



Pediatric palliative care through the eyes of healthcare professionals, parents and communities: a narrative review

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Background and Objective: Pediatric palliative care is a holistic approach that aims to enhance the quality of life of seriously ill children and their families. Despite the documented benefits, many barriers challenge early integration of such care. The lack of knowledge and negative attitudes and beliefs toward pediatric palliative care are often cited among these barriers. This narrative review aims to summarize the existing literature regarding knowledge, attitudes and beliefs toward pediatric palliative care among healthcare professionals, parents and communities.

Methods: Four databases were searched: Medline, EMBASE, PsychINFO, and Cumulative Index to Nursing and Allied Health Literature Complete. The search strategy combined Medical Subject Headings, terms and keywords using Boolean operators to retrieve references addressing each concept of interest within the English literature. The initial search was conducted in August 2020 and updated in August 2021. No date limits were set. Two independent authors screened the retrieved papers for eligibility.

Key Content and Findings: The majority of the 60 retrieved articles (n=49, 82%) were derived from high-income countries, with almost half of them from the United States. The references from developing countries were scattered across continents. The perspectives of healthcare professionals were more extensively explored compared to parents and community samples. Reports describe confusion between pediatric palliative care and end-of-life care. Yet, a positive attitude toward pediatric palliative care prevails whenever respondents possess accurate information about such care.

Conclusions: This comprehensive review of different perspectives on pediatric palliative care helped in identifying the literature gaps and provided direction for future research in this area. The need to enhance accurate knowledge and promote understanding especially in developing countries was emphasized. This review also highlighted factors that influence knowledge, attitudes and beliefs toward pediatric palliative care, and identified the need for validated tools for research.

Keywords: Palliative care; pediatric; knowledge; attitudes

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Introduction

According to the World Health Organization (WHO) (1), pediatric palliative care (PPC) aims to improve the quality of life of the child and family as it involves preventing and alleviating physical, psychological and spiritual suffering of children with serious illness. In 2014, the World Health Assembly issued a global resolution for palliative care as part of universal health coverage to promote accessibility to palliative care as a “human right”. The resolution particularly highlighted the need to train healthcare professionals (HCP) and family members in order to reduce patient suffering (2).

The level of PPC integration within the healthcare systems varies by country. Arias-Casais and colleagues mapped PPC development in 51 European countries (3). High-income countries (HICs) hosted the vast majority of PPC services (92%), regulations, and professional development activities (3).

In practice, primary PPC is generally provided by the multidisciplinary team who regularly follow up with the patients. This level includes basic skills in addressing distressing symptoms (4). In more complex cases with refractory symptoms and challenging psychological and communication problems, specialized palliative care teams are consulted for their advanced trainings and experience in the field (4). These specialized PPC services are often available in HICs where palliative care is well established as a recognized specialty (3). Many reports have described the benefits of specialized PPC teams in terms of patient, family and system outcomes. Timely integration of specialized PPC services in the treatment of pediatric patients yielded better symptom management, quality of life, communication with the children and their families, and reduced care cost (5-9).

In low middle-income countries (LMICs), many barriers—such as lack of human and material resources, training and policies—challenge the development and provision of specialized PPC services (9,10). Despite the limited resources, several PPC programs in hospitals or hospices are available primarily in urban areas in these countries (11). Home-based services are commonly adopted to enhance accessibility while promoting the continuity of care and symptom management through coordination between HCP and the family (10,11). In addition, palliative care at home may fit the cultural context better than hospital settings. For example, in Lebanon, a recent policy brief stipulates the provision of palliative care at patients’ residence

as a “viable option”, valuing the family ties (12). The scarcity of resources and cultural features in LMICs seem to intensify the family role, particularly in primary PPC delivery.

Despite the inclusive WHO definition, PPC and end-of-life care were used interchangeably in healthcare settings for the last two decades. As such PPC has been integrated late in the disease trajectory, typically in the terminal phases of the child’s illness (9). This discrepancy between PPC philosophy and practice resulted in negative PPC views, often cited as barriers to the timely integration of PPC.

The literature regarding perspectives on PPC extensively described the knowledge, attitudes, beliefs (KAB) and practices in palliative care of HCP, where a lack of knowledge was commonly cited (13-15). In this article, HCP refer to members belonging to medical or nursing or other disciplines trained to provide healthcare services. The lack of knowledge and negative attitudes among HCP constituted a barrier to early integration of PPC in cancer treatment (16-19). Interventions to educate HCP on PPC improved their knowledge, skills and attitudes (20-22). In parallel, these educational interventions were found to improve quality of care (23), timely referral to PPC services, advanced care planning (24) and spiritual care (22). While evidence exists on HCP’ perspectives and their influence on patient outcomes, few studies describe KAB toward palliative care among parents and communities.

Research addressing parents’ views towards PPC predominantly relies on HCP’ reports (16,25). Health care professionals reported that parents carry misconceptions regarding PPC as conflicting with cure; therefore, they associate PPC with “giving-up” (16,25). Consequently, HCP commonly cite parents’ perspectives as barriers to integrating PPC in the treatment of children with cancer (18). However, few recent studies conducted in HICs with parents of children with cancer challenged these findings by reporting positive attitudes toward PPC among the parents (26-28). Overall, the patients’ and parents’ perspectives on PPC are poorly described in HIC (29) and unexplored in LMICs.

Several reviews of the literature summarized palliative care perspectives among HCP (30-32), patients/caregivers (33) and the community (34). These reviews address palliative care as an overarching concept without focusing on the pediatric context *per se*. Moreover, palliative care is often discussed from the narrow angle of the end-of-life period. To the best of the authors’ knowledge, no reviews have synthesized the literature available globally on the views on PPC including HCP, ill children and their

Table 1 The search strategy summary

| Items | Specification |
|--------------------------------------|---|
| Date of search | August 27, 2021 |
| Databases and other sources searched | MEDLINE, Embase, CINAHL, PsychINFO |
| Search terms used | <p>Examples of MeSH terms: child/ or pediatrics/, Exp Palliative Care/ or terminal care/ or hospice</p> <p>Examples of keywords: (baby or babies or toddler or toddlers or minor or minors or boy? or boy?hood or girl? or kid? or child or children or childhood or adolescen* or juvenil or youth* or teen* or (under adj age) or pubescen* or pubert* or p?ediatrics or p?ediatric or pre-school* or preschool* or school*).mp.</p> <p>((palliative or comfort or terminal or “end of life” or “end-of-life” or eol or supportive or support or supports or supporting or bereavement or hospice* or respite*) adj (care or caring or carer or carers)).mp.</p> <p>Appendix 1 includes the complete search strategy in MEDLINE</p> |
| Timeframe | 2001–2021 |
| Inclusion and exclusion criteria | <p>Inclusion: qualitative and quantitative studies, English language</p> <p>Exclusion: case reports, conference proceedings</p> |
| Selection process | Independent by two authors |

parents, and community samples. Recent studies report divergent views between HCP and patients/parents toward PPC (18,27,28). Synthesizing the literature on these views will help identify the literature gaps and provide direction to promote PPC on the research, policy, practice and education levels. The current narrative review aims to summarize studies that address KAB toward PPC among HCP, parents of pediatric patients and community. Specifically, the objectives of the review were to:

- ❖ Identify the knowledge (awareness, perceived level of knowledge and existing information) regarding PPC among HCP, parents and communities;
- ❖ Describe the attitudes and beliefs on barriers and facilitators toward PPC;
- ❖ Determine the factors that influence the KAB toward PPC.

The Theory of Planned Behavior (35) laid the theoretical foundations of this review. The Theory posits that three sets of beliefs drive the behavior. Behavioral beliefs pertain to attitudes. Normative beliefs examine social norms and expectations regarding the behavior. Control beliefs capture barriers and facilitators to perform the behavior. The three types of beliefs are affected by background factors which include knowledge about the behavior (35). From this theoretical lens, exploring KAB toward PPC provides a comprehensive understanding of elements

contributing to PPC provision. We present the following article in accordance with the Narrative Review reporting checklist (available at <https://apm.amegroups.com/article/view/10.21037/apm-22-525/rc>).

Methods

Using the narrative review methodology (36), four databases were searched: Medline, EMBASE, PsychINFO, and Cumulative Index to Nursing and Allied Health Literature (CINAHL) Complete. *Table 1* summarizes the search strategy designed with a medical librarian. For each database, Medical Subject Headings (MeSH) terms and keywords were combined ([Appendix 1](#) includes the search strategy in Medline).

