

Palliative care services in paediatric oncology centres across Europe: A cross-sectional survey

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ABSTRACT

Background: Palliative care (PC) is an integral part of cancer treatment. However, data on service availability is limited in childhood cancers.

Aim: To describe the availability of PC services in paediatric oncology centres across Europe, and to identify barriers and facilitators for implementing and providing paediatric palliative care (PPC).

Methods: Paediatric oncology centres across Europe were invited to complete an online questionnaire.

Results: A total of 158 paediatric oncology centres from 27 European countries participated. More than half of the centres (n = 102, 64.6 %) reported offering specialised PPC (defined as 24/7 coverage services with a specialised physician and a multidisciplinary team). Most centres included a multidisciplinary care team (n = 123, 80.9 %) and PC at home (n = 105, 69.1 %). In 38.7 % centres, service capacity was reported to be lower than demand. In most centres, PC consultation was initiated for a refractory neoplasm (n = 126, 81.2 %). Few centres (n = 11, 7.1 %) offered PC consultation at the time of a new cancer diagnosis. Eighty-two centres (52.6 %) reported having bereavement services. Negative parental perception (n = 99, 64.7 %) and late referrals (n = 91, 59.5 %) were major barriers to implementation perceived by health care providers.

Conclusion: Our results suggest that specialised PPC is available in more than half of paediatric oncology settings across Europe. Although half have had PPC available for > 10 years, many cannot fulfil the demand for service. Barriers to implementation (i.e., parental education, staff training) should be addressed, with resources and services further expanded to cover the demand for PPC, including bereavement care.

1. Introduction

“Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family” [1] to reduce suffering and improve quality of life. Paediatric palliative care (PPC) should thus be provided by a multidisciplinary care team [2]. International health organizations recommend that PPC is introduced when diagnosing a life-limiting or life-threatening disease (as cancer),

irrespective of prognosis [1,3–5], meaning that PPC should be offered alongside curative treatment, and continue throughout the course of the illness, even after death and during bereavement [1,6,7]. Furthermore, providing palliative care (PC) is a moral responsibility of healthcare systems and an ethical duty of healthcare providers (HCP) [8]. Awareness on the importance of PPC has increased over the past 15 years [2]. Still, important individual and organizational barriers to its implementation persist [7,9–13].

Abbreviations: EOL, End-of-life; PC, Palliative Care; PPC, Paediatric Palliative Care; HCPs, Health care providers.

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Despite significant advancements in the treatment of paediatric cancer over six decades [14], the disease necessitates PPC for millions of children annually worldwide [15,16]. In Europe, the annual incidence of childhood cancer is around 140 cases/million children and adolescents [17], bringing a financial and psychosocial burden on families and society. PPC services are crucial in reducing the impact of a childhood cancer diagnosis [15]. In addition, approximately 20 % of children with cancer in Europe die [14]. The bereaved families have special needs after losing a child, and support by dedicated bereavement services through resources such as psychosocial counselling, phone-calls, cards and memorial days, aim to comfort the grieving family [18,19].

Few studies have investigated the availability of PPC, including bereavement services, in Europe. Former studies show high variability in Europe, with low-to-middle-income countries having less provision/access compared to high-income ones [20,21]. Still, data on available PPC specific to paediatric oncology in Europe remains unknown. Thus, we aimed to describe the availability of PPC, including bereavement services, in paediatric oncology centres in Europe, and identify barriers and facilitators for implementing and providing PPC.

2. Methods

2.1. Study design

A cross-sectional survey among paediatric oncology centres across Europe from February 2021 to July 2022.

2.2. Enrolment procedure

All paediatric oncology centres in Europe (European Union, Schengen area and British Isles) were eligible. Contact information of these centres was obtained from country representatives [22]. The research team, country representatives, or medical societies sent an invitation to paediatric oncology centres for participation, including study information and a link to the online survey. We asked one HCP from each centre most familiar with their PC services in paediatric oncology to answer the online questionnaire. Reminders were sent between 6 and 10 weeks after the first e-mail. In case of more than one respondent from a centre, we only considered the answer from the HCP with the longest clinical experience. Countries were divided into five regions (British Isles, Northern, Southern, Western, and Eastern) [22,23].

2.3. Data collection

Data was collected through an online questionnaire (Qualtrics®; SAP, Utah, US). The original instrument was designed by an interdisciplinary team following the Tailored Method of Survey Design; and was piloted, revised, and re-piloted before its use among 142 paediatric oncology centres, mainly in the USA [24]. For the current study, the questionnaire was modified based on previous experience [24] and additional literature, to adapt it to the European setting. The questionnaire underwent internal validation by an international panel of experts (PPC specialists, paediatric oncologists, paediatrician, psychologist, and bioethics expert) who reviewed each item and response choice before implementation.

