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PERINATAL PALLIATIVE CARE IN POLAND – AN INTRODUCTION

PERINATALNA OPIEKA PALIATYWNA W POLSCE – ZAGADNIENIA WPROWADZAJĄCE

Summary: The article aims to present perinatal palliative care as a relatively young form of palliative care. The author undertook an attempt not only to reveal the essence of this form of care by elaborating on the terminological issues, but also drew attention to its development in Poland, pointing to the significance of the decision of the Constitutional Tribunal of October 22, 2020 in this regard. To indicate the ways parents whose children are affected by lethal defects can be supported it also became necessary to conduct comparative research aimed at presenting the forms of support in other countries, including those with corresponding legal culture. Taking advantage of the experience of other countries, as well as referring to the current development of perinatal palliative care in Poland, it might be possible to formulate conclusions indicating the direction which this form of care should develop towards.

Keywords: lethal defects, perinatal palliative care, perinatal hospice, child, pregnancy termination

Streszczenie: Celem artykułu jest ukazanie perinatalnej opieki paliatywnej jako stosunkowo młodej formy opieki paliatywnej. Autor podjął się nie tylko przedstawienia istoty tej formy opieki poprzez ukazanie zagadnień terminologicznych, ale także zwrócił uwagę na jej rozwój w Polsce, wskazując na znaczenie w tym zakresie wyroku TK z 22 października 2020 r. By wskazać sposoby wsparcia rodziców, których dzieci dotknięte są wadami letalnymi, konieczne stało się także przeprowadzenie badań porównawczych idących w kierunku zaprezentowania form wsparcia obecnych w innych państwach, w tym tych o podobnej kulturze prawnej. Wydaje się bowiem, że wykorzystując doświadczenia innych państw, a także odnosząc się do dotychczasowego rozwoju perinatalnej opieki paliatywnej w Polsce, możliwe stanie się sformułowanie wniosków dotyczących tego, w jakim kierunku opieka ta powinna zmierzać.

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Słowa kluczowe: wady letalne, perinatalna opieka paliatywna, hospicjum perinatalne, dziecko, terminacja ciąży

METHODOLOGICAL ASSUMPTIONS

Perinatal palliative care is an issue that evokes extreme emotions. On one hand, what is assumed in this regard is support for parents who learn that their anxiously anticipated child is affected by a severe developmental defect, which means that the child may not live to see the day of their own birth, and if they do, they will probably die soon after. On the other hand, parents have numerous doubts, they do not know whether their child is going to suffer or not, they wonder whether it would be better to terminate the pregnancy. These terrible dilemmas have become even more dramatic as a result of the decision of the Constitutional Tribunal of October 22, 2020. The Tribunal declared unconstitutional the premise enabling termination of pregnancy by a medical doctor in a situation in which “prenatal tests or other medical grounds indicate a high probability of severe and irreversible impairment of the fetus or an incurable disease threatening its life¹.” As a consequence, every child, including those who are practically incapable of living, must be born. In order to support parents in these traumatic moments, the state is trying to develop palliative perinatal care. The aim of the article is a comprehensive approach to this relatively young form of palliative care. Hence it seems necessary not only to present the essence of this form of care by presenting the terminological issues, but also to focus on its development in Poland. Obviously, a reflection on the ways of supporting parents whose children are affected by lethal defects also requires conducting a comparative research aimed at presenting the forms of such support in other countries, including those with a similar legal culture. It seems that taking advantage of the experience of other countries, as well as referring to the current development of perinatal palliative care in Poland, it will be possible to draw conclusions indicating the path which this form of care should embark on. Such approach to the subject determines the choice of research methods, as well. First of all, it seems necessary to analyze the existing legal solutions in this area with the use of the dogmatic method, which is supported by an analysis of the case-law and literature research, which are crucial to define the essence of perinatal palliative care. Especially an analysis of the ruling of the Constitutional Tribunal of October 22, 2020, from the point of view of parents deciding what is good for their child, seems particularly important. Moreover, due to the fact that the regulations of the international law or those adopted in other countries have a strong impact on Polish normative acts, it also seems critical to present some legal comparative remarks.

¹ Constitutional Tribunal ruling of 22 October 2020 r., file no K 1/20, OTK ZU no 4/A/2021.

INTRODUCTION

Today's development of medicine allows parents to know the health condition of their child even before he or she is born. Unfortunately, some of them happen to hear an unfavorable diagnosis of their offspring's congenital defect during prenatal examinations. These malformations are defined by the World Health Organization (WHO) as structural or functional disorders of organs and tissues that arise in fetal life. They can be detected prenatally, after birth, or in early childhood². Worldwide epidemiological data indicate that 2-4% of newborns have major developmental defects, and multiple birth defects are diagnosed in 0.7% of children, approximately.

