

Review Article

Enhancing Quality of Life in Pediatric Palliative Care: Insights, Challenges, and Future Directions—A Systematic Review

Laia Riera-Negre , **Maria Rosa Rosselló** , and **Sebastià Verger** 

Department of Applied Pedagogy and Education Psychology, Facultat d'Educació, Universitat de les Illes Balears, Valldemossa Road, km 7.5, Postal Code 07122, Palma de Mallorca, Spain

Correspondence should be addressed to Laia Riera-Negre; laia.riera@uib.cat

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Pediatric palliative care (PPC) programs are essential in encompassing not only the affected children but also their family system and the healthcare and educational professionals involved. Despite the field's significance, there is a notable scarcity in current literature, which underscores the pressing need for further research into the attributes of PPC programs that effectively enhance the quality of life (QoL) for pediatric patients. This study particularly emphasizes the pivotal role of schools as key community resources within this framework, highlighting the crucial aspect of educational integration in PPC. Through a systematic review of relevant literature and applying stringent inclusion and exclusion criteria, we identified pertinent studies across various databases. Of these, 30 articles met our criteria and were subject to a thorough qualitative analysis. Our findings indicate that while PPC programs may vary in their methodologies, they consistently share certain core elements that significantly boost the QoL for pediatric patients. These include a holistic approach that addresses the physical, emotional, psychosocial, and spiritual facets of care; encourages the active involvement of the patient in decision-making processes; and ensures timely access to PPC services. Importantly, our analysis identified the critical role of educational settings in enhancing QoL, shedding light on the vital need for educational inclusion and the integration of schools into the broader spectrum of PPC services. The distinct individual perceptions of QoL and the varied international practices in PPC underscore the imperative to tailor successful strategies to specific local contexts, thereby fostering the global well-being of pediatric palliative care patients.

1. Background

In recent decades, advances in medicine have shifted the approach to managing life-limiting or long-term illnesses from survivorship to specialized care [1]. Consequently, there has been a significant increase in the demand for pediatric palliative care (PPC) due to a growing number of pediatric patients in need [2, 3]. PPC programs adopt a multidisciplinary approach to address the comprehensive needs of pediatric patients with long-term illnesses, aiming to enhance their quality of life (QOL) [4, 5]. Achieving this goal requires the early integration of PPC, encompassing physical, psychological, social, and spiritual well-being, not only for the children but also for their families [6, 7].

While the focus of medicine has evolved to maximize health-related quality of life (HRQOL) [1], it is important to

recognize that the well-being of these children and their families is often under considerable stress [3], affecting various aspects of their lives. To capture the multifaceted nature of QOL, Schalock et al. [8] proposed a multidimensional model including categories such as personal development, emotional well-being, and interpersonal relationships. PPC programs should address each of these areas to comprehensively impact QOL. Children and young individuals facing illness express the need for productivity, challenges, and educational achievements, underlining the essential role of family support and connections [9]. Education plays a vital role in stimulating cognitive and psychosocial development, promoting normality, and reducing emotional stress [10]. Recognizing this, it is critical to consider PPC programs that incorporate a broad spectrum of care, including the pivotal role of educational inclusion

and the supportive environment schools can provide. Unfortunately, PPC programs are often not considered until the later stages of the disease [7], hindering early educational interventions [11].

Children with life-limiting illnesses prioritize education among their diverse needs [12]. Inclusive education, a critical element in PPC, must encompass all people at risk of social exclusion [13] and requires coordination between hospitals, families, and communities, particularly schools [14, 15]. Failure to create inclusive environments can result in educational deficits [16], emphasizing the need for accessible education at all levels [17–21] to improve the QOL of children requiring palliative care [20]. To provide a comprehensive PPC response, it is imperative to involve not only the children but also the school, healthcare professionals, and the family system [21–24]. In summary, comprehensive education is a fundamental component of PPCs [2], and further research on palliative care for children with complex medical needs is warranted [25].

Following the World Health Organization guidelines [26], effective PPC programs adopt a multidisciplinary approach involving children and their families from the time of diagnosis. This approach encompasses various aspects of the child's development. Evaluating existing PPC programs is crucial to understand their principles and their impact on improving the QOL of children facing severe illnesses, especially in how they leverage educational institutions as community resources.

The primary objective of this systematic review is to identify the key characteristics of successful PPC programs that demonstrably enhance the QOL of pediatric palliative patients, with a specific focus on programs incorporating education. This review seeks to answer the research question: What are the key characteristics of successful PPC programs that demonstrably enhance the QOL of pediatric palliative patients and under what circumstances are these characteristics more effective? Our approach aligns with realist principles, aiming to provide explanatory insights into what works, for whom, and under what circumstances [27]. As of our knowledge, the cutoff date is September 2023, but no comprehensive review of this nature has been conducted. The outcomes of this review will empower healthcare professionals in the care of pediatric palliative patients, helping them navigate the complex landscape of PPC programs. Ultimately, this will contribute to the development of practical and widely applicable principles for end-of-life care services, thus improving the well-being of these vulnerable individuals.

