

Provision of Bereavement Care for Siblings: Insights from Pediatric Palliative Care Teams Nationwide

Nguyen Thanh Huy^{1*}, Pham Quang Minh¹, Le Thi Bich²

¹*Department of Integrative Nursing Systems, Vietnam National University, Hanoi, Vietnam.*

²*Department of Palliative Healthcare Sciences, Can Tho University, Can Tho, Vietnam.*

Abstract

Bereavement support represents a fundamental standard of care within pediatric palliative care (PPC) teams. Assisting grieving siblings often involves distinct challenges. Providing care tailored to the child's developmental stage can support children as they process their grief. To outline the perspectives of providers (including their mission and program development) regarding bereavement care for siblings, and to detail the bereavement follow-up interventions that hospital-based PPC teams offer to siblings across the country. A qualitative study was performed through semi-structured telephone interviews. At least one representative from each PPC team took part. All interviews were transcribed word-for-word and examined using grounded theory. 21 teams participated (response rate: 91%). Most teams (80%) delivered individual psychotherapy to families, while a small number (28%) provided group interventions. PPC teams aim to broaden their bereavement services and strengthen partnerships with community-based services. Nevertheless, constraints such as insufficient human resources, inadequate facilities and funding, and large geographical distances frequently hindered the growth of bereavement care programs. PPC teams consider support for bereaved siblings to be an essential component of palliative care. While PPC teams cannot address every need of grieving families, they can serve as key reference points, gathering information on local resources and delivering informed recommendations to families and community providers. Increased public recognition of childhood bereavement, together with closer collaboration with community organizations, could help reduce several recurring barriers to service expansion. Additional research is needed to assess bereavement services both in France and in other healthcare systems.

Keywords: Bereavement, Child, Death, Pediatrics, Palliative care, Siblings

Introduction

Pediatric palliative care (PPC) is described as the comprehensive active care of children living with life-limiting illnesses. It includes continued support for the entire family once the patient has died [1]. In France, deaths among children, adolescents, and young adults (under 24 years) account for roughly 1% of all deaths in the country each year [2]. Similarly, research from the United States has indicated that almost 1.5% of children across the nation will experience the loss of a sibling before turning 18 [3]. Even though it is a frequent occurrence, bereavement may lead to harmful short- and long-term effects on physical, psychological, and socioeconomic well-being when adequate support is not available [4]. Extending care past the death of a child by means of family bereavement support constitutes an international core standard for PPC teams [5, 6].

Growing evidence, primarily from intensive care and oncology settings, shows that hospital-based transitional bereavement care offers benefits to both families and healthcare professionals [7]. For staff members, maintaining ongoing relationships forms a central element of their personal grieving process [8], and they often find this role

Corresponding author: Nguyen Thanh Huy
Address: Department of Integrative Nursing Systems, Vietnam National University, Hanoi, Vietnam.
E-mail: ✉ huy.nguyen@gmail.com
Received: 03 August 2024; **Accepted:** 24 November 2024;
Published: 20 December 2024

How to Cite This Article: Huy NT, Minh PQ, Bich LT. Provision of Bereavement Care for Siblings: Insights from Pediatric Palliative Care Teams Nationwide. *J Integr Nurs Palliat Care.* 2025;5(2):303-13. <https://doi.org/10.51847/gnBvkoOJ4z>

meaningful and rewarding [7, 9]. For parents, the sudden disappearance of the hospital community following their child's death can feel abrupt and difficult. Continued contact with staff helps create a fresh network of supportive relationships among peers, which may enhance psychosocial outcomes [7]. For siblings, peer groups organized through the hospital are especially valuable in normalizing their grief, decreasing feelings of isolation, and helping them re-engage with social activities [7, 9, 10]. Although the benefits of continuity of care have long been recognized, most hospital-based interventions primarily target parents. Only a limited number focus directly on siblings [7, 8]. More insight is required, from the perspective of PPC professionals, to clarify their responsibilities in supporting bereaved siblings, the approaches they use, and the difficulties they encounter.

PPC teams in France were established in 2013 as part of the national governmental plan to develop palliative care [11]. Twenty-three multi-professional "Regional PPC Resource Teams" (Equipes Régionales Ressources de Soins Palliatifs Pédiatriques) were established to deliver PPC services across their designated geographical areas. Each team is linked to a tertiary care hospital and operates as a mobile consultation service that collaborates with colleagues in both hospital and community environments. At the time of the study, no dedicated inpatient PPC facilities (such as pediatric hospices) were available [12]. The French model of PPC stands out in Europe because teams are organized at the national level to ensure equal access to PPC services nationwide [13]. These 23 PPC teams were assigned five core missions: (1) foster a palliative care culture among pediatric teams, (2) raise awareness of the specific characteristics of PPC teams, (3) deliver continuous support to families (including bereavement care), (4) educate and assist healthcare professionals and volunteers, and (5) contribute to research advancement [14]. Although bereavement support is explicitly listed as a mission and a cornerstone of high-quality PPC, only one French program specifically designed for bereaved siblings has been documented and assessed to date [10].

