Korzeniewska-Eksterowicz *et al. BMC Palliative Care* (2025) 24:38
https://doi.org/10.1186/s12904-025-01671-z

BMC Palliative Care

RESEARCH **Open Access**

Outcomes of delivery in patients with diagnosed life-limiting fetal condition and evaluation of perinatal palliative care program: a retrospective review of palliative care service over 7 years

Aleksandra Korzeniewska-Eksterowicz[1,2*], Hanna Moczulska[3], Mariusz Grzesiak[4,5] and Piotr Kaczmarek[6]

Abstract

Background The parents with a diagnosis of life-limiting fetal condition should receive medical information about the nature of defect, prognosis, possibilities of care and obstetric complications and receive psychological, spiritual, legal support. In our model of care, the perinatal hospice - functioning outside the hospital structure - offers a multidisciplinary support and coordinates care in close cooperation with hospitals. The aims of study are: analysis of the birth outcome in patients with life-limiting fetal conditions, perinatal palliative care model evaluation and analysis of factors affecting earlier contact of patients with perinatal hospice.

Methods We conducted retrospective reviews of medical records of perinatal hospice patients in 2014–2020. The study population was divided into two groups. Group 1 comprised deliveries which ended with the birth of a living newborn; Group 2: pregnancies with intrauterine fetal death and death during delivery. Separately, we analysed patients who underwent cesarean birth.

Results Out of 72 families, 68 decided to continue pregnancy. The most common diagnoses were trisomies 18 and 13. In 47 cases, deliveries resulted in a live-born newborn; in 21 pregnancies, fetal death occurred. Nineteen pregnancies were delivered via cesarean on obstetric indications. The time interval from diagnosis to first palliative consultation was, on average, 48 days in group 1 vs. 33 in group 2. Women with stillbirths contacted the hospice at an earlier stage of pregnancy ($p = 0.0469$), and multidisciplinary team consultation in the hospital took place earlier ($p = 0.0045$) and in a shorter time interval from the first consultation in hospice ($p = 0.0298$). Patients who were older and lived in large cities contacted hospice earlier.

Conclusion System solutions should be considered, obliging the physician to refer the pregnant woman to a perinatal palliative care program. Shortening the interval between diagnosis and palliative care consultation would allow for more effective professional support and more time to prepare the parents for losing a child.

---

*Correspondence:
Aleksandra Korzeniewska-Eksterowicz
aleksandra.korzeniewska-eksterowicz@umed.lodz.pl

Full list of author information is available at the end of the article

Keywords Prenatal diagnosis, Perinatal hospice, Life-limiting fetal condition

Introduction

Perinatal palliative care (PPC) is a branch of medicine dedicated to families where, in the course of prenatal studies, a life-limiting fetal condition (LLFC) is diagnosed. The current literature suggests that PPC programs may be comprehensive, initiated early, and integrative [1, 2]. PPC should be conducted by an interdisciplinary specialist team from prenatal diagnosis throughout the pregnancy, birth and postpartum; it includes the care of newborns and infants [1–4]. The parents with a LLFC diagnosis should receive comprehensive medical information about the nature of the defect, prognosis, and possibilities of care and receive psychological and legal support [5]. Consultations should include possible obstetric complications and management plans [3, 6–8].

Perinatal palliative care program

Our Pediatric Palliative Care Center has been operating since 2005. The structure of the center includes a home-based pediatric palliative team (home hospice), a stationary pediatric hospice and a PPC team. PPC team support is realized in the outpatient consultation system, but the context of Polish health system such support is called perinatal hospice (PH). The establishment of PH was a consequence of our experience with home-based pediatric palliative. In 2005—2011, fifty-three neonates and infants were admitted to our home hospice, but none of the families had been informed during the pregnancy about the possibility of PPC [9]. There are 14 perinatal hospices in Poland, and organisations with pediatric palliative home care experience created them. So far, however, no national standard for PPC has been developed, and each center develops its model of care adapted to local needs and conditions [10, 11].

Most publications on PPC talk about hospital-based care, mainly in obstetrics and neonatal centres or wards [3, 4, 12–16]. In our model, the PH - functioning outside the hospital structure - offers multidisciplinary support and coordinates care in close cooperation with hospitals. When developing the assumptions of the PPC model, we followed the document drawn up by the British Association of Perinatal Medicine entitled “Framework for Clinical Practice in Perinatal Medicine” [17]. PH team consists of multidisciplinary professionals: pediatric palliative care physicians, obstetrics and genetic consultants, a midwife, a psychologist, a social worker, a chaplain and a bereavement photographer. The number, frequency and type of consultations are determined individually for each family. During prenatal care, the PH physician arranges multidisciplinary team consultations at the hospital. The parents, PH physician and psychologist, hospital obstetrician, neonatologist, midwife and psychologist participate in the meeting. During multidisciplinary team consultation the individualized birth plan is discussed before delivery and included the following elements: intrapartum fetal monitoring, mode of delivery (including cesarean delivery for fetal or maternal indications), and plans for assessment and care of the newborn. After the consultation, a protocol is prepared in three copies: for parents, for the hospital and for HP. Close cooperation between PH and hospital teams is possible thanks to the appointment of a PPC coordinator in the hospital; usually, it is a midwife. We offer each family the opportunity to take pictures by a professional photographer immediately after the delivery. In the case of the child’s death at the hospital, the parents receive adequate psychological, social and spiritual support, which is continued during the bereavement period. If a child can be discharged from the hospital, the family is admitted - depending on the needs – to our home or stationary hospice. Rules for palliative care in neonatal units were developed based on the Standards of Medical Care for Newborns in Poland (Polish Neonatal Society) where the management protocol after the diagnosis of LLC was included [18]. Pregnancy management was conducted in accordance with the guidelines of The Polish Society Of Gynecologists And Obstetricians (formerly The Polish Society Of Gynecologists). Earlier recommendations (2011 and 2020) included screening ultrasound diagnostics for all pregnant women between 11 and 13 + 6 weeks of pregnancy and then between 18 and 22 and 28–32 weeks. Current Recommendations (2022) included combined test and NIPT as first-trimester screening all pregnant women [19]. Any abnormality or its suspicion is an indication for fetal examination at a reference center.

