

## Original Article

# Health Professionals' Views on Pediatric Palliative Care: A Mixed Methods Systematic Review

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### Abstract

**Introduction:** Providing care for children in the end of life entails special challenges and exceptional requirements for all health professionals involved.

**Aim:** The aim of the study is to explore the views of health professionals about pediatric palliative care.

**Methods:** Systematic review of published relevant studies in PubMed and Scopus. The bibliography search took place for articles published from 2017 to 2022. The study included articles on qualitative, quantitative or mixed studies of health professionals in hospitals or in the community that provided pediatric palliative care to people <25 years of age, published from 2015 onwards, exploring their views on palliative care.

**Results:** The results of 15 studies performed on 1,505 health professionals showed that their views focused on the rewards gained and challenges experienced from providing pediatric palliative care, the relationship they develop with the child and family, the collaboration and role of the interdisciplinary team, the role of communication and education, and to the effect of the care on patients and their families as well as on their own personal lives. They identify barriers at individual, team, organizational, hospital, community, and policy level. To address these barriers, they used strategies to support health professionals, patients and families, work and care organization strategies, strategies to improve relationships, communication, education, collaboration and intercultural care.

**Conclusions:** Pediatric palliative care is considered both a reward and a challenge for health professionals but it is obvious that their poor and/or inadequate education and insufficient organization of work and care is in need of improvement in order to provide it effectively.

**Keywords:** pediatric palliative care, end of life, children, healthcare professionals, perspectives

### Introduction

Worldwide estimated 21 million children with end-stage disease (Marston, Boucher & Downing, 2018). The International Network for Palliative Care defines end-stage conditions as conditions for which there is no cure and death is inevitable, either in childhood or early adulthood where some

life-threatening diseases develop rapidly and others can cause a slow deterioration for many years (Connor et al., 2014). The death of a child can have profound consequences for the parents, family members, and health care professionals who provided care for the child. Parents of the seriously ill child face unique challenges, as they must act as the legal authority for health care decisions for

children, while in parallel the wishes of the child must be taken into account (Bradford et al., 2014). As a result of health professionals need to balance the core values of social work, the bioethical values and the psychosocial issues posed by such situations (Thieleman et al., 2016). The grief experiences of physicians and nurses caring for children dying of cancer showed for both groups, that the death process and the death of children were very stressful experiences and triggered a process of mourning. It seems that the grieving process of health professionals is influenced by how they perceive their role, their interventions and contribution to the care of the dying child, and by the social and cultural context in which care is provided to children with cancer. But at the same time, it seems that despite the anxiety caused by the death of children, both nurses and physicians have identified specific rewards from caring for children with end-stage disease (Papadatou et al., 2002). The aim of this study was to explore the views of health professionals about pediatric palliative care.

## Methods

**Study Design:** This is a systematic review of the literature from 2017 to 2022.

**Search strategy:** The research articles were retrieved using keywords: “pediatric palliative care, end of life, children, healthcare professionals, perspectives” from PubMed and Scopus. The criteria for inclusion of articles in the study were presented in Table 1. For the purposes of the study, we defined specialized pediatric palliative care as services provided by trained and qualified health professionals providing health care as defined by the World Health Organization's palliative care (World Health Organization, 2018).

**Article selection process:** The PRISMA methodology was applied for the selection of articles that includes identification, screening, eligibility and included (Liberati et al., 2009).

**Identification:** The databases gave a total of 3,540 articles. After applying the bibliography search filters and examining the title, 1,997 articles that did not meet the inclusion criteria were rejected (Table 1). Also, 8 articles concerning duplicate registrations were rejected.

**Screening:** The title of 1,535 articles related to pediatric palliative care was evaluated and 1,308 articles were rejected. After evaluating the summary of these articles, 160 were rejected, as they concerned patients >25 years old or concerned only patients' caregivers.

**Eligibility:** The full text of 67 articles for eligibility with PICOS approach was evaluated. In these articles we examined the provision of palliative care by health professionals and the age of patients. Following the evaluation, 37 articles were rejected because they concerned patients >25 years of age or concerned only patient caregivers.