The final version consisted of 40 items covering four domains, namely, (a) healthcare provider's professional profile, (b) cancer centre characteristics, (c) communication-decision support and family's needs, and (d) bereavement services. The survey was available in English and can be found in the appendix (Appendix A).

A service is considered a collection of resources that hospitals offer to their patients. We defined specialised PPC as a service that includes a multidisciplinary team, a specialist palliative care physician, and inpatient coverage 24/7. Bereavement service was defined as a dedicated team/programme providing support to bereaved families through different resources (e.g., psychological counselling, phone calls, cards,

funeral information, follow up meetings).

2.4. Ethical consideration

Before study initiation, approval was obtained from the Ethics Commission of North-western and Central Switzerland (Study ID: EKNZ 2020–01322). Country-specific ethics approval was not needed. Participation was voluntary. No monetary compensation was given to participants.

2.5. Statistical analysis

Descriptive analysis was conducted using means (SD) and percentages, as appropriate. We compared the responses according to the region using chi2 tests (for nominal/categorical data), and ANOVA (for continuous data). We evaluated associations and performed multinomial logistic regressions (trigger diagnosis) and multivariate logistic regressions (time of palliative care introduction). Additionally, we performed list-wise deletion for incomplete responses and missing data. A sensitivity analysis was performed to estimate response rate, explore selection bias, and responder's bias (Appendix B-E). All analyses were performed using Stata 17 (StataCorp, Texas, US). We performed two-tailed tests and considered p value < 0.05 as a statistically significant association.

3. Results

3.1. Study sample / demographics

In total, 158 paediatric oncology centres participated (78 % University hospitals; Table 1). Respondents were HCPs with diverse professional backgrounds (mostly paediatric oncologists (84 %) and/or palliative care specialists (37 %), multiple responses possible), with mostly >5 years of experience in paediatric oncology and PPC (Appendix F).

Table 1
Characteristics of the Paediatric Oncology Centres.

General characteristics	n	%
Type of Paediatric Oncology Centre		
University Hospital	123	78
Public Hospital (not university-hospital)	30	19
Private hospital	1	1
Other (research, cancer centre, hospice)	3	2
Maximum age of patients		
Mean (SD), in years	19 (0.3)	
Paediatric Oncology Cases per Year		
<20 cases	18	11
20–50 cases	50	32
51–100 cases	48	31
101–150 cases	21	13
>150 cases	20	13
PPC cases in Paediatric Oncology Centres/year		
Mean (SD)	12.7 (19.1)	
Existence of PPC		
<5 years	29	19
5–10 years	55	36
11–20 years	43	28
>20 years	19	13
Not sure/ do not know	6	4
Capacity versus demand		
Capacity significantly higher than demand	7	4
Capacity higher than demand	12	8
Capacity matches the demand	76	49
Capacity lower than demand	49	32
Capacity significantly lower than demand	11	7

PPC: paediatric palliative care. Some participants might not have answered certain questions such that numbers do not always add up to the total N of 158.

3.2. Aim 1: availability of PPC services in paediatric oncology centres

3.2.1. Paediatric palliative care services and resources

Almost all centres provided some form of PC (n = 153, 97 %). Two thirds of centres (n = 102, 64.6 %) indicated that they offered specialised PPC services, 44 centres (29 %) had a PPC care provider but not specialised PPC service, and seven (4 %) received support from an adult PC service. Only five (3 %) reported not offering any PC for children (Fig. 1). Most centres have had PPC services available for >5 years (n = 117, 77 %) (Table 1). Two thirds of centres (n = 98, 62 %) treated between 20 and 100 childhood cancer patients per year.

The UK and Ireland (British Isles) had the highest proportion of centres (82 %) with specialised PPC as compared to other regions (p = 0.003), followed by western and northern regions (Fig. 1). Various professions were involved in PPC for paediatric oncology patients, mostly paediatric oncologists (n = 149, 96 %), psychologists (n = 136, 88 %), palliative care specialists (n = 118, 76 %), and social workers (n = 118, 76 %) (Fig. 2).