2. Methodology

In pursuit of our research objectives, a systematic review was chosen as the preferred method, given its rigorous evaluation of pertinent literature [28]. The systematic review adheres to the guidelines outlined in the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) 2020 statement, along with recommendations and quality procedures established by experts [29, 30].

2.1. Search Strategy. Our initial exploration took place in the Web of Science (WOS) database, utilizing an initial search equation that was refined based on the relevance of the outcomes. This preliminary query yielded 1337 results. We then conducted a co-occurrence analysis via an association matrix, employing the visualization of similarities (VOS) technique with the VOSViewer tool. For this analysis, keywords were selected based on the criterion of a frequency of five or more occurrences, with clusters containing a minimum of fifteen items or keywords. VOS allowed us to categorize keywords into thematic groups [31, 32].

The visualization map generated by the correlation network analysis identified 129 items grouped into four clusters. Although this initial search produced items closely related to our research objectives, some adjustments were needed, as keywords related to school or education had lower frequencies and occurrences. Table 1 presents the most significant items from each of the four clusters.

In light of these findings, we refined the search equation within WOS to focus more specifically on inclusive education. A second search conducted on the same day produced 821 publications, which underwent co-occurrence analysis (see Table 2). The co-occurrence analysis of the second search yielded a single cluster comprising sixteen items (see Figure 1). This accurate visualization map of the connection networks indicates a harmonious alignment between the search equation and the desired outcomes. The size of the circles signifies the significance of each item and its number of associations, as validated by the strength of association analysis. Table 3 details the frequency of links, the strength of these connections, and the occurrence count for each item.

2.2. Co-Authorship Network Analysis. In addition to our keyword-based analysis, we conducted an assessment of co-authorship networks, a recognized indicator of publication productivity and scientific impact [33]. Results from this analysis (refer to Figure 2) were obtained using VOS analysis, with a selection criterion requiring at least two joint publications. This analysis involved a total of 286 authors, averaging 2.18 authors per publication. Among these authors, only 18 met the criterion of having collaborated on at least two publications. The visualization map revealed collaborative connections between authors, illustrating both homophily and heterophily within the field of social sciences [34, 35]. Cluster 1 authors represented various universities and hospitals in North America, while Cluster 2 authors hailed from different institutions in Germany, demonstrating monophyletic and heterophyletic collaboration. Several authors had publications involving different author groups without repetition. Notably, based on the results of the WOS search, the authors with the most publications on this topic were Wolfe, J. (25); Dussel, V. (8); Feudtner, C. (8); and Rosenberg, A. R. (7).

2.3. Extension of the Search. Following the validation of our search string, we extended our exploration to other platforms of interest (see searches 3 to 9 in Table 2). In Scopus,

TABLE 1: Elements resulting from the map of visualizations in the search no. 1.

Cluster	Number of items	Items
1	39	Cancer, care, caregivers, communication, education, end, impact, life, palliative care, parents, quality
2	31	Childhood, health, quality of life, social support, symptoms, decision-making
3	30	Anxiety, children, depression, prevalence, quality of life, mental health, stress, school
4	29	Adolescence, adolescents, chronic illness, disease, health care, interventions, self-management, youth

due to platform configuration, the search was limited to titles, abstracts, and keywords. To accommodate the rigidity of the search equation and increase the number of results on platforms 4, 5, 6, 7, and 8, we simplified it to focus on the three primary elements identified in the VOS analysis from search no. 1.

2.4. Selection Criteria and Screening Procedure. To select studies for this systematic review, we implemented well-defined inclusion and exclusion criteria, ensuring the effective attainment of our research objective. Temporal criteria played a crucial role in this process, with a particular focus on the temporal aspects of the selected studies. In particular, we excluded articles published more than 20 years ago, based on careful consideration of the evolution and enhancement of palliative care practices in recent decades. The field of pediatric palliative care has witnessed substantial growth in knowledge, focus, and available resources over time.

By limiting the inclusion of studies to those published in the last two decades, we aimed to ensure that this review's findings and conclusions would reflect the most contemporary practices and approaches aligned with current best practices in pediatric palliative care. This decision was made to provide updated and relevant insights into the subject matter, offering a reflection of the latest trends and advancements in this field. Furthermore, given the limited availability of scientific literature in this area, it was deemed essential to concentrate on the most recent and relevant developments in pediatric palliative care. This selection strategy guarantees that the studies included in this review provide current and representative information about the characteristics and effective approaches in pediatric palliative care programs, enabling a critical analysis of contemporary practices in this domain.