The primary aim of the study is retrospective analysis of the birth outcome in patients with LLFC; the secondary aims are: to review the organizational experience at our center over 7 years and to analyse factors affecting earlier contact of patients with PH. We sought to better understand the pattern of antenatal referrals and the role that a social and medical factors can play in supporting families after LLFC diagnosis.

Materials and methods

We conducted retrospective reviews of medical records to obtain demographic and clinical data about women under the care of PH between September 1, 2014, and December 31, 2020.

The following variables were extracted from the medical records: maternal age (years); place of residence; clinical information (fetal diagnosis, obstetric history, family history); and follow-up information (period from confirmed diagnosis to initial referral (days), period from reporting to the multidisciplinary team consultation in the hospital (days), period from multidisciplinary team consultation to birth (days); gestation at delivery (weeks), type of delivery, death of the child, time of death, extract from the neonatal ward, duration, and model of postnatal palliative care). The study population was divided into two groups regardless of the birth mode. Group 1 comprised births of a living newborn. Group 2 comprised pregnancies with intrauterine fetal death (IUFD) or death during delivery. Separately, we analysed patients who underwent cesarean birth. Women who decided on induced abortion were included only to descriptive statistics .

Statistical analysis

Statistica 13.3 (StatSoft) was used to analyse the obtained data. Chi2 analysis was used in the study of the dichotomous data. For the analysis variability between mean age, time of diagnosis, hospice application, and delivery, Student t-test and U Mann-Whitney test were used. The decision to use the test depended on the normality of distribution (Shapiro-Wilk test) and equality of variance. Values ≤ 0.05 were considered statistically significant.

GraphPad Prism was used to create the charts.

Results

Study population characteristics

Within the analysed period, 72 women contacted PH. Patients were referred to the PH after the diagnosis of LLFC; all have been referred before the delivery (liveborn or stillbirth) The characteristics of the whole group are presented in Table 1. Four twin pregnancies were included in the study population, considering the diagnosis of a LLFC in one of the twins in 3 cases and one case with conjoined twins with no possibility of separation.

The largest group ($n = 24$, 33%) were pregnant women with trisomy diagnosed in the fetus: 17 cases of trisomy 18, 5 of trisomy 13 and 2 trisomy 21.

In the studied group of 72 couples, 68 decided to continue the pregnancy, and four decided on induced abortion. In 47 cases, births resulted in a live newborn (group 1). In 21 pregnancies (30.8%), IUFD or intra-delivery death occurred (group 2). In 19 cases, pregnancy was delivered via cesarean section; in two instances, the fetus died during surgical birth. The structure of diagnoses and mode of deliveries have been presented in Fig. 1. All 68 families consented to take photos; a professional photographer took pictures of 54 families, and 6 families were photographed by hospital staff or themselves.

Characteristics of Group 1

Group 1 constituted 65% ($n = 47$) of the whole studied population. The characteristics of Group 1 have been presented in Table 2. Multidisciplinary team consultation was conducted in 36 (77%) patients. A consultation was not carried out due to the mother's residence in a different region in 6 cases, due to late admission to the hospice (after the 37th week of pregnancy in 3 cases and in 2 cases patients cancelled consultation.

LLFCs were diagnosed in 42 live newborns, mainly with trisomy 13 and 18 (Fig. 1); 26 died on the first day of life, 10 within the first week, and the remaining six lived from 15 to 262 days (Fig. 2). Palliative care was implemented after delivery in all 42 children with LLFC; 38 children died in the hospital, and four were discharged from the hospital to our stationary (3 children) and home (1 child) hospices. Life-threatening conditions were diagnosed in 5 newborns (2 x trisomy 21, 1 x heart defect, 1 x spina bifida, 1 x Turner syndrome), and after delivery, they did not require hospice care.

One family had a positive family history of defects (Matthew-Wood syndrome); in 12 cases, previous pregnancies ended with miscarriage below 13 weeks of gestation.