Multidisciplinary teams (n = 123, 80 %), consultations at home (n = 105, 69 %), and a specialised physician with training in palliative care (n = 95, 62 %) were available in more than half of centres (Fig. 2). The most common resources available to all paediatric oncology patients and families were symptom management, individual counselling, family counselling, and physio-therapy (Fig. 2). Forty centres (26 %) had hospice service, of these 35 were paediatric facilities. Other characteristics can be found in the Appendix (Appendix G).

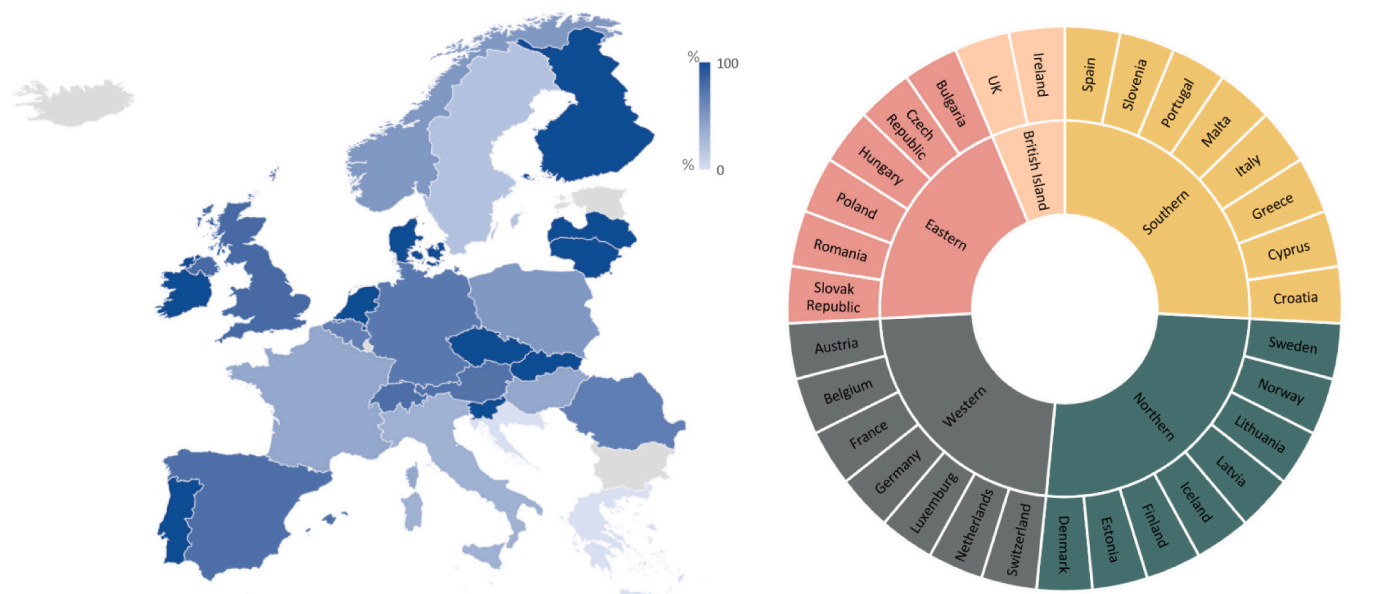
Service capacity was reported to be lower than demand in 60 centres (n = 39 %; Table 1), with Northern and British Isles (UK and Ireland) regions having the most centres with low reported capacity compared with the other regions (p = 0.013).

3.2.2. Communication with patients and families in palliative paediatric oncology care

Most centres (n = 105, 69 %) introduced PPC to patients and their families at disease-specific time points, 41 centres (27 %) at no uniform time, and only seven centres (4.6 %) introduced them at the time of diagnosis. Refractory neoplasm (n = 126, 81 %), and difficulties in managing symptoms (n = 92, 59 %) were common reasons or triggers for referrals to PPC teams (Table 2). Reasons were similar across regions. The presence of triggers resulted in the introduction of PPC to patients and families 4.5 times (p < 0.03) more frequently compared to no trigger. When necessary, 122 centres (79 %) of patients and families were usually/always offered developmentally appropriate communication regarding end-of-life care (Fig. 3), often by written material, websites, videos, and personal discussion with HCPs. Advance-care planning was offered in 111 centres (72 %).

3.2.3. Bereavement services and resources

Eighty-two centres (53 %) offered bereavement services. However, more centres (n = 154) reported provision of resources such as phone calls from the health care team (n = 104, 67 %), psychological counselling at the centre (n = 97, 63 %), and medical debriefing for bereaved families (n = 95, 62 %; Fig. 2). Fifty-nine centres (38 %) always assessed the needs of bereaved families. This was more prevalent in Northern region compared to other regions (p < 0.001). In most cases (n = 111, 72 %) bereavement needs were assessed by a contact person who personally knew the family (Fig. 3 c.d.). This was reported to be offered more often in the Northern, Western, and Southern regions (p = 0.019). Although the length of bereavement follow-up varied notably, most centres provided bereavement follow-up during the first two years after the death of a child (n = 86, 56 %; Table 2).