**Included:** After the thematic analysis of the full text of the articles, 15 articles were included in the study (Figure 1). The authors evaluated the quality of the articles using the PRISMA methodology (Liberati et al., 2009). They used the “Checklist of items to include when reporting a systematic reviews” (7 sections, 27 items) to evaluate the quality of the articles (Liberati et al., 2009). The 15 articles included in the study were considered to be of high (or moderate to high) quality and related to the aim of this systematic review.

**Data analysis:** The thematic analysis of the studies included 3 stages: preparation, organizing, reporting. In the preparation stage, the results of the full text of the articles were read several times in order to fully understand their meaning and conclusions drawn. Following the content of each article, on the views and experiences of health professionals about end-child palliative care, evaluated and the relevant information was highlighted for the second stage of data analysis. When organizing the data, we organized the content of the text using codes, creating categories and grouping the codes under headings. In the final step, we reported the results of the narratives concerning the views and experiences of health professionals about palliative care for end-stage children.

For each article, data was extracted from a pre-configured spreadsheet. Data fields include first author, year of publication, country, aim, sample/setting, methods, main inclusion criteria, main results. The findings of the studies included were summarized in Table 2.

## Results

### Characteristics of studies

The articles included concerned qualitative (n = 12) and mixed studies (n = 3). The majority of studies were conducted in the USA and the rest in the United Kingdom (n = 3), Canada (n = 2) and one each in Italy, Ghana and Switzerland. Six articles were concerned monocentric studies and another 9 were multicenter studies (Table 2).

No article used pre- and post-measurements to compare the results of pediatric palliative care. No article compared the experiences of health professionals at the beginning of the application of pediatric palliative care with those of another group of health professionals at a more advanced stage of the application of palliative care.

The majority of studies (n = 10) were included an interdisciplinary approach by health professionals such as nurses, nurse assistants, physicians, social workers, physiotherapists, psychologists, social workers, other therapists, priests, music therapists and physiotherapists. The 6 studies were concerned only the views of nurses working in pediatric oncology care structures at the end of life and one study were concerned only social workers' views. Most studies (n = 11) were performed in a hospital setting, 2 studies in community settings and 2 in both above mentioned settings.

### Evaluation of quality of studies

The methodological quality of the research designs was high. All studies (n = 15) were rated with high quality. The research questions were clear and the data collection methods appropriate.

### Analysis

The qualitative and quantitative results of the 15 studies conducted on 1,505 health professionals (Table 2) were divided into 3 categories:

#### Views on pediatric palliative care

The health professionals in the studies we reviewed reported that the rewards and challenges of providing palliative care were related to child and family care, team and organizational strengths, individual resilience, and work motivation (Taylor & Aldridge, 2017). Most participants rated end-stage care as a very important aspect of their work and emphasized its impact on their personal development (Muskat, Brownstone & Greenblatt, 2017). Participants report that the main goal of

providing pediatric palliative care was the ability to build a relationship with the dying child and its family that enables the provision of high quality care (Bergsträsser, Cignacco & Luck, 2017; Montgomery, Sawin & Hendricks-Ferguson, 2017; Sisk et al., 2021).

It is highlighted through the results that the discussion within the interdisciplinary team is an important process for the management of nurses' suffering (Taylor & Aldridge, 2017; Taylor et al., 2020; Cappi et al., 2020; Montgomery, Sawin & Hendricks-Ferguson, 2017, Sisk et al., 2022; Sisk et al., 2021).

Health professionals consider the provision of palliative care as a privilege and report that it has an impact on their prospects, they value their connection to families, report that pediatric palliative care affects their personal relationships, has an emotional cost and they indicate a lack of support and information for pediatric palliative care (Montgomery, Sawin & Hendricks-Ferguson, 2017; McConnell & Porter, 2017).