These malformations are one of the main causes of early mortality in newborns and infants. Early pregnancy miscarriage concerns more than half of fetuses with severe congenital abnormalities, while the rate of birth defects in stillborn infants reaches as much as 10%³. The above-mentioned defects are divided into major defects, i.e. those significantly impairing the functioning of the body or shortening life – often requiring medical intervention (e.g. hydrocephalus, cleft lip and palate, or umbilical and diaphragmatic hernias) and minor defects, having no serious consequences for the quality of a person's life or their lifespan – which can be referred to as anomalies and are often of only cosmetic significance⁴. The most severe of the major defects are lethal defects, which are defined as:

1. developmental disorders leading to spontaneous internal miscarriage, premature birth or intrauterine death,
2. developmental disorders leading to premature death of a live-born child, regardless of the treatment applied,
3. developmental disorders qualified for termination of pregnancy in accordance with the applicable law.

The developmental disorders belonging to the third category may or may not be lethal per se; however, in all three above-mentioned situations, the defect leads to the death of the fetus directly or indirectly, i.e. it proves to be lethal⁵. It is beyond doubt

² T. Dangel, *Wady letalne u noworodków – opieka paliatywna jako alternatywa wobec aborcji i uporczywej terapii*, „Standardy Medyczne” 2007, no. 9(31), p. 108.

³ After: B. Skotnicka, *Prenatalne, perinatalne i postnatalne czynniki zagrożenia niepełnosprawnością intelektualną: profilaktyka i edukacja*, „Problemy Edukacji, Rehabilitacji i Socjalizacji Osób Niepełnosprawnych” 2014, no. 18/1, pp. 76-77.

⁴ A.T. Midro, *Zespół Downa. Przyczyny powstawania, diagnoza i elementy poradnictwa genetycznego*, [in:] B.B. Kaczmarek (ed.), *Wspomaganie rozwoju dzieci z zespołem Downa – teoria i praktyka*, Kraków 2008, pp. 21-36.

⁵ This is by far the most frequently invoked definition by dr hab. n. med. T. Dangel from the Warszawa Hospice for Children Foundation. see T. Dangel, *Wady...*, p. 108. This is why I am quoting it despite the fact that after the ruling of the Constitutional Tribunal of October 22, 2020, it has partially become outdated. A slightly different definition of lethal defects was formulated by J. Krzeszowiak, R. Śmigiel in the article *The role and tasks of a midwife as a member of the team caring for a pregnant patient with a diagnosed lethal fetal defect*, „Pielęgniarstwo i Zdrowie Publiczne” 2016, No. 6/1, p. 58. Accord-

that recognizing a child's congenital defect, and especially a lethal one, is one of the most difficult life experiences for parents. After all, pregnancy constitutes a time of joy, hopes and dreams concerning the birth of a healthy baby for most mothers and fathers. Meanwhile, in the event of a major birth defect being diagnosed, parents must get used to the idea that their child may not survive the labor at all, and even if he or she does, they are going to die in a relatively short time. What is worth noting here is the fact that before January 27, 2021, when the ruling of the Constitutional Tribunal of October 22, 2020 on the unconstitutionality of termination of pregnancy for embryo-pathological reasons was published in the Journal of Laws, parents used to have the opportunity to make a very difficult decision whether to continue the pregnancy or terminate it in accordance with Art. 4a sec. 1 point 2 of the Act on family planning, protection of human foetus and conditions for termination of pregnancy⁶ (hereinafter: the act on family planning). From that day on, they lost the possibility.

Taking the aforementioned into account, it seems necessary to analyze the ruling briefly, which should indicate the arguments for leaving the decision in the hands of parents. In the above-mentioned decision, the Tribunal upheld the position expressed earlier, according to which "(...) human life constitutes a value at every stage of development and as a value, derived from constitutional provisions, it should be protected by the legislator, not only in the form of provisions guaranteeing the survival of a person as a purely biological entity, but also as a holistic being, whose existence requires appropriate social, living and cultural conditions, all of which contribute to the existence of an individual. According to the Tribunal, an unborn child, as a human being – a person, who is entitled to inherent and inalienable dignity, is a subject with the right to life, and the legal system – pursuant to Art. 38 of the Constitution⁷ – must guarantee proper protection of this central good, which this subjectivity would be crossed out without (...) there should be no doubt that the constitutional provisions guarantee protection of the health of a conceived child, and in particular it can be deduced from these provisions that the legislator is obliged to introduce a prohibition against violating the health of a conceived child and the establishment of legal measures to ensure sufficient compliance with this prohibition”.