Bereavement care refers to the support provided to every member of the family of the deceased child. Care for grieving siblings builds upon this foundation but demands a more tailored strategy, particularly services that take age and developmental stage into account. For this reason, gaining a clearer picture of how PPC teams view and pursue their objectives in sibling bereavement care seemed essential. The present study has two main goals: to describe provider perspectives (mission and development) on bereavement care for siblings, and to describe the bereavement follow-up interventions that hospital-based PPC teams provide to siblings at the national level. To our knowledge, this is the first national-scale survey of French bereavement support for siblings that specifically examines the role of PPC teams.

Materials and Methods

Participants

A qualitative study was conducted with PPC teams across France. In January 2021, all 23 teams received an invitation by email to join the research. Two follow-up reminder emails were sent every 2 weeks. Every French PPC team qualified for inclusion. Teams that declined the invitation or did not reply were left out. At least one representative from each team was interviewed, with preference given to the person most actively involved in the team's bereavement support activities. No particular profession was required, and there was no limit on the number of team members who could participate. The only requirement was that the interviewee was currently working with the team; no further exclusion criteria were applied. All individuals provided informed consent to participate. To reach theoretical data saturation and obtain a full picture of bereavement care for siblings provided by French PPC teams, the largest possible number of teams had to be included [15].

Procedures

Semi-structured telephone interviews took place between February and April 2021. Teams were emailed a set of questions 1 month before their scheduled interview. Sending the teams a set of questions 1 month before their scheduled interview gave them enough time to discuss the topics internally before their chosen spokesperson answered. The open-ended questions focused on four key areas: how the mission is defined and assessed, the interventions currently offered, ways of working with other services, and the overall development of bereavement care. Every interview was anonymized (PPC team 1–21), audio-recorded, and transcribed verbatim. All interviews were carried out in French by the first author (a female hospital physician (MD) experienced in qualitative palliative care research) in a quiet, private space inside the hospital. Participants were fluent in French and had no prior professional hierarchy or personal connection with the researcher.

Analysis

Quantitative information was examined using simple counts and percentages to produce descriptive statistics. Qualitative data were studied following the 'Grounded Theory' approach described by Walker and Myrick [16]. The interview transcripts underwent a three-stage coding process: open coding, axial coding, and selective coding. In the first stage, line-by-line open coding was used to identify key anchors that captured the main ideas in the data (e.g., 'avoiding abandonment', 'emptiness', 'keeping contact', or 'maintaining a connection'). Axial coding

then organized these codes into larger concepts by grouping similar content (for instance, ‘reducing isolation’ or ‘continuing walking with families’). In the final selective coding stage, broader clusters of concepts were combined into overarching categories or themes, such as ‘continuing care’, to better describe the central topic under investigation (how providers perceive the mission and development of bereavement care for siblings). The entire analysis was conducted by the research team and refined through repeated discussions until a complete consensus was reached. Results are presented in line with the consolidated criteria for reporting qualitative research [17].

Results and Discussion

Twenty-one teams participated in the study (91% response rate). One team declined because it had only recently been created, and another could not be reached; both were therefore excluded. Altogether, 30 PPC team members joined the interviews: 15 psychologists, 9 nurses, 5 doctors (4 pediatricians and 1 child psychiatrist), and 1 secretary. Fourteen interviews were held with a single team member, five with two members, and two with three members. The median interview length was 27 min (range 18–76 min). The principal themes identified from the interviews were organized into the three categories described below.

Defining the mission of bereavement care for siblings

Analysis of the interviews identified four subthemes that illustrate how PPC teams understand their mission in providing bereavement care.

Essential work

Three-fourths of the teams (76%, n = 16) regarded bereavement care as ‘important’ and ‘essential’ work for PPC teams. The main explanation offered was that other pediatric healthcare professionals rely on PPC teams to provide appropriate ongoing support for grieving families, especially because the service is free and the staff have particular expertise in supporting children through grief. Several teams saw bereavement care as equally vital to their other responsibilities. However, it must be regularly reviewed and adapted to each family’s unique situation and the team’s available resources and capacity.

Continuing care

Bereavement support was regarded as a way to remain alongside families — above all siblings and parents — for a considerable length of time. Both the PPC teams and the families valued this sustained involvement. Families appreciated not having to recount their experience again and welcomed the opportunity to speak with professionals who were already familiar with their child. Team members emphasized the importance of staying connected with families and ensuring they received the guidance required to cope with their loss. Moreover, some pointed out that ongoing contact could ease the feeling of being left behind that many families face when medical attention ends following the death:

“Bereavement support is a fundamental aspect of palliative care practice. In essence, it is simply the continuation of care for the child who has passed away and for the entire family.”

PPC team 11.

“Families can be overwhelmed by a profound sense of abandonment and emptiness, especially after the intense activity that surrounded the illness... The aim is to avoid deserting the families we supported throughout the child’s illness and to preserve that relationship.”

PPC team 8.

Second-line support

Close to half of the participants, however, noted that their teams could not meet every bereavement need for siblings in their area. It was therefore important for them to adopt a helpful ‘second-in-line’ position. Adopting a helpful ‘second-in-line’ position meant referring families to suitable specialist assistance, working together with local community organizations, and offering advice and training to other ‘frontline’ professionals who had less familiarity with grief in children:

“We concentrate on fulfilling our resource-oriented role. This involves acting as a resource for parents and siblings rather than delivering ongoing direct follow-up ourselves; our goal is to strengthen the network of support available to each family.”