	British Isles (n=11)		Eastern (n=14)		Northern (n=18)		Southern (n=44)		Western (n=71)	
Availability of (self-reported):	N	%	n	%	n	%	n	%	n	%
Specialised PPC service ¹	9	82	9	64	11	61	25	57	48	68
Adult PC service			1	7	3	17	2	5	1	1
PPC provider, but not specialized PPC service	2	18	1	7	4	22	16	36	21	30
No PC service to children			3	21			1	2	1	1

Fig. 1. Proportion of Centres with Specialised Palliative Care Services per Region. ¹Self-report, includes: a) a specialised physician with training in palliative medicine, b) a multidisciplinary care team, and c) 24/7 coverage. PPC: paediatric palliative care. PC: palliative care. Map (EU/Schengen area): The intensity of colours shows the proportion of centres with Specialised PPC in each country.

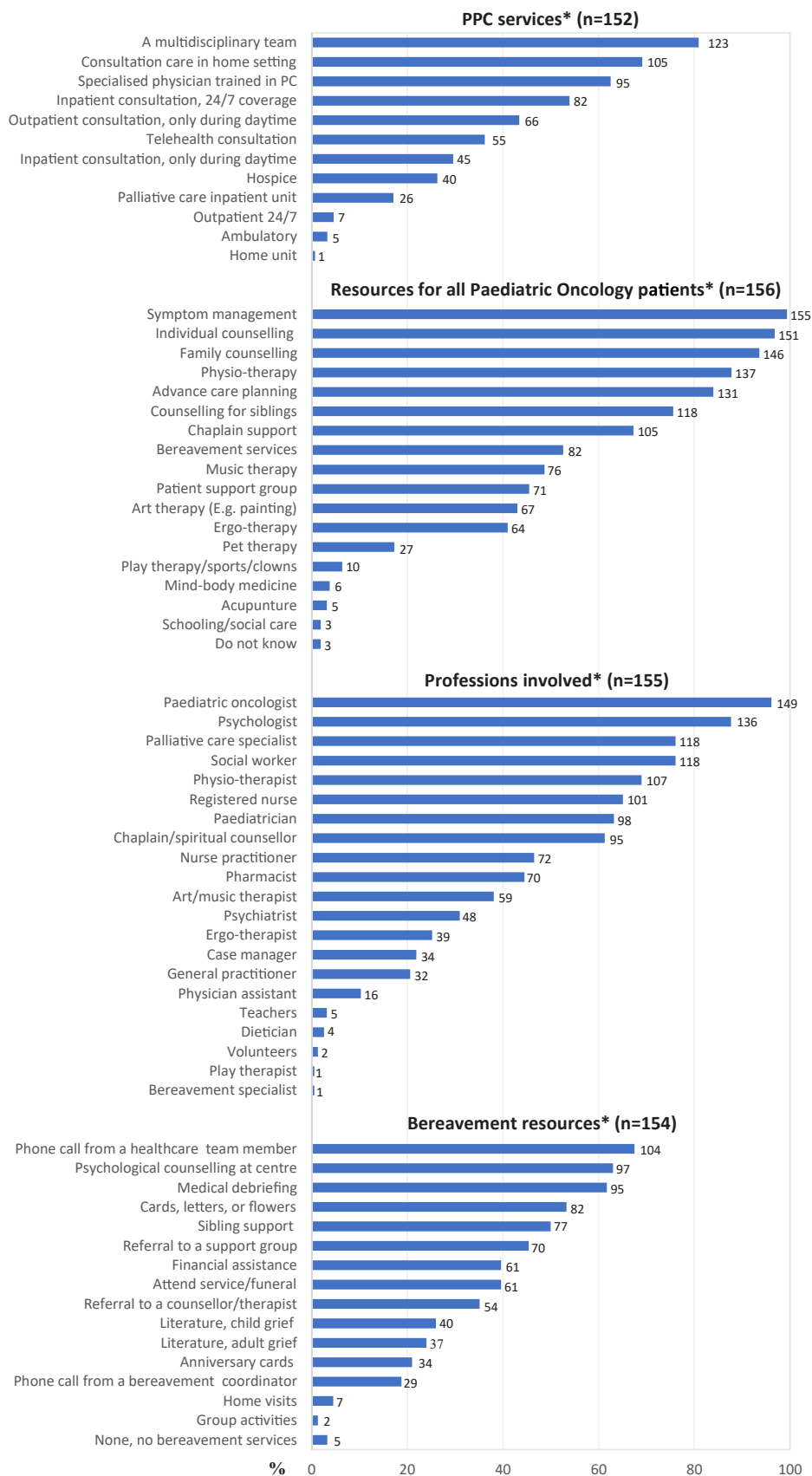


Fig. 2. Paediatric palliative care and bereavement services. Professions and resources involved (%). Footnote: PPC: paediatric palliative care. PC: palliative care. * Multi-responses possible. Crude numbers written next to each bar.

Table 2
Communication of paediatric palliative concepts to families and follow-up for bereavement care.

	n	%
Communication with patients/families in PPC		
Timepoint introduction of PPC concepts		
At disease-specific times (e.g. relapse, refractory disease, or refractory symptoms)	105	69
No uniform	41	27
At diagnosis	7	5
Situations that trigger PPC referrals^a		
Diagnosis of refractory disease	126	81
Difficult-to-manage symptoms or high symptom burden	92	59
Discussion advanced care planning	76	49
New cancer diagnosis with poor prognosis	73	47
Diagnosis of recurrent disease	71	46
Difficult social situation	49	32
Experimental treatment (phase 1 and 2)	39	25
New cancer diagnosis (any type)	11	7
Upon consultation with bone marrow transplant	4	2
Clinical practice guidelines	3	2
Home care assistance	1	1
No trigger diagnosis	20	13
Bereavement care-Follow up		
None, no bereavement care services	11	7
At the time of death only	16	10
First month	8	5
2–6 months	18	12
7–12 months	21	14
1–2 years	23	15
3–5 years	12	8
6–10 years	4	3
> 10 years	19	12
Do not know	22	14

PPC: paediatric palliative care; ^a Multiple response possible
Some participants might not have answered certain questions such that numbers do not always add up to the total N of 158.

3.3. Aim 2: Perceived barriers and facilitators to the implementation of PPC in oncology

Perceived barriers to implement PPC were mainly parental negative perception of PPC (n = 99, 65 %), late referrals (n = 91, 59 %), and colleagues unaware of the scope of PPC (n = 57, 37 %). Only 21 centres reported no difficulties implementing PPC (14 %; Fig. 4). There was no significant difference between regions (p = 0.670).