Referring to the very prerequisite for abortion, when “prenatal tests or other medical grounds indicate a high probability of severe and irreversible impairment of the fetus or an incurable life-threatening disease,” the Tribunal stated that: “The assessment of the admissibility of termination of pregnancy, if prenatal tests or other medical reasons indicate a high probability of severe and irreversible impairment of the fetus or an incurable

ing to the authors, “A lethal defect includes severe developmental abnormalities with an uncertain or poor outcome. It can lead to miscarriage of a stillborn fetus, premature stillbirth and death of the child immediately after birth or in early infancy, regardless of the treatment applied.”

⁶ Ustawa z dnia 7 stycznia 1993 r. o planowaniu rodziny, ochronie płodu ludzkiego i warunkach dopuszczalności przerywania ciąży (tekst jedn. Dz.U. z 2022 r., poz. 1575).

⁷ Konstytucja Rzeczypospolitej Polskiej z dnia 2 kwietnia 1997 r. (Dz.U. nr 78, poz. 483, z późn. zm.).

disease threatening its life, and thus the possibility of sacrificing the good of the child, requires an indication of an analogous good on the part of other people (...) in the wording of Art. 38 in conjunction with Art. 30 and 31 sec. 3 of the Constitution, it follows that circumstances related to the health of a child may not be the independent grounds for termination of pregnancy. According to the act on family planning, what is indicated as a prerequisite is not a state of diagnostic certainty, but only a “high probability” of severe and irreversible impairment or an incurable life-threatening disease. However, it is not permissible under Art. 31 sec. 3, the first sentence of the Constitution, to juxtapose human health with their life, as the problem of weighing the good cannot be considered when both the good sacrificed and the good saved belong to the same subject.” The Tribunal also shared the opinion that “(...) in the case of the premises specified in Art. 4a sec. 1 point 2, the mere fact of fetal impairment (an incurable disease) cannot independently determine the admissibility of termination of pregnancy in the constitutional perspective. For neither the care for the quality of the genetic code transferred (eugenic grounds in the strict sense), nor the consideration for the possible discomfort of a sick child’s life can justify the decision to take action to cause the child’s death (...) All the more so, an event that can only likely to be fulfilled, cannot constitute grounds for termination of life.” The argumentation presented by the Constitutional Tribunal seems to be very unilateral and does not take into account numerous constitutional values which also require protection. Undoubtedly, it is clear that the right to life is a value that must be absolutely protected, but it must be noted that the protection of the life of a child with the so-called lethal defects are often beyond the means of his or her parents, who learn that he or she will probably die soon after their birth in great suffering. Therefore, in my opinion, the need to protect other constitutional values, the principle of inviolability and respect for human dignity, above all, means that the decision to terminate pregnancy in such cases should be left to the mother (parents) of the child, bearing in mind that it is always under the supervision of a medical doctor. It is the parents of the child, according to their own conscience and professed values, and having professional medical assistance provided, who should be able to jointly decide whether to continue the pregnancy or to terminate it. They cannot be deprived of this right in the name of absolute respect for the right to life, at all costs. In the event that the parents jointly decide that the child is going to be born, it is necessary for the state to take care of them, so that they are not left alone in the situation. Providing such support should have a comprehensive dimension and take the form of perinatal palliative care.

TERMINOLOGICAL ISSUES

The concept of perinatal palliative care has not yet been legally defined. An attempt to define it was made by T. Dangel, a specialist in palliative medicine, who stated that this type of care consists in “providing comprehensive support to par-

ents of fetuses and newborns with lethal defects and care for newborns with such defects, focused on ensuring comfort and protection against persistent and futile therapy. It includes symptomatic treatment of the child and parents' psychological, social and spiritual support, as well as support for parents in mourning. Child care can be provided in the neonatology ward or at home by parents and hospice if the baby survives delivery and is discharged from hospital⁸. This form of support is intended for parents caring for children with severe and irreversible disabilities or incurable life-threatening diseases that occurred in the prenatal period of the child's development or during childbirth. It is carried out in the prenatal phase up to the 28th day after delivery. In accordance with §7a of the ordinance of the Minister of Health on guaranteed benefits in the field of palliative and hospice care⁹, it includes medical advice and consultations, as well as psychological advice at a palliative outpatient clinic, a home hospice for children or an inpatient hospice. Moreover, it is implemented through the coordination of care that includes:

1. ensuring cooperation with a healthcare provider providing services in the field of obstetrics and gynecology or neonatology, in the form of hospital treatment or specialist advice,
2. ensuring cooperation with a home hospice for children or an inpatient hospice, allowing for continuity of care for a child in the event of the possibility of discharging from the ward where the child is staying,
3. ensuring cooperation with a prenatal diagnostics center, a prenatal cardiology center or a genetics department,
4. informing parents about the possibility to bid farewells to the deceased child and the method of burial,
5. providing information on the procedure in case of a child's death,
6. ensuring the continuity of treatment according to the state of health, after the completion of the service guaranteed within the perinatal palliative care, including, in justified cases, palliative care after the child's birth and support in mourning after the child's death by participation in a bereavement support group.