PPC team 2.

Anticipating grief

Several teams highlighted the need to prepare for bereavement care in advance. Right from the beginning of palliative care, they informed families that accompaniment would continue even after the child’s death. Some

believed that building a relationship with families while the child was still alive could help prevent more difficult grief reactions and lead to higher-quality support after the loss:

“Engaging with the family before the child dies helps minimize complicated grief... and results in improved care once the death has occurred.”

PPC team 13.

Current bereavement care services

Intervention type

While all teams aimed to keep in contact with families, just over half (57%, $n = 12$) adopted a more structured approach, involving planned bereavement check-ins at defined times using specific methods. The most usual methods were sending a condolence card (52%, $n = 11$) or making a phone call (57%, $n = 12$) addressed to the whole family, including both siblings and parents. These contacts occurred at regular intervals, from less than 1 week to up to 3 years after the death. A few teams consistently proposed an in-person consultation (14%, $n = 3$) or a home visit (19%, $n = 4$), with siblings invited to take part. These meetings generally occurred between 1 and 5 months after the death. **Figure 1** presents the various contact methods and timing options adopted by the PPC teams.

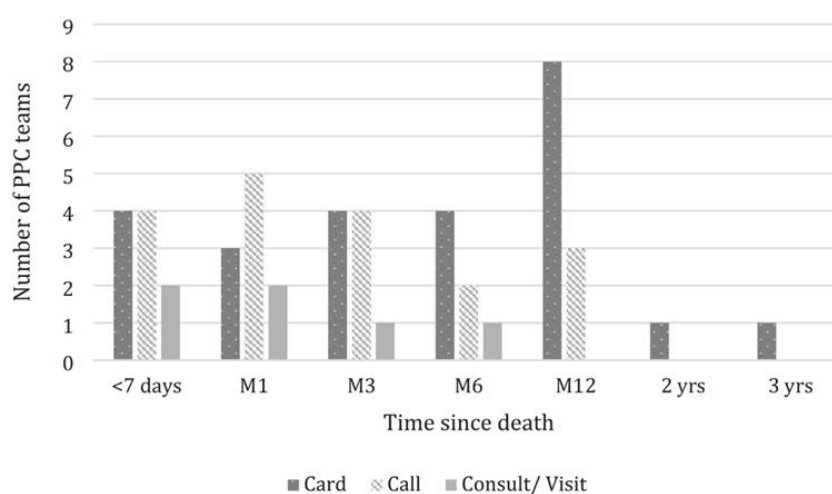


Figure 1. Bereavement follow-up.

The most frequent type of bereavement intervention offered by French PPC teams was individual psychotherapy (80%, $n = 17$), delivered by the psychologists working within the teams. Sessions were conducted either at the hospital ($n = 9$) or at the family’s home ($n = 15$), or both. Holding sessions away from the hospital was preferred to create a more neutral environment and allow greater flexibility. The majority of teams did not set any fixed limit on how long therapy could last ($n = 10$). One-third of the teams ($n = 7$) imposed an upper limit, either restricting it to 2–5 separate meetings ($n = 3$), to 1 year ($n = 2$), or to 2–3 years ($n = 2$). The main reason cited for introducing a time limit was the shortage of staff resources for extended support.

Six teams ran group-based interventions. These varied in format (group sessions, playgroups, or camps) and were mainly facilitated by psychologists along with other team members. Apart from the playgroup, all programs were designed specifically for children who had lost a sibling. The activities combined focused grief work with lighter, more creative, and recreational elements. In terms of access, families were nearly always referred by the PPC team that had previously supported them. Only three teams that provided group programs actively promoted the service and opened it to participants from outside their own families.

Regarding funding, all group activities were led by PPC team members during their normal working hours, so their salaries fully covered their time. External funding sources covered any additional costs. Every group program, including weekend camps, was provided free of charge to participating families. A full description of each group intervention is available in **Table 1**.

Table 1. Group interventions.

PPC team	Intervention format	Staff	Inclusion criteria	Grief-focused activities	Recreational activities	Follow-up	Parent involvement	Funding
2	Two-day workshops delivered	2 psychologists per group	Siblings aged 6–15 who experienced	Group discussions: Day 1: Personal storytelling,	Show-and-tell, drawing, painting, collage,	Memory book with workshop	No involvement during sessions; one	Funded by government and non-profit