Facilitators of PPC implementation were reportedly staff training (n = 117, 76 %), more staff (n = 107, 69 %), more time (n = 89, 58 %), more finances (n = 71, 46 %), and guidelines on PPC (n = 63, 41 %; Fig. 4). To facilitate better bereavement resources, responders suggested: referrals to a support group (n = 57, 40 %), sibling support (n = 44, 31%) and child/adult PPC literature (n = 37, 26% and n = 35, 24.5% respectively; Fig. 4).

3.4. Sensitivity analyses

We estimated a response rate of 49.6 % from approximately 318 eligible paediatric oncology centres from the EU [25]. We obtained response from 27 of 31 eligible countries (87 %). Details on responder's bias testing can be found in the Appendix B-E.

4. Discussion

Our study revealed that more than half of the participating paediatric oncology centres offer specialised PPC service to patients and families. This is lower compared to a similar survey done in the US in 2018 (75 %) [24], and similar to a study among high-income countries from 2010 [26]. However, we found that other forms of PC were provided in the absence of a specialised service. In our study, the majority of centres offered multidisciplinary team services and homecare consultation, with more than half having PC specialists. In addition, almost half of the

centres provide coverage 24/7, indicating that PC services are increasingly available for children with cancer in Europe [2,17,27]. However, responses could be interpreted as merely a perception of HCPs and not an actual availability of PPC services. Based on their own perception, the demand for PPC exceeds the capacity in more than one third of centres, suggesting that PPC needs to be expanded and strengthened. The capacity-demand discrepancy was particularly high in those countries with good implementation of PPC services, which suggests that profound knowledge in PPC is needed to perceive the real demand.

According to paediatric oncology standards of care, introducing PPC concepts and services should be provided in the early stage of life-limiting or life-threatening diseases [28]. Our findings have shown that these were rarely introduced at time of diagnosis, but rather, and similar to previous studies [24,29], at disease complications. The use of these trigger points helped to increase the likelihood of PPC being offered, as previously found in a US study [24]. Thus, although it is not ideal to introduce PPC at later stages, HCPs recognize the need for these services at crucial time points.

