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Accessibility and challenges of perinatal palliative care in Poland

Abstract

Background: This article examines the legal status and level of accessibility to perinatal palliative care (PPC) in Poland, with a focus on the number of services provided and the number of parents receiving PPC services.

Material and methods: The desk research was based on information obtained from the National Health Fund regarding the number of units that signed a contract for the provision of guaranteed PPC services from 2018 to the first half (January–June) of 2022; the number of parents receiving the service from 2018 to 2022; and the number of services provided by a doctor, a psychologist and by primary care midwives (PCMs). In addition, the Map of Health Needs and National Transformation Plan data were used to prepare the data.

Results: In Poland, since 2018, PPC services have been provided with public funds under contracts signed with the National Health Fund. Since 2022, these type of services has been provided by 17 centres. Care was provided to 1,860 pregnant women diagnosed with lethal foetal anomaly and to four fathers. There are still voivodeships in which there is a lack of provision of PPC services that are financed from the state budget.

Conclusions: In Poland, there is no full accessibility to publicly funded PPC in every voivodeship. The lack of a sufficient number of PPC centres and the lack of a uniform national standard of practice for this type of care — provided in hospices, hospitals and home settings — prevents women from having continuity of professional perinatal care. There is a need to ensure the quality of the services provided and make progress towards the employment of midwives in PPC facilities by service providers to ensure that women receive obstetric care from the moment of an adverse diagnosis, professional preparation for childbirth and the postnatal period.

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Key words: perinatal palliative care, perinatal hospices, midwife, health services, lethal foetal anomaly

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Introduction

Specialist prenatal diagnosis and advances in ultrasound technology, biochemical testing and invasive diagnostics made it possible to detect developmental anomalies in foetuses at an early stage of pregnancy [1–3]. Prenatal genetic diagnostics provides key information for decision-making regarding pregnancy and perinatal management following a prenatal diagnosis with a poor prognosis [4, 5]. It is estimated that approximately 5% of congenital malformations diagnosed are lethal ones (developmental disorders leading to intrauterine premature death or death of the child after birth), regardless of the treatment used [6]. According to epidemiological data, 2–4% of live-born newborns have isolated congenital malformations, while multiple congenital malformations are found in approximately 0.7% of newborns [7]. Despite modern medical therapies, it is not always possible to offer intrauterine treatment to the foetus or carry out effective treatment of the child after birth.

Research indicates that few families are prepared to make difficult decisions when their unborn child is diagnosed with a defect with an unequivocally poor prognosis. Both the birth of a child with a life-limiting defect and the termination of a pregnancy due to a foetal anomaly can be a traumatic life event for parents [1]. There are several publications in the world literature in which authors describe the dilemmas of women who have decided to terminate a pregnancy after receiving an adverse prenatal diagnosis [8–10]. Other studies indicate that social, cultural or spiritual beliefs prevent parents from terminating a pregnancy, so they choose to continue it despite an adverse prenatal diagnosis. These parents benefit from perinatal palliative management in view of their child's short life.

In October 2020, the Constitutional Court in Poland that terminating a pregnancy due to an irreversible foetal defect (including a lethal diagnosis of the foetus) is unconstitutional. Regulations on abortion have seen a radical change, so the group of PPC recipients may be increasing [11]. However, as this legal status is effective from January 2021, the results of the impact of the Constitutional Court's ruling on the number of parents receiving PPC are not yet known. In the last decade, there were several publications in which authors described the experience of families who continue a pregnancy after a prenatal diagnosis with a lethal prognosis [10, 12–18]. For this group of women, perinatal palliative care (PPC) offers non-aggressive obstetric management, allowing natural childbirth without life-sustaining therapy for the child. Women who were offered a coordinated model of PPC express positive views regarding care tailored to their individual needs [1, 19, 20].

Perinatal palliative care (PPC) is defined as the continuous perinatal care of a woman diagnosed prenatally with foetal abnormalities with a lethal prognosis. Doctors of various specialities — gynaecologists, neonatologists, geneticists, psychiatrists but at the same time psychologists, nurses and midwives — provide medical, psychological and, if necessary, spiritual care to the whole family [15, 21, 22]. Perinatal palliative care (PPC) aims to comprehensively provide quality of life for families awaiting the birth of a child with a life-limiting diagnosis. Comprehensive, multidisciplinary care also includes the bereavement period to help parents adjust to life without their child [12]. This article aims to describe the legal status and level of accessibility to PPC in Poland, considering the number of services, the number of mothers/fathers receiving PPC and the number of pregnant women with diagnosed lethal foetal anomaly (LFA), who receive care from PCMs.

The review analysed laws and regulations in force in Poland and data obtained from the National Health Fund — through access to public information. The data obtained relate to the period from 2018 to the first half (January–June) of 2022, as no publicly funded PPC services were provided in 2017. The analysis included data on the number of contracts concluded with the National Health Fund for the provision of PPC services, the number of guaranteed services provided in this area and the number of women receiving PPC. Also, the analysis covered the services provided by PCMs compared to the number of women receiving these services.