What constitutes by far the most common form of perinatal palliative care providing comprehensive support is a perinatal hospice¹⁰. The institution has not been defined in its legal dimension to this day. Attempts are still being made, however, to

⁸ T. Dangel, J. Szymkiewicz-Dangel, *Propozycja programu ochrony życia w przypadku rozpoznania wady letalnej w badaniach prenatalnych*, https://perinatalne.pl/pliki/Artykul/1037_hospicjum-perinatalne-materialy-informacyjne.pdf [access: 24.11.2022].

⁹ Regulation of Minister of Health dated October 29, 2013 on guaranteed benefits in the field of palliative and hospice care (Journal of Laws 2022, item 262, uniform text).

¹⁰ Out of 23 facilities offering services in the field of perinatal palliative care, as many as 17 have a perinatal hospice in their name. Most of them function as part of a larger structure, usually separated as part of a children's hospice, less frequently as a part of a hospital – cf. an announcement of the National Health Fund on perinatal palliative care - <https://www.nfz.gov.pl/aktualnosci/aktualnosci-centrali/komunikat-dotyczacy-perinatalnej-opieki-paliatywnej,7857.html> [access: 24.11.2022].

define its constitutive features. It is worth highlighting here that people dealing with this issue emphasize that perinatal hospices cannot be presented as separate places of support, and the interdisciplinary nature of the activities undertaken within them are pointed out¹¹. According to M. Małkowska, in turn, “a perinatal hospice is not a place. It’s rather a way of thinking (...). It is accompanying the family on their way through pregnancy, the act of giving birth, and death. A dignified death. One that is not. One that leaves an extremely difficult experience in the memory, the experience of welcoming and saying goodbye to a child; difficult, yet full of love¹².” As K. Szmyd rightly points out, it is difficult to provide a definition of an institution whose activity can be referred to as specialized and omnidirectional. The functioning of perinatal hospices results from the need to support families and couples who, during pregnancy, received a diagnosis of their child’s incurable and life-threatening disease. The areas of activity of perinatal palliative care are diverse and require the cooperation of a number of specialists related to various fields, including medicine, psychology, as well as those providing spiritual care, possessing “the necessary knowledge, skills and readiness to accompany the family in such a difficult period of their lives”¹³. A slightly different definitional approach was presented by T. Dangel, according to whom it constitutes “palliative care for the family which begins before the birth of the child, in cases of prenatal diagnosis of severe, irreversible fetal impairment or incurable disease threatening its life”¹⁴.

PERINATAL PALLIATIVE CARE – AN INTERNATIONAL PERSPECTIVE

The foundations of perinatal palliative care can be found in the most important acts of international law, from the point of view of respecting human rights. The broadly understood right to health protection is included in the International Covenant on Economic, Social and Cultural Rights¹⁵. The act refers directly, however, to the need for the countries to take action in order to protect the life and health of a child before their birth in art. 12 sec. 2 stipulating that “The steps to be taken by

¹¹ B Kmieciak, Z. Szafrąńska-Czajka, R. Dorosiński, *Perinatalna opieka hospicyjna, raport*, Ordo Iuris Bioethics Center Institute for Legal Culture, Warszawa 2016, <http://docplayer.pl/23681201-Perinatalna-opieka-hospicyjna-wizja-dzialania-oraz-wyzwania.html> [access: 22.11.2022].

¹² M. Małkowska, *Pokochoć od początku. Hospicjum to też życie*, „Kwartalnik Hospicyjny” 2013, no. 1, pp. 12-13.

¹³ See. A research report of the Hospice for an unborn life, <https://formuladobra.pl/wp-content/uploads/2019/04/Hospicjum-dla-zycia-poczetego-raport-z-badan.pdf> [access: 24.11.2022].

¹⁴ T. Dangel, J. Szymkiewicz-Dangel, *Propozycja programu ochrony życia w przypadku rozpoznania wady letalnej w badaniach prenatalnych*, https://perinatalne.pl/pliki/Artykul/1037_hospicjum-perinatalne-materialy-informacyjne.pdf [access: 24.11.2022].