The experiences they report relate to the balance between end-of-life and acute care, the impact of family relationships on themselves, and the opportunities for professional development (McConnell & Porter, 2017; Sisk et al., 2022). The perceptions they report relate to the impact on themselves of initial experiences of sadness and feelings, the continuous vigilance, the evaluation and optimization of family-centered care and the promotion of a competent, thoughtful and supportive workforce (McConnell & Porter, 2017; Muskat et al., 2020). Health professionals distinguish 5 common important perceptions of communication in palliative care: the evolution of palliative care at end-of-life, the skill of knowledge sharing, the broader concept of care, the experienced nurse as advocate, and the appreciation of the individual response to grief. All these experiences provided nurses with the know-how to fulfill the roles of communication, care and advocacy for children and families (Taylor & Aldridge, 2017; Price et al., 2017; Jack et al., 2018; Taylor et al., 2020; Cappi et al., 2020; Montgomery, Sawin & Hendricks-Ferguson, 2017; McConnell & Porter, 2017; Sawin et al., 2019;

Kaye et al., 2020; Sisk et al., 2022; Sisk et al., 2021).

The comfort of health care professionals in providing care to children was statistically significantly correlated with previous experience of end-of-life pediatric palliative care ( $P < 0.001$ ), with receiving formal education in end-of-life pediatric palliative care ( $P < 0.001$ ), with higher quality of care ( $P = 0.01$ ) and with the individual level of providing pediatric palliative care at the end of life ( $P < 0.001$ ) (Kaye et al., 2020).

The clinical experience of end-of-life pediatric palliative care was the most important variable for comfort with its overall provision and its provision at the end of life. Formal education was the most influential variable for comfort with the management of severe symptoms at the end of life (Taylor & Aldridge, 2017; Price et al., 2017; Cappi et al., 2020; Sawin et al., 2019; Kaye et al., 2020; Sisk et al., 2022; Sisk et al., 2021).

#### **Barriers in the application of pediatric palliative care**

Health professionals in the studies examined reported quality care, teamwork, job sharing, parental expectations, care environment, educational needs and concerns, and work stress as stressors and rewards (Taylor et al., 2020; Cappi et al., 2020; Montgomery, Sawin & Hendricks-Ferguson, 2017; Sisk et al., 2022; Sisk et al., 2021). Health professionals mention the absence of a common and objective criterion for making difficult decisions about palliative care that deprive them of a common and objective criterion for managing the most difficult decisions. They compare pediatric palliative care with quality of life, overall care of the individual, proportionality of care, early recognition of the need for palliative care (Cappi et al., 2020).

The challenges faced by pediatric oncology nurses in providing palliative care were: time-consuming care, poor work motivation, insufficient logistical support, work stress, poor workforce, lack of knowledge and lack of teamwork and the perception that they have cancer themselves (Bergsträsser, Cignacco & Luck, 2017; Nukpezah et al., 2021). Other challenges they report include supporting parents' hopes, revealing all possible outcomes to patients and their families, building

relationships while maintaining personal boundaries, revealing sensitive information, and validating parental beliefs, or decisions. Some challenges represented conflicts between different communication objectives. Others represented conflicts between one communication goal and another obligation (Taylor & Aldridge, 2017; Price et al., 2017; Sisk et al., 2021).

The effect that pediatric nurses reported from providing palliative care to children with cancer include a sense of privilege to care for these patients, the impact of care on their personal relationships, the physical and emotional cost of care, and the impact on their views on life (Muskat, Brownstone & Greenblatt, 2017).

Health professionals report 6 levels of communication barriers: barriers from the individual, the team, the management, the hospital, the community, and the policies. Several barriers were identified at each level. Some barriers, such as lack of comfort with difficult issues, cultural differences, lack of a common group mental model and time pressure, manifested themselves similarly among health professionals. Other obstacles, such as the need for boundaries, the fear or embarrassment of the family, the vague roles and authority and the excessive logistical demands, manifested themselves differently among health professionals (Nukpezah et al., 2021; Muskat et al., 2020; Sawin et al., 2019; Kaye et al., 2020; Sisk et al., 2022; Sisk et al., 2021).

Ethical dilemmas and problems of cooperation within the interprofessional team can hinder the provision of pediatric palliative care and lead to significant stress among health professionals (Bergsträsser, Cignacco & Luck, 2017; Jack et al., 2018; Sisk et al., 2022).

