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ORIGINAL ARTICLE

Palliative care in Swiss pediatric oncology settings: a retrospective analysis of medical records

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Abstract

Purpose This study examined the provision of palliative care and related decision-making in Swiss pediatric oncology settings. The aim was to determine if and when children who died from cancer received palliative care, whether there were differences by cancer diagnosis, and inclusion of children in decision-making regarding palliative care.

Methods Using a standardized data extraction form, a retrospective review of medical records of deceased pediatric patients was conducted. The form captured information on demographics, diagnosis, relapse(s), treatments, decision-making during palliative care, and circumstances surrounding a child's death.

Results For 170 patients, there was information on whether the child received palliative care. Among those, 38 cases (22%) did not receive palliative care. For 16 patients, palliative care began at diagnosis. The mean duration of palliative care was 145 days (*Mdn* = 89.5, *SD* = 183.4). Decision to begin palliative care was discussed solely with parent(s) in 60.9% of the cases. In 39.1%, the child was involved. These children were 13.6 years of age (*SD* = 4.6), whereas those not included were 7.16 years old (*SD* = 3.9). Leukemia patients were less likely to receive palliative care than the overall sample, and patients with CNS neoplasms received palliative care for a longer time than other patients.

Conclusions There are still high numbers of late or non-referrals, and even children older than 12 years were not involved in decision-making regarding palliative care. These results do not align with international organizational guidelines which recommend that palliative care should begin at diagnosis.

Keywords Pediatric palliative care · Decision-making · Involvement of the child · Pediatric oncology

Elaine Acheson and Michael Rost contributed equally to this paper.

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Introduction

Since the early 2000s, pediatric palliative care guidelines have carefully distinguished palliative and hospice care, and ultimately recommended an integrative model for concurrent administration of curative treatment and palliative care [1–4]. This integrated model starts at diagnosis and continues throughout the illness trajectory, irrespective of the outcome [5, 6]. It focuses not only on symptom management of the child, but also on the social, psychological, and spiritual well-being of both the child and the family [1, 5]. However, palliative care (PC) for children is frequently deemed infeasible within the clinical practice for many reasons, including disagreement with the definition of PC as psychological and social support may already be part of the curative treatment [1]. It thus appears that the traditional understanding of PC, namely a dualistic model of curative and palliative,

predominates in clinical care [7–9], and, accordingly, a chasm between guidelines' recommendations and actual clinical practice exists.

Although several studies highlight general improvement in the early implementation of PC [10, 11], PC still does not always begin at the time of diagnosis of a life-threatening disease as recommended by existing guidelines. For instance, a Canadian study found that pediatric oncology patients did not receive PC at diagnosis, but most were referred during the course of their illness [9]. A survey of pediatricians in the USA concluded that children with life-limiting illness are referred to PC late, that is, at the end of their illness trajectory when no other curative options exist [7]. One study revealed an average time of 461 days after being diagnosed with cancer for pediatric patients to be referred to PC [9]. Similarly, a nationwide retrospective medical record review of pediatric oncology in Sweden found that the transition to non-curative care took place between the last day of life to over 4 years before death, with a median of 60 days [8]. The large range was attributed to varying types of cancer, as children with leukemia were treated curatively until very close to death, while those with brain and solid tumors received PC earlier. An Australian study reported an average duration of 69.4 days of PC provision [12]. Lastly, a US study found that the time between PC consultation and death ranged from 1 to 96 days (median 18 days) [13]. Reasons for late referrals are many: misconception of PC as not belonging to cure-oriented therapy [14], thus referring to PC only when no curative treatment exists; an uncertain prognosis compounded with families' refusal to acknowledge the incurable condition [15] and fear that the family may feel abandoned by primary caregiver if PC is discussed [16]; and physicians' difficulties with objectivity and uneasiness in diminishing hope [14].

Closely related to the issue of provision of palliative care for children is the question of their inclusion in such decisions. In Switzerland, there is no age at which children become legally competent to make decisions (Art 16. Swiss Civil Code). In the literature and in international guidelines, children's participation is recommended along with provision of information adapted to their personality, cognitive ability, maturity, and age [2–5, 17]. Coyne and colleagues [17] found that healthcare professionals strongly supported a transparent approach to information sharing. However, parents wished to protect their children from burdensome information to maintain hope, and children trusted their parents to act as their advocates [17, 18]. Several other studies underline the involvement of the patient and his or her parent in palliative cases [19–22].

