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Original research article

Language validation of a measurement instrument to assess the needs of parents and children in palliative care – a pilot study

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Abstract
Introduction: Pediatric palliative care is a specialized form of care provided to children with terminal illnesses or life-threatening conditions. Its aim is not only to control symptoms, but also to improve the overall quality of life of the child and its family. It includes comprehensive support and care that respects the individual needs of the child and its family, including physical, emotional, social, and spiritual aspects.
Objective: To translate and implement the language validation of the Pediatric Palliative Care – Parent & Child Needs Survey (PCNeeds) tool and to determine the level of needs of families caring for a child with a life-limiting or life-threatening illness.
Methods: To determine the needs of parents of children in palliative care, a quantitative method of a questionnaire survey was used in which 20 parents participated. Data analysis was carried out using descriptive statistics.
Results: The highest level of needs of families was in the area of coping with the child's symptoms, including pain. Parents felt emotional strain, social isolation, and overall pressure on the family, including financial burden. However, they also expressed a high degree of satisfaction in many areas, such as communication with health professionals, clarity of information, and the relationship with their child.
Conclusion: The study demonstrated the high internal consistency of the Czech version of the PCNeeds measurement instrument. It will be further tested for psychometric properties in the next stage of the research.

Keywords: Assessment tool; Children; Needs; Palliative care; Parents

Introduction

Pediatric palliative care is a multidisciplinary approach to the assessment, prevention, and management of multifaceted symptoms and to the support of children with life-threatening conditions and their families, regardless of diagnosis and stage of disease. The aim is not to cure the disease, but to provide comprehensive support and care that improves the quality of life of children and their families (Cho-Hee et al., 2022). It differs significantly from palliative care for adult patients in several areas. It is primarily the time period when the palliative care needs to be provided, since it may last from a few days to months to several years. Many children live to adulthood despite their unfavorable diagnosis. The number of these children has been increasing in recent years, and the prevalence is highest in children under one year of age (Djakow and Exnerová, 2021).

There is currently no empirical data on the number of children requiring palliative care but based on the latest study by Lorna Fraser in 2020, it may be approximately 13,280 children and their families (Institut Pallium, 2022a). The whole family is the focus of care and parents are expected to become the caregivers (Fraser et al., 2020). Caring for such a child takes an incredible toll on the health and well-being of the parents, which may have a negative impact on other family members, especially healthy siblings. The family is often exposed to financial difficulties due to inability to work and subsequent loss of income (Boyden et al., 2022). The differences between palliative care for adults and children are highlighted by various international organizations and policy documents, especially the World Health Organization, which defines the pediatric palliative care as an approach that improves the quality of life of patients, adults and children, and their families (WHO, 2020).

Diseases requiring palliative care are divided into five categories based on international standards. The original version within the IMPaCCT project from 2007 was revised by an international group of experts in 2022 through the GO-PPaCS (Global Overview – PPC Standards) project. The original document only defined the standards in Europe; the goal of GO-PPaCS was to update the standards on an international scale (Benini et al., 2022). In children's palliative care, a comprehensive assessment of the needs of the child and the fam-

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ily is essential, and based on such evaluation, a care plan and priorities should be drawn up (Benini et al., 2023). Among the priorities there are primarily sufficient information, motivation, tools to overcome anxiety and parental involvement, as well as social and spiritual support. The siblings of sick children are also part of the family system, and there are significant differences in their adjustment to the situation (Adistie et al., 2020; Chin et al., 2018). The pCSNAT is a validated foreign tool to identify the support needs of family caregivers during end-of-life care and is structured into 14 broad domains (Aoun et al., 2020). The PELIKAN (PaPEQu) questionnaire, developed in 4 phases in 2012–2014, is a tool for assessing parents' experiences and needs during end-of-life care of a child. Psychometric properties were assessed on a sample of 224 bereaved parents (Zimmermann et al., 2015). A more recent tool to assess the level of needs of children and parents is the PCNeeds, which was adapted from NEST – an instrument validated for the adult population (Donnelly et al., 2018). The EXPERIENCE @ Home tool specifically measures parents' experiences with pediatric palliative and hospice care provided in the home setting (Boyden et al., 2021).