The selection criteria were applied through the screening process, involving two independent reviewers. The stages of this process followed the PRISMA flow diagram (see Figure 3), with all peer-reviewed studies considered for inclusion if they met the following criteria:

- (i) Must include the search elements in at least the title, abstract, and/or keywords
- (ii) The publication must be in English or Spanish
- (iii) The field of publication should fall under the applied social sciences, such as education, pedagogy, and/or psychology

- (iv) The year of publication must be within the last two decades at the time of the research (2002–2023)
- (v) The subject matter must align with the topic of interest

Only empirical research studies were included, as no reviews with the same objective as this review were identified.

In terms of exclusion criteria, articles duplicated across multiple databases or not subjected to blind peer review were excluded. Duplication was found in only one instance, resulting in a final selection of $nT = 30$ articles.

2.5. Data Extraction and Reporting. Adhering to the Population Intervention Comparison Outcome Study (PICOS) design methodology [36], we gathered the following information: population, intervention, comparison, outcome, and study type. This allowed us to comprehensively assess the eligibility of the selected articles from the systematic search. To compile data from the reports, two independent researchers conducted an in-depth review of each study, extracting relevant findings related to the topics of interest in this study. The resulting articles were categorized into four groups, as depicted in Table 4: pediatric palliative care program or intervention (C1), educational program or intervention (C2), awareness program (C3), and quality-of-life dimensions (C4). The articles were analyzed and summarized using a matrix method following the PICOS methodology, with the groupings determined through consensus between two independent researchers. Due to the heterogeneous nature of the resulting articles, they are presented in a narrative format.

3. Results

The findings reveal that 50% of the studies employ intra-group or repeated-measures comparisons, while the remaining half utilize intergroup comparisons. Regarding methodology, 48% adopt a quantitative approach, an equal percentage use a qualitative methodology, and only 4% employ a mixed-methods approach. An examination of the publication years demonstrates a growing interest in the subject over the past two years, with 2021 registering the highest number of publications, totaling 7, as of February 2022, with a median of 2.14 articles per year. Among the 30 articles, 26 are published in English (86.67%) and 4 in Spanish (13.33%). Refer to Supplementary File 1 for the characteristics of the included studies.

TABLE 2: Documentary sources and search strings for all databases.

Search	Database	Search strings	No. of results	Date (day/month/year)	No. of clusters	No. of items
1	Web of Science	(((ALL = (palliative or long term illness or terminal illness or chronic illness)) AND ALL = (youngsters or childhood or child or children or pediatrics or "young adult")) AND ALL = (well-being or quality of life or hrqol)) AND ALL = (family or education or school or hospital pedagogy or hospital classroom or classroom)) AND ALL = (inclusive education or education or inclusive or educative or learning or process)	1337	4/8/2023	4	129
2	Web of Science	(((ALL = (palliative or "long term illness" or "terminal illness" or "chronic illness") AND ALL = (youngster* or child* or pediatrics or "young adult")) AND ALL = (wellbeing or "of life" or hrqol or "health related quality of life")) AND ALL = (family or "hospital pedagogy" or "hospital class*" or class*)) AND ALL = ("inclusive education" or education or inclusive or educative or learning or process or school)	821	4/8/2023	1	16
3	Scopus	(TITLE-ABS-KEY (palliative or "long term illness" or "terminal illness" or "chronic illness") AND TITLE-ABS-KEY (youngster* or child* or pediatrics or "young adult")) AND TITLE-ABS-KEY (wellbeing or "quality of life" or hrqol or "health related quality of life") AND TITLE-ABS-KEY (family or "hospital pedagogy" or "ospital class*" or class*)) AND TITLE-ABS-KEY (education OR school OR inclusive OR educative OR learning OR process OR "inclusive education")	523	7/8/2023	—	—
4	Dialnet Plus	ALL (cuidados paliativos, calidad de vida, pediatri*)	4	7/8/2023	—	—
5	ScienceDirect Elsevier	"Palliative care" AND (child OR pediatrics) AND ("quality of life" OR wellbeing) AND ("hospital pedagogy" OR "education" OR "school" OR "inclusive education")	3663	7/8/2023	—	—
6	Eric	"Pediatric palliative care program" AND quality of life AND child AND school	279	7/8/2023	—	—
7	SciELO	ALL (hospital pedagogy)	9	8/8/2023	—	—
8	WorldWideScience	"Palliative care" AND (child OR pediatrics) AND ("quality of life" OR wellbeing) AND ("hospital pedagogy" OR "education" OR "school" OR "inclusive education")	958	8/8/2023	—	—
9	PubMed	(((Palliative or "long term illness" or "terminal illness" or "chronic illness") AND (youngster* or child* or pediatrics or "young adult")) AND (wellbeing or "quality of life" or hrqol or "health related quality of life")) AND (family or "hospital pedagogy" or "hospital class*" or class*)) AND = ("inclusive education" or education or inclusive or educative or learning or process or school)	1215	8/8/2023	—	—

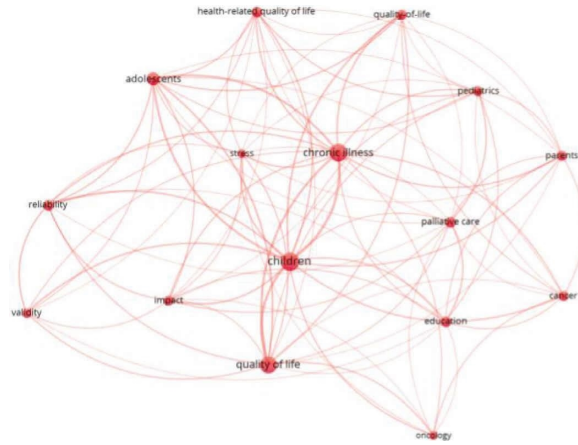


FIGURE 1: Visualization map of the correlation network of search no. 2 in the WOS database.