Laws and regulations on perinatal palliative care in Poland

Guaranteed PPC services in Poland were first defined in the Regulation of the Minister of Health of 2017 on guaranteed palliative and hospice care services [23]. According to the document, PPC services can be provided in prenatal diagnostic centres, prenatal cardiology centres, genetics departments, palliative medicine clinics and in-home hospices for children or inpatient hospices. The service is dedicated to the parents of a child, including a child in the prenatal stage, with a severe and irreversible disability or an incurable life-threatening disease that occurred during the prenatal period of development or at birth [23, 24]. Accordingly, the eligibility criteria for PPC are selected conditions beginning in the perinatal period and congenital malformations, anomalies and chromosomal aberrations defined by codes P00–P96 and

Q00–Q99, according to the ICD-10 clarification [25]. Guaranteed services under PPC are publicly funded and can be provided under contracts concluded between the National Health Fund and the units specified in the aforementioned regulation [23, 26, 27].

As part of the guaranteed PPC services, parents of a child diagnosed with LFA can receive medical advice and counselling as well as advice from a psychologist. Medical advice and counselling are provided by a specialist in paediatrics, neonatology, perinatology, paediatric neurology, paediatric oncology and haematology, anaesthesiology, anaesthesiology and resuscitation, anaesthesiology and intensive care, paediatric surgery, palliative medicine, or family medicine, with proven experience of at least two years in palliative care and at least one year in a PPC centre. These services also include care coordinated with hospital treatment, specialist advice in obstetrics, gynaecology or neonatology, and cooperation with prenatal diagnostic centres and hospices when a child can be discharged from the hospital. The coordinator should provide parents with continuity of care appropriate to the situation, and inform parents of the opportunity to say goodbye to the deceased child, the method of burial and possible bereavement support [28, 29].

The provision of guaranteed services under palliative and hospice care, including PPC, defines the terms and conditions for this provision, which, among other things, include collaboration with the PCM [30]. The provisions in Appendix 2 of the Regulation on guaranteed palliative and hospice care services [25] define the terms and conditions for the provision of guaranteed services under PPC, which include i.e. collaboration with the PCM. By the Order of the President of the National Health Fund, the PCM — in the case of a woman with a high-risk pregnancy with diagnosed foetal malformations according to the ICD-10 classification — may, on a case-by-case basis, conduct antenatal education visits for pregnant women in preparation for childbirth and parenthood, starting from 21 weeks gestation to delivery, and patronage visits for the care of the postpartum woman. The PCM provides care to a woman with a high-risk pregnancy based on a referral issued by a doctor who has diagnosed foetal malformations according to ICD-10.

Provision of perinatal palliative care in Poland

Based on National Health Fund data, contracts for the provision of guaranteed PPC services were signed with 13 medical facilities in 10 voivodeships in 2018. The following years brought an increase in the number of medical facilities. In 2019 and 2020, 16 facilities signed the contract, while in 2021 and 2022, 17 facilities provided this type of service. However, it should be remembered that 2022 only includes data for the first half of the year. In 2022, 13 voivodeships were contracted to provide PPC services; however, there are still three voivodeships — Kujawsko-Pomorskie, Świętokrzyskie and Zachodniopomorskie — that do not provide PPC services with public funds (Table 1). The largest number of medical facilities providing PPC services is in the Śląskie Voivodeship (n = 3) and the Dolnośląskie Voivodeship (n = 2).

In 2018, when PPC services were first contracted with the National Health Fund, 2 fathers and 293 mothers received them. From 2018 to 2020, there was a steady increase in the number of parents of a child who were receiving PPC services, particularly women. National Health Fund data show that from 2018 to the end of June 2022, only four fathers received PPC in the Dolnośląskie (in 2018), Warmińsko-Mazurskie (in 2019) and Pomorskie (in 2020) voivodeships. The largest number of women received those services in 2020 (n = 503). There was a slight decrease in the number of female patients in 2021 (n = 465). Considering the administrative division of the country, by far the largest number of women who received PPC services were those in the Mazowieckie Voivodeship (n = 1,322), while 538 women received PPC services in all other voivodeships. There are still three voivodeships where PPC services are not provided with public funds (Table 2).

In the first year of the publicly-funded PPC services, a total of 59 pieces of advice were provided, including 12 pieces of medical advice and 47 pieces of psychological advice. The highest amount of medical and psychological advice was provided in 2019 (n = 1021). When broken down by the amount of medical advice and counselling and the amount of psychological advice, the highest amount of medical counselling was provided in 2019 (n = 417) while the highest amount of psychological counselling was provided in 2021 (n = 616). The least amount of advice in 2018–2022 was provided in the Warmińsko-Mazurskie Voivodeship (n = 6) and the Lubuskie Voivodeship (n = 4). This result correlates with the number of patients receiving PPC in the Warmińsko-Mazurskie (n = 6) and Lubuskie (n = 4) voivodeships.