The results of all four databases were exported to Endnote X9 bibliography software for storing and removing duplicates. Two independent reviewers (R Saad and SD Sailian) screened the articles for title and abstract, resolved disagreements, then conducted full text reviews and manually extracted data from eligible articles. Inclusion criteria were: qualitative and quantitative studies including observational studies (cohort studies, case-control studies), controlled and uncontrolled pre-/post-studies; retrospective and cross-sectional studies. For a comprehensive search, study conditions incorporated the four disease categories

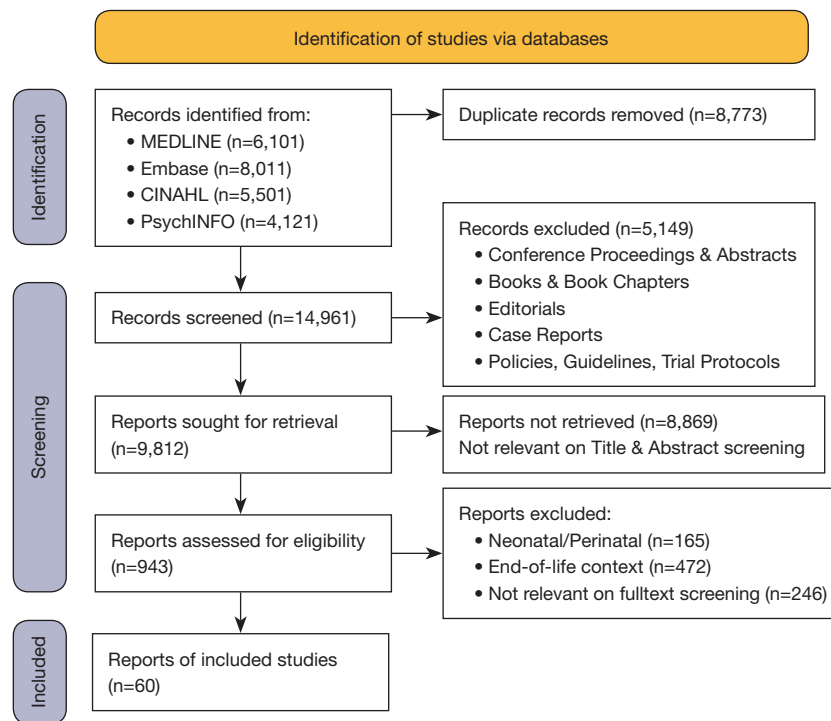


Figure 1 The PRISMA flow diagram illustrates the selection process of studies included in the review along with the reason for exclusion when applicable.

of life-limiting and life-threatening conditions requiring PPC (37). These categories include: life-threatening conditions where curative treatment exist but may fail (e.g., cancer); conditions entailing intensive and at times prolonged treatment but where death is inevitable (e.g., cystic fibrosis), progressive conditions where exclusively palliative care is offered (e.g., Baten's disease) and non-progressive disease with severe and irreversible disabilities (e.g., cerebral palsy) (37). Likewise, no limit was set on the date of publication.

The exclusion criteria were non-English references, animal studies, conference abstracts or proceedings, case studies, correspondence/letters, books and book sections or chapters. Studies specifically addressing perinatal/neonatal palliative care or palliative care in neonatal intensive care were also excluded due to the specific considerations in this context (38). Moreover, studies pertaining to specific aspects to end-of-life period (such as advanced care planning, bereavement, end-of-life care) were excluded. The WHO definition of PPC (1) covers the entire disease trajectory, not only end-of-life. However, the two terms are used interchangeably. Excluding end-of-life studies is intended to uncover the researchers' and participants' broader

understanding of PPC rather than narrowing it to end-of-life care. *Figure 1* illustrates the PRISMA chart of the review process. The data extracted from reviewed articles included the study title, country, purpose, study design, data collection method, sample and key findings (see *Table 2*: Summary of reviewed studies conducted among HCP and *Table 3*: Summary of reviewed studies conducted among parents and communities).

Findings and discussion

After data extraction, the articles were narrowed down from 23,734 to 60 articles. The majority of the articles (n=49, 82%) were derived from HIC, with almost half of them from USA. The references from LMICs were scattered across the remaining continents. One study was conducted in many countries across continents (14) and another one in countries across Eurasia (69). *Figure 2* presents the frequency of studies by country.

Over the years, the perspectives of HCP on PPC were extensively explored compared to parents and communities. Several studies combined parents' and patients' views (27,28,82,85). The last 4 years witnessed a surge in the

Table 2 Summary of reviewed studies conducted among healthcare professionals

| Title | Year | Country | Purpose | Design | Data collection method | Sample | Key findings |
|--|------|----------------------------|--|--|---|---|---|
| Palliative care in the community for children with cancer in South East England (39) | 2001 | South England | Describe how health-care professionals interpreted palliative care, and identify initiatives for service improvement | Qualitative | In-depth interviews | N=40 community healthcare professionals providing PPC | Palliative care refers to the care that is not aiming for a cure. Interpretations varied in terms of the duration of palliative care and the type of support it involves |
| Practices in paediatric palliative care in Lebanon (13) | 2008 | Lebanon | Determine the knowledge of, attitudes to and practices in paediatric palliative care among doctors and nurses in Lebanon | Quantitative cross-sectional descriptive | Self-administered survey (French and English) | N=96 paediatric nurses N=27 paediatricians | <p>Knowledge: few of paediatric nurses (20.2%) and paediatricians (3.7%) reported receiving continuing education in palliative care. Both groups scored highly in PPC knowledge</p> <p>Attitude: participants had average scores in the section on PPC attitudes (mean 74.077; possible range, 61–86). Paediatric nurses more likely to consider that a patient's family needs to be involved in the treatment choice**. A high percentage of participants endorsed informing the family and patient on prognosis</p> <p>Barriers: lack of development, lack of training, communication</p> <p>Facilitators: sharing the same religious beliefs</p> <p>Practice: average practices scores (mean 159.89; possible range, 114–189)</p> |
| Pediatric palliative care: a qualitative study of physicians' perspectives in a tertiary care university hospital (40) | 2008 | Canada | Assess the concept of palliative care for a group of physicians in a tertiary care pediatric university hospital | Qualitative Grounded theory | Semi-structured interviews | N=12 physicians | Palliative care is defined as the relief of physical symptoms. PPC is equated to comfort care. The definition varied between physicians. None of the physicians referred to the internationally accepted WHO definition. Some physicians who had more involvement with palliative care evoked a team approach (focusing on physical symptom management), family-oriented care, quality of life of the child, participation of the sick child in his usual activities (school, play, birthday parties, etc.). The timing of PPC integration varied |
| Paediatricians' perceptions of and preferred timing for pediatric palliative care (16) | 2009 | USA (Florida & California) | Investigate physicians' definitions of palliative care and their perceptions regarding the timing of referrals to PPC for 13 common diseases | Quantitative cross-sectional descriptive | Mailed and online survey | N=303 pediatricians (random sample) | <p>Knowledge: 41.9% defined PPC as hospice care, 31.9% offered alternative definitions. Some respondents (3.1–35.6%) stated that palliative care was not indicated or did not know when to refer patients</p> <p>Factors associated with knowledge: working in academic institution</p> <p>Attitudes: one half (44.3–59.7%) of the respondents indicated that they would refer patients during the course of an illness (early or middle stage), with one third to one half (29.6–44.2%) preferring to refer patients when curative therapy was no longer the goal, at the EOL</p> <p>Factors associated with attitude: Hispanic ethnicity and having a larger proportion of patients with Medicaid (51% of patients), were associated with earlier referrals</p> <p>Practice: 49.3% had ever made a referral</p> |
| Pediatric residents' and fellows' perspectives on palliative care education (41) | 2009 | USA | Determine the extent of training, knowledge, experience, comfort and competence in palliative care communication and symptom management. Obtain residents' and fellows' views on key palliative care concepts. Identify topics and methods for palliative care education | Quantitative cross-sectional descriptive | Survey adapted from previous study | N=52 residents N=44 fellows | <p>Knowledge: 54% of participants received previous training</p> <p>Attitude: residents and fellows disagreed that palliative care is best left to oncologists, critical care specialists, or palliative care specialists and that initiating palliative care feels like giving up on the patient. Education made them more comfortable, they all acknowledge that PPC would improve patient care</p> |
| Paediatricians' perceptions on referrals to paediatric palliative care (42) | 2009 | USA (Florida & California) | Estimate the association between paediatrician characteristics and the decision to refer children to palliative care and the preferred timing of referrals. Determine how those associations vary across several illness trajectories | Quantitative cross-sectional descriptive | Mailed and online survey | N=303 pediatricians | <p>Attitude: 92% and 98% of paediatricians would refer a child to paediatric palliative care across all the illness trajectories. Between 54% and 92% of paediatricians would refer prior to the EOL, with trajectories 1 (child with a potentially curable disease but has significantly high risk of mortality) and 2 (child who will likely die from a severe congenital anomaly)</p> <p>Factors associated with referrals: years of experience, practice setting, Hispanic ethnicity, percentage of Medicaid patients</p> |

Table 2 (continued)

Table 2 (continued)

| Title | Year | Country | Purpose | Design | Data collection method | Sample | Key findings |
|---|------|----------------------------|--|--|---|------------------------------------|--|
| Paediatric palliative home care by general paediatricians: a multimethod study on perceived barriers and incentives (43) | 2010 | Germany | Examine potential barriers, incentives, and the professional self-image of general paediatricians with regard to paediatric palliative care | Phase I: qualitative exploratory Phase II: quantitative cross-sectional | Phase I: semi-structured interviews Phase II: self-administered survey | Phase I: n=5 Phase II: N=293 | Knowledge: 55.2% (N=293) had no experience and 81.1% agreed with the statement on early integration of palliative care Attitude: 75.1% willing to engage in PPC Barriers: parents' reluctance, lack of experience (40.7%) financial burden (31.6%), sole responsibility without team support (31.1%), formal requirements such as forms and prescriptions (26.6%) inhibition in confrontation with death and dying (10.7%) Facilitators: support by local specialist services (83.0%), access to a specialist PPC (82.4%), exchange with colleagues (60.1%) Factors associated with barriers and facilitators: willing to engage in PPC, gender (in some barriers), experience (in some barriers and facilitators) |
| A study investigating the need and impact of pediatric palliative care education on undergraduate medical students in Japan (21) | 2011 | Japan | Identify and explore the need for PPC education and the impact of that education on medical students in Japan | Quantitative prospective cohort | Survey administered before, during, and after a small group lecture on PPC. A second survey administered after six months | N=30 (fifth year medical students) | Knowledge: in the first survey, none of the students reported any exposure to PPC. All participants defined PPC as pain management in EOL care for children with cancer Factor associated with improved knowledge: the intervention (PPC education) Attitude: attitude toward the lecture was positive |
| Pediatric palliative care instruction for residents: an introduction to IPPC (44) | 2012 | USA | Report the development and intervention of a 1-day pediatric palliative care education experience | Quantitative pre/posttest | Survey administered before and after PPC education | N=26 interdisciplinary staff | Participants reported having gained new knowledge, and having enhanced own pediatric palliative care knowledge, skills, and attitude toward PPC after the training out of 5 |
| Paediatric palliative care services in Queensland: an exploration of the barriers, gaps and plans for service development (45) | 2012 | Australia | Identify barriers and gaps and to plan for the future of the pediatric palliative care service | Qualitative | Focus groups | N=38 healthcare professionals | Barriers: equity in access to services; awareness, understanding and fear from clinicians and families; experience of health professionals; funding and resources, lack of respite options, lack of resources and lack of coordination |
| Factors associated with perceived barriers to pediatric palliative care: a survey of pediatricians in Florida and California (46) | 2012 | USA (Florida & California) | Describe the barriers to PPC as reported by a group of pediatricians practicing in two large States in the US. Identify factors associated with these perceived barriers | Quantitative cross-sectional descriptive | Mailed and online survey | N=303 pediatricians | Barriers: families' reluctance to accept palliative care (95%) and families viewing palliative care as giving up (94%) Factors associated with barriers: ethnicity of pediatrician, practice setting, and the percentage of low-income patients |
| Paediatric palliative home care in areas of Germany with low population density and long distances: a questionnaire survey with general paediatricians (47) | 2012 | Germany | Evaluate involvement in and contribution of general paediatricians in paediatric palliative care and their cooperation with other paediatric palliative care providers | Quantitative cross-sectional descriptive | Self-administered questionnaire | N=141 general pediatricians | Knowledge: 90.8% had professional experience with PPC and 20.6% were aware of the PPC home services. The reasons for consulting PPC providers were supportive therapy (59.6%) pain and symptom management (55.3%), psychosocial support (71.6%) Attitude: more than half (52.5%) of the participants would engage in palliative home care for children Barriers: time-consuming (29.6%), lack of opportunities to exchange information with colleagues (25.5%), discontinuity of care (15.6%); feeling overwhelmed (13.5%) Facilitators: education in basic palliative medicine (84.4%) sufficient information exchange (82.3%), availability of 24/7 on-call telephone service for PPC (74.5%) |