TABLE 3: Co-occurrence analysis of search no. 2.

Cluster	Element	Frequency	Link strength	Occurrences
1	Adolescents	13	47	13
	Cancer	10	19	7
	Children	15	81	25
	Chronic illness	14	70	23
	Education	11	21	8
	Health-related quality of life	12	24	8
	Impact	12	17	7
	Oncology	8	14	5
	Palliative care	13	23	8
	Parents	11	20	7
	Pediatrics	11	23	7
	Quality of life	15	54	21
	Quality-of-life	11	26	7
	Reliability	10	29	8
	Stress	12	23	5
	Validity	8	21	6

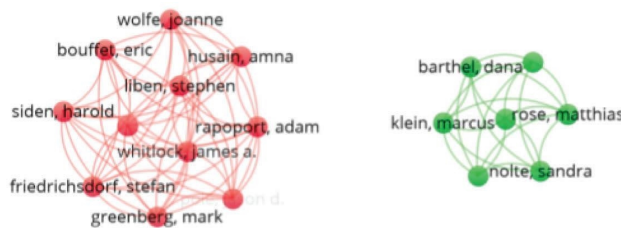


FIGURE 2: WOS search 2 co-authorship network visualization map.

3.1. *Pediatric Palliative Care Programs or Interventions.* Articles in category C1 concentrate on the efficacy of pediatric advanced care planning (pACP) as a distinct component within PPC programs. Of the 6 articles in this category, 4 are randomized controlled trials, 1 is an exploratory review, and 1 involves a qualitative analysis of 2 pACPs. Furthermore, 3 of the articles focus on pediatric oncology patients, one on pediatric chronic pain patients, and another on pediatric palliative patients regardless of diagnosis.

Symptoms and pain associated with debilitating diseases inflict significant suffering on pediatric patients, hindering optimal functioning in various domains, including psychosocial aspects [37]. It is important to clarify that pACPs, while integral, represent just one aspect of comprehensive pediatric palliative care programs. These programs aim to enhance the quality of life of pediatric patients and their families by improving functioning across physical, psychosocial, and even spiritual dimensions [7]. According to O’Quinn et al. [38], pACPs represent not just organized