	twice, spaced 1 month apart		bereavement due to illness within the past year; initial assessment via a psychologist interview	funeral practices, life adjustments. Day 2: Maintaining connections and memory-making	Memory book creation, Decorating face masks, Video production, Picnic, and outdoor play	photos sent to families	parent-child session at the end of Day 2	organizations; free for families
7	Weekend camp exclusively for siblings	Psychologist and music therapist	Siblings aged 8–12 bereaved by illness 6–12 months earlier; includes two pre-camp family meetings	Group discussions using “Photolanguage” (images used to facilitate communication about grief)	Music therapy, Outdoor play, Arts and crafts	Family meeting held 2 weeks after camp ends	No	Funded by a non-profit organization; free for families
14	Support group with five 2-hour sessions over 5 months	Psychologist and art therapist	Siblings aged 6–18 bereaved by illness, typically more than 1 year prior; intake interview with psychologist and pediatrician	Guided discussions on: Building trust and introductions, Sharing personal loss experiences and rituals, Future planning and personal development	Pottery, painting, fresco work, Memory box creation, family tree reconstruction, creative writing, and poetry	Family meeting 3 months after program completion	Parent discussion group led by a pediatrician during children’s sessions	Funded by non-governmental and philanthropic organizations; free for families
15	Weekend camp for entire families	PPC team (psychologist, pediatrician, nurses)	Siblings over 6 years old bereaved by illness between 6 months and 3 years earlier	Facilitated discussions on grief and coping, conducted in both separate and joint parent-child sessions	Arts and crafts (separate and joint sessions), evening free time	No follow-up	Parent workshops held במהלך the weekend	Funded by external non-governmental sources; free for families
20	Weekly open-access playgroup	Psychologist and nurse	Any child with a loved one receiving palliative care, including siblings	Staff available to respond to children’s questions as they arise	Games and arts/crafts activities	No follow-up	No	Conducted במסגרת staff working hours; free for families
21	Support group with four 90-minute sessions over 4 months	2 psychologists and child psychiatrists per group	Siblings aged 6–18 bereaved (any cause) at least 3–6 months prior; intake interview with psychologist and pediatrician	Facilitated discussions guided by participant questions (no fixed agenda); typical themes include school, family dynamics, isolation, fears, and ongoing bonds	Arts and crafts: Drawing or sculpting representations of loved ones, Emotion mandala coloring, collage work about family and future, group painting project	Follow-up meetings with the psychologist and pediatrician in the months after completion	Parent discussion group led by volunteers during children’s sessions	Funded by non-profit and philanthropic organizations; free for families

Abbreviation: PPC = pediatric palliative care.

Collaboration with community services

All teams partnered with a wide variety of local community organizations, such as non-profit groups (n = 17, 80%), regular schools (n = 11, 52%), specialized schools and centers for children with disabilities (n = 15, 71%), and home-based hospice services (n = 6, 28%). These partnerships mainly provided indirect help to grieving siblings by supporting the professionals who worked directly with them. PPC teams made referrals to non-profit organizations running group programs and assisted families living in remote areas in finding nearby care. One team even created its own non-profit entity specifically to organize bereavement groups. Within schools, PPC staff supported teachers in addressing death and loss with pupils and occasionally spoke directly with students when required. Two teams delivered presentations at school counselor training sessions, while another team held meetings with the district school superintendent, school nurses, and physicians to explain their objectives and offerings clearly. In addition, PPC teams regularly conducted debriefing sessions for community professionals after a child had died.

Intervention staff

Psychologists were responsible for organizing and delivering bereavement care across every team. In the majority of teams (n = 16, 76%), doctors and nurses also participated by keeping in touch with families via cards or phone calls. Their clinical knowledge proved especially valuable during home visits and consultations whenever families sought clearer medical information about the child's treatment or the events surrounding the death. Three-quarters of the staff (n = 16, 76%) had no formal training focused specifically on grief in children and had instead acquired their skills through hands-on experience (PPC team 3). Five teams had completed dedicated training on how children grieve and on leading group conversations. However, most staff had received only general palliative care training, with bereavement receiving limited coverage.

Two-thirds of the teams (n = 14, 66%) arranged regular team debriefing sessions. For most of them (n = 10), these meetings occurred once every 2 to 4 months and were guided by an outside psychologist or psychiatrist. However, the discussions covered all aspects of pediatric palliative care. Four teams — all of which ran group programs — organized targeted supervision sessions focused solely on bereavement issues right after each group activity. When asked about emotional fatigue, fewer than one in four teams (n = 5, 23%) considered it a significant obstacle to the services they had previously offered. Common approaches to prevent burnout included pairing staff members and conducting team supervision. Interestingly, one team reported the reverse situation, explaining that 'being unable to offer proper bereavement support creates the sense of delivering incomplete care to families' (PPC team 20) and could actually trigger professional burnout. Another team described providing bereavement care as a way for staff to 'bring the care full circle' (PPC team 1).

Development of bereavement care services

When asked whether their current services were adequately addressing family needs, only 1/3 of teams responded affirmatively (n = 7, 33%). Most teams (n = 14, 66%) felt that important changes and enhancements were necessary. **Table 2** summarizes the teams' aspirations for the future and the main barriers they identified to expanding sibling bereavement care.

Table 2. Future vision and common obstacles to the development of bereavement care for siblings.