Table 2 (continued)

Table 2 (continued)

| Title | Year | Country | Purpose | Design | Data collection method | Sample | Key findings |
|--|------|----------------|--|--|---------------------------|--|---|
| Implementing a program to improve pediatric and pediatric ICU nurses' knowledge of and attitudes toward palliative care (48) | 2012 | USA | Investigate pediatric nurses' knowledge and attitudes about pediatric palliative care | Quantitative pretest-posttest, pre-experimental design | Self-administered survey | N=25 pediatric ICU nurses | Knowledge: the mean score for knowledge significantly increased after the educational program (paired <i>t</i> -test: $t_{24} = 2.48^*$) Attitude: the mean score for attitude significantly increased after the educational program (paired <i>t</i> -test: $t_{24} = 6.38^{**}$) |
| The needs of professionals in the palliative care of children and adolescents (49) | 2013 | Switzerland | Describe the needs of pediatric healthcare professionals taking care of children with palliative care needs. Develop a concept for the first center of competence for PPC in Switzerland | Qualitative | Semi-structured interview | Part I, n=21 Part II, n=55 | Knowledge: the participants defined PPC according to the World Health Organization and the Association of Children with terminal illness definition. PPC is linked with disease progression and complex needs Attitudes: participants identified the collaborative efforts within palliative care. Many staff members described myths around PPC Barriers: uncertainty about palliative care timing, uncertainty about many children's prognoses, and difficulty communicating with parents |
| Pediatric oncology providers' perceptions of barriers and facilitators to early integration of pediatric palliative care (25) | 2013 | USA | Investigate pediatric oncology providers' perceptions of barriers and facilitators to early integration of PPC | Qualitative | Four focus groups | N=15 physicians, seven nurse practitioners, two social workers, and nine inpatient and outpatient nurses | Barriers: provider role, conflicting philosophy, patient readiness, emotional influence Facilitators: patient eligibility and timing, overall benefit, education of providers and families, evidence-based medicine, enhanced communication |
| Attitudes about palliative care: a comparison of pediatric critical care and oncology providers (50) | 2014 | USA | Compare oncology and critical care providers' attitudes regarding palliative care | Quantitative cross-sectional descriptive | Electronic survey | N=152 | Attitude: critical care physicians were more likely to incorporate palliative care for psychosocial support. Oncologists consult PPC for symptom control Factors associated with attitude: palliative care education, gender (women are more likely to integrate PPC and integrate it earlier) |
| Underlying barriers to referral to paediatric palliative care services: knowledge and attitudes of health care professionals in a paediatric tertiary care centre in the United Kingdom (51) | 2014 | United Kingdom | Investigate knowledge and attitudes towards palliative care amongst health care professionals | Quantitative cross-sectional descriptive | Online and paper survey | N=132 healthcare professionals | Knowledge: 48% reported the need to refer children to PPC at diagnosis. 68% reported prior referral to PPC team over the last year Attitude: 63% disagreed with the statement "palliative care is primarily about providing care at the EOL" (22% agreed and 15% neither agreed nor disagreed). 75% agreed with the statement "palliative care is as important as curative" and 66% disagreed with the statement "referring to palliative care services too early will undermine the parents' hope" Barriers: the most commonly cited reason for not referring to palliative care was that "referral would not be acceptable to the parents" (39%) |
| Paediatric palliative care in Malaysia: Survey of knowledge base and barriers to referral (52) | 2014 | Malaysia | Explore the knowledge and practice of healthcare providers and their barriers to referral for palliative care prior to development of a nationwide service | Quantitative cross-sectional descriptive | Self-administered survey | N=292 pediatricians and pediatric nurses | Knowledge: more paediatricians (40.5%) than nurses (25.1%) had basic knowledge in palliative care*. Misconceptions exist mainly among nurses about the concept of palliative care and morphine use Barriers: the common perceived barriers for referral are the family's understanding of illness and issues within the family. Among pediatricians: 79.4% reported the lack of accessible palliative care services. More than half of paediatricians thought that "uncertain prognosis" (50%) and "unsure when to refer" (51.5%) were barriers. Among the paediatricians, the lack of accessible paediatric palliative care services was the predominant perceived barrier to referral. More paediatricians than nurses perceived that communication between the staff and the family and cultural differences were barriers to PPC |

Table 2 (continued)

Table 2 (continued)

| Title | Year | Country | Purpose | Design | Data collection method | Sample | Key findings |
|--|------|---------------|---|--|---------------------------------------|--|---|
| Referral practices of pediatric oncologists to specialized palliative care (53) | 2014 | Canada | Describe the attitudes and referral practices of pediatric oncologists specialized palliative care and to compare them with those of adult oncologists | Quantitative cross-sectional descriptive | Self-administered paper questionnaire | N=646 adult and pediatric oncologists | <p>Knowledge: 96% of pediatric oncologists had access to inpatient PPC services. Only 27% reported having access to an outpatient palliative care clinic (vs. 73% adult oncology). Fewer pediatric oncologists than adult oncologists reported prior rotation in palliative care during training (26% vs. 51%^{**})</p> <p>Attitude: pediatric oncologists were more likely to agree that they would refer earlier if palliative care were renamed “supportive care” (58% vs. 33%^{**}), that palliative care adds too many providers (17% vs. 7%^{**}), and that palliative care was perceived negatively by their patients (60% vs. 43%[*])</p> <p>Practice: 40.4% of pediatric oncologists referred at the diagnosis of metastatic disease, and 46.8% during the course of chemotherapy. Only 13% tended to refer after stopping chemotherapy or transfusions</p> |
| The impact of a palliative care team on residents’ experiences and comfort levels with pediatric palliative care (54) | 2014 | USA | Evaluate the impact of a palliative care team on pediatric and internal medicine/pediatric (IM/Peds) residents’ knowledge, comfort level and experience providing PPC | Quantitative cross-sectional descriptive | Electronic questionnaire | N=294 pediatric and IM/Peds residents | <p>Knowledge: around 2/3 of participants selected the description stating that PPC starts at the time of diagnosis regardless of treatment goals</p> <p>Factors associated with knowledge: presence of a PPC team at institution</p> <p>Attitude: 55.3% (95% CI: 49.2–61.3%) were comfortable providing pain management</p> <p>Factors associated with attitude: presence of a PPC team at the institution</p> |
| Physician Perspectives on Palliative Care for Children With Neuroblastoma: An International Context (14) | 2016 | International | Explore physicians’ perceptions or knowledge of palliative care | Quantitative cross-sectional descriptive | Online survey | N=53 pediatric oncologists | <p>Knowledge: 58% of participants responded initiating PPC when curative treatment has failed and 33% responded that palliative care is initiated within the last six months of the child’s life. Less commonly chosen inappropriate answers were “Initiated only after curative therapy has stopped” (17%) and “Initiated after a DNR order is in place” (13%). 17% of respondents inappropriately considered palliative care as that initiated only after curative therapy is stopped</p> |
| Pediatric Cardiology Provider Attitudes About Palliative Care: A Multicenter Survey Study (55) | 2017 | USA | Describe attitudes towards PPC consultation. Identify barriers to PPC. Characterize physician perceived competence PPC | Quantitative cross-sectional descriptive | E-mailed survey | N=155 pediatric cardiologist in 19 centers | <p>Knowledge: 30% received training. Mean level of knowledge 2.94±0.77 out of 5. Over 90% percent reported no role for palliative care involvement unless the patient is expected to die within weeks to months or if he/she is actively dying</p> <p>Factors associated with knowledge: training and number of patients</p> <p>Attitude: 85% agreed that palliative care consultations are helpful</p> <p>Barriers: undermining parents’ hope (45%) and parents views as giving-up (56%), parents’ refusal to refer to PPC (27%), lack of availability (22%)</p> <p>Practice: 60% felt competent caring for children with heart disease around EOL, and 80% felt competent discussing goals of care and code status</p> |
| Palliative care in paediatric oncology in nursing education (56) | 2017 | Brazil | Identify the view of students regarding palliative care in paediatric oncology during a graduate programme | Qualitative exploratory | Semi-structured interviews | N=20 nursing students | <p>Knowledge: PPC perceived as care when there is no possibility for cure</p> <p>Attitude: students reported being unprepared and avoiding this specialty</p> |
| Towards culturally competent paediatric oncology care. A qualitative study from the perspective of care providers (57) | 2017 | Netherland | Explore obstacles in paediatric cancer care that lead to barriers in the care process for ethnic minority patients | Qualitative framework approach | Semi-structured interviews | N=12 paediatric oncologists and 13 nurses of two different paediatric oncology wards | <p>Barriers: language barriers between care provider and parents hindered the exchange of information. Cultural barriers between care provider and parents about sharing the diagnosis and palliative perspective hindered communication</p> |