Table 1 The characteristics of the whole study group

	Number of patients	mean ± SD	minimum	maximum
Age (years)	72	32.44 ± 5,98	19,00	44,00
Suspicion of LLFC (gestational week)	72	15,40 ± 4,30	11.00	30.00
Amniocentesis/other invasive procedure (gestational week)	50	17.56 ± 4.53	13.00	30.00
Final diagnosis (gestational week)	72	19.19 ± 4.88	12.00	32.00
First consultation in PH (gestational week)	72	24.72 ± 6.50	13.00	39.00
Multidisciplinary team consultation in the hospital (gestational week)	50	28.02 ± 5.73	17.00	38.00
Period from diagnosis to the first consultation in PH (days)	72	42.28 ± 35.44	1.00	156.00
Period from the first consultation in PH to multidisciplinary team consultation in the hospital (days)	50	22.08 ± 28.79	1.00	146.00
Birth (gestational week)	71	33.79 ± 6.73	19.00	41.00
Period from multidisciplinary team consultation in the hospital to birth (days)	50	6.70 ± 5.17	1.00	22.00

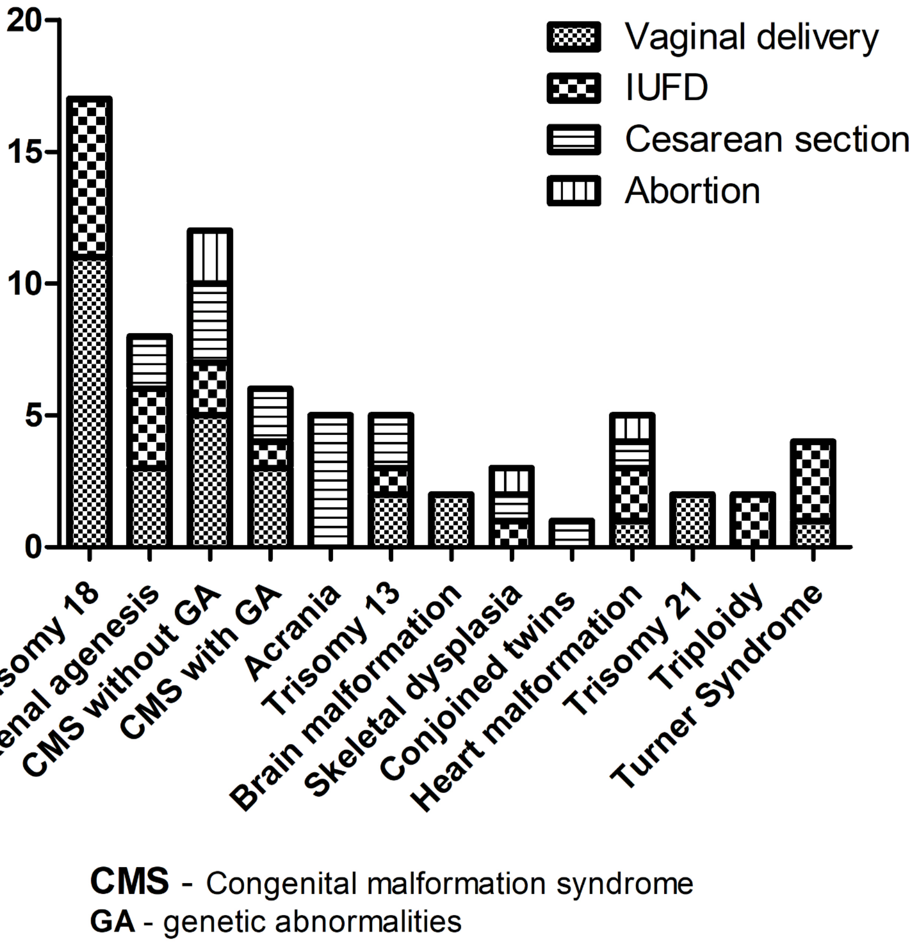

Fig. 1 The structure of diagnoses and mode of birth

Table 2 Comparative characteristics of group 1 and 2

	Number of patients	Group 1 mean ± SD	Number of patients	Group 2 mean ± SD	*P* value
Age (years)	47	30.89 ± 5.73	21	35.90 ± 5.74	0.0014
Suspicion of LLFC (gestational week)	47	15.47 ± 4.65	21	15.43 ± 3.78	0.9728
Amniocentesis/other invasive procedure (gestational week)	32	18.19 ± 4.95	16	16.50 ± 3.72	0.2359
Final diagnosis (gestational week)	47	19.62 ± 5.42	18	18.39 ± 3.45	0.4715
First consultation in PH (gestational week)	47	26.21 ± 6.54	21	22.90 ± 5.43	0.0469
Multidisciplinary team consultation in the hospital (gestational week)	36	29.69 ± 5.10	12	24.67 ± 4.91	0.0045
Period from diagnosis to the first consultation in PH (days)	47	48.77 ± 37.47	21	33.76 ± 29.14	0.1087
Period from the first consultation in PH to multidisciplinary team consultation in the hospital (days)	36	26.89 ± 32.57	12	9.75 ± 6.66	0.0298
Birth (gestational week)	47	37.51 ± 2.70	20	27.80 ± 6.08	< 0.0001
Period from multidisciplinary team consultation in the hospital to birth (days)	36	7.86 ± 5.31	12	4.00 ± 3.62	0.0239

In the studied group, 30 pregnancies were vaginally delivered; pre-term birth occurred in 4 cases. Seventeen pregnancies were delivered by cesarean.