Category	Theme	Description	Illustrative quotes
Future vision	Developing and expanding group interventions	High demand for groups	"After surveying bereaved families, support groups for siblings emerged as a major need." (PPC team 9) "We aim to introduce sibling groups... there seems to be a general lack of such services in our region, and some physicians have encouraged us to create them." (PPC team 19) "Children are very drawn to group settings; they often say they appreciate meeting peers with similar experiences." (PPC team 21)
		Extending services to all age groups	"We intend to design group interventions for children under 6, with a low staff-to-child ratio." (PPC team 21). "We would like to broaden our weekend camp to include other age groups and potentially add a follow-up discussion group." (PPC team 7)
	Strengthening collaboration with community services	Importance of partnerships	"As the only psychologist on the team, building partnerships within the community is essential." (PPC team 10). "Collaboration with schools needs improvement. Teachers may struggle with grieving children due to limited information; working together could benefit both." (PPC team 14)
		Empowering community professionals	"We want to help other professionals identify grief and complicated grief in families. Raising awareness—especially among healthcare workers—is crucial. As resource teams, we should share knowledge beyond our services." (PPC team 7)
	Clarifying and promoting PPC services	Maintaining focus on mission	"Defining bereavement care offerings is a team effort to ensure professional and personalized support." (PPC team 10). "This mission is revisited more frequently than others... it requires continuous team commitment." (PPC team 9)

		Improving access to information	“We plan to develop a website and brochures so hospitals and schools can easily access information about sibling support groups.” (PPC team 14) “We continuously update a directory of local groups, and some organisations contact us for information.” (PPC team 2) “We created a pamphlet on grief and available resources at local and national levels; it is widely used in hospital wards.” (PPC team 5)
Common obstacles	Limited human resources	Insufficient time	“Time constraints are a major issue. We already handle many responsibilities, leaving little time to launch groups.” (PPC team 8). “Projects that are too ambitious are difficult to sustain long term.” (PPC team 2)
		Need for more psychologists	“We’ve requested more paid hours for psychologists to allow greater focus on follow-up care. Other duties often reduce time for bereavement support.” (PPC team 14) “Working part-time allows basic support, but not deeper psychotherapy. With more time, I could do more for families.” (PPC team 13) “If we had at least 2 psychologists, each sibling could have individual attention... one person cannot be the intermediary for everyone.” (PPC team 8)
	Limited material resources	Lack of appropriate spaces and need for neutral locations	“Since the whole team shares a single office, we often visit families at home. Many prefer this, especially if they do not want to return to the place of death. I travel across the entire region.” (PPC team 6) “We would like to offer services at the hospital, but returning there can be difficult for families; neutral locations are often better.” (PPC team 12)
		Insufficient funding for group development	“Securing funding can be challenging; our doctor had to advocate for it strongly.” (PPC team 2) “Groups would likely need to take place on weekends when families are available, but funding outside working hours is uncertain.” (PPC team 9) “Bereavement care is still underdeveloped in our work, likely due to limited time and financial resources.” (PPC team 20)
	Geographical challenges	Long travel distances for teams	“It’s frustrating when families live far away; home visits aren’t always feasible. Our region can span up to 300 km.” (PPC team 8). “Many families live outside the city, and we’ve had to decline follow-ups due to excessive travel distances.” (PPC team 17)
		Limited accessibility for families	“In socially disadvantaged areas, families may lack the means to travel to city-based groups.” (PPC team 8). “Providing care close to families is difficult; while options exist in the city, they are hard to access from the suburbs and often have waiting lists.” (PPC team 15)

Abbreviation: PPC = pediatric palliative care.

Future vision

Teams highlighted three priority areas for improving bereavement support for siblings: setting up or expanding group-based programs (n = 11), strengthening partnerships with community organizations (n = 6), and clarifying and promoting their available services (n = 6).

Parents and other professionals had expressed a clear need for more sibling support groups. Children often benefit from the shared experience, as ‘they frequently express relief and happiness at meeting peers who understand what they are going through’ (PPC team 21). Several teams also wished to reach younger children, specifically ‘those below six years old, provided the staff-to-child ratio remains low’ (PPC team 21).

Building stronger ties with community services was seen as crucial, especially for psychologists who were frequently ‘the sole psychologist within the team’ (PPC team 10). The goal was to better prepare local providers to handle grief-related needs, for example, by teaching ‘other professionals how to identify grief reactions’ (PPC team 7) or by collaborating with schools to assist ‘both pupils and educators in managing grief’ (PPC team 14). Teams emphasized the need to regularly review their mission to guarantee they could ‘deliver skilled and individually adapted care’ (PPC team 10) and because ‘maintaining the service requires ongoing collective commitment’ (PPC team 9). Many teams planned to raise awareness of their offerings among ‘other hospital departments and schools’ (PPC team 14) and to keep ‘a current directory of available local support groups’ (PPC team 2).

Common obstacles

Teams identified three key barriers to the growth of bereavement care: a shortage of personnel (n = 17), a lack of material and financial resources (n = 21), and large geographical distances (n = 10).

Time constraints made it hard to launch ‘any large-scale initiatives’ or sustain them ‘over the long term’ (PPC team 2). Psychologists in particular highlighted the need for more staff ‘to allow sufficient time for follow-up contacts’ (PPC team 14) and ‘to explore issues more thoroughly with families’ (PPC team 13).

Shortages in material resources also restricted what could be achieved. Obtaining funding proved ‘very challenging’ (PPC team 2), which resulted in many projects remaining ‘underdeveloped’ (PPC team 20). Teams

often lacked suitable meeting spaces for families, and some families preferred meeting locations away from the hospital. To address this, several teams arranged 'home visits' that felt 'more comfortable and welcoming for families', sometimes driving 'across the entire region' to respond to requests (PPC team 6).

