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Paediatric Palliative Care in Clinical Practice: Ethical Issues in Advance Care Planning and End-of-Life Decisions

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ABSTRACT

Rationale: This study examines ethical challenges faced by a paediatric palliative care (PPC) team when making end-of-life (EOL) decisions for children with life-limiting conditions.**Aim:** To assess the team's attitudes towards ethical issues and propose innovative solutions.**Methods:** The data was collected in 2022 at the University Children's Hospital Ljubljana. A researcher-made questionnaire was developed based on team experience. Ten PPC team members participated anonymously, evaluating ethical concerns in communication, decision-making, and patient characteristics. Mann-Whitney *U* test was used to analyze the data.**Results:** Ethical issues emerge when coordinating treatment opinions becomes challenging, resulting in excluding a child from PPC. Situations involving communication, differing healthcare opinions, and patient characteristics were seen as ethical issues, highlighting the importance of communication and shared decision-making.**Conclusions:** Ethical complexities in paediatric EOL care require adept communication and interdisciplinary teamwork. Poor communication may be associated with excluding children from PPC. Innovative strategies and ongoing training are vital to address these challenges effectively, ensuring optimal care for children and their families.

1 | Introduction

Paediatrics is a clinical field characterized by a high degree of emotional involvement and complex interpersonal relationships between healthcare professionals, patients, and patients' relatives. As such it is prone to ethical questions and dilemmas. It has been noted that caring for dying children and making decisions about withholding or withdrawing life-sustaining treatment is particularly demanding and emotionally taxing [1].

Withholding or withdrawing life-sustaining treatment is ethically permissible when the treatment is no longer considered

optimal care and would cause more harm than good [2–5]. The primary ethical obligation is to act in the best interest of the child. In general, the best interest of a child is influenced by several factors: the child's mental and health needs, the emotional ties and relationships between the child, their family and caregivers, and the caregivers' ability to provide an acceptable quality of life. Identifying the child's best interest in such circumstances is often a very difficult task and as such represents a special ethical challenge [1, 2, 4, 6, 7].

In paediatrics the healthcare professionals and parents act in partnership to uphold the best interest of the child. Shared

Abbreviations: EOL, end-of-life; ICU, intensive care unit; PPC, paediatric palliative care.

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decision-making is essential. Patients and families bring their values to the discussion, while physicians bring clinical expertise to reach optimal decisions for the child [6, 7]. The parents are active participants in the provision of their child's care, ensure an acceptable quality of life for the child and are faced with many difficult decisions [8]. Healthcare professionals need to determine the extent to which parents wish to assume responsibility for decision-making in EOL ensuring their comfort and confidence in the choices made [1].

Contemporary paediatric guidelines recommend that every child and adolescent living with a life-limiting or life-threatening condition should receive paediatric palliative care (PPC) [9–14]. It should not be reserved for those children who are actively dying [1]. PPC should commence at the time of an incurable disease diagnosis or when curative treatment is no longer a viable option. This interdisciplinary approach aims to deliver comprehensive support to children and their families, addressing their physical, emotional, and spiritual needs to alleviate suffering and enhance their quality of life [4, 15]. The healthcare team, consisting of various paediatric specialists and PPC consultants, collaborates with the child's parents to formulate a tailored interdisciplinary care plan that adapts to the child's evolving needs over time [12, 16]. This plan provides clear guidance on treatments to avoid, as they may cause harm or prolong the dying process, and on treatments that are ineffective in preserving life or restoring health [11, 17–20]. Early implementation of this plan can avert dilemmas regarding further treatment in cases of sudden severe deterioration [1, 6, 7, 21].

Nonetheless, numerous barriers to effective PPC implementation exist, including misconceptions about the timing of PPC and the emotional burdens experienced by both parents and healthcare providers [16, 22, 23]. Improved staff training in communication skills and PPC may help overcome some of these barriers. It is important to recognize that uncertainty is inherent in the care of critically ill children, and that an uncertain prognosis should be a cue to initiate PPC promptly rather than to delay it [22]. When paediatric professionals lack knowledge about palliative care options disagreements may arise, and optimal decision-making may be impeded [23, 24]. Healthcare professionals should have access to appropriate training in palliative care and a firm grasp of the ethical and legal standards pertaining to EOL decisions for children with progressive incurable conditions [25, 26].

With patients whose prognosis is unpredictable, opinions about the optimal treatment can differ among healthcare professionals and ethical dilemmas may occur. [27–29].