The highest amount of medical and psychological advice, under the PPC code, was provided in the Mazowieckie Voivodeship (n = 2 158). According to the information obtained from the National Health Fund, medical and psychological advice is financed as a lump sum, and hence service providers are not obliged to include the actual unit amount of advice provided in their report to the National Health Fund.

Table 1. Number of contracts signed with the National Health Fund for the provision of guaranteed perinatal palliative care (PPC) services in 2018–2022 by voivodeship

Voivodeship	Number of contracts signed with the National Health Fund for the provision of perinatal palliative care (PPC) services				
	2018 N = 13	2019 N = 16	2020 N = 16	2021 N = 17	2022 N = 17
Dolnośląskie	2	2	2	2	2
Kujawsko-Pomorskie	0	0	0	0	0
Lubelskie	1	1	1	1	1
Lubuskie	0	0	0	1	1
Łódzkie	1	1	1	1	1
Małopolskie	1	1	1	1	1
Mazowieckie	1	1	1	1	1
Opolskie	1	1	1	1	1
Podkarpackie	1	1	1	1	1
Podlaskie	0	1	1	1	1
Pomorskie	2	2	2	2	2
Śląskie	2	3	3	3	3
Świętokrzyskie	0	0	0	0	0
Warmińsko-Mazurskie	1	1	1	1	1
Wielkopolskie	0	1	1	1	1
Zachodniopomorskie	0	0	0	0	0

Table 2. Number of patients in service type 15 — palliative and hospice care within the scope — 15.2181.028.02 perinatal palliative care in 2018–2022 (first half — H1) by voivodeship

Voivodeship	2018		2019		2020		2021	2022*
	F N = 2	M N = 293	F N = 1	M N = 480	F N = 1	M N = 503	M N = 465	M N = 119
Dolnośląskie	2	16	0	28	0	23	30	8
Kujawsko-Pomorskie	0	0	0	0	0	0	0	0
Lubelskie	0	5	0	10	0	10	13	4
Lubuskie	0	0	0	0	0	0	0	3
Łódzkie	0	6	0	8	0	15	13	5
Małopolskie	0	5	0	11	0	5	12	2
Mazowieckie	0	234	0	374	0	396	276	42
Opolskie	0	1	0	2	0	0	5	0
Podkarpackie	0	15	0	24	0	18	37	26
Podlaskie	0	0	0	1	0	3	5	1
Pomorskie	0	7	0	5	1	13	18	4
Śląskie	0	2	0	16	0	11	15	3
Świętokrzyskie	0	0	0	0	0	0	0	0
Warmińsko-Mazurskie	0	2	1	1	0	1	1	0
Wielkopolskie	0	0	0	0	0	8	40	21
Zachodniopomorskie	0	0	0	0	0	0	0	0

*Data for 6 months (January–June 2022)
M — Mother; F — Father

At the same time, it is not possible from the data obtained to calculate the actual amount of advice per patient receiving publicly funded PPC services. In each of the years analysed, more amount of psychologist counselling than medical advice was provided. At the same time, the number of services provided remained at a constant level over the years.

Challenges of perinatal palliative care

In Poland, publicly guaranteed PPC services are provided in 13 voivodeships, while this type of service is not provided in three voivodeships. Since 2018, there has been a steady increase in the number of women who receive PPC services after a prenatal diagnosis with a lethal prognosis. As part of these services, women are entitled to receive advice from a doctor and a psychologist. A woman receiving PPC services can also benefit from the care of PCM, who provides education to a woman diagnosed with LFA and patronage visits for the care of the postpartum woman — LFA. Funding for services provided by PCMs is based on contracts signed with entities for the provision of guaranteed primary care services. PPC focuses on respect for parents' preferences, acceptance of their choices, support for their involvement and respect for their child both before and after birth [31]. Two stages of PPC are described worldwide: hospital-based perinatal palliative care and community-based perinatal palliative care [32–34].

Hospital-based palliative care involves the care of the mother and the newborn baby, burdened with a diagnosis with a lethal prognosis. Interprofessional care of pregnant, parturient and postpartum women requires the involvement of a team of different specialities. Most of the care is provided to the mother by the obstetric team and to the newborn by the neonatal team. The mother can give birth in one hospital, and palliative services can be provided in another children's hospital [31]. Home-based hospice care for children, with a focus on the needs of the family, has a special place in community-based hospice care. According to the research, empathetic and compassionate care is important for parents, a new quality domain in home-based hospice care for children and palliative care for children. Being at home with a sick child provides relational and community-based care [35, 36].