In sum, it is evident that a sizable fraction of children and their families still do not benefit from holistic and quality of life-enhancing PC at early stages of the illness and data concerning children's inclusion in decision-making (DM) regarding PC is lacking. This study examined provision of PC in Swiss Pediatric Oncology Group (SPOG) settings to determine if and when children who died from cancer received PC, whether there were differences by cancer diagnosis, and inclusion of children in their DM process. We chose to raise these questions in the Swiss settings in response to our previous nation-wide project on treatment DM and inclusion of children in these decisions [20, 22–24]. During the course of our interviews in the previous project with children, their parents, and corresponding physicians as well as survey of parents and physicians, we were unable to obtain data on palliative cases mostly due to hesitancy to discuss this issue with patients and their families. Therefore, we choose to exclusively examine PC in this setting using a retrospective study design.

Methods

Seven of the nine SPOG-centers in Switzerland participated in this study because they had collaborated with the researchers on the previous project. Using a standardized data extraction form, a retrospective review of medical records of deceased pediatric patients was conducted. All responsible ethics committees approved this study. The list of children who comprised our study cohort was provided by the Swiss Childhood Cancer Registry (SCCR). Please see Fig. 1 for inclusion and exclusion criteria.

Data collection

The data extraction form captured the following information: (a) demographics, (b) type and date of diagnosis, as well as number and dates of relapse(s), (c) type of treatment(s), (d) DM during PC, and (e) circumstances

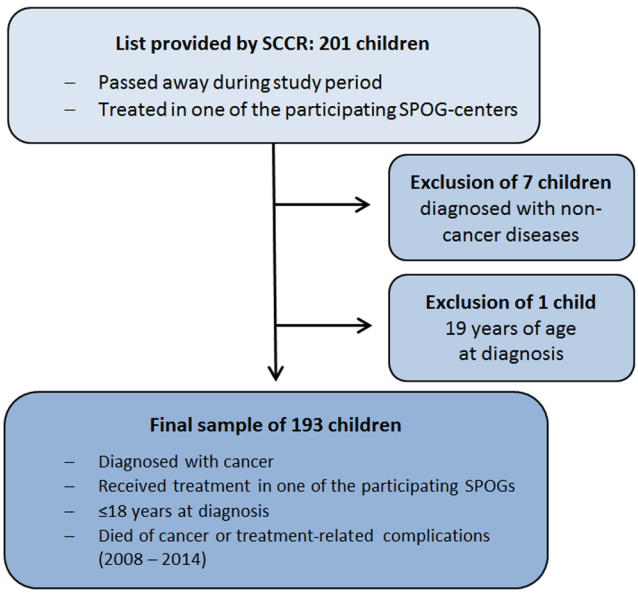

Fig. 1 Inclusion criteria

surrounding the death of the child. These items were developed based on the research team's knowledge in the field and discussions with collaborating physicians. Not all information was available in the medical records for all cases. In such cases, the researchers had the opportunity to consult the collaborating physicians. However, several missing values remained, which caused different sample sizes for some analyses. For example, the exact date when PC was initiated was not always available and consequently the duration of PC could not be calculated for these cases. The medical records were read carefully by four researchers who extracted the data. To ensure consistency of data collection, the first five extractions were discussed among the researchers; these discussions continued throughout the data collection period. Data was collected on-site from July 2015 to July 2016, and to ensure anonymity, an alphanumeric code was created for each child based on a predefined algorithm.

Data analyses

All extracted data were entered into SPSS.22 by a research assistant and verified by another researcher for accuracy. Statistical analyses were performed using SPSS.22 (SPSS Inc., Chicago, IL). For analyses described below, reported *P* values are two-sided and statistical significance level was set at $P < .05$. The variable of interest, PC, was identified either by an explicit reference to "palliative care" or when the records' content on treatment implied that PC was started, for example: curative treatment was stopped and quality of life was envisaged via best supportive care. The variable "Provision of PC" indicates that children received PC (as per our interpretation of the medical records) characterized by a focus on quality of life and a supportive intent as compared to previous curative treatment with a focus on life prolongation and a restorative intent. The variable "transition to PC" marks the point where it was clear from the medical records that curative treatment was no longer viable and thus, a PC was chosen.

After performing descriptive analyses, we divided our sample into three diagnosis-based subgroups (leukemia, CNS neoplasms, and other diagnoses) which were compared using analysis of variance and Chi-square test of independence. Besides the quantitative analysis, content analysis was used in order to qualitatively analyze the discussions between medical professionals and the family [25].