Table 2. Comparative characteristics of groups 1 and 2.

Characteristics of group 2

In 19 women, intrauterine fetal death (IUFD) occurred, and in 2 pregnancies delivered by cesarean, intra-delivery death occurred. All deaths were observed after 20 weeks of gestation (mean ± SD; 27.8 ± 6.08; min 21, max 39). There were 6 IUFDs in the second trimester and 13 in the third trimester. Multidisciplinary team consultation was conducted in 12(57%) patients. In 3 cases, patients cancelled consultation; in the remaining cases, IUFD occurred before the scheduled consultation date. Characteristics of the group 2 has been presented in Table 2.

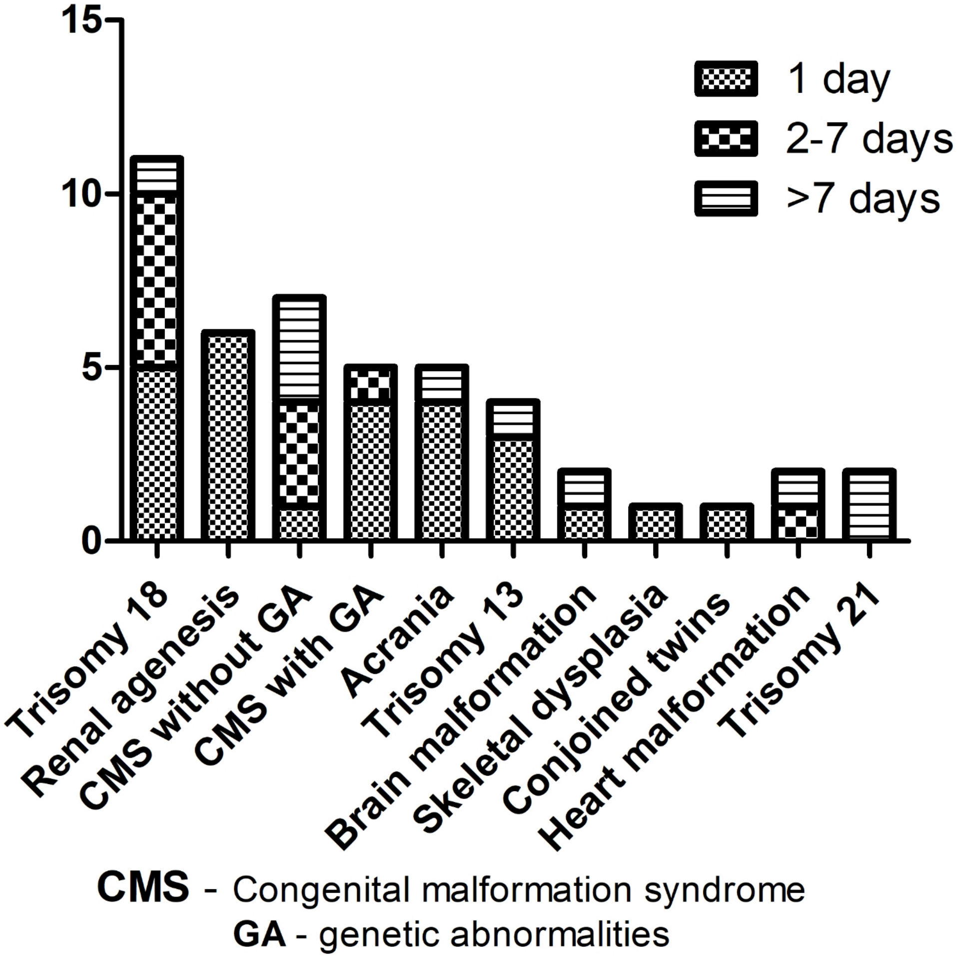

Fig. 2 Survival in the group of live-born newborns

None of the families had a positive family history of defects, but in 3 cases, previous pregnancies ended with miscarriage below 13 weeks of gestation. In 16 women, invasive diagnostics were performed, and in 14 cases, the genetic background of the diagnosed abnormalities was confirmed - the most common diagnosis was trisomy 18. In all 19 women, the vaginal birth was induced without complications.

Comparative characteristics of groups 1 and 2

Women who gave birth to a live newborn were younger than those in group 2 ($p = 0.0014$). Women with stillbirths contacted the hospice earlier in pregnancy ($p = 0.0469$). It was also noted that in group 2, the time from the initial diagnosis to the first PH consultation was shorter (on average, 33 vs. 48 days), but this difference was not statistically significant. In group 2, multidisciplinary team consultation in the hospital occurred at an earlier stage of pregnancy ($p = 0.0045$) and in a shorter time interval from the first consultation in PH ($p = 0.0298$). In group 2, the period from multidisciplinary team consultation to delivery was also significantly shorter (on average 4 vs. 7 weeks; $p = 0.0239$).

Analysis of factors affecting earlier contact of patients with PH

The criterion of early contact with PH was 21 days from the diagnosis of fetus abnormality. Twenty-two women fulfilled this criterion. The analysis showed a correlation between early contact with PH and place of residence ($p = 0.0375$) and age of pregnant women ($p = 0.0342$). Women who were older and lived in large cities contacted PH earlier (Fig. 3). In the case of women who came to PH earlier, consultation at PH was organized at an earlier stage of pregnancy ($p = 0.0347$), but the period from PH contact to hospital case conference was longer ($p = 0.0325$).