Table 2 (continued)

Table 2 (continued)

| Title | Year | Country | Purpose | Design | Data collection method | Sample | Key findings |
|--|------|---------|--|--|---|--|---|
| Physician Perspectives on Palliative Care for Children with Advanced Heart Disease: A Comparison between Pediatric Cardiology and Palliative Care Physicians (58) | 2018 | USA | Compare the perspectives of PPC physicians and pediatric cardiologists regarding palliative care in pediatric heart disease | Quantitative cross-sectional descriptive | Web-based survey | N=183 pediatric cardiologists N=49 PPC physicians | More pediatric cardiologists (63%) than PPC physicians (48%) agreed that the availability of PPC is adequate*. The majority of both groups indicated that PPC consultation occurs "too late" Barriers: PPC physicians overestimated how much pediatric cardiologists worry about PPC introducing inconsistency in approach (60% vs. 11%**), perceive lack of added value from PPC (30% vs. 7%**), believe that PPC involvement will undermine parental hope (65% vs. 44%**), and perceive that PPC is poorly accepted by parents (53% vs. 27%**) |
| Building Bridges, Paediatric Palliative Care in Belgium: A secondary data analysis of annual paediatric liaison team reports from 2010 to 2014 (59) | 2018 | Belgium | Describe the characteristics of children cared for by Pediatric Liaison Team and the different activities provided by Pediatric Liaison Team in order to document how continuity of care is ensured in Belgium | Qualitative | Secondary data analysis Thematic analysis | Annual reports of five specialized pediatric liaison teams | Knowledge: difficulty expressed by pediatric liaison team to define the timing of palliative care. There is a need for continuous PPC training for pediatric liaison team. Family confusion with death requires clear explanation of PPC since the beginning of treatment Barriers: "palliative" frightens the families and it may be a barrier to palliative care services |
| Perceptions of barriers and facilitators to early integration of pediatric palliative care: A national survey of pediatric oncology providers (26) | 2018 | USA | Assess pediatric oncology providers' perceptions of palliative care to validate previously identified barriers and facilitators to early integration of a pediatric palliative care team in the care of children with cancer | Quantitative cross-sectional descriptive | Electronic survey | N=1,005 pediatric oncology providers | Barriers: over half agreed on overlapping roles between the oncology team and the PPC team Facilitators: all participants moderately agreed that introducing PC early does not create an overall burden for parents. All participants disagreed with the statement that PC is inconsistent with curative care. All participants moderately agreed that evidence-based literature regarding early integration of PC is needed |
| Providing pediatric palliative care Education Using Problem-Based Learning (60) | 2018 | USA | Test the effectiveness of a PPC module on third year medical students' and pediatric faculty's declarative knowledge, attitudes toward, perceived exposure, and self-assessed competency in PPC objectives | Quantitative prospective cohort study | Self-administered survey at 3 time points (baseline, follow-up and end of rotation) | N=190 medical students | Knowledge: declarative knowledge and perceived exposure improved significantly on each objective after the intervention** Self-assessed competency and students' perceived exposure improved significantly after the intervention** |
| Awareness of pediatric palliative care among health care workers (61) | 2018 | Ukraine | Assess the awareness of pediatric palliative care among healthcare workers providing medical services to children | Quantitative cross-sectional descriptive | Structured interviews | N=578 healthcare workers | Knowledge: one quarter of respondents did not know the definition of pediatric palliative care. 71.5% linked PPC with cancer. Only 59.7% of respondents knew that palliative care should begin with the diagnosis of an incurable disease, and not at the EOL. The majority of respondents recognized the lack of their knowledge regarding PPC (85.8%) and almost all (94.5%) expressed the desire for PPC education Factors associated with knowledge: position of respondents |
| Impact of Educational Training in Improving Skills, Practice, Attitude, and Knowledge of Healthcare Workers in pediatric palliative care: Children's Palliative Care Project in the Indian State of Maharashtra (20) | 2018 | India | Evaluate the impact of PPC education and training on skills, practice, attitude, and knowledge of healthcare workers | Quantitative pre/post test | Researcher-administered survey | N=62 healthcare workers | Knowledge: 43% of the doctors and 45% of the nurses scored 70 or above. Above 73% of participants believed that palliative care should be started at the time of diagnosis, and 9% when treatment fails Factors associated with knowledge: Palliative care training Attitude: 64% of doctors and 67% of nurses endorsed PPC after the training |

Table 2 (continued)

Table 2 (continued)

| Title | Year | Country | Purpose | Design | Data collection method | Sample | Key findings |
|--|------|---------|--|---|----------------------------|--|--|
| The timing and circumstances of the implementation of pediatric palliative care in Hungarian pediatric oncology (62) | 2018 | Hungary | Explore physician's attitudes and practices concerning pediatric PC | Qualitative: inductive analysis | Structured Interviews | N=22 pediatric oncologists | <p>Knowledge: most physicians (n=21) equated palliation with EOL care</p> <p>Attitude: the majority of respondents voiced distrust concerning the early implementation of PC, and cited parents' anxiety and concerns on the doctor-family-patient relationship</p> <p>Barriers: conceptualization of palliation equated with EOL care</p> <p>Practice: the common practice of timing is still at the end of curative treatment</p> |
| National Impact of the EPEC-Pediatrics Enhanced Train-the-Trainer Model for Delivering Education on Pediatric Palliative Care (24) | 2018 | Canada | Examine the impact of an enhanced implementation of the Education in Palliative and EOL care for Pediatrics curriculum on, knowledge dissemination, health professionals' knowledge, practice change, and quality of PPC | Quantitative pretest-posttest | Electronic survey | N=3,475 health professionals in 15 sites | <p>Knowledge: the majority (96.7%) agreed that their PPC knowledge improved after the training</p> <p>Quality of care: 10/15 sites achieved practice change quality improvement goals. The only improvements in care quality were an increased number of days from referral to PPC teams until death by a factor of 1.54 (95% CI: 1.17–2.03) and from first documentation of advance care planning until death by a factor of 1.50 (95% CI: 1.06–2.11), after adjusting for background variables</p> |
| Knowledge, Beliefs, and Behaviors Related to Palliative Care Delivery Among Pediatric Oncology Health Care Providers (15) | 2018 | USA | Evaluate the knowledge and beliefs of pediatric oncology HCPs regarding involvement of PPC. Assess potential barriers that interfered with its utilization | Quantitative cross-sectional descriptive | Electronic survey | N=156 pediatric oncology providers | <p>Knowledge: more than half of nurses reported no palliative care education or training, compared to 22% of physicians. Twenty percent of participants defined PPC as EOL</p> <p>Attitude: 99.4% of participants felt that involving PPC benefits children and their families. More than 90% agreed that PPC improves symptom management, patient and family outcomes, and family support. 71% of respondents disagreed that PPC involvement decreases families' hope</p> <p>Barriers: misconception of PPC as "giving-up" (49%), misunderstandings of PPC definition (46%), family resistance to PPC (38%), and discomfort discussing PPC or limited knowledge regarding PPC services (36%). Nurse reported barriers at higher frequency</p> <p>Practice: 56% of providers stated they never or rarely involve PPC</p> |
| Pediatric Oncology Providers' Perceptions of a Palliative Care Service: The Influence of Emotional Esteem and Emotional Labor (63) | 2018 | USA | Explore how pediatric oncology providers at one institution perceived the hospital's PPC service and the way these perceptions may influence the timing of consultation | Qualitative modified grounded theory approach | Semi-structured interviews | N=16 pediatric oncology providers | <p>Attitude: positive contributions of PPC service on the care of children with advancing cancer. Favorable opinions about the PPC services</p> <p>Barriers: emotional labor involved in early PPC consultation</p> |
| Factors Associated With Knowledge and Comfort Providing Palliative Care: A Survey of Pediatricians in Mexico (64) | 2019 | Mexico | Examine what factors determine the degree of knowledge and level of comfort Mexican pediatricians have providing pediatric palliative care | Quantitative cross-sectional descriptive | Electronic survey | N=242 pediatricians | <p>Factors associated with knowledge: exposure to oncologic patients** and previous palliative care education*, pediatrician's age**</p> <p>Factors associated with attitude: PPC knowledge**, exposure to oncology patients, prior PPC education</p> <p>Barriers: feeling uncomfortable when addressing these issues with patients and families</p> |
| Training in pediatric palliative care in Italy: still much to do (65) | 2019 | Italy | Determine the availability of training programs in PPC and EOL care for Italian postgraduates specializing in Pediatric Medicine and how the knowledge and skills offered as part of their training is structured | Quantitative cross-sectional descriptive | Web-based survey | <p>N=14 directors of Italian postgraduate pediatric medicine programs</p> <p>N=116 postgraduate students in pediatric medicine</p> | <p>Knowledge: 33.6% of the students were aware of local PPC services. 96.6% correctly defined PPC. In 65.5% of the cases, PPC was correctly defined as a care that should start when the diagnosis of incurability. Between 90% and 100% of participants denied several PPC misconceptions</p> <p>Attitude: 68.1% of students did not feel ready to care for a pediatric patient with life-limiting disease</p> <p>Practice: 68.1% (n=79) did not feel ready to care for a pediatric patient with life-limiting disease</p> |

Table 2 (continued)