In Slovenia, the majority of children diagnosed with chronic progressive life-limiting or life-threatening conditions are identified at the University Children's Hospital in Ljubljana. To address the needs of these patients and their families, a hospital-based interdisciplinary hospital PPC team was established few years ago, comparable to teams of other tertiary pediatric healthcare institutions in Central European countries. This team is composed of ten members: two pediatric pulmonologists, two pediatric neurologists, a pediatric nephrologist, a clinical geneticist, two registered nurses and two clinical psychologists. All team members are PPC-qualified and have over

15 years of work experience in their respective fields. The team provides consultations, aid with advance care planning and ongoing support until the child's death. It also organizes PPC training for pediatric healthcare professionals from other institutions in the country [30]. As the patients treated at the University Children's Hospital come from all over the country, the team coordinates healthcare professionals from different healthcare levels—primary, secondary and tertiary. All are included in designing an advance care plan for the child, including the plan for the EOL period. Coordinating various perspectives while meeting the expectations of the patient's parents using palliative principles is a challenging task, even with national ethical recommendations [31, 32] and other recommendations [1, 12, 19] guiding decision-making in the intensive care unit (ICU) for EOL treatment and palliative care. Since its establishment, while caring for approximately 80 patients, the members of the hospital PPC team have encountered various ethical issues. To improve the effectiveness of the hospital PPC team's work and prevent unnecessary ethical dilemmas, we decided to analyze the attitudes of the PPC team regarding the ethical issues that they encounter in their daily clinical practice. Our findings have implications for supporting ethical practice and training practitioners in the future.

To our knowledge this study is the first to look into ethical issues faced by paediatric palliative care providers.

2 | Materials and Methods

2.1 | Questionnaire Design

Since we did not find any established validated questionnaire in the field of various ethical issues in PPC or in EOL decisions for children with chronic progressive life-limiting or life-threatening conditions in the literature, a special questionnaire based on our experience was developed specifically for this study (Supplement S1). For the purposes of the study, all ten members of the team anonymously listed ethical issues arising in their work (Supplement S2). The listed ethical issues were collected and transformed into questions in a questionnaire entitled "Ethical issues in my work in the Children's Palliative Care Team." The questionnaire was developed through extensive consultations led by the team leader, involving palliative care professionals and various healthcare experts within our institution, which helped shape the ethical considerations in our questionnaire. Subsequently, a coauthor, experienced in PPC, but not affiliated with the PPC team, independently refined the questionnaire. The questionnaire covered questions from three areas: 1) communication between healthcare professionals and parents, 2) communication between healthcare professionals and 3) specific characteristics of patients (patients with intellectual and motor disabilities, neonatal patients, or an emotional attachment of the participant to the patient). The questions were formulated to describe various possible outcomes arising from discussions about further treatment. The participants were asked to choose a situation that poses an ethical issue for them and evaluate its severity with weights from 1 to 3, with 1 meaning a mild ethical issue and 3 signifying a severe ethical issue. A situation that does not pose an ethical issue for them was to be marked as zero (0).

The National Medical Ethics Committee of the Republic of Slovenia decided their approval is not required for this study, since this was an observational study of willing medical professionals. Informed consent was obtained from all individual participants included in the study.

2.2 | Data Collection

The data was collected in 2022 at the University Children's hospital in Ljubljana, Slovenia. All ten members of the hospital PPC team were invited to participate in the study voluntarily and anonymously. Nine out of ten members completed the questionnaire. The data was collected and analyzed by an independent author. Since the PPC team at University Children's Hospital Ljubljana is the only team of its kind in our country, we can consider the data representative in our environment.

2.3 | Statistical Analysis

Statistical analyses were performed with SciPy library (Version 1.7.1) in Python (Version 3.9.7). D'Agostino-Pearson test was used to determine the normality of the data. Mann-Whitney U test was used to compare statements, since the data was nonnormally distributed. Bonferroni correction determined the significant *p* values < 0.005.

3 | Results

Nine members of the PPC team filled in the anonymous questionnaire, representing 90% of all members. All participants were female, their average age 47.2 years (41–56; SD 5.12). The average years of experience working in a tertiary paediatric center was 21.22 (16–31; SD 5.65). Their average years of experience in PPC was 4.78 years (4–5; SD 0.44). All respondents allocate 20% of their practice to PPC.

The number of responses by statement is presented in Table 1.

3.1 | Communication between Healthcare Professionals and Parents

Statement 1 A, where a unanimous decision is reached by all involved in the decision-making process, was not recognized as an ethical issue by the majority (six) of the participants, while three participants assessed it as a mild ethical issue.

The situation 1B of not reaching consensus with the child's parents about certain aspects of treatment was evaluated as a mild ethical issue by six of the participants, as moderate by two, and was not considered as an ethical issue by one of the participants.

One participant evaluated the situation 1C, when consensus about the child's best interest is not reached while discussing further treatment with parents as a severe ethical issue, five as a moderate one and three of the participants as a mild ethical issue. None felt this was not an ethical issue.

3.2 | Communication Between Healthcare Professionals

Discussion between professionals ending without a final decision, while expecting to coordinate opinions in the future (Statement 2A) was not considered as an ethical issue by the majority of the participants [6], while three considered it a mild ethical issue.