The first comprehensive study focused on the needs of children with life-limiting or life-threatening diseases and their families in the Czech Republic was performed in 2017 by the Children's Palliative Care Section of the ČSPM ČLS JEP. Its goal was to map the needs of families in the area of health services and psychosocial needs in the Czech environment. Information was obtained through interviews with parents who were caring for a seriously ill child and with parents who had lost their child (Poláková et al., 2017). In March 2021, Mr. and Ms. Vlček contributed to a major development in pediatric palliative care in the Czech Republic by establishing a foundation that aimed to bring pediatric palliative care to the world's best level by 2031 (Nadace rodiny Vlčkových, 2021). For the care to be effective, a broad multidisciplinary approach is necessary, along with expert discussions, publishing activity, empirical data on the state of children's palliative care in the Czech Republic, education, and presenting the topic to the public. Another important element is communication and care planning using the case coordinator model. Its implementation in practice is one of the goals of the Concept of Care for Children and Adolescents with a Serious Diagnosis and Their Families from 2022 (Institut Pallium, 2022a). However, the field still faces various challenges, including a lack of specialized staff, funding, and legislative adjustments (Institute Pallium, 2022b).

Materials and methods

The aim of the research was to implement the language validation of the PCNeeds tool and to determine the level of needs of families caring for a child with a life-limiting or life-threatening illness. The first step was to obtain the author's permission (prof. James. P. Donelly – University at Buffalo, New York) to use and translate the PCNeeds (Pediatric Palliative care – Parent & Child Needs Survey) measurement tool. The research was carried out in accordance with the basic ethical principles for research on a human sample, with approval from the Ethics Committee. Then, the questionnaire was translated from English to Czech using the back translation method. International guidelines for transcultural transfer of tools in the healthcare sector created by the International Society for Pharmacoeconomics and Outcomes were followed, so that not only the linguistic but also the cultural point of view was considered (Mandysová, 2019). The translation methodology was carried out in ten stages. First the translation from the source language to the target language was carried out by two independent translators. Both versions were compared and, based on the discussion, modified and integrated into a unified version, which was subsequently translated from Czech back into English by a native English speaker who had been living in the Czech Republic for a long time. It was then compared to the original version.

A pre-test was also carried out, where the comprehensibility of the questionnaire was verified on three users/parents, the language comprehensibility was verified orally, and the comments were subsequently incorporated. Four questionnaire items related to physical problems and needs, religious and spiritual support, and items asking about the frequency of parents' conversation with someone other than health professionals about the child's illness were modified. Subsequently, the final version of the questionnaire was created (Fig. 1), and the pilot testing followed. The research design was quantitative research, the data was collected using the PCNeeds tool. Parents estimated the level of needs on an 11-point scale, from the minimum to the maximum estimate of need. This was indicated on a scale of 0–10, where 10 means the highest level of the need. The PCNeeds tool was adapted from the Needs at the End-of-Life Screening Tool (NEST), a tool validated for the adult population that reflects the findings from the pediatric palliative and hospice care needs literature and expert findings from researchers in the field. It was created with the cooperation of experts as well as parents and includes problems specific to the pediatric palliative and hospice population. It is brief but comprehensive, consists of 22 items, and is divided into 3 domains: *Interaction with health professionals*, which includes 8 questionnaire items (relationship between patient/parent and doctor, respect of the family by the healthcare team, approach of health professionals to care, communication with doctors, clarity of information, possibility to make decisions about treatment, possibility to make decisions about end-of-life care, and satisfaction with the services of the healthcare team). The second domain is *Coping with the symptoms* of the child's illness, containing 5 items (pain, other physical symptoms, difficulty in providing for physical needs, difficulty in providing for psychological needs, and the possibility of involving the child in favorite activities). The final domain is *Impact on parents and family*, where the remaining items are included – life satisfaction, parent-child relationship, social connectedness, mental symptoms, personal acceptance, spirituality/religion, financial burden, and impact on family (Donnelly et al., 2018).

At the end of the questionnaire, parents could comment and state other needs that were not addressed in the questionnaire. The criteria for inclusion in the research group were parents caring for a child aged 0–19 years with a previously diagnosed chronic life-threatening disease. They received information on the research project, where they were introduced to the aim and description of the study, its course, duration, matters of privacy protection, and the voluntary nature of participation. They confirmed their consent by signing an informed consent form. 30 questionnaires were distributed and 20 returned, representing a 67% return rate. Data collection took place once using the pencil-paper method in the period September-December 2023. The completed questionnaires were placed in an envelope provided. Part of the questionnaire was the collection of sociodemographic characteristics of parents and children.