Pregnancies delivered by caesarean

Cesarean birth was performed in 19 cases; in 2 of these patients, the fetus died during the procedure. Caesarean deliveries were performed between 25 and 41 weeks of gestation (35.53 ± 4.06). Women came for the

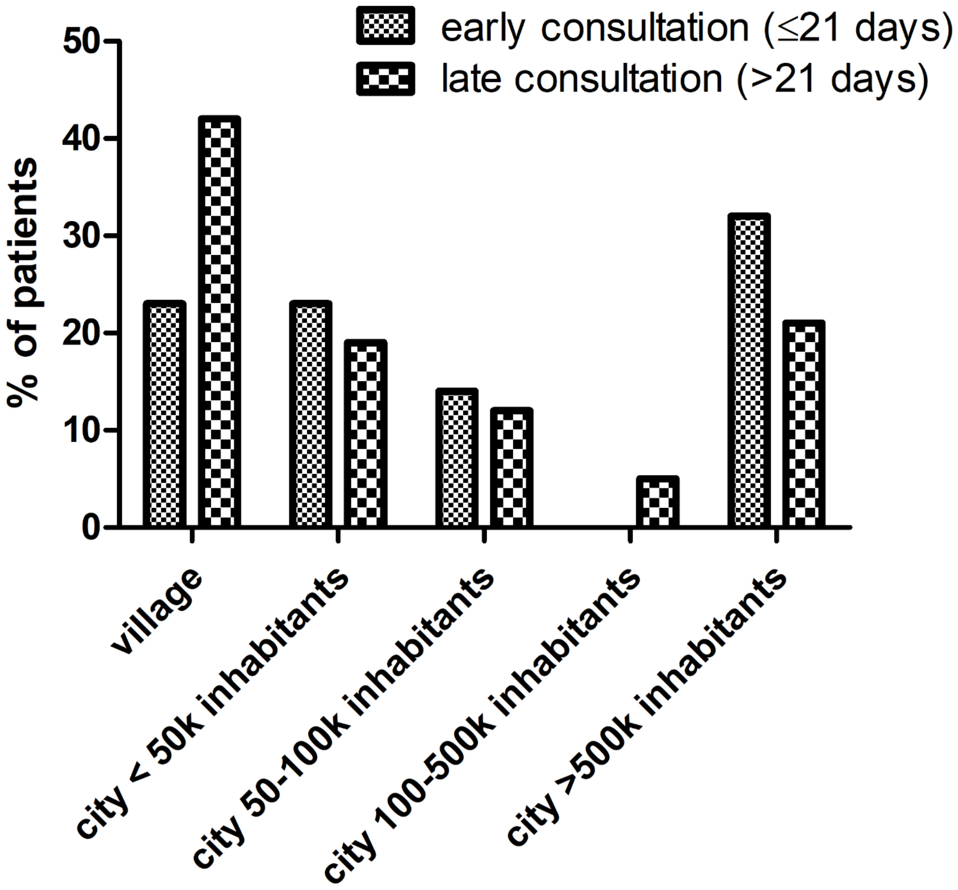

Fig. 3 Correlation between early contact with PH and place of residence

first PH consultation on average 50 days after diagnosis (50.37 ± 40.96, min 5 days, max 156 days). Two women had a previous cesarean birth.

In 5 cases, indications for cesarean birth were lack of labour progress due to acrania of the fetus. There were four pre-term cesarean births in twin pregnancies. In 3 of them, one of the twins had LLFC diagnosed (2 x renal agenesis, 1 x congenital syndrome); the 4th pregnancy was with conjoined twins with no possibility of separation. In one of the above pregnancies, urgent cesarean birth was necessary due to the separation of the placenta (the twin with abnormality born with no life signs). Two other twin pregnancies were complicated by hypertension.

In 4 single pregnancies, pre-term cesarean birth was performed due to placenta separation ($n = 2$; 1 child was born with no life signs) and hypertension ($n = 2$).

In 5 cases, elective cesarean birth was planned. The first newborn with a heart defect was finally qualified for cardiac surgery. In the second case, the woman was diagnosed with obesity, hypertension and diabetes, and her previous pregnancy was also delivered by cesarean. In the remaining 3 patients, cesarean birth was scheduled due to (1) SMA type III in the woman and previous cesarean birth, and cephalopelvic disproportion due to (2) hydrocephalus and (3) myeloencephalocoele. There were no complications after the procedure.

Discussion

Consultation with parents after prenatal diagnosis of a LLFC is a considerable challenge [12]. It should be a planned process involving medical, psychological and spiritual aspects. Individual management plans and systematic evaluation of the pregnancy progress decrease the risk of potential complications and protect the newborn with a LLC from futile therapy [7, 17, 18].