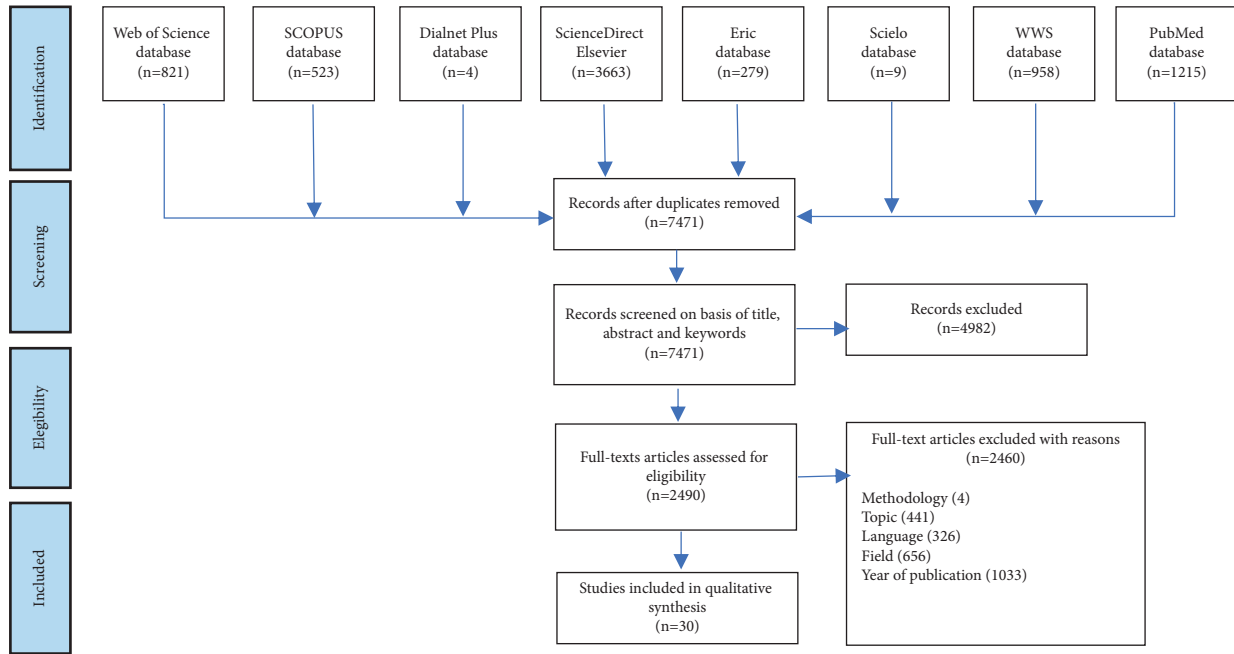


FIGURE 3: PRISMA flow diagram illustrating the study selection process.

TABLE 4: Categorization of the articles for the data extraction.

	Category			
	C1	C2	C3	C4
No. of articles	6	12	2	10

programs but also a philosophy that encompasses services and programs for family care, sibling support, counseling, and community resources. In essence, they should accompany patients and their families throughout the disease process, assisting them in making life plans or treatment decisions to enhance their quality of life. However, quality of life is a broad and subjective concept. O’Quinn et al. [38] cite the World Health Organization’s (WHO) 1995 definition, emphasizing its dependence on each individual’s perception of life. Schreiner et al. [9] acknowledge the complexity of measuring the quality-of-life construct, choosing Giorgi’s phenomenological analytical approach to understand each participant’s experience individually. The authors argue that the quality of life of young individuals hinges on physical, mental, emotional, and social health, fostering a life lived in the present without fear of the future. They underscore the importance of active participation in activities, respecting autonomy without falling into paternalism. Adolescents with serious illnesses possess the cognitive capacity to play an active role in decision-making regarding their care [39]. Involving them in shared decision-making empowers young patients, which is associated with a reduction in psychosocial comorbidities [40]. It is also critical to note that not all patients and families may be ready to engage with pACP early in the disease trajectory, and special considerations are required for adolescents with severe neurological impairments who may not have decision-making capacity.

PACPs have demonstrated utility in the mental health care of pediatric patients [38], significantly reducing anxiety levels [36], even six months after discharge [37]. The authors assert that pACPs contribute to improving perceived self-efficacy and reducing depressive symptoms. The findings illustrate that pACPs can enhance emotional quality of life (QOL) [38] and emotional well-being [37]. Additionally, Schreiner et al. [9] stress the significance of young patients feeling normalized in their situation by engaging in activities typical of their peers. According to the authors, this necessitates the inclusion of social care, encompassing emotionally profound relationships and robust support systems, which, as per O’Quinn et al. [38], also involve the participation of siblings and family members. pACPs have also proven effective in enhancing physical health, leading to a reduction in overall pain intensity and improved functioning [37]. Finally, Schreiner et al. and Greenley et al. [9, 40] emphasize the importance of pediatric patients feeling productive, capable of tackling challenges such as educational achievements or experiences. The limitations of pACPs stem from the fact that these programs are often not considered until the disease is advanced, with early intervention proving effective in enhancing the quality of life of these patients [7]. According to these authors, another weakness of pACPs is the lack of preparedness and training among healthcare professionals in palliative care, diminishing the benefit to the patient.

3.2. Educational Program or Intervention. Category C2 encompasses articles proposing, integrating, and/or evaluating teaching materials or health programs within school or hospital classrooms. Among the 12 resulting articles, 4 employ a quantitative methodology, while the remaining 8 employ qualitative research.

A comprehensive pediatric palliative care program should extend beyond the hospital environment and encompass the school or other community settings to enable and support children's engagement in education [41]. As Boo et al. [42] suggest, community outreach not only imparts crucial values to healthcare professionals but also equips them to address practical, real-world challenges. Considering educational programs in the context of pediatric palliative care patients is shown to be an essential tool for their recovery [40]. The results underscore that play activities are fundamental, fostering personal development, providing joy for children [43], establishing a support network, and enabling skill development [44], thereby enhancing the QOL of both the children and their families [44, 45], to such an extent that Rau et al. [46] highlight the importance of early promotion of psychological well-being in schools. Verger et al. [45] point out that, in some countries such as Spain, there is no adequate legal framework regulating the care of these students. In contrast, other countries possess specific regulations and legal frameworks addressing this issue, while others rely on general guidelines for inclusive health care and education. Similar to C1, the limited involvement of health professionals beyond their medical responsibilities is highlighted due to human resource shortages and heavy workloads [43], along with inadequate communication between educational and health professionals [45, 47].

Nevertheless, several factors facilitate the inclusion of these children in school. The pivotal role of teachers as advocates and educators [44] is fundamental for the emotional and physical development of these students [45], and effective coordination between professionals supports their educational progress [41, 45, 48, 49]. This coordination should allow for appropriate adaptations tailored to the needs of each student, rather than segregating them from the classroom [49]. The educational process can be complemented with support from school nurses. Engelke et al. [50] demonstrate that their involvement in schools leads to a higher self-perceived QOL for the users. In cases where physical attendance is not feasible due to hospitalization or other factors, telepresence can reduce their isolation [51] and improve their social well-being [52].