Statement 2B, where coordination in the future might not be possible, but the patient will be included in PPC was evaluated as a moderate ethical issue by three participants, mild one by two, and was not recognized as an ethical issue by four participants.

The situation 2C of not reaching a consensus among healthcare professionals, not involving parents in a discussion and consequently not including the patient in PPC was recognized as a severe ethical issue by five of the participants. Two evaluated it as a moderate ethical issue, one considered it to be a mild ethical issue, while one participant did not feel like this was an ethical issue.

The situation where no coordination of opinions is reached by the healthcare professionals who then proceed to discuss further treatment options with the parents and they refuse PPC for the child (2D) was as an ethical issue by all the participants. It was assessed as a severe ethical issue by six, moderate by one and a mild ethical issue by two participants.

3.3 | Patient Characteristics

The majority of the participants (six) felt that discussing further treatment of a patient with disabilities (3A) was a mild ethical issue for them, while three did not evaluate this situation as an ethical issue.

TABLE 1 | Questionnaire results.

Statement		1A	1B	1C	2A	2B	2C	2D	3A	3B	3C
Not an ethical issue (0)	No of answers	6	1	0	6	4	1	0	3	4	2
Severity of an ethical issue	Mild (1)	3	6	3	3	2	1	2	6	3	5
	Moderate (2)	0	2	5	0	3	2	1	0	2	1
	Severe (3)	0	0	1	0	0	5	6	0	0	1

Situation 3B, when the team was discussing further treatment of a new-born, was evaluated as a moderate ethical issue by two and a mild ethical issue by three participants. Four of the participants did not consider this to be an ethical issue to them.

Two participants did not consider it an ethical issue when discussing further treatment of a child that they are emotionally attached to (3 C). Five participants accessed it as a mild ethical issue, one as moderate and one as severe.

3.4 | Comparison of Statements

Table 2 presents the average, median and p-value of Mann-Whitney U test of the weights given to statements by participants. As discussed in the methods section, due to Bonferroni correction p-values below 0.005 are deemed statistically significant. The statement 2D is the only statement significantly different from the rest, and has the highest average value, thus representing the most severe of ethical issues encountered by the team.

4 | Discussion

EOL decisions in paediatrics undoubtedly involve various ethical issues. In this article we focused on issues in the treatment of children with medical complexity and life-limiting disorders, faced by members of a hospital PPC team. Our results show that the most important ethical issue to our PPC team members is the situation where healthcare professionals cannot successfully coordinate different opinions, a plan of further treatment is not designed, certain questions about EOL care remain open and consensus about the child's best interests, for example, limitation of invasive treatment, is not reached. We did not identify any published articles on this specific theme, precluding a direct comparison with the findings of other researchers. Consequently, we examined the existing literature on adult palliative care to identify potential parallels, analyze the underlying causes of our results, and underscore the significance of our study in enhancing awareness of the future importance of pediatric palliative care (PPC).

4.1 | Communication Between Healthcare Professionals and Parents

Majority of our PPC team felt that not reaching an agreement with parents was an ethical issue that they encounter in their practice. Since professionals can feel ill-equipped or uncomfortable communicating with and about children with life-limiting or life-threatening conditions, this might be the cause of suboptimal care of the child. Therefore, it is important

to understand what high-quality communication is and how to accomplish it within PPC [33]. Parents of children with life-limiting or life-threatening illnesses regard communication with healthcare professionals as optimal if it is open and honest, acknowledges emotion, actively involves families and occurs within established and trusting relationships [34]. Meyer et al in 2006 [35] also wrote how important respectful and effective communication is from the parent's perspective regarding children in critical condition. Effective communication is critical for eliciting value-based goals of care and for guiding parents through the patient-centered and potentially difficult decision-making process [36].

However, certain parents may persistently resist reducing technical support or restricting interventions, even when provided with excellent communication and access to palliative care clinicians, thereby exemplifying the moral distress of the staff [1, 37]. In these cases, we usually cannot reach an agreement of EOL care in advance care plan, which, as the results show, means an ethical issue for the members of the PPC team.

4.2 | Communication Between Healthcare Professionals

Situations where healthcare professionals are unable to coordinate their different opinions are the worst-case scenario for our respondents. Participants identifying the situation where the child is not included in PPC as the most important ethical issue is in accordance with the definition of an ethical issue. An ethical issue occurs when a certain decision, scenario or activity causes a conflict with a person's moral principles [38]. When assuming the role of an advocate for decisions in the child's favor, it is therefore expected that hospital PPC team members understand the implementation of PPC as part of their moral commitment to the patient. A situation that disables this process obviously represents a very important ethical issue for them. Although our research was a small qualitative study conducted at a single institution, the results are comparable to other studies in the field [39–41].