Bereavement services were found to be available in around half of paediatric oncology centres across Europe. However, bereavement services were unevenly distributed across Europe, being available less frequently in the Southern, Eastern, and Western regions. Only one centre reported having a bereavement specialist, and few provided contact of a bereavement coordinator as follow-up. Follow-up can be important for bereaved families as it provides a valuable opportunity to screen for bereavement risks and connect to further support [30]. In our study, the time for bereavement care after death varied considerably, suggesting a lack of standardised guidelines. Nevertheless, centres offered a variety of resources for bereaved families [31–34], such as psychological counselling, phone calls, and medical debriefing. According to published evidence-based psychosocial standards of care [18], at least one meaningful contact with the bereaved families should be done after the loss of a child. Thus, while European centres may still be lacking bereavement services, various resources were available to fill this gap.

Finally, our study identified HCPs' perceived barriers and facilitators to the provision of appropriate PPC. The three most important barriers were (a) "parents' negative perceptions", as seen in other studies [35], (b) "late referrals", and (c) HCPs' lack of awareness, similar to findings from the US study [24]. Knowledge about the meaning and purpose of PPC should be provided by HCPs to patients, families, but also extended families, or schools. It is crucial that HCPs recognize that PC is not just about end-of-life care, but quality of life and reducing suffering for those facing life-limiting and life-threatening illnesses such as childhood cancer. As proposed by respondents, more education and training might help improve this situation [36,37], but also more staff time and funding, the development of guidelines, and better recognition and research in PPC.

4.1. Strengths and limitations

To our knowledge, this is the first systematic assessment of the availability of PPC in paediatric oncology centres in Europe. Other published studies include narrative reviews, administrative reports, and survey studies of other regions or target populations [20,21,24,27, 37–40]. A previously validated questionnaire adapted to the European context was used in our study. We replicated the methods in a different setting, verifying the validity of previous findings, building on previous knowledge. We included respondents from most European countries to provide a comprehensive overview of PPC for oncology in our region. We ensured that all countries were systematically approached during the survey process, making our findings more generalizable to the region than previous assessments.

However, several limitations are important to note. Because one person per centre completed our survey, there is potential for self-report bias. Social desirability might potentially lead to an overly positive