3.3. Awareness Program. Category C3 comprises 2 articles focusing on health awareness programs in schools. Stewart et al. [53] implement a prevention program and subsequently evaluate it, while Beccaro et al. [54] employ a pre-and post-test methodology to examine mainstream school students' knowledge about palliative care after awareness training.

In this context, an "awareness program" refers to a set of activities or initiatives designed to raise awareness and understanding of a specific health-related topic, in this case, palliative care. These programs aim to educate students and the broader community about the importance and key concepts of palliative care, promoting a deeper understanding of health care in critical health situations.

Facilitating factors for awareness-raising, as identified by Stewart et al. [53], are rooted in the establishment of a shared mission and principles between the school and the hospital, fostering shared responsibility and mutual understanding. Challenges highlighted by Beccaro et al. [54] underscore the importance of participatory health promotion, involving various community sectors to enhance collaboration. They emphasize that schools, and more specifically, students, play a crucial role, as they constitute the foundation of future society. The authors further note that the existing literature on school-based palliative care interventions is scarce or virtually nonexistent, underscoring the significance of addressing awareness within this domain.

3.4. Quality-of-Life Dimensions. Chronic or limiting illnesses often lead to increased school absenteeism and worsened mental health [55], impacting the quality of life of affected individuals. Therefore, as Alonso et al. [56] argue, it is essential to provide psychopedagogical support to these children and young people, enabling them to express and understand their emotions. Anxiety and distress have been shown to have a detrimental effect on their health-related quality of life (HRQOL) [57–59]. Another factor impeding the well-being of these students is delayed diagnosis, which also affects their educational performance [60].

Walker et al. [58] identify several factors that enhance the perceived QOL of children and young people with limiting illnesses. Encouraging social relationships and motivating these patients through challenges that boost their self-confidence and self-esteem are highlighted as particularly relevant for school-based interventions. Adistie et al. [61] emphasize the importance of communication about issues that are of utmost concern to children, especially as they approach the end of life, as this helps reduce future anxiety, fear, or depression responses. Zaidman-Zait et al. [62] note in their study that participants had lower scores in the categories of self-esteem and socialization. Furthermore, consistent with articles in the previous categories, the relationship and coordination between educational and health professionals emerge as essential elements in ensuring the well-being of these students, with inclusive education holding great significance [63].

However, as Vente et al. [57] point out, there are several measurement scales for examining QOL, making it challenging to integrate the results of studies on this topic. According to the author, QOL is a subjective construct dependent on each individual's unique definition. Nevertheless, despite this subjectivity, there are common elements that contribute to promoting QOL, with an emphasis on fostering socialization and healthy relationships [57].

Table 5 offers a succinct presentation of findings across the four research categories within the domain of PPC. The results in this table directly align with the primary objective of this systematic review, which is to identify the key characteristics of successful PPC programs that demonstrably enhance the QOL of pediatric palliative patients. Special attention is given to programs that incorporate educational components into their operations. This table serves as a structured summary of research outcomes and offers a structured glimpse into the diverse aspects of pediatric palliative care research, shedding light on the impact of these programs on young patients' QOL, the significance of educational initiatives, and the dimensions influencing their overall well-being.

4. Discussion

This study highlights that PPC programs, due to their multifaceted nature, pose challenges not only to multidisciplinary hospital education teams but also to society at large. These challenges encompass aspects such as resource allocation, ethical considerations, and public awareness. It is evident that successful PPC programs must adopt a holistic approach, drawing on various community resources, including hospitals, schools, and family support networks. Instead of addressing only the physical health of pediatric patients, these programs should encompass all aspects of a child's development—emotional, psychosocial, physical, and spiritual. Achieving this requires seamless networking and communication among all professionals involved in each of these areas.

As emphasized by Hicks et al. [64], the organization of multidisciplinary services holds paramount importance in palliative care. However, it is crucial to acknowledge that QOL, being subjective and individual, demands personalized responses tailored to each child's specific circumstances.

The significance of schooling emerges as a critical factor in the QOL of children and young individuals with life-threatening illnesses. Schooling provides a sense of normalcy, enabling participation in activities typical of their peers and fostering the development of social skills and self-esteem. Currently, in Spain, the educational and home care service (SAED) facilitates education for students unable to attend school in person due to health reasons. Nevertheless, attending school physically can offer additional benefits through appropriate educational inclusion, which ideally involves support and coordination with health services, including the presence of a nurse when possible. The role of schools in enhancing the QOL of these children is undeniable, and PPC programs should prioritize and incorporate it as a key element whenever feasible. Early implementation is unequivocally crucial in PPC programs, which is why a protocol for action involving different institutions, initiated at the time of diagnosis, is considered pertinent.