#### **Problem solving strategies**

The problem-solving strategies used by health professionals in providing palliative care include self-awareness, self-care strategies and boundaries, support from family and peers, the disconnection and evolution of coping strategies (Taylor & Aldridge, 2017; Bergsträsser, Cignacco & Luck, 2017; Price et al., 2017; Jack et al., 2018; Taylor et al., 2020; Cappi et al., 2020; Montgomery, Sawin & Hendricks-Ferguson, 2017; Muskat, Brownstone & Greenblatt, 2017).

Nurses report that the community setting is more conducive to support staff and improving the requirements of their role, as it includes support from colleagues/organizational services and ongoing training in key aspects of pediatric palliative care (Taylor & Aldridge, 2017). They also argue that they can improve their experience in providing pediatric palliative care with training in communication and knowledge sharing with other specialists (Taylor & Aldridge, 2017; Cappi et al., 2020).

Perceived ability to provide palliative care is significantly improved in intensive care unit nurses ( $P = 0.0001$ ) compared to other nurses. The mean score of perceived ability to provide palliative care was significantly higher when nurses had >10 years of experience ( $P = 0.0001$ ). Open-ended responses showed concerns about improving

communication behavior, decision-making, and facilitating follow-up care (Price et al., 2017).

Health professionals mention that it is very important to plan palliative care, including waiting to build a family relationship, introducing parallel planning, and avoiding a crisis situation. They argue that support is needed for care planning to be effective (Bergsträsser, Cignacco & Luck, 2017; Pice et al., 2017; Jack et al., 2018).

Most health professionals recognize communication, symptom control, and acceptance as characteristics of a "good death". Compared to physicians, non-physicians focus on relationships ( $P = 0.007$ ). Health professionals with  $\leq 10$  years of experience more often identify the benefits of the interdisciplinary team ( $P = 0.004$ ) (Taylor & Aldridge, 2017; Bergsträsser, Cignacco & Luck, 2017; Taylor et al., 2020; Sisk et al., 2021).

**Table 1.** PICOS and criteria for including articles in the study

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**PICOS Question:** What are the views and experiences of health professionals about palliative care for people <25 years of age?

**Population (P):** Health professionals in hospitals and/or the community caring for people <25 years old with end-stage cancer. The priests were also included.

**Intervention (I):** Views and experiences on pediatric palliative care.

**Comparator (C):** Without comparison or the usual (e.g. delayed) initiation of pediatric palliative care.

**Outcomes (O):** Qualitative, quantitative, or mixed data on the views and experiences of health professionals regarding child or family palliative care, challenges, problems, coping strategies, care-related processes or planning (such as communication, decision making and scheduling of specialist care, cooperation of the pediatric palliative care team, end-of-life care standards, mourning, initiation and implementation of pediatric palliative care, expediency and acceptance of pediatric palliative care care).