Nevertheless, long travel distances prevented some teams from offering home visits. Certain follow-up requests had to be declined 'because the distance involved too many kilometres' (PPC team 17). Isolated and socially disadvantaged areas presented extra difficulties, since community resources were limited and many families did not have 'the transportation or means to attend groups held in urban centers' (PPC team 8).

Main findings

PPC teams considered bereavement support for siblings to be a vital part of ongoing care. The majority of teams offered individual psychotherapy to families, while only a small number provided group-based interventions. PPC teams expressed a desire to broaden and promote their bereavement services and to build a more robust network of collaboration with community resources. Nevertheless, challenges such as insufficient staffing, inadequate facilities and funding, and large geographical distances frequently hindered the advancement of bereavement care.

Implications for current and future practice

Meeting siblings' emotional needs and concerns during their brother or sister's illness and after the death is a crucial element of care, since their distress is frequently overlooked. Current international guidelines for PPC state that psychosocial support should be 'available to all family members after the death of a child and, when possible, for as long as needed' [6]. French PPC teams recognized the coordination of bereavement care as an essential component of ongoing support, with each team adopting its own approach to delivering interventions. Bereavement support for siblings can be delivered in several formats, including group sessions, weekend camps, family therapy, and individual therapy. However, group interventions are the form most frequently reported in the existing literature [9]. Programs that combine grief-focused activities with recreational elements tend to be particularly helpful, as they encourage open dialogue and foster a feeling of community among grieving families [9]. Children who took part in these groups reported that the group setting enabled them to express and normalize their grief, decreased their sense of isolation, helped them reintegrate socially, heightened their self-awareness and understanding of others, and allowed them to enjoy themselves [9, 18-23]. Of the 21 teams interviewed, fewer than one-third ($n=6$, 28%) offered group interventions, yet half of the PPC teams ($n=11$, 52%) considered creating peer support groups an important future direction. Among all the interventions mentioned by the teams, the development of group interventions stood out as the top priority.

Although many French PPC teams recognized the value of such groups, their implementation was regularly constrained by a lack of human resources and financial support. Research commonly notes that sibling bereavement groups are often run by unpaid volunteers with diverse professional backgrounds [9]. While in North America other professionals, such as social workers, may serve as the main facilitators [8], in France, psychologists are responsible for leading hospital-based bereavement care and are paid for their work. The requirement that every PPC team include at least one psychologist reflects a governmental decision to include at least one psychologist in every PPC team to fulfill this role [24], given that supporting bereaved children presents specific challenges. A child's comprehension of death develops gradually alongside cognitive growth and maturity. Five key concepts are acquired over time: irreversibility (the permanent nature of death), personal mortality (the idea that death applies to oneself), universality (that all living things eventually die), non-functionality (the end of all life-sustaining functions), and causality (a realistic grasp of the causes of death) [25]. The age at which children reach a mature understanding of death varies across studies, ranging from 4 to 12 years, although most master the main biological and scientific aspects by age 7 [26]. Psychologists play a central role in guiding conversations in both individual and group settings, taking into account the child's cognitive development. This expertise is especially relevant for the future design of bereavement interventions aimed at very young children under 6 years of age. Even though many children may not need professional help or display symptoms of complicated grief, age-appropriate bereavement support is valuable and beneficial in assisting families as they navigate the grieving process [27, 28].

Even though French PPC teams are nationally united and financially supported by the public healthcare system, teams that ran group interventions frequently needed to secure additional funding from external non-governmental sources. In addition, the French teams did not describe organizing other common group activities, such as yearly remembrance events or memorial gatherings, which form a standard component of many hospital-based bereavement initiatives elsewhere [7, 8, 29]. Families often reported that these events had a beneficial effect on their grieving process and considered them among the most valuable parts of the program [29]. When staffing levels and budgets prevent the regular delivery of group sessions, creating annual commemorative gatherings could offer a useful and complementary option. This situation emphasizes the ongoing necessity to increase societal recognition of childhood bereavement as a significant public health matter and to push for better availability of dedicated services.

If internal services proved insufficient to address siblings' requirements, the teams turned to community-based alternatives. Every team partnered with local bereavement support through non-profit organizations (80%, $n = 17$), the educational system (52%, $n = 11$), specialized schools and centers for children with disabilities (71%, $n = 15$), and/or home-based hospice providers (28%, $n = 6$). French PPC teams operate as mobile consultant units, each covering a specific geographic zone that may span more than 100 km. Those interviewed recognized that their teams lacked both the time and the capacity to meet every demand of grieving families directly. Therefore, assuming an indirect, advisory "second-line" function became crucial, and this involved directing families to appropriate referrals, cooperating with established local resources, and educating others on how to support children facing loss. Educating the broader workforce and community about grief can strengthen the entire system's ability to respond thoughtfully and effectively to the requirements of bereaved children [30]. A large number of teams had contacted educators, nurses, physicians, and school leaders in regular and specialized educational settings to improve their ability to identify and help students experiencing grief. Greater social backing at school from teachers and classmates can promote better adaptation for siblings who have lost a brother or sister [31].