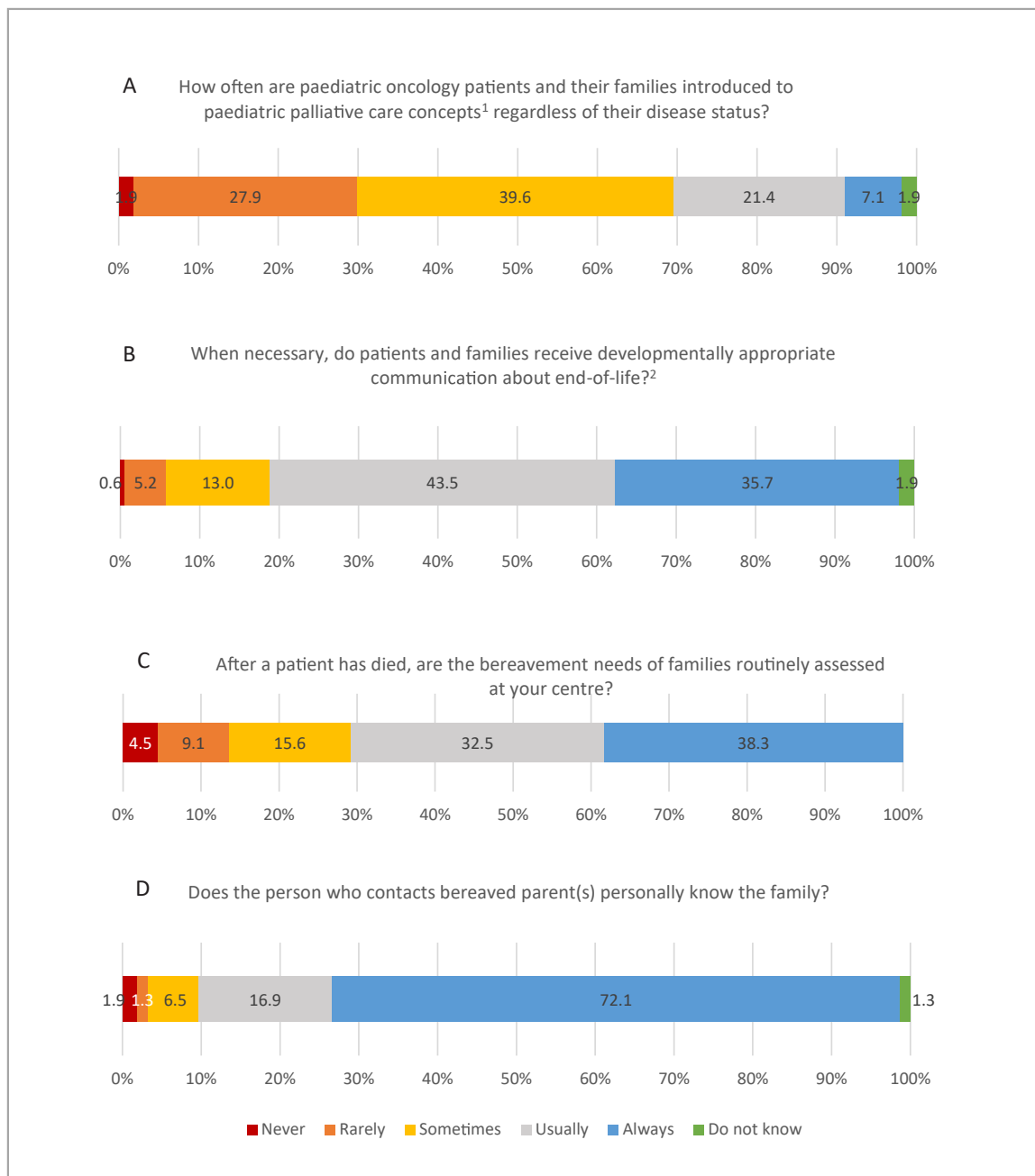


Fig. 3. Communication on paediatric palliative care principles and bereavement care provided by HCPs at paediatric oncology centres (n = 154). Paediatric palliative care and Bereavement contact/communication. ¹Palliative care concepts include symptom assessment and intervention; compassionate and honest communication; elicitation of decisional preferences in the form of advanced care planning. ²Developmentally appropriate communication includes individualized communication that respects the patient’s learning style and physical ability to interact. *HCPs (healthcare providers).

result. To avoid this, we specifically targeted HCPs with the most knowledge of the services in their respective facilities, who should also be aware about shortcomings. We performed sensitivity analyses to disprove this bias (Appendix B-E). A non-response bias may have happened in our survey. Some centres without PPC facilities may have chosen not to participate leading to an overestimation of the availability of PPC services. Our respondents represent 49.7 % of the approximate total number of paediatric oncology centres in Europe [25]. If we consider that all the non-respondents do not provide specialised PPC, the “worst-case” estimate would be 32.1 %, with the true availability of specialised PPC between 30 % and 60 % in Europe.

4.2. Implications for clinical practice

Our findings have clinical implications for paediatric oncology centres, medical societies, and other stakeholders to improve palliative care services. Identifying the availability or lack of specific PPC in each region can begin the process of growth in this practice area. Even when services are available, assessing the quality of services and how they are delivered should be evaluated nationally and internationally. This can lead to the development of implementation strategies [41], that can improve the quality of care, and provide the necessary follow-up support to affected children and their families. HCPs in our study reported the need for more education and training in palliative care. Training should focus on the benefits of early implementation of palliative care,