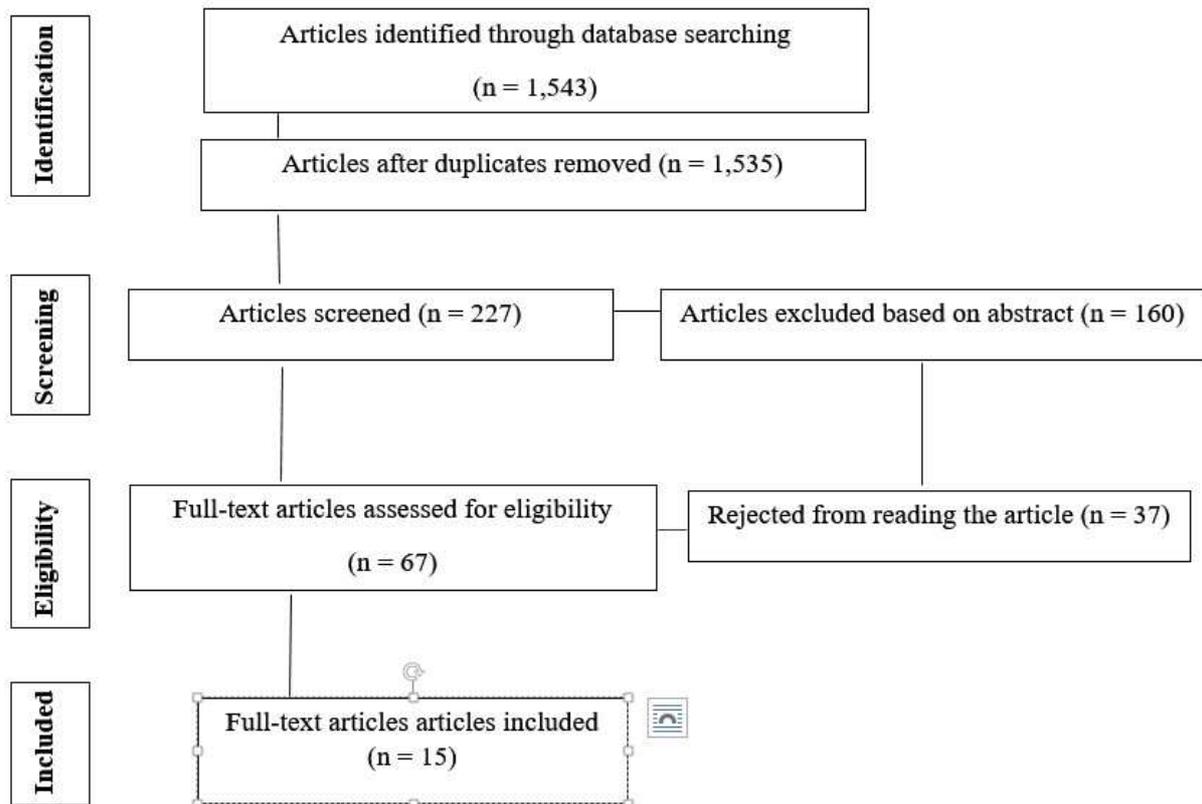
**Setting (S):** Hospital, community

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**Inclusion criteria**

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- Qualitative, quantitative or mixed studies.
  - Published from 2017-2022
  - Exploring views and experiences of health professionals about pediatric palliative care
  - Published in English language.
  - Published in peer reviewed journals.
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**Figure 1.** Articles selection flowchart



**Table 2.** Characteristics of the studies

<b>Author, year / country/ aim</b>	<b>Sample / setting</b>	<b>Methods</b>	<b>Main inclusion criteria</b>	<b>Main results</b>
Taylor et al., 2017, UK, Investigating the rewards & challenges of health professionals from pediatric palliative care.	Physicians, nurses n=20, other health professionals n = 27, heads & staff community settings n = 4. Total n = 51 (convenience sampling with judgement sampling of the groups). Single-center study.	Qualitative perspective study with 3 focus groups & group with semi- structured interviews	Previous service in pediatric palliative care	Rewards & challenges are related to caring for children & families, team dynamics & organizational structures, individual resilience & work motivation. Stress factors & rewards included quality of care, teamwork, job sharing, meeting parents' expectations, community setting, educational needs & work stress.
Bergstrasser et al., 2017, Switzerland, Exploring the experiences & needs of health professionals for institutional support & training in communication & dealing with emotional distress & inter-professional work in pediatric	Physicians n = 17, pediatric nurses n = 18, community nurses n = 6, social workers n = 4, psychologists n = 1, music therapists n = 1, ερείς n = 1. Total n = 44. Single-center study.	Quality, multicenter study, with inductive approach, with 6 inter-professional focus groups	Caring for at least one dying child last year	Most participants value end-stage care as a very important aspect of their work & for its impact on their personal development. They believe in the ability to build a relationship with the dying child & family that allows for high quality care. Ethical dilemmas & collaboration problems within the inter-professional team can hinder this goal & lead to significant stress among health professionals.