Moreover, considering international variations in PPC practices is essential. PPC programs vary globally in terms of focus, available resources, and regulations, making it crucial to understand and adapt best practices from one country to

another. Collaboration among countries to share best practices can enrich the understanding of how to enhance the QOL of pediatric patients in palliative care on a global scale. Policies and health systems, resource availability, education and training, and access to care may differ significantly between countries, influencing the delivery of PPC. As such, the development of PPC programs should consider these diverse international contexts and adapt accordingly, aiming for improved patient outcomes and enhanced QOL for pediatric palliative patients across borders.

Regarding the training of professionals involved in PPC, it is worth noting that families of pediatric patients often express concerns about a lack of empathy in healthcare professionals caring for their children. Furthermore, in Spain, education degrees currently do not include subjects related to hospital pedagogy, understanding hospital pedagogy as the specialized field that combines educational theory and practice to support the learning and emotional needs of children and young individuals receiving medical treatment or who are in a hospital setting. It emphasizes creating a supportive and adaptive educational environment that accommodates the unique circumstances of each child, ensuring their continued academic development and emotional well-being despite medical challenges. Therefore, teacher training programs become vital mechanisms for fostering teaching skills among educators [65, 66], which should extend to healthcare professionals and others involved in PPC. In essence, a robust PPC program must have competent and empathetic staff, making awareness-raising an indispensable initial step before the implementation of a comprehensive PPC program [67].

To address the research question regarding the characteristics of PPC that enhance the QOL of pediatric palliative patients, we have identified recurring elements throughout the analysis of 30 articles (see Table 6). For a PPC program to be comprehensive, it must effectively utilize community resources through networked coordination and communication among professionals. Prior training and awareness of palliative care are essential components. Equally important is the holistic approach to a child's development, beyond just physical health improvement. PPC should encompass the understanding and expression of emotions. Normalization holds significant value for these children and young individuals, with schools playing a pivotal role in reducing their isolation and enabling active participation, empowering them. In cases where physical presence is not suitable for a child's situation, telepresence emerges as a viable alternative. Finally, early implementation of PPC at the time of diagnosis, which is currently not prioritized, stands out as a crucial factor in improving the QOL of pediatric palliative patients.

Barriers serve as clear indications of elements to be addressed or improved in tertiary care, while enablers should be promoted as essential elements in PPC programs. However, evidence gaps exist due to the heterogeneity and diversity of the interventions reviewed, which is precisely due to the lack of a systematized design for PPCs. Also, the diversity within the PPC population highlights the need for

TABLE 5: Summary of findings in pediatric palliative care research categories.

Category	Number of articles	Primary methodology	Key findings
Pediatric palliative care programs	6	Mixed, quantitative, qualitative	<ul style="list-style-type: none"> (i) Positive impact on the quality of life of pediatric patients (ii) Reduction in anxiety and depressive symptoms (iii) Benefits in emotional and physical well-being (iv) Limitations include delayed consideration of programs and lack of healthcare professionals' training
Educational programs	12	Quantitative, qualitative	<ul style="list-style-type: none"> (i) Importance of educational programs in pediatric palliative care (ii) Benefits in personal development and children's quality of life (iii) Challenges include lack of coordination between healthcare and education professionals
Awareness programs	2	Quantitative, pre-post	<ul style="list-style-type: none"> (i) Awareness programs increase knowledge about palliative care (ii) Importance of collaboration between schools and hospitals in awareness programs
Quality-of-life dimensions	9	N/A	<ul style="list-style-type: none"> (i) Chronic illnesses affect the quality of life of children (ii) Promotion of social relationships, emotional development, and coordination between healthcare and education professionals are essential

TABLE 6: Compilation of the future directions for PPC programs or interventions gathered from the qualitative synthesis of the reviewed articles.

Category	Minimum essential elements
Tertiary attention	<ul style="list-style-type: none"> (i) <i>Addressing all areas</i> of the patient's life that are affected <ul style="list-style-type: none"> (a) Physical (b) Emotional (c) Psychosocial (d) Educational (e) Spiritual (ii) <i>Comprehensive individualized plan</i> (iii) Care and attention to the <i>family</i> (iv) Accompaniment in <i>decision-making</i> (v) Use of <i>community services</i> (vi) Active role, promotion, and respect for the <i>autonomy</i> of pediatric patients (vii) Consideration of their cognitive abilities (viii) <i>Early implementation</i> (ix) <i>Training</i> and preparation of the professionals involved
Educative inclusion	<ul style="list-style-type: none"> (i) <i>Legal framework</i> that adequately regulates the educative inclusion (ii) <i>Communication and collaboration</i> between the services involved (health, education, community) (iii) <i>Tailored strategies</i> for inclusion (telepresence, medical accompaniment, etc.)
Awareness	<ul style="list-style-type: none"> (i) Need to deepen school-based palliative interventions
Effect on the QoL	<ul style="list-style-type: none"> (i) Facilitators <ul style="list-style-type: none"> (a) Psychopedagogical care (b) Promoting social relations with peers and role models for the development of their maturing skills (c) Communication on issues of concern to them (d) Effective inclusive education (e) Empowerment (f) Including elements of categories 1 and 2 (ii) Barriers <ul style="list-style-type: none"> (a) Delay in diagnosis (b) Delay in access to a PPC program (c) Isolation (d) Overprotection (e) Lack of autonomy (f) Not including elements of categories 1 and 2