Table 2 (continued)

| Title | Year | Country | Purpose | Design | Data collection method | Sample | Key findings |
|---|------|--|--|--|---|--|--|
| The conceptual understanding of pediatric palliative care: a Swiss healthcare perspective (17) | 2019 | Switzerland | Examine understanding of and attitudes towards pediatric palliative care from the perspective of health care providers working in pediatric oncology | Qualitative (thematic coding) | Mixed focused group | N=29 pediatric oncology providers | Knowledge: most participants associated PPC with non-curative treatment Barriers: difficulties in addressing palliative care services to families due to the strong stigma Facilitators: use synonyms such as comfort or supportive care and positive "word of mouth" |
| A survey demonstrates limited palliative care structures in paediatric nephrology from the perspective of a multidisciplinary healthcare team (66) | 2019 | Germany | Investigate the attitudes and expectations of a multidisciplinary paediatric nephrology team, towards palliative care | Quantitative cross-sectional descriptive | Online survey | N=52 healthcare professionals | Knowledge: the majority of participants (96%) responded that the timing of PPC is at EOL. Two thirds the nephrology care team agreed on integrating PPC at EOL and for patients with high morbidity. Only one-sixth of the respondents felt that palliative care should be provided to patients in stable condition Attitude: physicians rated the importance of PPC as 1.8, nurses as 1.6 and psychosocial health professionals as 1.9 (1= very important) Barriers: lack of expertise (74%), lack of adequate funding (47%) and lack of specialized care teams (42%) |
| Use of an Electronic Journal Club to Increase Access to and Acceptance of Palliative Care Literature across General Pediatricians and Pediatric Subspecialties (67) | 2019 | USA | Explore the impact of a monthly electronic journal club to increase the number of palliative care-relevant articles read and discussed and to enhance provider comfort with the integration and introduction of palliative care | Quantitative predesign-post-design | Online survey | N=71 pediatric providers | Attitude: the journal club intervention increased participant personal comfort with integrating palliative care principles at the bedside** and introducing pediatric palliative care to patients and families** |
| Defining the Boundaries of Palliative Care in Pediatric Oncology (68) | 2020 | USA | Assess pediatric oncology practitioners' understanding of PPC. Describe the extent to which PPC is integrated into current care via primary PPC delivered by the oncologist. Describe reported barriers to PC provision to pediatric oncology patients | Mixed-method | Semi-structured interviews content analysis | N=76 pediatric oncology providers | Knowledge: PPC was not limited to EOL as reported by 75% of respondents. All participants acknowledged primary PPC skills as part of their daily clinical activities some reported confusion about the benefits of PC consultation Practice: variation in the comfort and time spent performing primary PPC tasks Barriers: discomfort providing palliative care, tensions between subspecialty palliative care and oncology |
| A multicountry assessment in Eurasia: Alignment of physician perspectives on palliative care integration in pediatric oncology with World Health Organization guidelines (69) | 2020 | Eurasia (Armenia, Azerbaijan, Belarus, Kazakhstan, Kyrgyzstan, Moldova, Mongolia, Russia, Tajikistan, Ukraine, and Uzbekistan) | Assess the perspectives and knowledge of physicians caring for children with cancer on palliative care in 11 countries in Eurasia | Quantitative and qualitative items | Electronic survey with paper-based option | N=424 responses from 11 countries in Eurasia | Knowledge: the mean alignment between provider perspectives and WHO recommendations was 70% (range, 7–100%). Above 90% of respondents described the role palliative care as pain and symptom management, psychological support, and addressing quality of life. The most common regional misconceptions was early consultation with palliative care causes increased parental burden and anxiety Factors associated with knowledge: prior palliative care education Attitude: Two-thirds of respondents reported lack of confidence in delivering at least one component of palliative care. Only 7.7% described palliative care more positively, as a celebration of life. Participants responded being confident about managing the physical (57%) and patients' emotional needs (63%) Practice: 57% indicated that palliative care is administered in the absence of curative therapy and 36% at the EOL. Access to PPC consultation was reported in 54% of the cases |

Table 2 (continued)

Table 2 (continued)

| Title | Year | Country | Purpose | Design | Data collection method | Sample | Key findings |
|--|------|-------------|--|---|--|---|---|
| The effect of web-based pediatric palliative care education on the palliative care knowledge level and practices of nursing students (70) | 2020 | Turkey | Investigate the effect of web-based pediatric palliative care education on nursing students' knowledge level and practices related to palliative care | Quantitative case-control pre-post training | Electronic survey | N=265 nursing students | Knowledge: the difference between pre-post test scores was statistically significant in the intervention and control groups* Practice: the difference between the pretest and posttest score on PPC practice was statistically significant in the intervention and control groups*. The education program explained 36% ($R^2=0.360$) of the increase in the level of the change in self-reported palliative care practices, while receiving the education increased the level of change in self-reported palliative care practices by 0.600 times ($\beta=0.600$) |
| Paediatric oncology providers' perspectives on early integration of paediatric palliative care (71) | 2020 | Lebanon | Explore the perceptions of paediatric oncology providers regarding the integration of early PPC in the management of children with cancer | Qualitative descriptive | Focus group discussions semi-structure interviews | n=10 pediatric oncology nurses n=7 pediatric oncologists | Knowledge: palliative care is understood as pain relief and psychological support, mainly at the EOL. The timing of PPC integration is linked to EOL, advanced disease or treatment failure Attitude: the benefits of early integration were noted by nurses Barriers: parents' views as giving-up, lack of training and specialization, Difficulties in communication with patients/families, emotional attachment to patients Facilitators: respecting religious beliefs, team approach/collaboration, involvement of trained nurses |
| Perceptions of pediatric palliative care among Physicians Who Care for Pediatric Patients in South Korea (72) | 2020 | South Korea | Explore physicians' perceptions of PPC and the differences therein between non-oncologists and oncologists | Quantitative cross-sectional descriptive | Electronic survey | N=141 physicians | Attitude: oncologists showed higher confidence levels in decision-making and communication with patients and families with poor prognosis* and education and providing EOL care**. Oncologists preferred earlier referrals than did non-oncologists Barriers: lack of resources in PPC (60.2%), patients' or caregivers' negative recognition (55.9%) |
| Feasibility, Acceptability, and Education of Pediatric Oncology Providers Before and After an Embedded Pediatric Palliative Oncology Clinic (73) | 2021 | USA | Explore whether an embedded PPO clinic is associated with improved pediatric oncology provider palliative care comfort, knowledge, and attitudes toward PPC and if the model is feasible for both clinical care and education of providers | Quantitative cohort | Electronic survey (baseline, 6 months, and 1 year after the start of an embedded PPO clinic) | N=29 oncologists, advanced practice providers, and fellows | Knowledge: embedded clinic: The non-PPO group had a greater mean change over 1 year in self-efficacy** and knowledge** Attitude: all providers reported positive attitudes about PPC, seeing it as essential to patient care, helpful in relieving suffering, and beneficial for a comprehensive patient care |
| Congenital Cardiothoracic Surgeons and Palliative Care: A National Survey Study (74) | 2021 | USA | Describe perspectives of pediatric cardiothoracic surgeons regarding palliative care in pediatric heart disease | Quantitative cross-sectional descriptive | Web-based survey | N=31 cardiothoracic surgeons | Attitude: 45% of respondents would refer to PPC upon prenatal diagnosis and 30% upon failure of treatment options Barriers: perception of "giving-up" (40%) and concern for undermining parental hope (36%) Practice: around 83% initiated or encouraged PPC. Reasons for consultation included: setting the goals of care (87%) EOL care (90%), symptom and pain management (74%) |
| Qualitative analysis of family-centered care for children with cancer in palliative wards: An evaluation of needs and barriers in resource-limited settings (75) | 2021 | Indonesia | Assess the perspectives of nurses regarding family-centered treatment in Indonesia's palliative wards for children with cancer | Qualitative content analysis | Semi-structured interview | N=10 nurses | Barriers: limited information regarding the timing initiating palliative and family centered care, inconsistency in patient classification, lack of palliative and family centered care awareness, lack of awareness, lack of practice skills about palliative and family centered care Facilitators: multidisciplinary collaboration |

Table 2 (continued)

Table 2 (continued)

| Title | Year | Country | Purpose | Design | Data collection method | Sample | Key findings |
|--|------|----------------|--|--|------------------------|---|---|
| Attitudes and Practices of Pediatric Oncologists Regarding Palliative Care Consultation for Pediatric Oncology Patients (76) | 2022 | USA | Describe palliative care services available to children with cancer along with pediatric oncologists' current and ideal practices of palliative care involvement in children with cancer | Quantitative cross-sectional descriptive | Electronic survey | N=265 | Attitude: more than half of oncologists agreed that palliative care should "always" be consulted for the following scenarios: new diagnosis of advanced/metastatic disease (53%), uncontrolled symptoms (65%), BMT (55%), relapsed/refractory disease (73%), and EOL (89%). None of the participants reported that palliative care should "never" be consulted for all scenarios outlined in the survey. More than 90% reported that PPC services should be consulted more frequently |
| Palliative care for children with complex cardiac conditions: survey results (77) | 2022 | United Kingdom | Examine current practices, attitudes, confidence and perspectives of participants on providing palliative care to children with complex cardiac conditions | Quantitative cross-sectional descriptive with open-ended questions | Electronic survey | n=86 Palliative Care Practitioners n=91 Cardiac Care Practitioners | Knowledge: both groups reported that palliative care extended beyond the EOL phase, and it could be initiated even when management had not yet been decided Attitude: significant difference between groups regarding the acceptability of PPC and the effect of early PPC on parental hope. Both groups agreed on PPC value as a support to clinicians in managing symptoms Practice: the most common reasons for PPC referral were: assistance with preferred place of death discussions, advance care planning, and symptom management. Both groups reported confidence in discussing goals of care and providing EOL care |

*, P value <0.05; **, P value <0.001. ICU, intensive care unit; IM/Peds, internal medicine/pediatric; WHO, World Health Organization; PPC, pediatric palliative care; PPO, pediatric palliative oncology; EOL, end-of-life; HCP, healthcare professionals; DNR, do not resuscitate; PC, palliative care.