Furthermore, French PPC teams almost always limit their bereavement support to families who were already receiving care from them before the child's death. Professionals and families frequently seek advice from these teams regarding suitable onward referrals. Up-to-date familiarity with local group programs run by non-profits and community groups is therefore essential for providing accurate direction. While bereavement care is clearly important, it is only one of several responsibilities for PPC teams. Forming strong partnerships with community services to develop a wide-ranging support network is essential for closing existing gaps and better serving children in grief.

Taking part in hospital-based bereavement follow-up brings clear psychosocial advantages to both participating families and the staff involved [7]. Team members commonly experienced a sense of purpose, professional satisfaction, and emotional resolution when helping parents shift from hospital care into community support [7, 8, 32]. The present study shows that similar rewards apply to PPC professionals when they assist bereaved siblings. Remarkably, three-fourths of the teams (76%, $n = 16$) did not regard bereavement work as emotionally draining when suitable protective measures were implemented. On the contrary, many described it as a meaningful and enriching aspect of their profession, keeping families supported and contributing to a sense of completion. Healthcare workers themselves may go through personal grief after losing a pediatric patient [33]. Encouragement from colleagues and focusing on the constructive aspects of the patient's passing were major factors in easing this grief.

In contrast, insufficient backing from the organization and limitations on showing grief tended to make the experience more difficult [7, 33]. Finally, three-fourths of PPC team members had never undergone specialized training focused on childhood grief. Insufficient expertise and advanced competencies in death-related matters have been associated with greater challenges in delivering care [34], highlighting the clear need for focused professional development. Additional tools, including materials designed for different age groups, can help equip professionals to handle delicate discussions more confidently [35]. Structured team debriefings, together with targeted training, represent key building blocks for PPC teams in general and are particularly valuable for bereavement support.

Study limitations

The study presented certain limitations. For most teams, only a single representative attended the interview, raising the possibility of reporting bias. Efforts were made to address this issue by sharing the interview questions ahead of time so teams could review and discuss them together, and by asking the most informed person about bereavement practices to serve as spokesperson. The inclusive selection criteria yielded a high participation rate, providing a robust national picture of existing bereavement interventions. Although the research concentrated on sibling-specific bereavement care, several respondents broadened their comments to cover parents and the wider family unit. Consequently, the findings may be less precise in places and should be considered with appropriate caution. Second, data collection involved relatively short telephone interviews, which may have introduced collection bias. Lastly, variations in resource levels and population density across each team's service area were not examined in the analysis and could also affect how bereavement services are delivered.

Conclusion

In conclusion, PPC teams view support for bereaved siblings as a core component of palliative care. They use whatever resources are at hand to build a supportive network around each family. While it is understandable that PPC teams cannot meet every need of grieving siblings on their own, they can serve as reliable points of reference. They consolidate information on locally available services and deliver informed recommendations to families and community professionals alike. Heightened public understanding of childhood bereavement, combined with active involvement from community organizations, could help overcome many typical barriers to expanding these

services. Future research assessing the practicality and outcomes of such services within France, as well as additional country-wide investigations linking service delivery to different pediatric palliative care frameworks, would be beneficial. PPC teams regularly come into contact with grieving siblings and hold significant potential to guide families along their path through bereavement.

Acknowledgments: The authors would like to extend their sincere gratitude to the pediatric palliative care team members who participated in this study.

Conflict of interest: None

Financial support: None

Ethics statement: This study was approved in November 2020 by the local research committee (Institutional Clinical Research and Innovation Review Board of the University Hospital of Besançon—reference number EI/2020/747). All participants consented to partake in the study.

References

1. World Health Organization. Integrating palliative care and symptom relief into paediatrics: a WHO guide for health care planners, implementers and managers. Geneva: World Health Organization; 2018.
2. INSEE. Causes of death among youth and children – annual data from 2000 to 2016 (translated from French). <https://www.insee.fr/fr/statistiques/2386052> (accessed 1 Sep 2024).
3. Hulsey EG, Hill RM, Layne CM, Saltzman WR, Pynoos RS, Steinberg AM, et al. Calculating the incidence rate of sibling bereavement among children and adolescents across the United States: a proposed method. *Death Stud.* 2020;44(5):303–11.
4. Schonfeld DJ, Demaria T; Committee on Psychosocial Aspects of Child and Family Health; Disaster Preparedness Advisory Council. Supporting the grieving child and family. *Pediatrics.* 2016;138(3):e20162147.
5. European Association for Palliative Care Task Force on Palliative Care for Children and Adolescents. IMPaCCT: standards for paediatric palliative care in Europe. *Eur J Palliat Care.* 2007;14(3):109–14.
6. Benini F, Papadatou D, Bernad  M, Downing J, Carter B, Nyatanga B, et al. International standards for pediatric palliative care: from IMPaCCT to GO-PPaCS. *J Pain Symptom Manage.* 2022;63:e529–43.
7. Donovan LA, Wakefield CE, Russell V, Phillips C, Hendrick G, Gibson F, et al. Hospital-based bereavement services following the death of a child: a mixed study review. *Palliat Med.* 2015;29(3):193–210.
8. Contro N, Sourkes BM. Opportunities for quality improvement in bereavement care at a children’s hospital: assessment of interdisciplinary staff perspectives. *J Palliat Care.* 2012;28(1):28–35.
9. Ridley A, Frache S. Bereavement care interventions for children under the age of 18 following the death of a sibling: a systematic review. *Palliat Med.* 2020;34:1340–50.
10. Ridley A, Revet A, Raynaud JP, Bouteyre E, Besson J, Dauchy S, et al. Description and evaluation of a French grief workshop for children and adolescents bereaved of a sibling or parent. *BMC Palliat Care.* 2021;20(1):159.
11. French Ministry of Health. National palliative care development program 2008–2012 (translated from French). Paris: Ministry of Health; 2008.
12. Arias-Casais N. EAPC atlas of palliative care in Europe 2019. Vilvoorde: EAPC Press; 2019.
13. Ravello A, Falconnet M, Henry F, Blanc P, Dupont C, Martin L, et al. Regional pediatric palliative care resource teams: a first national assessment (translated from French). *M d Palliat.* 2016;15(5):270–9.
14. French Ministry of Health. Official text of December 17, 2010 – Visa CNP 2010-309 (translated from French). Paris: Ministry of Health; 2010.
15. Rahimi S, Khatooni M. Saturation in qualitative research: an evolutionary concept analysis. *Int J Nurs Stud Adv.* 2024;6:100174.
16. Walker D, Myrick F. Grounded theory: an exploration of process and procedure. *Qual Health Res.* 2006;16(4):547–59.
17. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349–57.
18. Bachman B. The development of a sustainable, community-supported children’s bereavement camp. *Omega (Westport).* 2013;67(1–2):21–35.
19. Creed J, Ruffin JE, Ward M. A weekend camp for bereaved siblings. *Cancer Pract.* 2001;9(4):176–82.
20. Davies B, Collins J, Steele R, Doyle C, Hebert R, Simons T, et al. Parents’ and children’s perspectives of a children’s hospice bereavement program. *J Palliat Care.* 2007;23(1):14–23.