PEDIATRIC PALLIATIVE CARE – PARENT AND CHILD NEEDS SURVEY

Your answers to the following questions will help us understand the problems you, your child, and your family are CURRENTLY facing.
Instructions for completing the questionnaire:
• Please circle the number on a scale from 0 to 10 that best describes the answer to the question.
• If you would like to include or add additional information, please write it in the comments of the relevant question.
1. To what extent do you feel that the medical team respects your child?
0 1 2 3 4 5 6 7 8 9 10

Not at all Absolutely

Fig. 1. Design of the form

Data analysis

Statistical analysis of the obtained data was carried out in MS Excel and Statistica programs. Analysis of questionnaire items was performed using descriptive statistics (mean, standard deviation, median, minimum, maximum, and missing responses). The internal consistency of the tool was verified using Cronbach's alpha coefficient.

Results

20 parents were involved in the pilot study. They were mainly women, mostly biological parents of the children, they had secondary school education with high school diploma, and they cared for a child together with its siblings; 9 children did not have any siblings. Four children from the sample were in the care of a single caregiver. All caregivers were women. The most common diagnoses were neurological and chromosomal diseases, followed by a combination of neurological and respiratory diseases, none of the children had an oncological diagnosis. Characteristics of parents and children are shown in Table 1.

The language validation of the tool was verified on three users by checking the tool's comprehensibility for the target group. Based on their comments, four items of the questionnaire were modified. Items 7 and 8, which ask about the child's physical problems and needs, were marked as less comprehensible, the term physical was supplemented with the term somatic. This was followed by item 13, which asked how often the parents talk to someone about the child's illness. It was unclear to the parents whether medical professionals were also included, so the item was edited to clearly state that it was not asking about the medical team. The last adjustment concerned the item assessing religious and spiritual support. Due to concerns over incorrectly marking the answer or failing to complete the item, the options "I did not use it" and "It was not offered" were added. Following the language validation of the PCNeeds evaluation tool, an internal consistency check was performed. The coefficient of 0.8523 shows the high reliability of the tool (Table 2). Reliability and content validity of the tool were calculated for the whole questionnaire and individual domains (Table 3).

The analysis of the individual items of the questionnaire showed that the domain *Coping with the symptoms* of illness (items 6–10) was rated as the worst by the parents. The possibility of involving the child in favorite activities was rated high (M = 2.7; SD = 2,64), as well as the difficulty of ensuring the child's physical and psychological well-being, including the management of pain. This was followed by the *Impact on parents and family* domain (items 11–16, 19–21), where parents indicated very little opportunity to devote themselves to their activities, frequent feelings of anxiety and depression, and thinking about the possibility of the child dying, as well as

Table 1. Characteristics of parents and children (*n* = 20)

Item name	*n*	*n* (%)
Gender and relationship to the child		
Women	16	80
Men	4	20
Biological parents	17	85
Foster parents	2	10
Guardian of the child	1	5
Education		
High school with high school diploma	10	50
College	4	20
Elementary	4	20
High school without high school diploma	2	10
Marital status		
Married	12	60
Divorced	3	15
Single	5	25
Cohabitation in the household		
With father or mother of the child	14	70
With partner	2	10
Alone with the child	4	20
With grandparents	1	5
The child's own siblings	8	40
Siblings in household (average)	3,6	
Child's step-siblings	2	10
Combination of own and half-siblings	2	10
Children without siblings	9	45
Child's diagnosis – illness		
Neurological	5	25
Respiratory and neurological	4	20
Respiratory and cardiac	2	10
Cardiac	1	5
Chromosomal	5	25
Metabolic	2	10
Unknown	1	1

Table 2. Cronbach alfa

Average inter-item covariance	1.384612
Number of items in the questionnaire	21
Reliability coefficient (Cronbach alpha)	0.8523

Table 3. Content validity and reliability of individual domains

Domains	M	SD	Min	Max	α
Interaction with health professional	8.18	1.95	3.5	10.0	0.8534
Coping with the symptoms	5.66	2.66	0.6	9.6	0.8387
Impact on parents and family	6.18	2.76	0.5	9.4	0.8425