individualized care approaches. Children receiving palliative care present with a wide range of conditions, each affecting their physical, emotional, and social well-being differently. Furthermore, family beliefs, values, and dynamics play a crucial role in care planning. Given this variability, palliative care must be tailored to meet the specific needs of each child and their family, emphasizing a holistic, patient-, and family-centered approach. This adaptability is essential for providing effective and compassionate care in the complex landscape of pediatric palliative care. Future research is needed to determine whether interventions that include all of the above elements provide a major benefit to the QoL of pediatric palliative patients, compared with currently implemented programs or the lack thereof.

4.1. Limitations. The systematic search included published articles and those pending publication on platforms that allow this option. However, access to unpublished titles was limited, resulting in a loss of information. Further synthesis is needed to determine if the findings regarding the minimum essential elements for a PPC program are transferable.

The exclusion of non-English or Spanish studies due to a lack of access to qualified translation services covered by project funding led to a loss of information. The number of articles included in the systematic review is considered low due to the scarce existing literature on the subject, which is highly specific. However, a positive trend has been detected in recent years, and we expect it to become a topic of interest for research.

5. Conclusions

This study underscores the complexity of PPC programs, highlighting challenges that extend beyond the healthcare setting to include broader societal concerns such as resource allocation, ethical considerations, and public awareness. To address the multifaceted needs of pediatric patients effectively, PPC programs must embrace a holistic approach that leverages diverse community resources, including hospitals, schools, and family support networks. Crucially, these programs should address not only the physical aspects of a child's condition but also their emotional, psychosocial, and spiritual development.

A key distinction must be made between the health education of professionals, which focuses on equipping healthcare providers with the knowledge and skills to deliver palliative care, and the school education of children and young people, which emphasizes academic learning and social engagement. Both forms of education are vital in the context of PPC, yet they serve distinct populations and purposes.

Furthermore, the role of advance care planning in PPC cannot be overstated. It is a critical component that ensures care aligns with the individual preferences and values of the child and their family, tailoring interventions to the unique circumstances of each patient. This personalized approach is fundamental to enhancing the quality of life for pediatric palliative patients.

We hope this research serves as a catalyst for further exploration and development in the field of PPC, encouraging new initiatives that build upon the insights provided here. By emphasizing the importance of education—both professional and academic—and advance care planning, we can work towards more comprehensive and responsive PPC programs that truly meet the needs of children facing serious illnesses.

Data Availability

The datasets generated and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Additional Points

Key Messages. (1). Pediatric palliative care (PPC) programs must adopt a holistic approach that addresses physical, emotional, psychosocial, and spiritual aspects to enhance the quality of life (QoL) of pediatric patients. (2). Schools play a pivotal role in improving the QoL of children and young individuals receiving palliative care, promoting normalcy, and fostering social skills and self-esteem. (3). Effective collaboration among healthcare, education, and community professionals is essential in PPC, and adapting successful practices internationally can contribute to enhanced QoL for pediatric palliative patients on a global scale.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Authors' Contributions

Laià Riera-Negre was responsible for conceptualization, formal analysis, and original draft preparation. Sebastià Verger was responsible for funding acquisition and review and editing. Maria Rosa Rosselló was responsible for project administration and review and editing.

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Supplementary Materials

Supplementary materials provide additional information and resources related to the systematic review conducted on enhancing the quality of life in pediatric palliative care. The supplementary materials include detailed tables and figures illustrating the data extraction process, the methodological flowchart of the included studies, and expanded statistical analysis outcomes that could not be included in the main manuscript due to space constraints. Extended data tables contain comprehensive data on the studies reviewed, including study design, population characteristics, interventions analyzed, and key outcomes relevant to pediatric palliative care. A visual diagram of the search and selection process details the inclusion and exclusion criteria at each stage of the study selection. Additional figures offer enhanced graphical representations of the key findings, including the effects of various palliative care interventions on the quality-of-life dimensions discussed in the review. Supplementary statistical analyses provide deeper insights into the robustness of the findings, including sensitivity analyses and subgroup analyses. The full research protocol is also included, outlining the systematic review's rationale, hypothesis, and planned methods, providing transparency, and allowing for the reproducibility of the research. These supplementary materials are intended to provide greater context and support for the findings presented in the main manuscript, offering readers, researchers, and practitioners additional resources to understand and apply the results of this comprehensive review. (*Supplementary Materials*)

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