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<p>end-of-life care units. Prise &amp; al., 2017, USA, Evaluation of nurses' knowledge, attitudes &amp; behaviors regarding the provision of pediatric palliative care &amp; identification of deficiencies for the provision of quality pediatric palliative care.</p>	<p>Nurses from: adults ICU n = 182, adults HDU n = 227, PICU n = 89, children HDU n = 85. Total n = 583. Single-center study.</p>	<p>Quantitative non-invasive comparative study with online use of the revised End-of-Life Care Questionnaire</p>	<p>Perceived ability to provide palliative care is significantly improved in ICU nurses (P = 0.0001). The mean scores were significantly higher when the nurses had &gt;10 years of experience (P = 0.0001). Open-ended responses showed their concerns about improving communication behavior, decision-making &amp; facilitating follow-up care.</p>	
<p>Jack &amp; al., 2018, UK, Investigating the views &amp; experiences of health professionals regarding the design of pediatric palliative care in the hospital.</p>	<p>Nurses n = 8, physicians n = 5, other health professionals n = 6 &amp; other therapists n = 2, Total n = 21 from 3 hospitals, a community setting for children &amp; its services.</p>	<p>Qualitative study with semi-structured telephone interviews (judgement sampling)</p>	<p>Health professionals providing pediatric palliative care at:  <ul style="list-style-type: none"> <li>• children with cancer 0-18 years old,</li> <li>• who had died in the last 18 months,</li> <li>• participated in the</li> </ul> </p>	<p>Health professionals report that it is very important to plan for palliative care, including waiting to build a family relationship, introducing parallel planning &amp; avoiding a crisis situation. They argue that support is needed to make care planning effective.</p>

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	Multicenter study.		study >3 months
Taylor & al., 2020, USA, Identifying the factors that pediatric oncology health professionals consider important for the positive death experience of children, adolescents & young adults & their families.	Physicians n = 8, specialized nurses n = 4, physiotherapists n = 1, clinical nurses n = 2, music therapists n = 2, teachers n=1, priests n = 1. Total n = 19 health professionals providing pediatric palliative care (snowball sampling). Single-center study.	Cross sectional comparative mixed study (online questionnaire & semi-structured interview).	Most health professionals have recognized communication, symptom control & acceptance as characteristics of a 'good death'. Compared to physicians, non-physicians focused on relationships (P = 0.007). Health professionals with ≤10 years of experience most often identified the benefits of the interdisciplinary team (P = 0.004).
Cappi & al., 2020, Italy, To investigate the perception that doctors, nurses & psychologists,	Physicians n = 6, nurses n = 6, psychologists n = 5. Total n = 17 (convenience sampling). Multicenter study.	Qualitative study (semi-structured interviews)	Health professionals report the absence of a common & objective criterion for making difficult decisions. Health professionals compare pediatric palliative care with quality of life, overall care, proportionality of care,

<p>operating in pediatric hospices, have of the appropriateness of the care they provide &amp; to understand what repercussions the perception of non-appropriateness has at individual &amp; team level.</p>	<p>Montgomery et al., 2017, USA, A description of nurses' perceptions of communication during pediatric palliative care &amp; their perceptions of barriers &amp; facilitators of effective communication.</p>	<p>Nurses n = 27 from 3 pediatric hospitals. Multicenter study.</p>	<p>Qualitative study (empirical phenomenological), using 12 focus groups &amp; semi-structured interviews</p>	<p>Nurses with &gt;5 years' experience</p>	<p>early recognition of the need for palliative care. Discussion within the group emerges as a privileged place for managing the suffering of health professionals.</p>
<p>Muskat et al., 2017,</p>	<p>Social workers n = 9</p>	<p>Qualitative study with</p>	<p>Social workers who</p>	<p>As experiences are mentioned: work is</p>	

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Canada, To investigate the experiences of pediatric social workers working with dying children & their families in a pediatric acute care hospital & the coping strategies they use.	(snowball sampling). Single-center study.	semi-structured interviews.	often provided end-of-life pediatric palliative care were included in the sample, while those who occasionally provided no.	considered a privilege, it has an impact on their perspective, in the connection with families, in personal relationships, it has an emotional cost & they indicate a lack of support & information of the team. Coping strategies include: self-awareness, self-care strategies & boundaries, family & peer support, disconnection & evolving coping strategies.
McConnell et al., 2017, UK, Exploring the experiences of end-of-life care team staff in a pediatric hospice.	Clinical nurses n = 8, registered nurses n = 3, nurse assistants n = 3, head nurses n = 1. Total n = 15 (judgement sampling). Single-center study.	Qualitative study using 12 semi-structured interviews & a focus group		The nurses state that the environment of the hospice is suitable for the support staff & the mitigation of the demanding aspects of its role, which includes support from colleagues / organizational services & regular continuous training in basic aspects of pediatric palliative care. Key recommendations for improving their experience include training in communication & knowledge sharing