As indicated in the description of the legal status, PPC in Poland can be provided in various types of centres and hospices. The scope of care is medical advice, psychological counselling and collaboration with service providers who can provide continuity of care, including the PCM [25]. Based on the data presented, there is a regional differentiation in terms of accessibility to services. In 2021, the problem was recognised by the Ministry of Health. The Department of Analysis and Strategy, in section 10 of "Palliative and hospice care" of its "Maps of Health Needs" document, recommended an increase in the accessibility to PPC for families requiring this type of care [29]. Furthermore, in the section "Key health needs and challenges of the organisation of the health system" of the National Transformation Plan, support for PPC by providing opportunities for psychological care for the family and dignified dying conditions for children with LFA are identified as priority measures. Out of the designed cross-regional measures, Measure 2.10.2 — Implementation of the "Palliative and hospice care" measure of the "Pro-life" family support programme — was accepted. It will result in increased accessibility to palliative and hospice care services for children requiring such care, including services for children with LFA [37].

According to the Order of the President of the National Health Fund, a woman can benefit from free PPC service at any facility with a contract with the National Health Fund in this respect, regardless of her place of residence. However, PPC is long-term care, so it can be very inconvenient or even impossible for a woman to receive PPC far away from where she lives. To enable midwives to provide PPC services, changes to postgraduate education, involving the development of a new curriculum for the specialist course "Palliative Care for Midwives" as well as updates to speciality training curricula to include topics in this area may be introduced.

The role of the midwife in perinatal palliative care

The international PPC standards emphasise the important role of the midwife in caring for a woman who continues her pregnancy after an adverse prenatal diagnosis. Midwives are closest to the woman during labour and are present throughout her hospital stay. During labour, they focus not only on providing physical care but also on fully engaging with the emotional and family issues of the woman, meeting her needs throughout the birth process. Studies reveal that well-implemented birth planning is associated with increased parental and family satisfaction, a better sense of control and less fear, anxiety and emotional distress [15, 38]. Midwives on the front line of care for this group of parents are in an ideal position to sensitively assess the needs of the parents and support them in saying goodbye. The support a mother receives after the death of her child is one of the most crucial elements in predicting the nature of the grieving process she will experience [39].

Table 3. Amount of medical and psychological advice within the scope of PPC services in 2018–2022 (H1) by type of advice and by voivodeship. National Health Fund data

Voivodeship	2018		2019		2020		2021		2022*	
	M	P	M	P	M	P	M	P	M	P
	N = 12	N = 47	N = 417	N = 604	N = 400	N = 514	N = 384	N = 616	N = 87	N = 149
Dolnośląskie	5	40	5	56	12	31	39	69	4	12
Kujawsko-Pomorskie	0	0	0	0	0	0	0	0	0	0
Lubelskie	0	0	10	10	10	10	13	13	4	4
Lubuskie	0	0	0	0	0	0	0	0	3	1
Łódzkie	5	5	10	7	12	12	10	10	4	2
Małopolskie	0	0	11	11	5	5	12	12	0	1
Mazowieckie	0	0	359	465	326	374	227	318	40	49
Opolskie	1	1	2	2	0	0	4	5	0	0
Podkarpackie	0	1	0	34	0	28	0	57	0	41
Podlaskie	0	0	1	1	2	7	3	10	1	1
Pomorskie	1	0	5	4	12	21	21	32	3	5
Śląskie	0	0	13	12	11	11	16	15	1	0
Świętokrzyskie	0	0	0	0	0	0	0	0	0	0
Warmińsko-Mazurskie	0	0	1	2	1	1	0	1	0	0
Wielkopolskie	0	0	0	0	9	14	39	74	27	33
Zachodniopomorskie	0	0	0	0	0	0	0	0	0	0

*Data for 6 months (January–June 2022)
M — medical advice and counselling; P — psychological advice

A significant disproportion can be observed in the National Health Fund data presented: with a relatively high percentage of medical and psychological advice, there is a low amount of midwifery advice in both antenatal education and patronage visits. This may be due to the lack of a standard of practice for PPC. In the underlying document, the "Regulation on guaranteed palliative and hospice care services", the possibility of midwifery care is not included. As a result, perinatal hospices do not employ midwives in their teams [23]. Furthermore, based on the "Regulation of the Minister of Health on guaranteed services in the area of primary health care" and "Order No. 79/2022/DSOZ of the President of the National Health Fund of 29 June 2022 on the terms and conditions for the conclusion and implementation of contracts for the provision of healthcare services in the primary healthcare setting", the PCM — in the case of women with a high-risk pregnancy with specific diagnosed foetal malformations — has the task of providing antenatal education for this group of women, including practical and theoretical preparation for childbirth [40, 41].