21. Kramer R. A weekend retreat for parents and siblings of children who have died. *J Palliat Med.* 2002;5(3):455–64.
22. Packman W, Greenhalgh J, Chesterman B, Taylor C, Hood K, Christ G, et al. Siblings of pediatric cancer patients: the quantitative and qualitative nature of quality of life. *J Psychosoc Oncol.* 2005;23(1):87–108.
23. Bugge KE, Haugstvedt KTS, Røkholt EG, Haugland BSM, Dyregrov A, Kristensen P, et al. Adolescent bereavement: embodied responses, coping and perceptions of a body awareness support programme. *J Clin Nurs.* 2012;21(15–16):2160–9.
24. French Ministry of Health and Prevention; Ministry of Solidarity, Autonomy and Persons with Disabilities. Interministerial instruction No. DGOS/R4/DGS/DGCS/2023/76 of June 21, 2023 concerning the continued structuring of territorial palliative care networks (translated from French). https://sante.gouv.fr/IMG/pdf/2023_76.pdf (accessed 1 Sep 2024).
25. Stein A, Dalton L, Rapa E, McPherson A, Woollard J, Gilbert R, et al. Communication with children and adolescents about the diagnosis of their own life-threatening condition. *Lancet.* 2019;393(10176):1150–63.
26. Speece MW. Children's concepts of death. *Mich Fam Rev.* 1995;1(1):57.
27. Worden JW, Silverman PR. Parental death and the adjustment of school-age children. *Omega (Westport).* 1996;33(2):91–102.
28. Osterweis M, Solomon F, Green M, editors. Bereavement: reactions, consequences, and care. Washington (DC): National Academies Press; 1984. <http://www.nap.edu/catalog/8> (accessed 14 Feb 2021).
29. Gundry A, Elvidge N, Donovan L, Davies B, Steele R, Russell V, et al. Parent and provider perspectives of a hospital-based bereavement support program in pediatric palliative care. *J Pain Symptom Manage.* 2023;65(5):388–99.
30. Griese B, Burns MR, Farro SA, Hebert RS, Koenig HG, Winter L, et al. Comprehensive grief care for children and families: policy and practice implications. *Am J Orthopsychiatry.* 2017;87(5):540–8.
31. Howard Sharp KM, Russell C, Keim M, Keim S, Christ GH, Packman W, et al. Grief and growth in bereaved siblings: interactions between different sources of social support. *Sch Psychol Q.* 2018;33(3):363–71.
32. Liisa AA, Marja-Terttu T, Päivi ÅK, Kaarina L, Helena S, Jorma P, et al. Health care personnel's experiences of a bereavement follow-up intervention for grieving parents. *Scand J Caring Sci.* 2011;25(2):373–82.
33. Barnes S, Jordan Z, Broom M. Health professionals' experiences of grief associated with the death of pediatric patients: a systematic review. *JBIEvid Synth.* 2020;18(3):459–515.
34. Chan WCH, Wong KLY, Leung MMM, Lin MKY. Perceived challenges in pediatric palliative care among doctors and nurses in Hong Kong. *Death Stud.* 2019;43(6):372–80.
35. Chan WCH, Yu CTK, Leung GSM, Lin MKY, Leung MMM, Kwok DKS, et al. Developing a storybook package for bereaved siblings: a pilot study of the effectiveness for enhancing the perceived knowledge and confidence of health and social care professionals in Hong Kong. *Death Stud.* 2024. Epub ahead of print.