¹⁵ International Covenant on Economic, Social and Cultural Rights, New York, December 19, 1966 (Journal of Laws 1977, no 38, item 169).

the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: (a) The provision for the reduction of the still-birth-rate and of infant mortality and for the healthy development of the child (...).” The very inclusion of the right to health protection in the Covenant on Economic, Social and Economic Rights proves that public international law qualifies it as belonging to the category of social rights, which, in turn, bears certain consequences. As rightly pointed out by C. Mik, “It is expressed that social rights, unlike personal and political rights, are of programmatic nature, as an individual can enforce them upon the state to a very limited extent. The duties of the state constitute the duty of care”¹⁶. It is the protection of a child’s life and health, also in the context of family planning, that Art. 24 of the Convention on the Rights of the Child and Art. 12 of the Convention on the Elimination of All Forms of Discrimination against Women¹⁷ also apply to. What deserves mentioning in this context is Art. 3 of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine proclaiming the principle of equitable access to health care¹⁸. Even though the provision does not establish individual claims, it obliges the states-parties of the Convention to shape the health care system in such a way that it would guarantee equitable access for patients to appropriate services, as specified in the national law. Equity should be understood not only as the absence of unjustified discrimination, but also as an obligation to provide health care that is effective from the point of view of the medical needs of a particular individual¹⁹.

Normative regulations concerning perinatal palliative care can also be found in the legal systems of other countries. Hospices operating in the United States have the widest perinatal care portfolio for both children and their parents. Obviously, due to the federal nature of the country, these regulations vary from state to state, but in practice each state offers at least one facility (in some cases even a few) where families looking for help can apply. Most facilities offering this type of palliative care constitute a part of a larger structure. These are sometimes medical facilities

¹⁶ C. Mik, *Koncepcja normatywna europejskiego prawa praw człowieka*, Toruń 1994, pp. 220-222.

¹⁷ According to this provision „States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.” Convention on the Elimination of all Forms of Discrimination Against Women of December 18, 1979 (Journal of Laws 1982 No 10, item 71).

¹⁸ The provision stipulates that “Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.” Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine Adopted by the Committee of Ministers on November 19 1996, https://www.coe.int/t/dg3/healthbioethic/texts_and_documents/ETS164Polish.pdf [access: 23.12.2022].

¹⁹ Cf. L. Bosek, *Komentarz do art. 68 Konstytucji*, [in:] M. Safjan, L. Bosek, *Konstytucja RP*, tom I: *Komentarz do art. 1-86*, Legalis.

(including universities), where the tasks of the perinatal hospice are carried out as part of an assistance program, with the possibility of taking advantage of the intellectual base (specialists) and technical infrastructure (medical equipment) of the unit. A number of facilities function in this way, e.g. a perinatal hospice in Alabama (*Hospice Family Care*) at Huntsville Hospital in Huntsville²⁰, *Pediatric Supportive Care Team* perinatology clinic at West Virginia University Children's Hospital in Morgantown, West Virginia²¹, and *Noah's Children Perinatal Care* at St. Mary's Hospital in Richmond, Virginia²². There also exist support groups created by parents for parents. This form of support is offered, for example, by *Embaracing Grace* in Richmond, Virginia²³ or *Isaiah's Promise* in Rockville, Maryland²⁴. Places where parents (or whole families) can apply are also facilities run by churches and religious associations, for example *St. Vincent Health System and Catholic Health Initiatives* in Arkansas²⁵, operating since 1888, founded by a religious congregation belonging to the Catholic Church. It is probably the oldest hospice in the United States. The vast majority of the perinatal care centers operating in the US are supported by private donations. Therefore, many of these facilities operate as non-profit organizations.

The perinatal care offer in Canada is also very extensive. The support system is not uniform there, too. It is different in particular provinces, and even within one province it looks different in different regions. Interestingly, there are only six typical children's hospices in Canada. In comparable circumstances, perinatal care is provided by units operating in pediatric hospitals, sometimes only associated with hospices. Pediatric palliative care (PPC) teams provide consultations to both inpatients and outpatients. The leading role in these teams is played by specialists from various fields (e.g. oncologists, neonatologists or cardiologists). It is worth noting that pediatric hospitals in Canada do not have separate palliative care wards, but a number of them have special rooms for families of dying children. It is very frequent that PPC teams take care of a patient for months, or even years. The place of care depends mainly on parents' preferences. When the death of a child is imminent, some families prefer to stay at home, while others crave for the support that only stationary care can provide. In such cases patients are admitted to stationary hospices, if there are such nearby, or to a hospital. Those who prefer their child to stay at home can be looked after directly by a PPC team or by doctors or health visitors who receive 24/7 support from the PPC team²⁶.

²⁰ <https://hhcaringforlife.org/about> [access: 8.12.2022].

²¹ <https://childrens.wvumedicine.org/patients-visitors/programs/perinatal-and-pediatric-supportive-care-program> [access: 8.12.2022].

²² <https://www.noahschildren.org/perinatal-care> [access: 8.12.2022].

²³ <https://evangelizerichmond.org/respect-life/embaracing-grace/> [access: 8.12.2022].

²⁴ <https://isaiahspromise.net/> [access: 8.12.2022].

²⁵ <https://www.chistvincent.com/clinical-services/palliative-care> [access: 8.12.2022].