The data made available by the National Health Fund (Table 4) show that the highest number of visits were made by PCMs in 2019, providing care to 20 women diagnosed with LFA. In the first half of 2022, PCMs completed 57 visits, providing care to 15 women. Considering the administrative division of the country, the highest number of visits (40) related to a diagnosed lethal anomaly was given by PCMs to 16 women in the Wielkopolskie Voivodeship. In the Kujawsko-Pomorskie and Zachodniopomorskie voivodeships, despite the lack of facilities providing PPC, PCMs provided advice to women diagnosed with a lethal anomaly. In 2018–2022, PCMs performed a total of 23 educational/patronage visits in the Kujawsko-Pomorskie Voivodeship, providing care to 13 women. In the Zachodniopomorskie Voivodeship, PCMs provided care to two women, giving eleven pieces of advice/visits. In terms of the type of visit in 2018–2022, the highest number of visits by the PCM was related to providing care to postpartum women (n = 132). Most patronage visits were carried out by PCMs in 2019 (n = 41). The visits provided by the PCM, involving antenatal education for pregnant women in the period from 32 weeks gestation to delivery, represented the smallest number in 2019 and 2020 (n = 6). In contrast, the lowest number of educational visits provided by PCMs to pregnant women between 21 and 31 weeks gestation was in 2018 (n = 2) (Figure 1).

It should be recalled at this point that the midwife's task is to professionally prepare the woman after

Table 4. The number of patients and amount of advice from the primary care midwife (PCM) by type of visit: patronage visit of the PCM/visit for the care of the pregnant woman and postpartum woman — lethal foetal anomaly, by voivodeship. National Health Fund data

Voivodeship	2018		2019		2020		2021		2022*	
	No. of patients	No. of visits	No. of patients	No. of visits	No. of patients	No. of visits	No. of patients	No. of visits	No. of patients	No. of visits
	N = 11	N = 43	N = 20	N = 66	N = 17	N = 38	N = 22	N = 53	N = 15	N = 57
Dolnośląskie	0	0	4	10	0	0	5	12	0	0
Kujawsko-Pomorskie	1	1	2	2	4	10	5	9	1	1
Lubelskie	1	5	4	4	0	0	0	0	2	13
Lubuskie	3	14	1	4	0	0	0	0	0	0
Łódzkie	0	0	0	0	0	0	0	0	0	0
Małopolskie	0	0	1	6	2	5	2	9	3	12
Mazowieckie	2	3	1	14	0	0	0	0	1	1
Opolskie	0	0	0	0	0	0	0	0	0	0
Podkarpackie	2	10	0	0	1	4	2	2	1	8
Podlaskie	0	0	1	2	1	3	0	0	0	0
Pomorskie	0	0	1	9	0	0	0	0	4	18
Śląskie	0	0	0	0	1	4	0	0	0	0
Świętokrzyskie	0	0	0	0	0	0	0	0	0	0
Warmińsko-Mazurskie	1	5	0	0	4	4	1	1	1	1
Wielkopolskie	1	5	3	4	4	8	7	20	2	3
Zachodniopomorskie	0	0	2	11	0	0	0	0	0	0

No. of visits — includes the sum of antenatal education visits to a pregnant woman between 21 and 31 weeks gestation — lethal foetal anomaly, antenatal education visits to a pregnant woman from 32 weeks gestation to the date of delivery — lethal foetal anomaly and antenatal midwife patronage visits/visits for the care of the postpartum woman — lethal foetal anomaly
*Data for 6 months (January–June 2022)

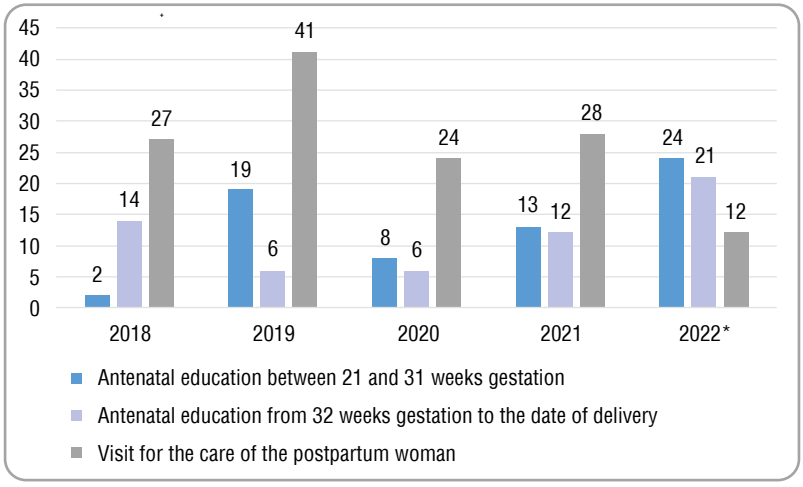

Figure 1. Amount of advice from the primary care midwife (PCM) involved in the care of a woman diagnosed with lethal foetal anomaly from 2018 to the first half of 2022

an adverse prenatal diagnosis to proceed by her wishes, expectations and religion (culture). The midwife accompanies the family during pregnancy by providing support and security and preparing for the birth. The essence of antenatal preparation is to make the parents aware of different scenarios and prepare them for the birth of a stillborn or dying child. The necessary knowledge about the physiology of pregnancy and the course of childbirth should be given to these parents by the midwife providing care as part

of the hospice activities. Preparation of parents for childbirth should include a discussion of the stages of labour, options for labour pain relief and birthing positions, learning breathing techniques, and lactation management in the postpartum period [42, 43]. The inclusion of a midwife in the PPC team would fill a gap in the process of care for parents who continue a pregnancy after a diagnosis of a lethal anomaly. The lack of uniform standards of practice in Poland hinders professional, continuous care for the woman and her family after an adverse prenatal diagnosis. Institutions providing hospice perinatal care have developed their own models of care [44]; however, these do not include midwifery care.