Data presented in the study show that 94% of the women contacting PH had fetuses with diagnosed LLFC. The largest group of defects – similar to observations of other authors – were trisomy 13 and 18 [8, 20–22]. In a few cases, life-threatening conditions were diagnosed, and neonates did not require hospice care after the birth. These pregnancies were monitored in a specialist reference center; families were included in the PPC program because of the need for close cooperation of specialists and the parents' preparation for various pregnancy scenarios. In these cases, the final decision on further corrective or conservative treatment was made after the birth. The situation in which pregnant women with an ambiguous diagnosis are admitted to the PPC program is not surprising and confirms the observations of other authors that some of the neonates do not require palliative care after birth [13, 22–24]. Compared to data from other authors, it seems that in our model, patients contact PH earlier [22, 25].

In the studied group every 3rd pregnancy ended with IUFD, which should not be surprising, considering the diagnoses. Genetic defects, particularly trisomy 18 and 13, 45,X and triploidy, are among the strongest risk factors of IUFD [8, 20, 21]. When the information about diagnosed defects is delivered to the parents, the risk of IUFD should be discussed, and they should be directed to PH immediately after the diagnosis. In cases of IUFD described in this study, the first hospice consultation took place on average 33 days from the diagnosis. In the authors' opinion, this time interval should be shorter, giving more time to prepare the parents for possible IUFD. Notably, however, these women contacted PH earlier than those who gave birth to a living newborn. The period from diagnosis to the first PH consultation was also shorter in this group. The earlier timing of PH consultation for women in Group 2 "could" indicate that their healthcare professionals urged them to present for consultation due to expecting a high risk of IUFD. This hypothesis deserve for further prospective research looking at.

at the decision making process following the diagnosis of LLFC. Our results show that if women entered PH care, hospital multidisciplinary team consultation was arranged in a short time. This observation confirms the effective and efficient cooperation between PH and hospitals. The authors introduced the PPC program initially through educational and promotional activities, which probably allowed them to avoid organizational problems and barriers described by other authors [4, 7, 12, 13, 26]. According to current standards, a woman who contacts PH gets personalized, individual management adjusted to her needs, health condition and fetal diagnosis. Creating a cooperation model between the hospital and PH teams increases the safety and comfort of the consulted parents and the medical staff. The findings of the multidisciplinary team consultation take the form of an official protocol; the family knows where to go and can be admitted to the hospital in any situation, and the staff has clear recommendation regarding the treatment of the mother and child. It should be noted, however, that – in our opinion - the crucial and weakest point in the whole system is too long period from diagnosis to the first PH contact and consultation. In the study, we demonstrated that women from rural areas and small cities contact PH later than those from large centers. the later timing of PH consultation could indicate cultural and social differences as well as the smaller availability of specialist care in those areas. For the purpose of our another study (not published data) we collected statistical data from our region and estimated the number of patients who could be referred to the PPC program - on average, only 16% of potentially eligible patients entered the PPC program and it is unsatisfactory, There is a need for activities to increase the wider public's awareness and knowledge about the availability of PH care among physicians and midwives outside of large centers. So far, in Poland, no scientific society or Ministry of Health has developed official PPC management standards. Current standards of the Polish Society of Gynaecologists and Obstetricians and the Polish Society of Human Genetics gave only recommendation: " The pregnant woman or both parents should be informed about specialist care and perinatal palliative care in case of a severe developmental defect or incurable disease in the foetus" [19]. In practice this recommendation is rarely realized, there are no law solutions in our country. Additionally, PPC issues are not included to the training and education standards Gynaecologists and Obstetricians.

In our group of women under PH care, 28% of pregnancies ended by cesarean birth. The selective character of the group and the small number of participants does not allow us to draw population conclusions; however, this is a significantly smaller percentage than that of the general population of pregnant women. According to data from the Euro-peristat report, the rate of cesarean births in Poland is amongst the highest in Europe – 42.2% - with the European average of 27% [27]. It should also be noted that according to detailed analysis, all cesarean births were performed due to obstetrical indications. The vast majority of parents contacting PH made a conscious decision to continue the pregnancy, accepting the risk of IUFD and other possible complications, and the scenario involving the cesarean birth was also discussed [1–3]. Providing reliable information about the risk connected with cesarean birth before the decision on the course of pregnancy is made is especially important in cases where the probability of cesarean delivery is high, e.g. because of concomitant problems in the woman, previous cesarean birth or selected anomalies such as acrania or hydrocephalus [8]. In this context, the current legal situation in Poland should be noted – from January 2021, there is no possibility of abortion if a LLFC has been diagnosed. The data presented in this study come from the period when such a possibility was available. The idea of PH directed by the authors was multidisciplinary care offered for the parents with a diagnosed LLFC, regardless of the decision to terminate or continue the pregnancy. The decision to continue pregnancy was thus conscious, made after consulting specialists and obtaining all important information. The authors do not want to comment on the new legal regulations from the moral, ethical or worldview point; however, from the medical issue, it should be noted that the lack of possibility of abortion after a LLFC in many cases will lead to the risk of obstetrical complications and necessity of cesarean birth. If this is the first pregnancy, the obstetrical history of the woman will be impaired, and future pregnancies may lead to complications, including potential death and orphaning older children [28–30].