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				with other specialists in pediatric palliative care.
Nukpezah & al., 2021, Ghana, Investigating the challenges faced by pediatric oncology nurses in child care in Ghana.	Pediatric oncology nurses n = 14 (judgement sampling). Single-center study.	Qualitative study using semi-structured interviews.	<ul style="list-style-type: none"> <li>• Pediatric oncology nurses.</li> <li>• Nurses with at least 2 years of experience.</li> </ul>	The challenges that pediatric oncology nurses face are: time-consuming care, poor work motivation, insufficient logistical support, work stress, reduced workforce, poor level of knowledge, lack of teamwork & perception that they are suffering from cancer.
Muskat & al., 2020, Canada, The investigation of the experiences of pediatric social workers working with dying children & their families in a pediatric acute care hospital & the coping strategies they use.	Physicians n = 8, nurses n = 8, & social workers n = 9. Total n = 25 (judgement sampling). Single-center study.	Qualitative study using semi-structured interviews.	Health professionals who often provided end-of-life pediatric palliative care were included in the sample, while those who occasionally provided no.	Experiences are about the balance between end of life & acute care, the impact of family relationships & career development opportunities. Personal impacts include a sense of privilege, the impact on personal relationships, the physical & emotional cost of care & the impact on participants' views on life.
Sawin & al., 2019, USA,	Managers of pediatric oncology nurses n = 11.	Qualitative study (empirical		Perceptions concern the impact of initial experiences of grief & feelings,

<p>A description of the perceptions of pediatric oncology nurse directors about end-of-life palliative care communication.</p>	<p>Multicenter study.</p>	<p>phenomenological) with 3 focus groups &amp; semi-structured interviews</p>	<p>the constant vigilance, evaluation &amp; optimization of family-centered care &amp; the promotion of a competent, thinking &amp; supportive workforce.</p>
<p>Kaye &amp; al., 2020, USA, Identification of factors related to the improved comfort of community nurses, by providing pediatric palliative care in the hospital &amp; in the community.</p>	<p>Community nurses n = 551 from 71 hospices Multicenter study.</p>	<p>Cross sectional study with qualitative analysis (mixed study) using an electronic questionnaire</p>	<ul style="list-style-type: none"> <li>• Pediatric oncology nurses providing palliative care</li> <li>• &gt;18 years old</li> <li>• With formal education in pediatric palliative care</li> </ul> <p>Nurses' comfort in providing palliative care to children was statistically significantly correlated with previous experience of end-of-life pediatric palliative care (P &lt; 0.001), formal education in end-of-life palliative care (P &lt; 0.001) &amp; higher level of hospitalization (P = 0.01) &amp; individual level of frequency of pediatric palliative care at the end of life (P &lt; 0.001). The clinical experience of end-of-life pediatric palliative care was the most important variable for comfort with total &amp; end-of-life provision. Formal education was the most influential variable for comfort with the</p>