Uncertainty of the prognosis and progression of some conditions, especially in the context of rapidly evolving therapies and interventions may contribute to clinician indecision and inconsistency of opinions [22, 23]. The challenges in communication between healthcare professionals when caring for the most seriously ill children as an ethical issue has already been described by other authors [39, 40, 42]. Defining the child's best interests can be a crucial point of disagreement [27]. Zahedi et al in 2022 [42] hypothesized that addressing and managing the challenges in communication can improve the overall quality of EOL care for children. Nevin et al in 2020 [41]

TABLE 2 | Average, median and p-values of Mann-Whitney U test of weights given to the statements by the participants.

Statement	1 A	1B	1 C	2 A	2B	2 C	2D	3 A	3B	3 C
Average	0.33	1.11	1.78	0.33	0.89	2.22	2.44	0.67	0.78	1.11
Median	0	1	2	0	1	3	3	1	1	1
p	0.014	0.9	0.05	0.014	0.5	0.009	0.001	0.2	0.3	0.95

emphasize the importance of education and training of non-palliative care specialists in palliative care principles to minimize conflict and disagreement between professionals. Further research into communication and other strategies to decrease the incidence of clinician indecision is needed.

4.3 | Patient Characteristics

Evaluation of the discussion on further treatment of a patient with intellectual and motor disabilities, of a newborn, of a child or young person to whom they are emotionally attached to or a discussion as such as an ethical issue by some members of the PPC team is an interesting result. These situations are not ethical dilemmas, questions, or problems by themselves, but bring the need for difficult decisions about further treatment of a child with many disabilities, chronic progressive life-limiting conditions and uncertainty of their prognosis. These decisions can often represent a moral dilemma and as such cause emotional distress to PPC providers. The process of deciding on the course of treatment itself has been identified as an important ethical concern of healthcare professionals by several authors [1, 36, 43–46].

Many children treated by the hospital's PPC team are children with a variety of disabilities. In many ways, the ethics that govern the management of these children do not differ from those that apply to other children. However, defining quality of life is not easy. The perception of quality of life for disabled children may differ significantly between healthcare professionals and the children's parents. Acceptance of different points of view may be in conflict with a healthcare professional's ethical orientation, hence decision-making in these cases may present an ethical issue for them [47].

4.4 | Future Considerations

Since not all participants viewed all situations as ethical dilemmas, further insight into these differences between individual PPC providers might guide our managing of resources, as well as further research.

In environments where ethical challenges in this field are expected, regular education in paediatric ethics is necessary to help healthcare professionals keep in mind the subtle but important moral distinctions [48]. This especially applies to the field of PPC in general, as well as the EOL treatment of children with life-limiting disorders. We concur with the findings of Vemuri et al in 2022 [49], which highlight the need for further research to fully understand the ethical issues surrounding the care of incurable progressive conditions and EOL decision-making approaches. Based on our results, ethical issues regularly occur in the setting of our PPC team. The effectiveness of hospital PPC teamwork, the relief for healthcare workers and the avoidance of emotional burden may be achieved by regularly including a clinical ethics consultant in discussions about the further treatment of these children. The PPC team and clinical ethics consultant can cooperate as two separate services with precisely defined tasks [50, 51].

Routine and standardized involvement of healthcare providers with training in clinical ethics may be the best way for physicians

to navigate this arena in paediatrics and provide the most appropriate care for each individual patient. As Feudtner and Nathanson in 2014 [52] suggest, PPC team members, given their collaborative communication skills may be able to manage most of the ethically challenging cases and thus run a risk of not drawing on the resources and potential benefits of the clinical ethics consultation in a timely manner. This may be especially true for cases in which PPC professionals have forged a strong therapeutic relationship with the patient or family. Clinical ethics consultation in these situations can provide a forum for dialogue, enhanced team-wide understanding of the goals of care, and ultimately better therapeutic relationships for the entire healthcare team. More needs to be understood about ethics consultants' effects on ethical dilemmas encountered by clinicians and the consequential patient exclusion from PPC.

4.5 | Limitations

Our study has limitations, primarily stemming from the small number of participating professionals and the single-institution setting. Additionally, the use of a not-yet-validated data collection instrument poses a limitation. We involved as many experts in the field as we could to mitigate for the lack of a validated tool.

5 | Conclusions

Our study offers valuable insights into the ethical challenges healthcare professionals face when providing PPC to children with life-limiting or life-threatening conditions. One of the most significant ethical dilemmas for palliative care providers is when a child is excluded from PPC due to healthcare professionals' indecision, which makes it impossible to plan EOL decisions effectively. Further research is warranted to deepen our understanding of the ethical dilemmas encountered by PPC providers, what factors facilitate and which alleviate them, and how these ethical dilemmas relate to patient exclusion from PPC and other outcomes of healthcare for children with life-limiting and life-threatening conditions.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.