The Polish primary health care (PHC) system provides a minimum of four home visits after childbirth, carried out by a midwife. Women following an adverse prenatal diagnosis are not excluded from such services. At the same time, practice shows that these women do not benefit from this support, or they are provided with such care only to a minimal extent in several voivodeships [40, 41]. Given individual needs and opportunities in accessing services, it is worthwhile to provide midwifery care to women both in the PHC and PPC setting. Currently, the lack of a midwife in PPC means that for the preparation of childbirth, a woman with a prenatally diagnosed lethal anomaly can only access the PCM or hospital outpatient clinic midwife, who does not cooperate with PPC. The optimal solution, ensuring continuity of care from diagnosis to delivery and postpartum, would be to allow midwives to work in a perinatal hospice.

Conclusions

In conclusion, the accessibility to perinatal palliative care (PPC) is insufficient, as confirmed by the results of the analysis and by the entries in the 2020 Maps of Health Needs document and the 2019 National Transformation Plan. There are disparities in access to publicly funded PPC facilities for women/families after an adverse prenatal diagnosis. There are still no PPC facilities in the three voivodeships. A key element is to optimise the PPC system by increasing the number of medical facilities; introducing a midwife into the PPC team, whose range of services will ensure continuity of perinatal care; and adopting a uniform standard of practice in PPC, including the provision of services in prenatal hospices, hospitals and home settings. The introduction of a midwife to the PPC team will increase the accessibility to PPC services in Poland. The adoption of the PPC standard of practice and the employment of midwives in PPC facilities will allow all PPC facilities to provide equal services and ensure that women receive obstetric care from the moment they receive an adverse diagnosis, through professional preparation for childbirth, and delivery to the postnatal period.

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Declaration of conflict of interests

The authors declare that there is no conflict of interests.

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References

1. Wool C. Systematic review of the literature: parental outcomes after diagnosis of fetal anomaly. Adv Neonatal Care. 2011; 11(3): 182–192, doi: 10.1097/ANC.0b013e31821bd92d, indexed in Pubmed: 21730912.
2. Wool C. Clinician confidence and comfort in providing perinatal palliative care. J Obstet Gynecol Neonatal Nurs. 2013; 42(1): 48–58, doi: 10.1111/j.1552-6909.2012.01432.x, indexed in Pubmed: 23181399.
3. Sun S, Yang M, Zhang J, et al. Family support for pregnant women with foetal abnormality requiring pregnancy termination in China. Health Soc Care Community. 2020; 28(3): 1020–1029, doi: 10.1111/hsc.12935, indexed in Pubmed: 31919920.
4. Best S, Wou K, Vora N, et al. Promises, pitfalls and practicalities of prenatal whole exome sequencing. Prenat Diagn. 2018; 38(1): 10–19, doi: 10.1002/pd.5102, indexed in Pubmed: 28654730.
5. Ramesh A, Parvathi VD. Prenatal diagnosis: A connotation on genetic counseling being indispensable. Indian J Public Health. 2020; 64(1): 83–85, doi: 10.4103/ijph.IJPH_116_19, indexed in Pubmed: 32189690.
6. Korzeniewska-Eksterowicz A, Respondek-Liberska M, Przysło Ł, et al. Perinatal palliative care: barriers and attitudes of neonatologists and nurses in Poland. ScientificWorldJournal. 2013; 2013: 168060, doi: 10.1155/2013/168060, indexed in Pubmed: 24288459.
7. Castańeda J, Oberszyn E. Wrodzone wady rozwojowe, zesoły genetyczne, wady letalne — możliwości diagnostyczne, roblemy kliniczne. Praktyka kliniczna, Etyka, Prawo, Psychologia. In: Rutkowska M, Szczepaniak S. ed. Postępowanie paliatywne w opiece perinatalnej. PZWL Wydawnictwo Lekarskie, Warszawa 2018: 47–65.
8. Jones K, Baird K, Fenwick J. Women's experiences of labour and birth when having a termination of pregnancy for fetal abnormality in the second trimester of pregnancy: A qualitative meta-synthesis. Midwifery. 2017; 50: 42–54, doi: 10.1016/j.midw.2017.03.014, indexed in Pubmed: 28388456.
9. Kamranpour B, Noroozi M, Bahrami M. Supportive needs of women who have experienced pregnancy termination due to fetal abnormalities: a qualitative study from the perspective of women, men and healthcare providers in Iran.