Note: M – mean; SD – standard deviation; Min – minimum; Max – maximum; α – Cronbach's reliability coefficient.

financial difficulties and the overall pressure on the family. In this domain, the relationship with the child was rated the best (M = 8.9; SD 2.6) as well as the satisfaction with religious and spiritual support. However, only eight respondents made use of the spiritual support which was not offered to four parents of the total sample and the others did not use it. The last domain assessed was *Interaction with health professionals*, which included items 1–5, 17, 18, and 22. The parents were satisfied with the respect for the child and parents expressed by the health professionals, with the clarity of the information that the doctors communicated to them, and they also expressed their trust in the health professionals regarding decisions about further care, including end-of-life care. They described securing the medical care as moderately difficult (M = 6.1; SD = 3.09) and indicated whether they would like to be more involved in treatment decisions (M = 5.2; SD = 3.49), where 10 means that they would like to participate much more. Based on the analysis of the questionnaire responses, it appears that the needs of the parents include the possibility to devote themselves more to their own activities, and they need help in meeting the physical and psychological needs of the children, including pain management. They often have feelings of anxiety, depression, thoughts of the child's possible death, and struggle with financial problems and the impact of the illness on the family. However, they express satisfaction with their relationship with their child. All results are included in Table 4.

Table 4. Descriptive statistics of questionnaire items (*n* = 20)

Item	*n*	M (SD)	Mdn	Min/Max	*n* (%) Missing
1. Respect: child *	20	9.2 (1.31)	10.0	5/10	0 (0)
2. Respect: parent *	20	8.8 (1.85)	9.0	2/10	0 (0)
3. Difficulty securing care	20	6.1 (3.09)	7.0	0/10	0 (0)
4. Health information *	20	9.4 (1.14)	10.0	6/10	0 (0)
5. Involvement in medical decisions	20	5.2 (3.49)	5.0	0/10	0 (0)
6. Frequency of pain	20	5.1 (2.59)	5.0	1/10	0 (0)
7. Physical problems (excluding pain)	20	7.8 (2.46)	8.0	2/10	0 (0)
8. Physical needs of the child	20	6.2 (2.67)	6.0	1/10	0 (0)
9. Emotional needs of the child	20	6.5 (2.96)	7.0	0/10	0 (0)
10. Fun activities for the child *	20	2.7 (2.64)	2.0	0/8	0 (0)
11. Fun activities for parents *	20	2.6 (1.64)	2.0	0/5	0 (0)
12. Relationship to the child *	20	8.9 (2.60)	10.0	0/10	0 (0)
13. Possibility to talk to someone *	20	5.9 (2.70)	7.0	1/10	0 (0)
14. Anxiety	20	6.2 (3.11)	6.5	0/10	0 (0)
15. Depression	20	5.0 (3.19)	5.5	0/10	0 (0)
16. Thoughts about the death of the child	20	5.6 (3.59)	5.0	0/10	0 (0)
17. Trust in care goals *	20	8.6 (1.82)	9.5	5/10	0 (0)
18. Goals of care in the final stages *	20	9.4 (1.14)	10.0	6/10	0 (0)
19. Religious/spiritual support *	8	9.4 (1.19)	10.0	7/10	12 (60)
20. Financial problems	20	7.8 (2.31)	8.0	3/10	0 (0)
21. Impact on the family	20	7.4 (2.96)	8.0	0/10	0 (0)
22. Fulfilling overall needs *	20	8.7 (1.72)	9.0	4/10	0 (0)

Note: * The item is reversed, so a higher number indicates a greater need. M – mean; SD – standard deviation; Mdn – median; Min – minimum; Max – maximum.

Discussion

The assessment of needs in children's palliative care is of fundamental importance, but specific tools are lacking. The PC-Needs measurement tool was developed by a research team of five community organizations in the US state of Illinois in conjunction with two academic centers. Its validity was assessed using correlations with the WHOQOL-BREF quality of life questionnaire, and it addresses the main issues of pediatric palliative care, such as symptom management, communication, financial and emotional impact (Donnelly et al., 2018).