Results

The average age of the sample ($N = 193$) at diagnosis was 7.2 years and 55.4% were male (Table 1). All 12 diagnosis groups of International Classification of Childhood Cancer 3 (ICCC3) were represented in our sample: CNS neoplasms (III) 34.2%, leukemias (I) 27.5%, neuroblastoma and other peripheral nervous cell tumors (IV) 11.9%, malignant bone tumors (VIII) 8.3%, lymphomas and reticuloendothelial neoplasms (II) 6.2%, soft tissue and other extraosseous sarcomas (IX) 6.2%, and the remaining six formed 5.7%.

When did palliative care begin?

For 170 patients, data was available on whether a child received PC. Of these, 77.7% ($n = 132$) received PC and 22.3% ($n = 38$) did not with the rationale being the following: in five cases, PC was discussed, but the child died before it could be started; in 25 cases, the child died before PC could be discussed; in four cases, the family opted for continuation of curative treatment even after physicians recommended PC; and in one case, parents refused both further curative treatment and PC. For three cases, there was no rationale documented in the medical records.

Of the 132 cases who received PC, information on when PC was started was available in all but one case. We found that PC began at diagnosis in 16 cases (12.1%) because of poor prognosis and at progression after diagnosis in 28 cases (21.2%). In the remaining 88 cases, PC started at first relapse or later (66.7%; Fig. 2); for six children, PC started after a second cancer diagnosis.

Duration of palliative care

Duration of PC was computed using the start date of PC and time of death, which were available in 104 out of the 132 cases (79%). Of these children, 11.5% received PC equal to or less than 1 week, 19.3% between 1 week and 1 month, 21.1% between 1 and 3 months, 22.1% between 3 and 6 months, and 26% more than 6 months. The mean duration of PC was almost 5 months or 146.6 days ($Mdn = 89.5$, $SD = 182.7$, range: 2–1111 days). For six children (5.8%), PC began the day before their death.

Decision-making regarding palliative care

Information on who was present at palliative care DM was found for 115 cases and on children's involvement for 113 cases. Decision to begin PC was discussed solely with both parents or with one parent in 60.9% of the cases (70 out of 115), with both or one parent and the child in 34.8% of the cases (40 out of 115), and first with the parents and afterwards with the child in 4.3% of the cases (5 out of 115). Children who were included in DM were on average 13.6 years of age ($SD = 4.6$), whereas children that were not included were on average 7.16 years of age ($SD = 3.9$; Table 2).

Although the participating SPOG-centers used different names (e.g., ethical committee, dialog ethic), all centers

Table 1 Demographics of children by SPOG-center ($N = 193$)

Center[a]	Mean age at diagnosis (Mdn, SD)	Mean age at palliative care begin [b] (Mdn, SD)	Sex (male)
Center 1	7.5 (7.0, 5.0)	9.6 (8.0, 4.8)	68.4%
Center 2	6.8 (6.0, 5.2)	7.8 (7.0, 5.0)	56.6%
Center 3	8.2 (8.0, 5.3)	11.5 (13.0, 4.7)	63.6%
Center 4	6.5 (6.0, 3.5)	9.6 (9.0, 4.1)	35.3%
Center 5	9.3 (10.0, 4.3)	11.55 (13.0, 4.5)	58.8%
Center 6	6.0[c]	12.7 [c]	100%
Center 7	6.8 (6.0, 5.5)	10.0 (10.0, 5.4)	46.1%
Total	7.2 (6.0; 5.1)	9.5 (9.0, 5.1)	55.4%

[a] In order to preserve anonymity, we do not provide absolute numbers for each center

[b] Palliative care time variable data available for 130 cases

[c] Due to the small number of children, median and standard deviation were not reported

generally employed discussion of ethically relevant and challenging issues, if indicated. Information on whether ethics relevant discussion took place was available for 175 cases. In 61 cases, an ethical discussion involving different professions was conducted (excluding family members), and for the remaining 114 cases, no information on ethical discussions was found.

Using the written statements in the medical records where information was given on discussions between medical professionals and family members, we categorized them into types of decisions and if children were included in these decisions (Table 3). This resulted in eight types of decisions, ranging from refusing a discussion to shared DM. Most of the decisions were described as a one-time act.