Table 3 Summary of reviewed studies conducted among parents and communities

| Title | Year | Country | Purpose | Design | Data collection method | Sample | Key findings |
|--|------|---------|---|--|---|--|--|
| Perceptions of the term palliative care (78) | 2006 | USA | Assess parents' and health care providers' perceptions of the name and description of a PPC program | Quantitative randomized, parallel-group survey | Written survey before and after reading description | N=105 parents N=79 healthcare providers | Knowledge: at baseline, more parents in the supportive care group (57.6%) reported knowledge about the program definition than in PPC group (36.4%) (Chi-square =4.562*). Reading the description significantly increased awareness in both groups (100% in supportive care vs. 89.7% in PPC group*). Among providers reading the description significantly increased awareness within the supportive care group only* Attitude: at baseline, parents in PPC group were less likely to use program than supportive care group*. The likelihood to use the program increased in both groups after reading the program description. Among providers the likelihood to use the program increased significantly in PC group after reading the description |
| Awareness, understanding and attitudes of Italians regarding palliative care (79) | 2011 | Italy | Examine the level of public awareness, understanding and attitudes of the Italian population regarding PC | Quantitative cross-sectional descriptive | Structured interviews | N=1,897 individuals from the general public | Knowledge: around 40% of participants have never heard about palliative care. Of those who have heard, only 23.5% reported adequate level of knowledge and 27% did not know or had confuse palliative care with EOL Factors associated with knowledge: gender (women were more aware), age, level of education, geographic location, income Barriers: in pediatric population the main concern was: being "separated" from family, friends, home and toys |
| How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times (80) | 2011 | USA | Clarify and illustrate the role of religion, spirituality, or life philosophy in the lives of parents of children with life-threatening conditions | Qualitative research approach nested in a prospective cohort study | Semi-structured interviews | N=73 parents | Facilitator: religious beliefs and religious commitment |
| Establishing Feasibility of Early Palliative Care Consultation in Pediatric Establishing Feasibility of Early Palliative Care Consultation in Pediatric Hematopoietic Stem Cell Transplantation (27) | 2015 | USA | Establish the feasibility of integrating palliative care early in the trajectory of HSCT (at the time of referral or admission to the HSCT program) and to measure the outcomes of such care experience | Longitudinal, descriptive cohort design | Structured interviews | N=12 families (caregivers and patients) N=20 healthcare providers | Attitude: all families (100%) rated the PC as helpful or very helpful in managing symptoms and stresses. All families indicated it was very important to offer palliative care services and that they were very likely to recommend the palliative care team to others. 70% of families were also very likely to recommend the institution to other patients and families based upon their experiences with the palliative care team |

Table 3 (continued)

Table 3 (continued)

| Title | Year | Country | Purpose | Design | Data collection method | Sample | Key findings |
|--|------|----------------|--|--|--|---|--|
| Patients' and Parents' Needs, Attitudes, and Perceptions About Early Palliative Care Integration in Pediatric Oncology (28) | 2017 | USA | Determine the perception of symptom burden early in treatment. Assess attitudes toward early integration of palliative care in pediatric oncology patient-parent pairs | Quantitative cross-sectional descriptive | Self-administered survey | N=129 dyads (patients =10-17 years and parents) | Knowledge: the majority of patients (98.4%) and parents (69.8%) reported that they had never heard the term "palliative care" Attitude: none of those who had heard about palliative care have negative attitude. When given a brief description: very few children (1.6%) or parents (6.2%) opposed early PPC integration. Children were significantly more likely than parents to endorse that the initiation of palliative care around the time of diagnosis would have been helpful for treating symptoms (40.3% vs. 17.8%, P value <0.001) |
| Needs and challenges of lay community health workers in a palliative care environment for orphans and vulnerable children (81) | 2017 | South Africa | Explore the role of lay health workers in a community organization located in rural Bronkhorstspuit, Gauteng Province of South Africa | Qualitative descriptive phenomenological case study design | Individual interviews Focus group discussions Observations | N=25 lay community workers N=21 in focus group discussions | Knowledge: participants reported lack of knowledge in term of palliative care itself |
| Exploring knowledge and perceptions of palliative care to inform integration of palliative care education into cystic fibrosis care (82) | 2018 | USA | Explore knowledge and perceptions of palliative care among patients with cystic fibrosis, caregivers, and care providers. Solicit opinions about incorporating palliative care into routine cystic fibrosis care and recommendations for cystic fibrosis-specific palliative care education | Qualitative descriptive | Semi-structured interviews | N=10 patients N=10 caregivers N=8 providers | Knowledge: half of patients and one third of parents had no knowledge. Those familiar with PPC associated it with EOL. Most of participants used "comfort" and "quality of life" in their description Attitude: after hearing description participants reported that PPC is helpful Barriers: association with EOL, patient/family denial and reluctance to discuss palliative care |
| Public awareness of palliative care in Sweden (83) | 2018 | Sweden | Investigate the awareness of palliative care in a general Swedish population | Quantitative cross-sectional descriptive | Electronic survey | N=2,020 individuals from the general public | Knowledge: around 84% have "no" or "some" knowledge about palliative care. The aims of palliative care were most frequently identified as EOL care (61.4%) and pain management (60.7%). The most common sources of information included: media, close friends and relatives receiving PC Factors associated with knowledge: gender, age, level of education, work setting and knowing someone receiving palliative care Barriers: fear, shame, taboo, perceived lack of information |
| Palliative Care Knowledge and Characteristics in Caregivers of Chronically Ill Children (84) | 2020 | USA | Describe palliative care awareness among caregivers of children with chronic conditions. Compare awareness to the whole survey population, the non-caregiver population, and the adult caregiver population. Identify socio-demographic and clinical factors associated with lack of palliative care awareness | Secondary data analysis (HINTS 5 cycle 2) | Self-administered mailed survey | N=131 caregivers of children with chronic conditions | Knowledge: 62% never heard (comparable to non-caregivers and adult caregivers). More than 90% of participants reported that palliative care helps coping emotional support and symptom management and 80% think that PPC is the same as hospice Factors associated with knowledge: age and level of education |
| Experiences of healthcare, including palliative care, of children with life-limiting and life-threatening conditions and their families: a longitudinal qualitative investigation (85) | 2021 | United Kingdom | Understand the experiences and perceptions of healthcare services of children with life-limiting and life-threatening conditions and their family members, including palliative care | Longitudinal qualitative | In-depth interviews (up to three interviews per participant) | N=31 participants (including 10 children) | Knowledge: palliative care conceptualized as a distinct service or phase of a child's condition, rather than a broad approach Facilitators: availability of specialist services, trust with healthcare professionals |
| Palliative Care in Duchenne Muscular Dystrophy: A Study on Parents' Understanding (86) | 2021 | India | Explore the parent's understanding of palliative care services available for children with DMD and the challenges faced by them in utilizing the same | Qualitative exploratory Grounded theory | Semi-structured interviews | N=6 parents | Knowledge: participants were aware of the term and aim of palliative care. Palliative care for children was not clear. The term palliative care was associated with ambiguity and death. Participants were unsure regarding the timing and indications of PPC Barriers: difficulty accepting the child's prognosis, lack of emotional acceptance of the child's condition, lack of open communication between the parents and the child |

*, P value <0.05. WHO, World Health Organization; PPC, pediatric palliative care; PC, palliative care; EOL, end-of-life; HSCT, hematopoietic stem cell transplantation; HINTS, Health Information National Trends Survey; DMD, Duchenne muscular dystrophy.

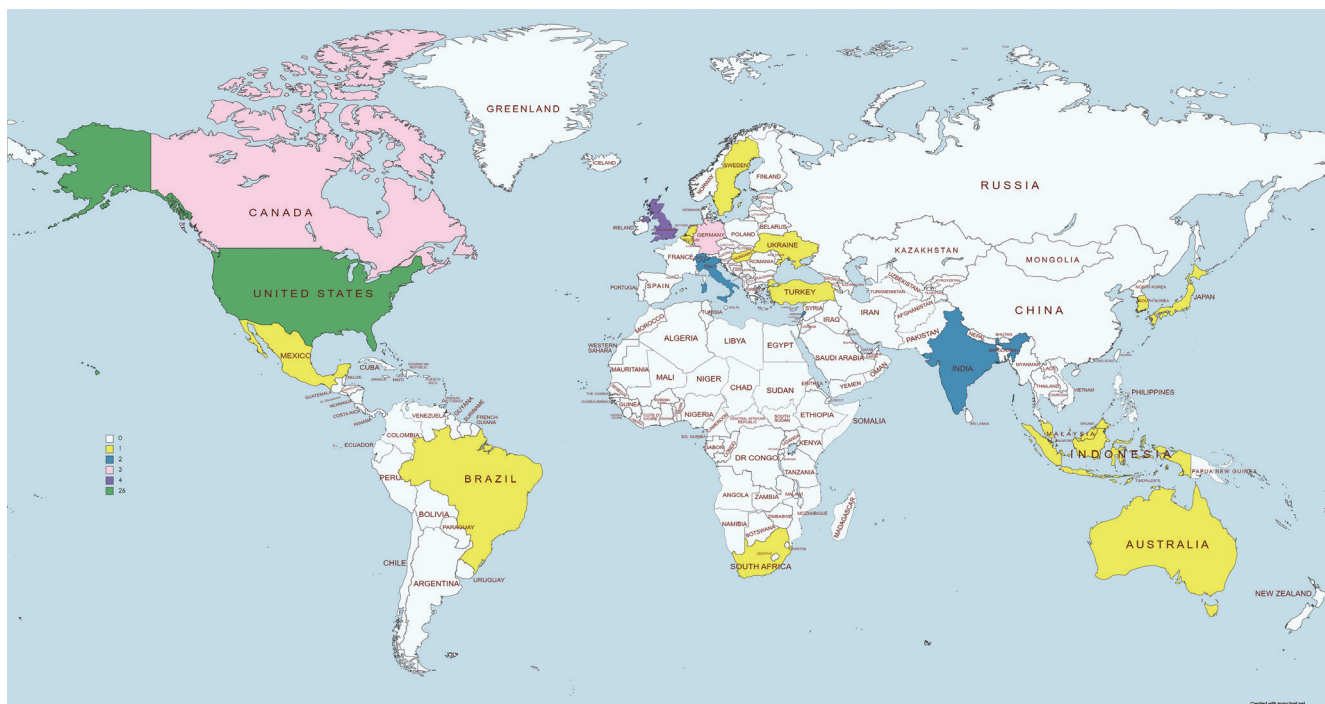


Figure 2 The number of studies by country is indicated. The green color represents the highest number with 26 articles per country. Purple indicates 4 articles per country. Pink represents 3 articles per country. Dark blue represents 2 articles per country. Yellow represents 1 article per country.

frequency of studies addressing KAB toward PPC. *Figure 3* illustrates the frequency over the years and by study population.