Our results showed that parents rated the *Coping with the symptoms* domain the worst, along with the difficulty of providing for the child's physical and psychological needs, including pain management. The treatment and alleviation of pain is the essential and important care for the pediatric patient, but its assessment is sometimes difficult due to the child's age and ability to communicate (Thomas et al., 2018). Various observation scales are used in practice, including assessment of changes in the child's physiological functions or behavior (Bužgová et al., 2019). Amery et al. (2023) recommend the QUEST approach: ask about pain, use pain assessment tools, assess behavioral changes, guide parents to be sensitive to the child's pain and be able to describe it and respond to it. Parents indicated the highest level of need mainly in the possibility of involving the child in its favorite activities.

Participants in the qualitative study by Coombes et al. (2022) in the United Kingdom, which involved interviews with both parents and their children, indicated that children wanted to live as normal a life as possible, they want to engage in children's activities such as school education, play, and planning for the future. The respondents emphasized the importance of coping with symptoms such as pain, seizures, and difficulty eating and drinking. According to Adistie et al. (2020) nurses and parents believe that play, school education and social support are important for children. Play is the universal language of childhood, a tool for communication and integral to the provision of pediatric palliative care (Boucher et al., 2014).

According to Article 33 of the Charter of Fundamental Rights and Freedoms, everyone has the right to education. This cannot be denied, even if it is necessary to provide care for chronically ill children in schools. Based on the 2022 amendment to the Act on Health Services, healthcare can also be provided in a school setting, when the care is provided by a home care provider or, with the consent of the parents, by the teacher (Steinlauf, 2023). In the *Impact on parents and family* domain, parents indicated little opportunity to devote themselves to their activities, frequent feelings of anxiety, depression, and thoughts about the child's possible death. They also reported financial difficulties and the overall impact on the family. However, they evaluated the relationship with their child positively and expressed satisfaction with religious and spiritual support, in cases when the spiritual support was offered to them and the parents made use of it. Spiritual care is different from religious care, but the two can complement each other. Spirituality is everything that gives meaning to a person's life – and may or may not relate to religion. Everyone has their own spiritual needs, therefore spiritual care should be offered to everyone (Amery et al., 2023). In our sample, spiritual care was not offered to four parents, while eight parents did not use it and would have preferred psychological or psychotherapeutic help.

Chvílová Weberová et al. (2023) state that spiritual care helps people to cope with a difficult life situation. It includes psychological, social, and spiritual aspects, and is not dependent on religious beliefs. It is an integral part of care but not firmly anchored in the Czech environment. Conversely, religious care builds on the theological foundations of faith (Amery et al., 2023). Religious families have certain traditions, customs and rituals that must be respected, and their perspective on caring for a seriously ill child can be very different from others (Wiener et al., 2013). Poláková et al. (2017) state that parents have very little opportunity to rest; third-party home care is not always available and is also financially demanding.

Feelings of isolation, emotional stress, and the need for recognition are also indicated by an Australian study which focused on identifying and meeting the parents' support needs (Aoun et al., 2022). The findings of the study by Coombes et al. (2022) also include the emotional and social impact of the illness on the family, on their communication with friends, concerns regarding existential questions and uncertain future. In the study by Aoun et al. (2022), parents stated their greatest needs to be time for themselves, practical help in the household, financial help, legal support or opportunity to work, as well as the need to know a single key worker they could turn to for anything.

The best-rated domain was *Interaction with health professionals*, where parents indicated satisfaction with the respect shown to the child and parents, the clarity of information provided by doctors, and expressed their trust in the health professionals when making decisions about further care, including the care at the end of the child's life. The authors of a qualitative study in Malaysia, whose aim was to determine the needs of parents caring for a child with an oncological disease, came to a different result. Parents reported insufficient information related to interactions with healthcare professionals, especially regarding the illness, treatment, and orientation in the healthcare system (Tan et al., 2021). Lack of knowledge about the disease was also reported by participants in a large online survey in Australia and New Zealand that focused on the parents' needs of support care in a diverse sample of families with rare diseases (Pelentsov et al., 2016). A study by Constantinou et al. (2023) provides valuable insight from experts in pediatric palliative care and looks at the needs of families and children from a different perspective. They agreed that the provision of care by a multidisciplinary palliative team, sufficient information, and proper communication are important to effectively care for a child with palliative needs. The results of the study by Poláková et al. (2017), who mapped the needs of families taking into account the specific characteristics of the Czech region, showed that the needs of families are very broad and differ according to the type of a child's illness.