Diagnostic groups and palliative care

Three diagnosis-based subgroups described in the literature on pediatric cancer patients [8, 26, 27] were created: (1) leukemia patients, (2) CNS neoplasms patients, and (3) patients with other diagnoses. These groups were compared with respect to whether a child received PC. The relation between *whether PC was received* and the diagnostic groups was significant, $X^2 = 30.9$ (2, $N = 170$), $p = .000$, indicating that diagnostic group has an impact on whether a child receives PC. Post hoc tests (Bonferroni correction was applied) illustrated that patients who died from leukemia were less likely to receive PC ($p = .000$), and patients with other diagnoses were more likely to receive PC ($p = .008$) than the overall sample. There was no significant result for patients with CNS neoplasms.

Furthermore, analysis of variance between the three diagnostic groups was conducted for further variables related to PC, revealing that there were significant effects of diagnostic groups on both initiation and duration of PC (see Table 4).

Discussion

The integrated model of PC recommends that it commence alongside curative treatment [5, 6], thus ensuring that all children with life-threatening diseases benefit from this approach irrespective of prognosis. First, in our study sample, one out of

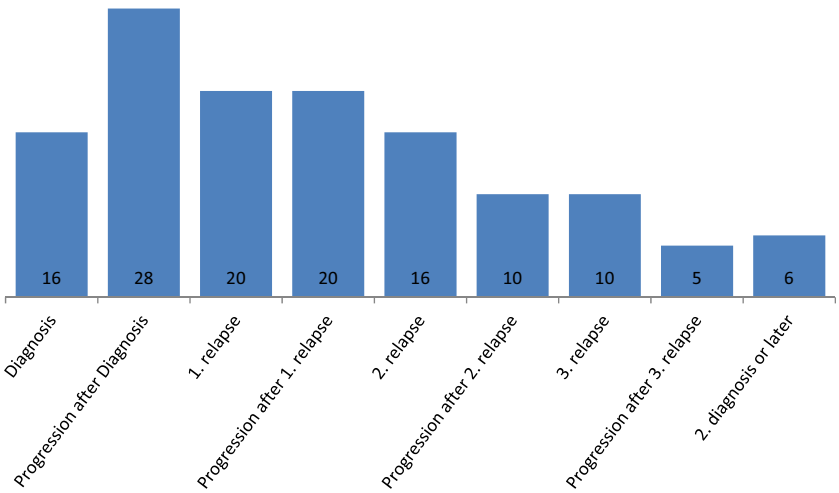

Fig. 2 When did palliative care begin? ($n = 131$)

Table 2 Involvement of children ($n = 113$)

Age	Not involved ($n = 70$)	Involved ($n = 43$)
0	2	0
1	1	0
2	4	0
3	4	1
4	6	0
5	12	2
6	7	2
7	6	1
8	4	1
9	5	2
10	5	1
11	2	2
12	1	0
13	6	4
14	1	6
15	1	5
16	1	4
17	2	5
18	0	6
19	0	1

eight children received PC at the time of diagnosis due to poor prognosis. For the remaining cases, there was a transition to PC with the realization that a curative intent would be ineffective. These results support the findings of Johnston and colleagues [9] that most patients received PC, but these referrals seldom occurred within a month of diagnosis. Unlike other studies [10, 11], we have no previous nationwide study to compare whether PC provision has improved in the country. However, recent investigations into PC in pediatric oncology do indicate that it is an important topic of national interest [20–22, 28, 29]. Second, 15% of our sample received PC for a week or less because PC was implemented very late or at the end of the illness trajectory [7]. Third, our results also indicate that the mean duration of PC of 145 days was longer than in analogous studies performed in Sweden [8], Australia [12], and the USA [13]. The longer PC duration may indicate earlier integration of PC in our sample, but can also be attributed to methodological differences (e.g., different definitions of when PC started), cultural perceptions of when a condition cannot be cured anymore (e.g., prognosis smaller than 10% versus 5%), or the composition of the sample.

Because discussing PC is sometimes associated with loss of hope and abandonment by the healthcare provider [16], it might be a strong argument for physicians to not call some of their efforts towards relieving pain and supportive care as PC and to use a less distressing term. There may be hesitations to discuss PC by explicitly mentioning the term (and consequently not recording it as such) even when it occurred or the term was avoided because supportive care and symptom management are generally considered parts of oncological treatment. Given physicians' tendency to avoid the term and families' discomfort when PC is suggested [16], it might be advantageous to use a term that is less threatening in this context, such as best supportive care. It has to be noted that, if this term was used (or any other term), it must be unambiguously defined to avoid conceptual confusion. Further, it should be clearly explained to families to avoid any misunderstanding associated with the terminology and, consequently, to help them better accept the initiation of PC at diagnosis. However, studies have shown benefits of providing PC consultation and including a PC specialist [11, 13], such as identifying the need of medication changes. Finally, irrespective of the terms used, this particular type of care has to be compassionate, individually tailored to the needs of the child and the family, and holistic embracing multiple domains of care such as physical, psychological, social, and spiritual care. Providing adequate PC also includes developmentally appropriate preparation for death.