²⁶ Cf. Palliative care is focused on life - an interview with Dr. Adam Rapoport, medical director of a hos-

In Central and Eastern Europe, it is true that Poland is the leader in providing perinatal care, the development of this form of assistance can also be observed in the Czech Republic from 2013 on. There are several dozen stationary and mobile hospices for adults across the country, and some of them offer home care for terminally ill children, as well. Many hospitals have specialized palliative care units. The first hospice for children, “*House on the road*,” was established in the village of Malejovice and since 2004 it has been offering a wide range of assistance to sick children and their families. Obviously, from the very beginning of its existence, in addition to sick children and their families, people expecting the birth of a seriously ill child and those whose child died during pregnancy, childbirth or just after the birth could find help there²⁷. Among other currently existing perinatal hospices, it is worth paying attention to the stationary and mobile hospice in Ostrava²⁸ and the entirely mobile hospice providing assistance via telephone and the Internet²⁹. Due to the fact that there is no system of government support for hospices, including the perinatal ones, such facilities are mainly supported by donations. It is worth pointing out that perinatal hospices in the Czech Republic have not yet specialized in perinatal palliative care. Care for women who are expecting to give birth to a sick child constitutes a part of a broader program that includes care for children and adults, within the framework of the adopted organizational structure. The obtained information also shows that it is primarily the families looking for help who initiate the hospice – patient relationship.

The situation seems to be slightly different in Slovakia. There are four mobile children’s hospices³⁰ that cover the whole country. None of the facilities is directly aimed at

pice for children in Toronto, Warszawa Hospice for Children Foundation Quarterly no. 4(98)/2021, p. 24, https://hospicjum.waw.pl/pliki/Artykul/1569_Kwartalnik-Hospicjum-nr-98-grudzien-2021.pdf [access: 8.12.2022].

²⁷ <http://klicek.org/hospic/projekt.html> [access: 8.12.2022].

²⁸ Mobile hospici Ondrášek is a hospice providing help for both children and adults. It is able to take care of fifteen adults and fifteen children at a time. The hospice operates in a stationary and mobile pattern – also in the hospital and at homes of its patients. The hospice staff consists of: doctors, nurses, social workers, a psychologist, a physiotherapist, a special teacher and a clergyperson. Perinatal care stricto sensu was provided once in practice. A spur to action were two cases of children who came to the hospice in 2015. In the prenatal period, they were diagnosed with serious birth defects and the hospice undertook a support group for their parents. These meetings were attended by parents whose child died shortly after the birth. - <https://www.mhondrasek.cz/> [access: 8.12.2022].

²⁹ The person responsible for its functioning is Lenka Pazdera, a midwife from Brno, who currently coordinates its work remotely – from Great Britain. The basic objective of the hospice is to provide care for pregnant women, their child(ren) and their families, from the moment of hearing the diagnosis to the end of the child’s life, which constitutes the main task of the hospice. The hospice coordinator attempts to promote the idea of a perinatal hospice through her actions and assistance, as well as her presence on the Internet (also on Facebook). In practice, the activity boils down to e-mail or telephone contact with people who contact her themselves. The midwife provides emotional support, advice and guidance, and puts her patients in touch with other people or facilities. - <https://perinatalnihospic.cz/o-nas/> [access: 8/12/2022].

³⁰ These are: *Plamienok* based in Bratislava, operating since 2002, *Svetielko Pomoci* based in Košice, which was established in 2011, *Svetielko Nádeje* based in Banská Bystrica, established in 2015, and *Pod Krížlami Dominiky* based in Nitra, operating since 2017.

helping parents and their sick children before their birth. In practice, however, they do not refuse to help pregnant women who come asking for support. These hospices employ a number of specialists, including: a team of doctors, a nurse, psychologists, a therapist, a pedagogue, a social worker and a fundraiser. The hospice employees provide palliative care to newborn children and the family, and their help is of comprehensive nature. They provide medical, psychological and therapeutic support, ensure that the family's living conditions and children's education are secured, and adapt the housing conditions to the needs of a child with a disability; they help in completing formalities in offices and overcoming difficulties in communication with the closest family and friends. The hospices also meet the spiritual needs of their patients, but, importantly, they are not associated with a church or a religious association. They ensure contact with clergy people of various denominations to those looking for spiritual support, as needed. Within the functioning of the hospices, there are also counseling and psychological support centers for children and their families who have experienced the loss of a loved person. The beneficiaries of such centers also include parents who have lost a child. The hospices also organize weekend meetings for bereaved families. The income comes mostly from donations made by individuals and businesses³¹. An important source of income are also deductions from the income tax in the amount of 2% made by Slovak citizens during annual settlements with the tax authorities³².