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Sisk & al., 2022, USA, The description of the challenges experienced by physicians & psychosocial professionals that affect communication in pediatric oncology.	Nurses n = 10, nurse assistants n = 18, physicians n = 17, psychologists n = 3, social workers n = 4, other therapists n = 3, priests n = 3, music therapists n = 1 from 2 hospitals. Total n = 59 (judgement sampling). Multicenter study.	Qualitative study with 2-3 focus groups per specialty of health professionals (total of 10 focus groups) & use of semi-structured interviews.	• Pediatric oncologists who have dedicated >20% of their professional effort to clinical work • Nurses, nurse assistants & psychosocial professionals with >1 year of clinical experience.	management of severe symptoms at the end of life. The challenges mentioned are supporting parents' hopes, revealing all possible outcomes, building relationships while maintaining personal boundaries, revealing sensitive information & validating parental beliefs or decisions. Some challenges represented conflicts between different communication objectives. Others represented conflicts between one communication goal & another obligation.
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<p>Sisk &amp; al., 2021, USA, Investigation of communication barriers between clinical health professionals &amp; patients in pediatric oncology.</p>	<p>Nurses n = 10, nurse assistants n = 18, physicians n = 17, psychologists n = 3, social workers n = 4, other therapists n = 3, priests n = 3, music therapists n = 1 from 2 hospitals. Total n = 59 (judgement sampling). Multicenter study.</p>	<p>Qualitative study with 2-3 focus groups per specialty of health professionals (total of 10 focus groups) &amp; use of semi-structured interviews.</p>	<p>• Pediatric oncologists who have dedicated &gt;20% of their professional effort to clinical work • Nurses, nurse assistants &amp; psychosocial professionals with &gt;1 year of clinical experience.</p>	<p>Six levels of communication barriers were identified by physicians: individual, team, organization, collaborating hospital, community &amp; policy. Several barriers were identified at each level. Some obstacles, such as lack of comfort with difficult issues, cultural differences, lack of a common group mental model &amp; time pressure, manifested themselves similarly in professions &amp; institutions. Other obstacles, such as the need for boundaries, the fear or embarrassment of the family, the vague roles &amp; the power &amp; the excessive logistical demands, manifest themselves differently between professions.</p>
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ICU: intensive care unit, PICU: pediatric intensive care unit, HDU: high dependency unit

## Discussion

It has been argued by the results of other studies that pediatric palliative care requires the organized effort of an interdisciplinary care team of physicians, nurses, psychosocial staff and other health professionals (McConnell, Scott & Porter, 2016; Swinney et al., 2007). Several researchers have shown that the views of health professionals on pediatric palliative care are symptom control, self-care (Slater & Edwards, 2018), cultural issues (Atout, 2020), religious guidance (Plante & Cyr, 2011), spirituality and communication (Kearney et al., 2009).

Studies on the barriers health professionals face when providing pediatric palliative care have found that health professionals report uncertainty, insufficient knowledge, low self-esteem and experience in discussing end-of-life care with patients (Hendricks-Ferguson et al., 2015; Yoshida et al., 2014). Adequate training of nurses helps them feel comfortable with death and enables them to reflect on their feelings about end-of-life care (McConnell, Scott & Porter, 2016; D'Antonio, 2017).

Results from other studies suggest that the quality of communication between children with cancer and their families, when providing pediatric palliative care, is a reward and privilege for health professionals. Health professionals believe that rewards and privileges are the open and honest discussions about scheduling end-of-life care, preventing conflicts with patients and their families, exploring their future desires and developing trusting relationships (Bowden et al., 2015; Ransie Yates & Coyer, 2012; Gulati, Dix & Klassen, 2014). In several studies in which health professionals described their most difficult experiences with caring for a dying child, they referred more often to personal pain (McConnell, Scott & Porter, 2016) and inadequate support (McConnell, Scott & Porter, 2016; Contro et al., 2004). End-of-life child caregivers seek support from their peers, their relatives, the hospital, society, institutions and the state. Support is vital for the

development of resilience assisting and health professionals to remain in care settings for dying children (McConnell, Scott & Porter, 2016; Slater & Edwards, 2018).

Whether active or passive, health professionals report in other studies that they implement strategies that allow them to manage their emotions when providing care to children at various levels of health, including children with end-of-life cancer (Slater & Edwards, 2018; Kearney et al., 2009). Numerous studies have also shown that palliative care requires the implementation of strategies that allow health professionals to continue their roles, benefiting from information and support, planning, work organization and training guidance, to avoid tensions and burnout (Ekberg et al., 2015; Davis, Lind & Sorensen, 2013; Cavaye & Watts, 2012).

Our findings have some important implications for practice. The articles included are in English language and there may be studies in other languages that were not included in this study. Most of the studies concerned qualitative or mixed studies. The lack of quantitative studies with strong methodology in bibliography is obvious in order to show strong indications.

**Conclusions:** Health professionals recognize several barriers in providing pediatric palliative care and have developed several strategies to address them. Pediatric palliative care is seen as a reward/challenge for health professionals but there is a clear lack of education and insufficient organization of work and care, in order to provide it effectively.

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