Comparisons of diagnostic groups suggest that leukemia patients began PC later than CNS neoplasms patients and patients with other diagnoses did, their duration of PC was shorter than that of CNS neoplasms patients, and they were less likely to receive PC than the overall sample. Also, the PC duration of patients with CNS neoplasms was significantly longer than for patients with other diagnoses, and the latter were more likely to receive PC than the overall sample. These findings relate to the Swedish study [8] in which children with hematological malignancies received curative treatment closer to death and transitioned later than children suffering from brain tumors. One explanation could be the higher survival rate of children suffering from leukemia compared to children with other types of cancer [30–32]. Additionally, successful curative treatment protocols are available in leukemia relapses using different treatment modalities, such as conventional chemotherapy, high-dose chemotherapy, allogenic hematopoietic stem cell transplantation, and many different experimental drugs. Therefore, there may be greater hesitation by the healthcare provider to recommend PC at diagnosis, as well as higher expectations of maintaining hope in leukemia cases [14, 16], whereas for CNS neoplasms patients, comparably bad prognoses might prompt the physician to begin PC earlier.

Although we did not collect data on the quality of communication and information provided, it was evident that parents and, in some cases, children were involved in the DM process (either actively in shared DM or passively in "informative" DM) and information was thereby given to them. Given the information in the medical records, shared DM appeared to be

Table 3 Results from the content analysis—decision-making regarding PC

Type of decisions	In which only parents were involved	In which child were involved
Parents refuse discussion ($n = 1$)	"(The transition) was discussed among the medical staff, parents refused to discuss it."	–
Parents want physician to make the decision ($n = 1$)	"She (the mother) expresses the desire that in the case of further progression of the disease, she does not want to make that decision (to continue or stop curative treatment). She wants the physicians to make that choice..."	–
Withheld information from the child ($n = 5$; children's ages; 9, 16, 11, 7, 10)	"The parents asked the physicians not to explicitly inform the child about the situation, and their request was respected."	–
Patient is aware of situation ($n = 6$)	–	"Patient was also aware of the bad prognosis and was living his life in the present, without making any project in the long term."
Family express wish for palliative care ($n = 11$)	($n = 5$) "In light of these facts (chance of survival or cure very low) parents themselves suggested the shift towards best quality of life, symptom control and palliation (…), physicians agreed that this makes sense."	(n = 6) "Family decided to receive palliative therapy at home, wish on the part of patient and family."
Agreement with physician's decision ($n = 16$)	($n = 10$) "After diagnosing third relapse: discussion with parents; given the progression of a third relapse the parents were informed that there is no curative option available; Parents agreed to palliative care."	($n = 6$) "Palliative treatment was recommended to parents and patient; Parents and patient agreed"
Parents informed about decision made by the physicians ($n = 30$)	($n = 22$) "Because of huge suffering and the low likelihood to cure the patient: palliative therapy in order to achieve freedom from pain without loss of vigilance; parents were informed about the consensus at the same day."	($n = 8$) "They (parents and patient) were informed "openly and in detail" about infaust prognosis in case of progression under chemotherapy; from now on: palliative treatment with focus on symptom management and QoL"
Shared decision making ($n = 48$)	($n = 28$) "After several discussions, the parents and the physicians decided to stop the chemotherapy treatment that had been initially intended and to begin the comfort care."	($n = 20$) "The child and his family were told that the chances of cure were almost inexistent … After several days, the child and his family chose to follow the combined treatment (radiotherapy and chemotherapy through bone, with palliative goal)."

the most frequently used approach to DM in our study. While this reflects only the physicians' perspectives and families may have perceived the DM process differently, this finding is in line with the calls for such a DM process in pediatric

Table 4 Summary of ANOVAs with respect to palliative care

Variable	*M* (N)			*df*	*F*	ω^2	*p*
	Leukemia	CNS	Others				
Begin of PC[b] *	5.22 (23)	3.00 (47)	4.18 (61)	2	9.290	.11	.000*
Duration of PC in days[a] **	81 (22)	224 (38)	113 (44)	2	6.112	.09	.003**