THE ORGANIZATION OF PERINATAL PALLIATIVE CARE IN POLAND

Perinatal hospices are relatively young institutions. However, the need to undertake this type of activity has been recognized in Poland for a long time and implemented by non-governmental organizations, often in the form of volunteer work. It was in 1999 when the first standards of pediatric palliative care were developed in Poland. It was also then that the first activities aimed at promoting the idea of a perinatal hospice were undertaken by prof. Joanna Szymkiewicz-Dangel and prof. Tomasz Dangel from the Warsaw Hospice for Children.

At that time, first scientific studies on the principles of hospice support for children with serious defects, disorders or diseases began to appear. In 2006, on prof. Dangel's initiative, an ultrasound laboratory affiliated with the Warsaw Hospice for Children was established. Since then, the hospice has begun a permanent form of providing support to parents of children diagnosed with lethal defects. It included a medical diagnosis, psychological support and the possibility of contact with fam-

³¹ Detailed data on pediatric palliative care in Slovakia can be found in the study: *Detská paliatívna starostlivosť na Slovensku. Súčasnosť a výzvy budúcnosti*, https://www.plamienok.sk/fm_source/1.1%20Brozura_A5_Web.pdf [access: 8.12.2022].

³² See e.g. <https://www.plamienok.sk/podporte-nas/darujte-2> [access: 8.12.2022].

ilies who had experienced similar problems. It is worth mentioning here that in 2012, at the request of the Polish Bioethical Society, the rules of conduct in case of decision-making in perinatal hospice were developed.

Currently³³, there are 23 facilities in Poland offering services in the field of perinatal palliative care. The vast majority have the term perinatal hospice in their name³⁴. In most cases, the entities conducting the activity are public benefit organizations³⁵. Perinatal hospices offer services in the field of perinatal palliative care in 13 voivodships. Unfortunately, the scope of care varies significantly depending on the location. In most cases, there is only one perinatal hospice in the voivodeship. Pomorskie and Śląskie Voivodships constitute the exceptions, as in each of them there are three centers providing assistance to families facing a prenatal diagnosis of a lethal defect, and Dolnośląskie and Małopolskie Voivodeships, where there are two hospices providing this type of assistance each.

In the following voivodships: Kujawsko-Pomorskie, Zachodniopomorskie and Świętokrzyskie, there are no such places at all. It can therefore be said that these voivodships remain blank spots on the map of perinatal hospices, despite the request of the Supreme Audit Office to the President of the National Health Fund (NFZ for Narodowy Fundusz Zdrowia) to ensure – as part of the supervision exercised over the regional branches – the access to perinatal palliative care services in all voivodships³⁶. Analyzing the statistical data available in the map of health needs³⁷, it turns out that the availability of perinatal palliative care facilities is the highest in the voivodships with the lowest number of births, i.e. in Lubuskie and Opolskie, whereas in Mazowieckie, which has the highest birth rate, there is only one perinatal hospice³⁸.

At this point, it is worth emphasizing the changes in the financing of perinatal palliative care that have taken place in recent years. For years, NFZ did not contract services provided by perinatal hospices, therefore the costs incurred by the facilities had to be covered from statutory funds, primarily transferred to public benefit organizations thanks to the “1% of tax”, as well as from private donations. It was only in 2018 when the situation changed, as the ordinance of the President of the

³³ July 06, 2022 status.

³⁴ Out of 23 facilities offering services in the field of perinatal palliative care, as many as 17 have a perinatal hospice in their name. Most of them function as a part of a larger structure, usually separated as part of a children's hospice, less often a hospital - cf. National Health Fund announcement on perinatal palliative care, <https://www.nfz.gov.pl/aktualnosci/aktualnosci-centrali/komunikat-dotyczacy-perinatal-paliatywne-are,7857.html> [access: 24.11.2022].

³⁵ In Katowice, this activity is carried out by a limited liability company, while in Poznań, Gdynia, Opole and Zielona Góra it is carried out as part of a health care facility.

³⁶ Supreme Audit Office, Providing palliative and hospice care. Information on control results, Warszawa 2019, <https://www.nik.gov.pl/plik/id,21371,vp,24011.pdf> [access: 23.12.2022].

³⁷ <https://basiw.mz.gov.pl/mapy-informacje/mapa-2022-2026/analizy/opieka-paliatywno-hospicyjna/> [access: 23.12.2022].

³⁸ <https://basiw.mz.gov.pl/mapy-informacje/mapa-2022-2026/analizy/opieka-paliatywno-hospicyjna/> [access: 23.12.2022].