BMC Public Health. 2019; 19(1): 507, doi: 10.1186/s12889-019-6851-9, indexed in Pubmed: 31053091.
10. Cope H, Garrett ME, Gregory S, et al. Pregnancy continuation and organizational religious activity following prenatal diagnosis of a lethal fetal defect are associated with improved psychological outcome. Prenat Diagn. 2015; 35(8): 761–768, doi: 10.1002/pd.4603, indexed in Pubmed: 25872901.
11. Wyrok Trybunału Konstytucyjnego z dnia 22 października 2020 r. sygn. akt K 1/20 Ruling of the Constitutional Court [Internet]. 2020. https://isap.sejm.gov.pl/isap.nsf/DocDetails.xsp?id=WDU20210000175 (5.01.2023).
12. Côté-Arsenault D, Denney-Koelsch E. "Have no regrets:" Parents' experiences and developmental tasks in pregnancy with a lethal fetal diagnosis. Soc Sci Med. 2016; 154: 100–109, doi: 10.1016/j.socscimed.2016.02.033, indexed in Pubmed: 26954999.
13. Côté-Arsenault D, Denney-Koelsch E. "Love is a choice": couple responses to continuing pregnancy with a lethal fetal diagnosis. Illness, Crisis & Loss. 2017; 26(1): 5–22, doi: 10.1177/1054137317740798.
14. Tataj-Puzyna U, Węgrzynowska M, Ryś M, et al. "This pregnancy makes sense": Experiences of women who have decided to continue pregnancy after lethal fetal diagnosis. Death Stud. 2023; 47(2): 149–158, doi: 10.1080/07481187.2022.2038310, indexed in Pubmed: 35201971.
15. Cole JCM, Moldenhauer JS, Jones TR, et al. et al.. A proposed model for perinatal palliative care. J Obstet Gynecol Neonatal Nurs. 2017; 46(6): 904–911, doi: 10.1016/j.jogn.2017.01.014, indexed in Pubmed: 28602660.
16. Fleming V, Iljuschin I, Pehlke-Milde J, et al. Dying at life's beginning: Experiences of parents and health professionals in Switzerland when an 'in utero' diagnosis incompatible with life is made. Midwifery. 2016; 34: 23–29, doi: 10.1016/j.midw.2016.01.014, indexed in Pubmed: 26971444.
17. Côté-Arsenault D, Denney-Koelsch E. "My baby is a person": parents' experiences with life-threatening fetal diagnosis. J Palliat Med. 2011; 14(12): 1302–1308, doi: 10.1089/jpm.2011.0165, indexed in Pubmed: 22077542.
18. Crawford A, Hopkin A, Rindler M, et al. Women's experiences with palliative care during pregnancy. J Obstet Gynecol Neonatal Nurs. 2021; 50(4): 402–411, doi: 10.1016/j.jogn.2021.02.009, indexed in Pubmed: 33775641.
19. Wool C. State of the science on perinatal palliative care. J Obstet Gynecol Neonatal Nurs. 2013; 42(3): 372–82; quiz E54, doi: 10.1111/1552-6909.12034, indexed in Pubmed: 23578106.
20. Kobler K, Limbo R. Making a case: creating a perinatal palliative care service using a perinatal bereavement program model. J Perinat Neonatal Nurs. 2011; 25(1): 32–41; quiz 42, doi: 10.1097/JPN.0b013e3181fb592e, indexed in Pubmed: 21311267.
21. Jalowska A, Krzeszowiak J, Stembalska A, et al. [Perinatal palliative care performed in obstetrics and neonatology wards and hospices for children - own experience]. Dev Period Med. 2019; 23(4): 253–262, indexed in Pubmed: 31913141.
22. Martín-Ancel A, Pérez-Muñuzuri A, González-Pachec N, et al. Perinatal palliative care. Anales Pediatría; 96(1): 60.e1–60.e7, doi: 10.1016/j.anpede.2021.10.003.
23. Rozporządzenie Ministra Zdrowia z dnia 31 stycznia 2017 r. zmieniające rozporządzenie w sprawie świadczeń gwarantowanych z zakresu opieki paliatywnej i hospicyjnej. Dz. U. z 2017r., poz. 236 2017.
24. Komunikat Prezesa Narodowego Funduszu Zdrowia z dnia 6 lipca 2022 r. dotyczący perinatalnej opieki paliatywnej.
25. Obwieszczenie Ministra Zdrowia z dnia 17 grudnia 2021 w sprawie jednloitego tekstu rozporządzenia Ministra Zdrowia w sprawie świadczeń gwarantowanych z zakresu opieki paliatywnej i hospicyjnej (Dz.U. 2021 poz. 262). 262 Dec 17, 2021.
26. Ciałkowska-Rysz A. An appraisal of the situation of palliative care in Poland in 2018. Palliattive Medicine. 2019; 11(4): 163–169, doi: https://doi.org/10.5114/pm.2019.93184.