PC palliative care, *CNS* CNS neoplasms

Begin of PC represents an ordinal variable that corresponds to the nine ordered categories shown in Fig. 2

[a] Welch ANOVA (an adjusted omega squared and Games-Howell post hoc test were used)

[b] One-way ANOVA (Tukey post hoc test was used)

*PC started later for both leukemia patients ($M = 5.2$, $SD = 1.6$) and patients with other diagnoses ($M = 4.2$, $SD = 2.2$) as compared to patients with CNS neoplasms ($M = 3.0$, $SD = 2.2$). The former two did not differ significantly

**Patients with CNS neoplasms ($M = 223.8$, $SD = 236.4$) received PC for a longer time than both patients with leukemia ($M = 81.4$, $SD = 138.6$) and with other diagnoses ($M = 112.5$, $SD = 117.6$). The latter two did not differ significantly

healthcare [17, 33–35]. At the same time, contrary to the suggestion that clear and appropriate information provision is helpful for young patients [5, 17, 36], in five cases, it was explicitly stated that information was withheld from the patient per their parents' wishes. The WHO and pediatric association guidelines recommend inclusion of children in their DM [2–4], which was not the case for all children in our sample. Specific to Switzerland is the issue of capacity, as most children aged 14, and many aged 12 are considered competent [37, 38] and therefore legally have the right to be included in their DM. With respect to DM and PC, Whitney and colleagues propose that in situations where cure is unlikely and PC services are the best option, the physician should take the lead in decision-making [39]. That is, they should exercise decisional priority by identifying the single best course of action and should explain to the parents (and child) that there is no curative treatment left and thus, quality of life becomes the new focal point. However, decisional authority, that is the nondelegable right of the parents to decide, remains with the parents and, as the child matures, decisions should be increasingly shared with the child.

This study has several limitations. The findings are limited to the quality of information available in the medical records. Not all information was available, resulting in missing values for several variables, which, in turn, resulted in different sample sizes for some of the analyses. It is also possible that the extracting researchers could not find the information in the medical records or that the information they were looking for, e.g., PC, was a term that was not used by the physicians unless it was absolutely clear that the case was end-of-life. However, sample sizes were sufficiently big to apply inferential statistics. Furthermore, the quality of information can vary across centers and individual health staff members. As the medical records were written in French, German, or Italian and translated into English by our team, we cannot exclude linguistic differences which could affect interpretation of the data. During the time covered by our analysis (2008–2014), the pediatric team involved in PC may have changed, resulting in variations in the information documented in medical records over time. Finally, the views of the families and children themselves are not directly represented, as the information in the records is solely noted by medical staff and is their impression of the communication between physicians and family. It is necessary to understand the views of family members as well to obtain a better picture of how provision of PC and DM surrounding it took place. Therefore, further studies are necessary to fully capture the intricacies of PC for children with cancer and inclusion of children in such delicate DM. Limited evidence exists on this issue in Switzerland, and considering the limitations of a retrospective study that used medical records, prospective studies are needed to further strengthen research in this field. In addition to more research, the medical team and the family may benefit from the introduction of a standardized form for the recording PC discussions and decision-making. Such standardization may also improve communication within the team as well as with the family and, thereby, facilitate shared DM.

In conclusion, the data on PC in the Swiss pediatric oncology settings presented in this study underline that only a very small proportion of the children received PC at diagnosis and for most children palliative care began late in the illness trajectory. These results on the timing of PC do not align with international organizational guidelines which recommend an integrated approach. However, integrated PC has been shown to be beneficial for children [10, 11, 40] and therefore, must be envisaged. Additionally, since it is not only the right of children to be involved in decisions that affect them, but also a need of a child [21], the possibility of including them in DM must be considered. Furthermore, our findings from the medical records could help discuss the usage of the terms best supportive care and PC, which as shown from our data collection, seems to be a term mostly understood as the opposite of curative care. Finally, reasons for not including children older than 12 years need to be further examined, especially for the Swiss context in which capacity of judgment is not strictly defined based on age of maturity and minor patients between 12 and 18 years are mostly expected to be capable of judgment.

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Compliance with ethical standards

All responsible ethics committees approved this study.

Conflict of interest The authors declare that they have no conflict of interest.

Research involving Human Participants

No human participants were involved.

Informed consent Not applicable.

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