The presented analysis suggests that if a LLFC is diagnosed, in most cases, the newborn dies in the first week of life (86%) out of which 62% die during the first day of their life. This observation is consistent with the data from other authors [13, 21–23]. Appropriate support for the parents, enabling a farewell to the child and securing memories are the key to proper mourning and future functioning of the family. Taking bereavement photos was one of the standards introduced in our hospice. However, it should be emphasised that it was one of the biggest problems at the beginning of our activity - for the hospital staff, it was shocking; they felt it was cruel to document death [31]. That is why preparing the hospital team to deal with such situations is so important. Close cooperation between PH and hospital teams and proper communication is of utmost importance [5, 14, 31, 32].

Decision-making process after diagnosis of LLFC requires consideration of varied actions (e, g termination of pregnancy, palliative care strategy vs. curative treatments) which are partly defined outside of the medical setting, in contexts where psychosocial influences lead to expectations and norms. Inclusion of palliative care in perinatal medicine must be considered in the multidimensional context involving not only medical issues but also psychological, spiritual and ethics aspects.

Limitations of the study

The single-center sampling limits this study, and the findings may not be extrapolated to other settings or populations. The paper presents the experiences of the only center in the region with over 20,000 live births every year. Another limitation is that we conducted a retrospective study. Furthermore, our study did not account for couples who may have been accepted to a perinatal palliative care program but were not referred and admitted for many reasons and barriers.

Conclusions

Our PPC model seems to be comprehensive, effective and efficient - families referred to the program receive multidisciplinary support. The process of referring and informing about the possibilities of support after diagnosis is unsatisfactory. System solutions should be considered, obliging the physician to refer the pregnant woman to a perinatal palliative care program. Shortening the interval between diagnosis and palliative care consultation would allow for more effective professional support and give more time to prepare the parents for losing a child.

The authors believe that it would be reasonable to introduce a PPC module into the gynaecology, obstetrics and midwifery training program.

Abbreviations

IUFD	Intrauterine fetal death
LLFC	Life-limiting fetal condition
PH	Perinatal hospice
PPC	Perinatal palliative care

Acknowledgements
Not applicable.

Author contributions

A.KE. conceptualized and designed the article, contributed to data acquisition, analysis, and interpretation, drafted the initial manuscript, and reviewed and revised the manuscript for important intellectual content; H.M., M.G., P.K. conceptualized the article, drafted the initial manuscript, and reviewed and revised the manuscript critically; all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Funding
This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study was conducted retrospectively from data obtained for clinical purposes. We consulted with the Bioethics Committee of the Medical University of Lodz, who determined that our study did not need ethical approval (RNN/140/22/KE).

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Author details
[1]Pediatric Palliative Care Unit, Department of Pediatrics, Oncology and Hematology, Medical University of Lodz, 36/50 Sporna str, Lodz 91-738, Poland
[2]Pediatric Palliative Care Center, Gajusz Foundation, 87 J. Dabrowskiego str, Lodz 93-271, Poland
[3]Department of Clinical Genetics, Medical University of Lodz, 251 Pomorska str, Lodz 92-213, Poland
[4]Department of Perinatology, Obstetrics and Gynecology, Polish Mother's Memorial Hospital- Research Institute, 281/289 Rzgowska str, Lodz 93-338, Poland
[5]Department of Gynecology and Obstetrics, Medical University of Lodz, 281/289 Rzgowska str, Lodz 93-338, Poland
[6]Department of Gynecology, Fertility and Fetal Therapy, Polish Mother's Memorial Hospital- Research Institute, 281/289 Rzgowska str, Lodz 93-338, Poland