National Health Fund on defining the conditions for concluding and implementing contracts in the area of palliative and hospice care³⁹ was published. From that moment on, NFZ covers the costs of services provided by those perinatal hospices that have concluded a relevant contract. Unfortunately, the amounts paid have not covered all the costs incurred by perinatal hospices from the beginning. In practice, with a huge increase in the operating costs, a facility receives a one-time lump sum of PLN 1.450 per family. Taking into account often long-term support for the family, this amount proves to be absolutely insufficient. Unfortunately, there is no indication that the situation in this regard is going to improve. In response to an appeal by the Ombudsman to increase expenditures on perinatal palliative care, the President of the National Health Fund informed that the current valuation of inpatient hospice/palliative medicine services is at a good level. At the same time, he pointed out that he did not have the authority to set tariffs for health services. However, he commented on the pricing plan of the Agency for Health Technology Assessment and Tariff System⁴⁰ regarding the need to re-evaluate the pricing of palliative medicine clinics in order to develop this form of care in Poland⁴¹.

As far as the internal organization of a perinatal hospice is concerned, it should be stated that its most important element is a physician (usually a pediatrician, a palliative medicine specialist or a cardiologist) working in a children's hospice, as well as a psychologist⁴². Depending on the circumstances and needs, specialists from other fields are included in the team, e.g. geneticists, gynecologists-obstetricians and prenatal diagnosticians. Families are also provided with the possibility of spiritual support. An important role in the hospice team is also played by a midwife who takes care of a woman before, during and after childbirth.

The perinatal support offered by hospices is also associated frequently with the help to get in touch with other families with a sick child, the help of a social worker (in matters related to obtaining a disability certificate, benefits, co-financing for medical and rehabilitation equipment, dealing with burial formalities, etc.), as well as assistance in the field of medical law. Moreover, some facilities providing perinatal palliative care share information on lethal defects and parents' situation after

³⁹ Ordinance No. 74/2018/DSOZ of the President of the National Health Fund of 31 July 2018 on defining the conditions for concluding and implementing contracts in the field of palliative and hospice care, <https://sip.lex.pl/akty-prawne/dzienniki-resortowe/okreslenie-warunkow-zawierania-i-realizacji-umow-w-rodzaju-opieka-35521156> [access: 23.12.2022].

⁴⁰ It is a consultative and advisory organizational unit established in 2005 having legal personality, supervised by the minister responsible for health, whose task is to provide the minister with data and information supporting the process of making reimbursement decisions for healthcare services. For more see <https://www.aotm.gov.pl/o-nas/co-robimy/> [access: 23.12.2022].

⁴¹ https://bip.brpo.gov.pl/sites/default/files/2022-12/Odpowiedz_NFZ_opieka_paliatywna_30.11.2022.pdf [access: 23.12.2022].

⁴² It helps parents identify and explain emotions related to the diagnosis and supports parents in making decisions (e.g. between persistent child therapy and palliative care).

prenatal diagnosis of a defect on their websites, along with various types of leaflets, guides and handbooks, as well as videos. Regardless of the above-mentioned, for the proper functioning of a perinatal hospice, it is necessary to cooperate with facilities specializing in perinatal medicine, as well as departments where women/families covered by perinatal palliative care are to give birth to their children.

CONCLUSIONS

In terms of the number of facilities providing perinatal palliative care, including, first of all, perinatal hospices, Poland stands out very positively among other Central and Eastern European countries. What seems to be a serious problem, however, is their uneven distribution across the country. First of all, they are located mainly in large cities, which makes them more difficult to be reached by the residents of small towns and villages; secondly, there are still three voivodships where there is not a single facility of this type. This means that there are places in Poland located several hundred kilometers away from the nearest perinatal hospice. Such a situation is undoubtedly very unfavorable, violating the constitutional principle of equal access to health care guaranteed by Art. 68 sec. 2. It needs to be emphasized that this provision, which was pointed out by the Constitutional Tribunal, expresses a citizen's guarantee right to equal access to benefits financed from public funds⁴³. Meanwhile, even in those voivodships where there are perinatal hospices, they are not distributed in proportion to the number of live births there. It seems that there is no planned, long-term policy in this regard. It can be stated that, even though perinatal palliative care has been legally regulated in Poland, a single model of this care has not been developed yet. All this means that the quality of this form of support varies depending on the place of residence and the particular facility which a family applies to. Being in an exceedingly difficult situation, parents of a child with a prenatal diagnosis of a lethal defect often do not even know where to look for help, as perinatal hospices often do not exist as independent entities, but constitute a separate part of a larger structure, e.g. a children's hospital or a hospice, where the parents have to report to in order to obtain the necessary information. Taking the above-mentioned into account, apart from increasing the financing of such facilities by NFZ, it seems necessary to provide even distribution of such facilities throughout the country and to conduct a wide-ranging information campaign that will allow to reach all the traumatized parents in need for help.

⁴³ Cf. Ruling of the Constitutional Tribunal of January 7, 2004, file ref. K 14/03, OTK-A 2004, No. 1, item 1.

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