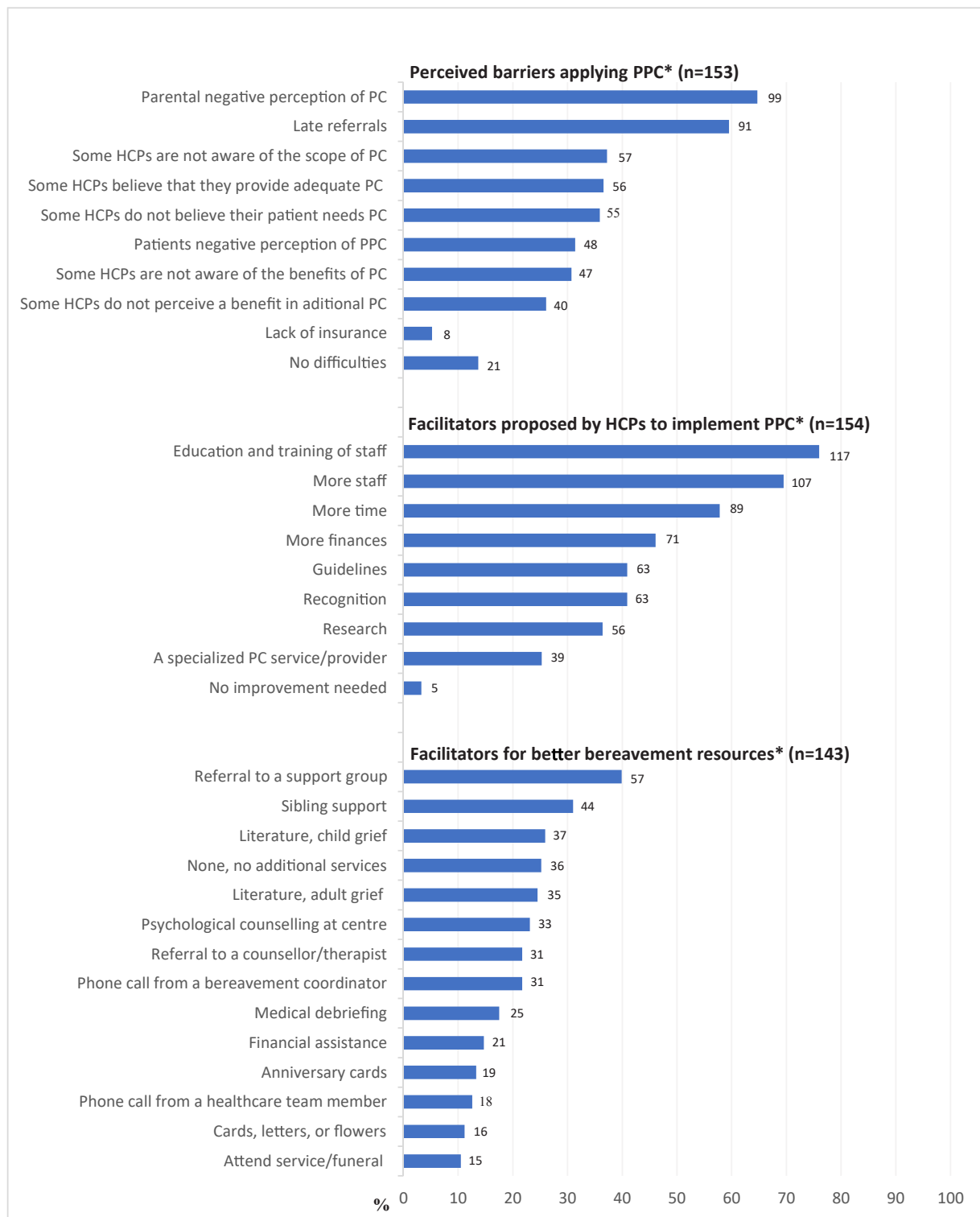


Fig. 4. Barriers perceived by health care providers (HCPs) when applying paediatric palliative care. PPC: paediatric palliative care. PC: palliative care. HCPs: Health care providers. * Multiple responses possible. Crude numbers written next to each bar.

expanding the focus of care by the integration of paediatric oncology and paediatric palliative care models [42]. Additionally, training should improve the quality of communication thereby avoiding negative parental perceptions of palliative care.

Bereavement care can be provided by establishing specialized bereavement programs in hospitals, aiming to identify negative physical and psychological outcomes in bereaved families. This will require

interprofessional collaboration, funding, clinical guidelines, and routine implementation within a comprehensive PPC service. Finally, collaboration with community-based programs can provide additional critically necessary support and follow-up for families.

5. Conclusion

Although some forms of PPC appear to be available in most paediatric oncology centres in Europe, it does not cover all aspects at the recommended level. The demand for PPC still exceeds capacity in many centres and this might even be more evident if PPC was integrated early on. Our study identified important areas for improvement. More training, personnel, finances, and guidelines are still needed. Barriers to implementation should be addressed, and resources and services should be further expanded to cover the demand for PPC, including bereavement care.

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CRedit authorship contribution statement

ECP, MJH, GM, LH and LW initiated the study (conceptualization). ECP, MJH and GM collected the data (methodology, software, resources, data curation). ECP, KR & PFR analysed the data (validation, formal analysis, investigation, data curation). ECP, AKV, PFR, EDC & GM wrote the first draft (writing original draft, visualization). MJH, KR, LH, AOvB, EMT, EB & LW, provided critical inputs on the manuscript (writing, review, and editing). GM supervised the conduct of the study (supervision, project administration). Acquisition of the financial support for the project leading to this publication: ECP, GM, LW (Funding). All authors approve the final version of the manuscript.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.ejcped.2023.100125](https://doi.org/10.1016/j.ejcped.2023.100125).

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