Received: 8 April 2024 / Accepted: 24 January 2025

References

1. Perinatal Palliative. Care Pediatr. 2019;144(6):e20193146.
2. Perinatal Palliative Care. Acog Committee Opinion, number 786. Obstet Gynecol. 2019;134(3):e84–9.
3. Cortezzo DM, Ellis K, Schlegel A. Perinatal Palliative Care Birth Planning as Advance Care Planning. Front Pediatr. 2020;8:556.
4. Rusalen F. Perinatal Palliative Care: a New Challenging Field. J Palliat Med. 2020;23(5):600.
5. Wool Ch, Catlin A. Perinatal bereavement and palliative care offered throughout the healthcare system. Ann Palliat Med. 2019;8(Suppl 1):S22–9.
6. Cortezzo DE, Bowers K, Cameron Meyer M. Birth Planning in Uncertain or Life-limiting fetal diagnoses: perspectives of Physicians and Parents. J Palliat Med. 2019;22(11):1337–45.
7. Lago P, Cavicchiolo ME, Rusalen F, Benini F. Summary of the Key concepts on how to develop a Perinatal Palliative Care Program. Front Pediatr. 2020;8:596744.
8. Quaerisma P, Homfray T, Greco E. Obstetric complications in pregnancies with life-limiting malformations. Curr Opin Obstet Gynecol. 2019;31(6):375–87.
9. Korzeniewska-Eksterowicz A, Przysło Ł, Kędzierska B, Stolarska M, Młynarski W. Who receives home-based perinatal palliative care: experience from Poland. Biomed Res Int. 2013;2013:652321. https://doi.org/10.1155/2013/652321
10. Jalowska A, Krzeszowiak J, Stembalska A, Szmyd K, Zimmer M, Jagielska G, et al. Perinatal palliative care performed in obstetrics and neonatology wards and hospices for children - own experience. Dev Period Med. 2019;23(4):253–62.
11. Rutkowska M, Szczepaniak S, Maciejewski TM, Jaczyńska R, Helwich E, Reśko-Zachara M. 25 years of work: the Interdisciplinary Team for Fetal Malformation at the Institute of Mother and Child in Warsaw - from counselling to clinical ethics. Dev Period Med. 2019;23(4):246–52.
12. Flaig F, Lotz JD, Knochel K, Borasio GD, Führer M, Hein K. Perinatal Palliative Care: a qualitative study evaluating the perspectives of pregnancy counselors. Palliat Med. 2019;33(6):704–11.
13. Davis SL, Harmon CM, Urquhart B, Moore B, Sprague R. Women and infants in the Deep South receiving perinatal and neonatal palliative and supportive care services. Adv Neonatal Care. 2020;20(3):216–22.
14. Wool Ch, Parravicini E. The neonatal Comfort Care Program: Origin and Growth over 10 years. Front Pediatr. 2020;8:588432.
15. Czynski AJ, Souza M, Lechner BE. The Mother Baby Comfort Care Pathway: The Development of a Rooming-In-Based Perinatal Palliative Care Program. Adv Neonatal Care 2021 Mar 25. https://doi.org/10.1097/ANC.0000000000000838. Epub ahead of print. PMID: 33783387.
16. Maher-Griffiths C. Perinatal Palliative Care in the neonatal Intensive Care Unit. Crit Care Nurs Clin North Am. 2022;34(1):103–19.
17. British Association of Perinatal Medicine. 2009. http://www.bapm.org/publications/documents/guidelines/Palliative_Care_Report_final_ Aug10.pdf
18. Standards of Medical. Care for a Newborn in Poland. Polish Neonatal Society. Warsaw. 2015.
19. Borowski D, Pietryga M, Basta P, Cnota W, Czuba B, Dubiel M, et al. Practice guidelines of the Polish Society of Gynecologists and obstetricians - Ultrasound section for ultrasound screening in uncomplicated pregnancy – 2020. Ginekol Pol. 2020;91(8):490–501. https://doi.org/10.5603/GP.2020.0110
20. Janvier A, Farlow B, Barrington KJ. Parental hopes, interventions, and survival of neonates with trisomy 13 and trisomy 18. Am J Med Genet C Semin Med Genet. 2016;172(3):279–87.
21. Lakovschek IC, Streubel B, Ulm B. Natural outcome of trisomy 13, trisomy 18, and triploidy after prenatal diagnosis. Am J Med Genet A. 2011;155A(11):2626–33.
22. Bertaud S, Brightley G, Crowley N, Craig F, Wilkinson D. Specialist perinatal palliative care: a retrospective review of antenatal referrals to a children's palliative care service over 14 years. BMC Palliat Care. 2023;22(1):177. https://doi.org/10.1186/s12904-023-01302-5
23. Tucker MH, Ellis K, Linebarger J. Outcomes following perinatal palliative care consultation: a retrospective review. J Perinatol. 2021;41(9):2196–200.
24. Kidszun A, Linebarger J, Walter JK, Paul NW, Fruth A, Mildenberger E, et al. What if the prenatal diagnosis of a Lethal Anomaly turns out to be. Wrong? Pediatr. 2016;137(5):e20154514.
25. Marc-Aurele KL, Nelesen R. A five-year review of referrals for perinatal palliative care. J Palliat Med. 2013;16(10):1232–6.
26. Tosello B, Dany L, Bétrémieux P, Le Coz P, Auquier P, Gire C, et al. Barriers in referring neonatal patients to perinatal palliative care: a French multicenter survey. PLoS ONE. 2015;10(5):e0126861.
27. Euro-Peristat Project. European Perinatal Health Report. Core indicators of the health and care of pregnant women and babies in Europe in 2015. November 2018. Available http://www.europeristat.com.
28. de Londras F, Cleeve A, Rodriguez MI, Farrell A, Furgalska M, Lavelanet AF. The impact of provider restrictions on abortion-related outcomes: a synthesis of legal and health evidence. Reprod Health. 2022;19(1):95. https://doi.org/10.1186/s12978-022-01405-x
29. Addante AN, Eisenberg DL, Valentine MC, Leonard J, Maddox KEJ, Hoofnagle MH. The association between state-level abortion restrictions and maternal mortality in the United States, 1995–2017. Contraception. 2021;104(5):496–501. https://doi.org/10.1016/j.contraception.2021.03.018
30. Stirnemann JJ, Mousty E, Chalouhi G, Salomon LJ, Bernard JP, Ville Y. Screening for placenta accreta at 11–14 weeks of gestation. Am J Obstet Gynecol. 2011;205(6):547e. 1-6.
31. Korzeniewska-Eksterowicz A, Kozinska J, Kozinski K, Dryja U. Prenatal diagnosis of a lethal defect: what next? History of first family in perinatal hospice. Palliat Support Care. 2022;20(6):906–7. https://doi.org/10.1017/S1478951521000870
32. Rusalen F, Cavicchiolo ME, Lago P, Salvadori S, Benini F. Perinatal palliative care: is palliative care really available to everyone? Ann Palliat Med. 2018;7(4):487–8.

Publisher's note