27. Dzierżanowski T. Accessibility of palliative care for adults in Poland. Palliative Medicine. 2020; 12(2): 75–83, doi: 10.5114/pm.2020.97405.
28. Sobolewska E, Harasim-Piszczatowska E, Kułak-Bejda A, et al. Perinatal hospice – is there a need for such units to function in the opinion of Polish society? Palliative Medicine. 2021; 13(3): 145–152, doi: https://doi.org/10.5114/mp.2021.108692.
29. Obwieszczenie Ministra Zdrowia z dnia 27 sierpnia 2021 r. w sprawie mapy potrzeb zdrowotnych na okres od 1 stycznia 2022 r. do 31 grudnia 2026 r.
30. Rozporządzenie Ministra Zdrowia z dnia 29 października 2013 r. w sprawie świadczeń gwarantowanych z zakresu opieki paliatywnej i hospicyjnej (t.j. Dz. U. z 2018r., poz.742). Dz. U. z 2018r., poz.742 2013.
31. Denney-Koelsch E, Black BP, Côté-Arsenault D, et al. A survey of perinatal palliative care programs in the united states: structure, processes, and outcomes. J Palliat Med. 2016; 19(10): 1080–1086, doi: 10.1089/jpm.2015.0536, indexed in Pubmed: 27559768.
32. Ziegler TR, Kuebelbeck A. Close to home: perinatal palliative care in a community hospital. Adv Neonatal Care. 2020; 20(3): 196–203, doi: 10.1097/ANC.0000000000000732, indexed in Pubmed: 32384326.
33. Denney-Koelsch EM, Côté-Arsenault D. Perinatal Palliative Care. A Clinical Guide. Springer Cham, Switzerland 2020: Available from: http://link.springer.com/10.1007/978-3-030-34751-2.
34. Kuchemba-Hunter J. Compassion and community in perinatal palliative care: understanding the necessity of the patient perspective through narrative illustration. J Palliat Care. 2019; 34(3): 160–163, doi: 10.1177/0825859719827020, indexed in Pubmed: 30776963.
35. Thienprayoon R, Grossoehme D, Humphrey L, et al. "There's just no way to help, and they did." parents name compassionate care as a new domain of quality in pediatric home-based hospice and palliative care. J Palliat Med. 2020; 23(6): 767–776, doi: 10.1089/jpm.2019.0418, indexed in Pubmed: 31880492.
36. Weaver MS, October T, Feudtner C, et al. "Good-Parent beliefs": research, concept, and clinical practice. Pediatrics. 2020; 145(6): e20194018, doi: 10.1542/peds.2019-4018, indexed in Pubmed: 32439815.
37. Obwieszczenie Ministra Zdrowia z dnia 15 października 2021 r. w sprawie krajowego planu transformacji (Dz. U. z 2021r., poz. 80).
38. Wool C, Côté-Arsenault D, Perry Black B, et al. Provision of services in perinatal palliative care: a multicenter survey in the united states. J Palliat Med. 2016; 19(3): 279–285, doi: 10.1089/jpm.2015.0266, indexed in Pubmed: 26652200.
39. Kelley MC, Trinidad SB. Silent loss and the clinical encounter: Parents' and physicians' experiences of stillbirth-a qualitative analysis. BMC Pregnancy Childbirth. 2012; 12(1): 137, doi: 10.1186/1471-2393-12-137, indexed in Pubmed: 23181615.
40. Zarządzenie NR 79/2022/DSOZ Prezesa Narodowego Funduszu Zdrowia z dnia 29 czerwca 2022 r. w sprawie warunków zawarcia i realizacji umów o udzielanie świadczeń opieki zdrowotnej w rodzaju podstawowa opieka zdrowotna. NR 79/2022/DSOZ 2022.

41. Rozporządzenie Ministra Zdrowia z dnia 24 września 2013 r. w sprawie świadczeń gwarantowanych z zakresu podstawowej opieki zdrowotnej (t.j. z 2021 r. poz. 540. t. j. z 2021r., poz. 540 2013.
42. Poryszewska A, Stefaniak M, Dmoch-Gajzlerska E, et al. Role and tasks of the midwife as a member of the hospice perinatal care team. Kwartalnik Naukowy Fides et Ratio. 2022; 3(51): 84–94, doi: 10.34766/fetr.v3i51.793.
43. Krzeszowiak J, Śmigiel R. The role and tasks of a midwife as a team member who takes care of the pregnant patient diagnosed with lethal fetal defect. Nursing Public Health. 2016; 6(1): 57–61, doi: 10.17219/pzp/61828.
44. Dangel T, Biały B. Standards and medical procedures for pediatric palliative home care in hospices for children. Standards for perinatal palliative care. Warsaw: The Warsaw Hospice for Children Foundation; 2019.