Our results also correspond with those of the authors of the PCNeeds tool, whose domain analysis showed that the *Coping with the patient's symptoms* domain showed the highest level of need, followed by the *Impact on parents and family* domain, and the *Care team interaction* domain had the lowest level of need (Donnelly et al., 2018). The norm not only abroad, but also in the Czech healthcare system, is compliance with the five key concepts of Family Centered Care, namely: respect, dignity, information sharing, participation, cooperation, and partnership. Parents are treated as equal partners, they have enough information, and further care is always up to them (Shields, 2015). There is a slight difference between the domains Coping with the symptoms and Impact on parents and family, and the results correlate with generally known facts, such as the availability of care, which often depends on the type of illness of the child, the family's place of residence, and the little availability of home care (Poláková et al., 2017).

The respondents in our study had the opportunity to provide additional information in the comments and thus indicate other problems that they, their child, or family face. Parents described the limited possibility of respite service for caregivers, especially when the care should be provided at home, so that the child does not have to be taken from its familiar environment. They cited a relatively large financial burden for respite services and would welcome the possibility of free substitute care. It was also difficult for them to make decisions, when there were more treatment options. Parents caring for a child with home artificial lung ventilation also described a lack of specific information. They also commented on the lack of a comprehensive service that would provide care for children with a serious diagnosis in the home environment, for example, physiotherapy, occupational therapy, speech therapy, and general health care. Parents also lack self-care. However, the parents' responses also indicate a high level of satisfaction in many areas, such as communication with health professionals and their respect for the child and the parents.

Caring for a child with a serious diagnosis is very demanding. The Charter of the Rights of Children with Life-Limiting and Threatening Illnesses clearly states that care should be provided in the home environment and that caregivers should be provided with adequate help and support (ICPCN, 2008). In the Czech Republic, the services are legally anchored, but not always available. The care system is often unclear and confusing for parents. Therefore, every family should have a designated contact person who coordinates the care plan. Support and help should be available 24 hours a day, 365 days a year, regardless of where the family lives and their economic situation (Poláková et al., 2017). Parents play an irreplaceable role in the care and are automatically expected to provide medical and sometimes highly specialized care in addition to their parental role. Legally, however, this role is not included in any document. The Ministry of Health of the Czech Republic makes efforts to include the medical respite care paid from the public health insurance in the Czech legislation, (Medical Tribune, 2023). A relatively new service is ethical counseling, which is based on the Concept of care for children and adolescents with a serious life-limiting and threatening diagnosis and their families. The support of an ethical counselor is beneficial for the family as well as professionals when making treatment decisions. The counselor may help resolve any ethical issues that could easily lead to legal conflicts (Matějek, 2023).

Limitations of the study

A limitation of the study is the small number of respondents, which meant it was not possible to perform an analysis using the method of confirmatory factor analysis. There are plans to supplement the research sample and verify the psychometric properties.

Conclusion

Children's palliative care is an essential part of the healthcare system. It requires a comprehensive approach and the cooperation of many experts. Ensuring quality care for children and their families is key to improving their quality of life. In the Czech environment, it is important to take cultural specificities into account, strengthen legal and financial support, and improve the availability of specialized services. It is also important to establish proper cooperation between the ministries of health, social affairs, and education. Assessing the individual needs of patients and their family members is important for providing individualized care. It also allows health professionals to identify areas that the patient and family consider important and where they need help and support. Caring for a child in palliative care has an impact on the entire family (including siblings and grandparents) and financial implications. Families need communication and care planning, availability of information, availability of services, aids, (often) housing modifications, substitutability in care, pre-school and school attendance for the child, financial support, care in the home environment, being close to the child and living normally. Finally, care for bereaved parents is also needed. The study showed the high internal consistency of the Czech version of the PCNeeds measurement tool. Limitations of the study include the small sample of respondents; therefore, data collection will continue so that in the next stage of the research the questionnaire can be tested for psychometric properties and possibly recommended for use in practice.

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Ethical aspects and conflict of interest

The study design was approved by the Ethics Committee of the Faculty of Medicine of the University of Ostrava (5/2023). The authors declare that the study has no conflict of interest.

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