The literature on KAB toward PPC among pediatric HCP represents various hospital and home settings (13,15,17,43,47,55,71,85). Twenty-two studies (36.6%) were conducted in pediatric oncology care settings. A handful of articles addressed PPC in the general population (79,81,83,84). *Tables 2,3* summarize the studies retrieved on KAB toward PPC.

KAB toward PPC among HCP

Studies from developed countries revealed that despite the adequate knowledge of PPC principles among pediatric professionals, there is confusion of PPC with hospice care or end-of-life care (16,39,51,62,66). Moreover, the level of PPC knowledge and attitudes are inconsistent among different care domains in PPC. Feudtner and colleagues (87) found that pediatric nurses reported being most competent in pain management and least competent in communication with patients and families.

Adequate PPC knowledge may be present even when

PPC services are less developed; however, PPC training remains a crucial need. For example, a study conducted in Lebanon examined the knowledge, attitudes and practices in PPC among 96 pediatric nurses and 27 pediatricians across 15 hospitals (13). While only 20.2% of the pediatric nurses and 3.7% of the pediatricians reported having received continuing education in palliative care, both groups demonstrated high knowledge scores. Yet, both groups had average scores on attitude and practices. As noted by the authors, the findings on attitudes and practices among pediatric professionals call for more training to ensure better PPC practices (13).

When comparing pediatric specialties, discrepancies in the reasons for incorporating palliative care were revealed. In a large study conducted in 18 institutions across the United States, physicians in pediatric critical care were more likely to integrate palliative care for psychosocial support, while pediatric oncologists integrated it for symptom management (50). The same study revealed that female clinicians and those who received palliative care education were more likely to incorporate palliative care, did so earlier and for reasons other than end-of-life planning compared to their counterparts (50). Another multicenter survey

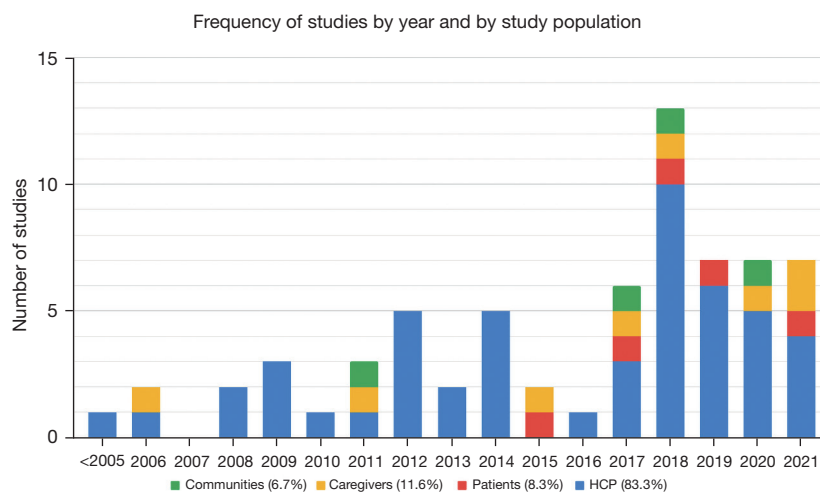


Figure 3 The distributions of study population across time highlights an increasing trend in the last 5 years. Healthcare professionals are the most studied group. HCP, healthcare professionals.

described attitudes toward PPC consultations among 183 pediatric cardiologists (55). The majority of the sample (85%) agreed that PPC involvement was helpful and 61% reported that it occurred “too late”. However, the most commonly cited barrier to PPC consultations was the providers’ concern of the parents’ views of PPC as giving-up on their child (55). These dichotomous views not only call for enhancing HCP’ knowledge regarding PPC, but also for investigating whether parents would report similar concerns.

Recent publications among pediatric oncology professionals also emphasize the need to improve KAB toward PPC (15,17,71). Authors alluded to the frequent interactions with the PPC team and proposed workplace training offered by this team as a substitute to formal training (15). Despite distinguishing PPC from end-of-life care, pediatric oncologists in Switzerland described the operational challenges in the timely integration of PPC. Participants attributed these challenges to the strong stigma surrounding the term among families, the reluctance of HCP to initiate PPC early in the disease trajectory, and the cultural and religious backgrounds of patients and families (17).

Many quantitative studies highlighted the positive association of knowledge and attitude toward PPC (20,48,50,54,64,67). Other qualitative findings emphasized the need for PPC education and formal support for HCP as means to correct misconceptions and enhance PPC integration (71). In addition to formal training, fostering experience and interactions with palliative care services

potentially promotes positive HCP’ attitudes, and aligns their practices with the PPC philosophy that is broader than end-of-life care.

KAB toward PPC among parents of pediatric patients

The perspectives of pediatric patients and their parents regarding PPC is still an underexplored area where only four identified studies addressed this issue (27,28,78,82). Early researchers reported that parents were more likely to use the services when named “supportive care” rather than when named “palliative care”. However, after receiving a description of each program, parents reported similar likelihood to use either services and expressed more receptivity to palliative care compared to baseline (78). As such, educating parents PPC may promote their perceptions of the services.

Over time, the negative parental views have been cited as a barrier to introducing PPC services (18). Authors reporting such a barrier often collected data from HCP rather than from parents (15,25,46,55). Conversely, recent findings suggest that more than half of oncology professionals from the United States (n=1,005) disagreed with the concern that early PPC would increase parental burden. Such change reflects the emerging literature in support of PPC and call for additional research among parents (26).

Emerging studies combining patients and parents also challenge the earlier findings and suggest endorsement of

PPC by parents. Lafond and colleagues (27) argued that parents may not be as resistant to PPC as perceived by professionals, and that this barrier to PPC is modifiable. More evidence from 129 dyads of children with cancer and their parents highlight the considerable symptom suffering within the first month of diagnosis (28). In addition to the need for PPC the authors reported a remarkable acceptance of early PPC integration among both children and parents. Rather than being considered barriers to PPC, children with cancer and their parents “are ready for an integrated model of care” (28). Cultural bias, lack of in-depth and qualitative reporting of existing knowledge among participants, and the use of non-validated instruments are considerable limitations of the study.

Despite these encouraging parents’ perspectives, authors are still reporting an inaccurate understanding of PPC within life-threatening and life-limiting conditions (85,86). Children with life-limiting and life-threatening conditions and their parents conceptualized PPC as relevant to a separate period of child’s disease, rather than a comprehensive approach to care (85). Parents of children with Duchenne Dystrophy expressed ambiguity about the term “palliative care” and its association with “death” (86).

Many authors explored the parents’ views on barriers and facilitators to PPC integration (82,88,89). In the context of cystic fibrosis, participants reported that the association of PPC with end-of-life and the patient/family denial and reluctance to discuss palliative care challenged its integration (82).

In fact, earlier studies addressing parents’ perspectives on PPC barriers and facilitators focus on the end-of-life phase and on specific aspects of care, such as decision-making, communication, symptom management and advanced care planning (88,89). Because of the focus on end-of-life, these studies shed light on parents’ perspectives of facilitators and barriers to PPC, however, from its narrower angle of end-of-life.

Recently, Walter and colleagues (90) developed a conceptual framework for barriers and facilitators to “regoaling”, particularly regarding PPC integration in the management of children with serious illness. For parents, facilitators to regoaling to a palliative care approach included: certainty about prognosis, awareness of the child’s suffering, support and good communication with the clinical team, knowledge of palliative care or hospice, establishing new attainable hopes, coping skills for negative emotions, and congruence with personal “good parent” beliefs (90). Barriers to regoaling consisted of: lack of

understanding of the medical situation; lack of knowledge about palliative care or hospice; sense of failure as a parent; uncertainty about the prognosis; unrealistic belief in the probability of cure; overwhelming negative emotions; desire to shield others from bad news; and lack of trust, support, and communication with clinical team (90).

Other researchers identified cultural contexts that may challenge PPC integration (18,91,92). Asian groups believe that speaking about the possibility of death can induce it (91). In Lebanon, evoking death remains a taboo (92). Native American families engage members from the extended family in making treatment decisions, such decisions are taken collectively rather than by the caregiver alone (91). Within these cultural characteristics, parents who equate PPC with end-of-life care might link PPC integration to the child’s death. On the other hand, spiritual and religious engagement may facilitate PPC integration (80,93). Religious and spiritual practices helped parents accept and understand the child’s condition, make treatment decisions (80), and experience emotional relief (80,93).

In summary, the literature on parents’ KAB toward PPC highlights the possibility of attenuating parents’ stigma about PPC through enhancing their knowledge about the care. Recent evidence on PPC misconceptions incite for timely actions taking into consideration the multifaceted barriers and facilitators at the parents’ level.

KAB toward PPC in community samples

Several studies addressing the perspective of the community regarding palliative care examined the phenomenon as an overarching concept for both adult and pediatric populations (34,94,95). These studies shed light on the understanding of palliative care from a non-healthcare viewpoint. Moreover, it is possible that study participants include parents of children in need of palliative care. Researchers investigated public awareness regarding palliative care and highlighted parents’ representation in their samples (84,95). Parents of children with serious chronic conditions (n=131) and participants from the community (n=106) were comparable with regards to palliative care knowledge (61.5% vs. 60.0%, P=0.76) (84).

