>38–40</sup>

According to the present review, barriers and facilitators arise at the socio-ecological level. It aligns with the palliative care approach and requires a public health strategy to address barriers at all levels. Implementing a public health strategy is crucial for translating new knowledge into evidence-based, cost-effective, early palliative care interventions accessible to the entire population.<sup>41</sup> For effectiveness, a public health strategy must be integrated at all healthcare system levels and supported by the community through collective action.<sup>41</sup> The World Health Organization (WHO) pioneered a public health strategy to integrate palliative care into existing healthcare systems, providing guidelines for governments on implementing national palliative care and, in particular, cancer control programs, positioning palliative care as one of the four pillars of comprehensive cancer care.<sup>42,43</sup> Effective integration requires addressing the four components of the WHO Public Health Model: 1) appropriate policies, 2) adequate drug availability, 3) education of healthcare workers and the public, and 4) implementation of palliative care services at all levels. The WHO’s comprehensive guidance ensures that early palliative care becomes an essential component of national health initiatives, supporting patients with chronic conditions from the time of diagnosis onward. This integrated palliative integration in public health is crucial for providing holistic, “whole person care” and achieving quality and continuous care at the end of life through partnerships with community and civic organizations.<sup>38</sup>

Public health palliative care recognizes that death, dying, loss, and caregiving are inherently social experiences that impact everyone.<sup>44</sup> This approach emphasizes the importance of social ecology, where relationships and connections provide meaning and purpose, which are essential at biological, psychological, and spiritual levels.<sup>44</sup> Public health palliative care expands traditional palliative models to include not only the individual or patient but also their care networks, promoting supportive relationships within these networks. It aims to integrate clinical palliative care with public health initiatives, moving beyond a narrow focus on symptom management to address broader social concerns.<sup>44</sup> A public health approach to palliative care involves community development, prevention, harm reduction, and early intervention, focusing on health promotion for all involved in death, dying, loss, and caregiving. This approach addresses social morbidities associated with palliative care, such as loneliness, stigma, and substance abuse, which can have long-lasting effects on patients and their caregivers.<sup>44</sup>

## Strength and Limitation

This review highlights the strengths and limitations of the presented evidence. The strengths of this review include the use of the socio-ecological model, providing a holistic view of the factors affecting early palliative care, encompassing individual, interpersonal, community, and policy levels. It includes diverse perspectives from patients, caregivers, and healthcare professionals, and offers a multifaceted understanding of barriers and facilitators.

Despite these strengths, this study has several limitations are essential to consider. These studies were conducted in middle-to high-income countries (Italy, Canada, Germany, the USA, and Belgium), potentially lacking global perspectives and variations in healthcare systems, especially in low-to middle-income countries. A previous study concluded that Asian culture in treatment is more aggressive than in Western countries<sup>45</sup> is Predominantly qualitative in design, and the studies provide in-depth insights but may lack the quantitative data needed for wider generalization. As a mini-review, this study inherently has limitations due to its less systematic search and narrower scope compared to full systematic reviews, potentially leading to weaker evidence that may not be robust enough for decision-making purposes.

## Conclusion

This review indicates that although there are barriers at the individual, interpersonal, community, healthcare professional, and policy levels, there are substantial prospects for improving the integration of early palliative care. Knowledge deficits, emotional barriers, and misconceptions must be addressed at an individual level. Family support and effective inter-professional collaboration also play crucial roles in this regard. Establishing precise definitions and guidelines for early palliative care has become critical at the policy level. Additionally, it is essential to facilitate community awareness and comprehension of debunked misconceptions and stigmas. These is encompassing customized learning, emotional assistance, interdisciplinary teamwork, and endeavors to alter societal perspectives. The significance of a precise comprehension of palliative care, efficient familial support, and collaboration among diverse parties in the healthcare industry underscores the necessity for educational enhancements, policy adjustments, and synchronized community endeavors. Propose the inclusion of palliative care education in professional healthcare training and continuing education programs as a means to address existing knowledge deficiencies and foster enhanced collaboration among diverse healthcare professionals.

## Disclosure

The authors report no conflicts of interest in this work.

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