In countries with developed palliative care services, community surveys revealed familiarity with the term “palliative care”; however, this awareness did not preclude inaccurate information (79,83,96,97). A recent scoping review examined thirteen articles on knowledge, awareness and perceptions of the community from various countries

including Canada, the United States, New Zealand, Ireland, Scotland, the United Kingdom, Korea, Sweden, and Italy (34). The authors reported a consistent poor awareness and knowledge about palliative care over the years. Across the articles, the proportion of participants having no knowledge about palliative care ranged from 32% to 71% of the samples. The studies also highlighted common participants' misperceptions of linking palliative care with end-of-life stages and with cancer. Factors associated with increased knowledge included gender, age, prior experience with palliative care and higher level of education (34).

Likewise, in a recent study in Australia, ninety percent of participants from the community (n=421) reported having heard of palliative care. Yet, only 12% had accurate knowledge about such care as evidenced by the complete correct answers on a previously validated and psychometrically tested scale. Overall, study participants endorsed palliative care. Older age, caregiving role, knowing someone who had received palliative care and more accurate knowledge predicted more favorable attitudes (95).

In less developed countries, these findings are echoed, with even lower percentages of both familiarity with and accurate knowledge of palliative care (94,98,99). Different contributing factors were also revealed. In India, urban habitants had higher level of knowledge than those living in rural areas (99). In Saudi Arabia, employment status correlated with better palliative care knowledge and more awareness (94).

Although to a limited extent, findings from community studies informed about similarities with parents' KAB toward PPC. Therefore, it is worth considering these studies in pediatric contexts to enhance a comprehensive examination of KAB toward PPC.

Limitations

Despite the rigorous process, this review is limited by restricting articles to English language, which may have resulted in missing different findings in papers published in other languages. Another limitation is the exclusion of studies solely addressing the end-of-life phases, which to a certain extent, excluded a major disease phase where PPC is implemented. To account for this limitation, studies encompassing all disease stages were retained. Yet, the confusion between PPC and end-of-life care was still evident in the reviewed studies addressing the perspectives of various stakeholders on PPC. These findings

underscore a pressing need for prompt interventions among professionals and for timely awareness among non-professionals to alleviate children's suffering. Finally, different results may have been overlooked due to the exclusion of conference abstracts and proceedings.

Summary

The literature highlights the lack of knowledge and negative attitudes toward palliative care that is common among HCP, patients and their parents, and community samples. Across studies, it is obvious that improving knowledge and attitude is needed despite the scattered findings of endorsement of PPC integration. Studies suggest that several factors are associated with knowledge and attitudes, including participants' demographic characteristics and patients' clinical information. These factors are worth considering in studies investigating knowledge and attitudes regardless of the perspective. Evidence on parents' views toward PPC integration are dispersed in the literature. A comprehensive instrument compiling parents' perspective on facilitators and barriers to PPC remains a need.

At the conceptual level, many authors focused on the end-of-life dimension of PPC. It is probable that such focus in studying KAB reinforced the link of palliative care with death. Thus, conducting palliative care research without emphasis on terminal phases would redirect the participants' understandings of the correct and broad definition that encompasses the entire disease trajectory. At the operational level, the lack of tools measuring KAB in PPC requires careful adaptation of existing measures.

As for the context, most of the studies focus on HCP' perspectives. A detailed exploration of parents' views of PPC is lacking. Despite being partners in decision-making and care, parents of pediatric patients are rarely the focus of research on KAB toward PPC. Few recent studies from the United States suggest that parents favor PPC when properly educated about it. Such studies lack in less developed settings, which hinders the possibility of comparing findings or distinguishing potential cultural variations. Considering the limited availability of PPC in LMICs, and the crucial involvement of parents in the care, it is pertinent to investigate parents' perspectives in these settings. Determining these views will form the basis for designing strategies not only to improve their KAB but also to enhance the entire PPC delivery.

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Footnote

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Appendix 1 Search strategy: Medline

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to August 26, 2020>

Search Strategy:

-
- 1 exp child/ or pediatrics/ or minors/ or Adolescent/ (3043114)
 - 2 (baby or babies or toddler or toddlers or minor or minors or boy? or boy?hood or girl? or kid? or child or children or childhood or adolescen* or juvenil or youth* or teen* or (under adj age) or pubescen* or pubert* or p?ediatrics or p?ediatric or pre-school* or preschool* or school*).mp. (4014819)
 - 3 exp Palliative Care/ or terminal care/ or hospice care/ or Respite Care/ or Hospices/ or Palliative Medicine/ or Advance Care Planning/ (83496)
 - 4 ((palliative or comfort or terminal or "end of life" or "end-of-life" or eol or supportive or support or supports or supporting or bereavement or hospice* or respite*) adj (care or caring or carer or carers)).mp. (115601)
 - 5 ((palliative or comfort or terminal or "end of life" or "end-of-life" or eol or supportive or support or supports or supporting bereavement or hospice* or respite*) adj (program* or speciali?ed or specialist? or service? or team?)).mp. (14007)
 - 6 (advanced adj care adj (plan* or team*)).mp. (444)
 - 7 1 or 2 (4014819)
 - 8 3 or 4 or 5 or 6 (130159)
 - 9 7 and 8 (19433)
 - 10 Health Knowledge, Attitudes, Practice/ or Attitude to Health/ or perception/ or *thinking/ or concept formation/ or attitude/ or attitude to health/ or health knowledge, attitudes, practice/ or Awareness/ (300298)
 - 11 (Knowledge* or attitud* or belief* or view* or opinion* or aware* or understanding* or perception* or perceived or thinking or thought* or practice? or (concept adj formation) or (Health adj (Knowledge* or attitud* or belief* or view* or opinion* or aware* or understanding* or perception* or perceived or thinking or thought* or practice? or (concept adj formation)))).mp. (3884440)
 - 12 10 or 11 (3884440)
 - 13 9 and 12 (7414)
 - 14 exp patients/ (65530)
 - 15 (Hospitali?ed or inpatient* or in-patient* or outpatient* or out-patient* or ((in or out) adj patient*) or institutional?ed or ((chronic* or terminal*) adj ill*) or ((cancer* or malignan* or metastati*) adj disease*) or client* or (care adj (recipient* or receiving))).mp. (2180580)
 - 16 14 or 15 (2197947)
 - 17 exp Parents/ or Caregivers/ or exp Legal Guardians/ (150058)
 - 18 (((primary or family) adj ((care adj giver?) or caregiv* or carer*)) or (significant adj other*) or mother* or father* or parent* or (legal adj guardian*)).mp. (709588)
 - 19 17 or 18 (734230)
 - 20 Public Opinion/ (18649)
 - 21 ((public* or (general adj population)) adj (Knowledge* or attitud* or belief* or opinion* or aware* or understanding* or perception* or perceived or thinking or thought*)).mp. (30859)
 - 22 20 or 21 (30859)
 - 23 health personnel/ or caregivers/ or faculty, medical/ or faculty, nursing/ or medical staff/ or exp medical staff, hospital/ or exp nurses/ or exp nursing staff/ or exp nursing staff, hospital/ or physical therapists/ or physicians/ or oncologists/ or pediatricians/ or physicians, family/ or physicians, primary care/ or physicians, women/ or exp religious personnel/ or social workers/ or Health workforce/ or education, medical/ or exp education, medical, graduate/ or education, medical, undergraduate/ or exp Students, Health Occupations/ (553780)
 - 24 ((health* adj (provider? or work* or personnel)) or caregiv* or ((medical or nursing or hospital*) adj (staff or faculty)) or nurs* or physician* or "family physician*" or "primary physician*" or oncologist* or p?ediatrician* or "primary care" or (physical adj therap*) or ((social or religious) adj (staff or personnel* or worker*)))).mp. (1617784)
 - 25 (physician* or doctor* or practitioner* or specialist* or generalist* or "medical student" or "medical students" or "house officer" or "house officers" or Resident or residents or intern or interns or nurse or nurses or "nursing assistant" or "nursing assistants" or "nurse aide" or "nurses aide" or "nurse aides" or "nurses aides" or orderly or orderlies or dietician* or psychologist* or counselor* or therapist* or pharmacist* or dentist* or hygeinist* or phlebotomist* or chiropracter* or acupuncturist* or anaesthesiologist* or anesthesiologist* or anaesthetist* or anesthetist* or perfusionist* or surgeon* or pediatrician* or paediatrician* or obstetrician* or gynecologist* or gynaecologist* or radiologist* or sonographer* or cardiologist* or gastroenterologist* or hepatologist* or endocrinologist* or diabetologist* or internist* or hospitalist* or intensivist* or rheumatologist* or immunologist* or dermatologist* or allergist* or otorhinolaryngologist* or otorhinolaryngologist* or oncologist* or hematologist* or haematologist* or orthopedist* or orthopaedist* or physiatrist* or podiatrist* or technician* or pathologist* or diener* or cytologist* or cytogeneticist* or geneticist* or hematopathologist* or haematopathologist* or neurologist* or neurosurgeon* or ophthalmologist* or optician* or urologist* or nephrologist* or pulmonologist* or neonatologist* or psychiatrist* or administrator* or supervisor* or receptionist* or personnel or team or staff or worker* or researcher or researchers or librarian* or informationist* or housekeeper* or janitor* or officer* or responder* or paramedic* or laboratorian* or coordinator* or navigator* or manager* or attendant* or cashier or cashiers).mp. (2645840)
 - 26 23 or 24 or 25 (3144691)
 - 27 16 or 19 or 22 or 26 (5542849)
 - 28 13 and 27 (6008)
 - 29 28 not (Animals/ not (Animals/ and Humans/)) (6007)
 - 30 limit 29 to English language (5656)