Quarterly Journal Fides et Ratio
Issue 3(51)2022, ISSN 2082-7067, Pages 84-93

Role and tasks of the midwife as a member of the hospice perinatal care team

Rola i zadania położnej jako członka zespołu hospicyjnej opieki perinatalnej[1]

https://doi.org/10.34766/fetr.v3i51.793

> „Every life, even handicapped according to the world, deserves to live (...) in the eyes of a hurt baby we can find much love if we only brave enough to love them (...)”
>
> *prof. Jerme Lejeune – International Family Congress, Warsaw 1994*

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Abstract: An unsuccessful prenatal diagnosis is a traumatic experience for parents expecting the birth of a child. Hospice Perinatal Care is aimed at families who are experiencing an unsuccessful prenatal diagnosis. It is a form of help and support by providing individualised care to the woman and her loved ones, tailored to their needs and expectations, allows to live parental experiences with dignity. The perinatal hospice care system is not regulated by law. There is a visible lack of unified standards of conduct. Each institution providing hospice perinatal assistance develops its own model of care, as a result of which the patient and her family do not have the opportunity to experience continuity of care. It is crucial to consider the problem of low level of medical staff consciousness on the aims, possibility of perinatal hospices and principles of prenatal hospice care. One member of the hospice perinatal care team is the midwife. The aim of this article is to present the role of the midwife and the tasks of individual specialists in the therapeutic management of a pregnant woman with a prenatally diagnosed lethal defect in the fetus. The role and tasks of the midwife as a member of the team taking care of a pregnant patient with a diagnosed fetal lethal defect is primarily to accompany the woman during this difficult period, provide emotional support and prepare parents for the birth of a sick child and focus activities on the real needs of parents and adapt to their expectations. Including a midwife to perinatal care team in hospice allows to completes the process of taking care of parents of a child with a lethal defect. At present, there are no standards and guidelines concerning the organisation of obstetric care for patients in the situation of prenatal diagnosis of a malformation. For this reason, it is important to carry out activities to prepare staff to provide professional assistance to families experiencing an unsuccessful prenatal diagnosis.

Keywords: lethal defect, midwife, prenatal diagnosis, prenatal hospice

Abstrakt: Niepomyślna diagnoza prenatalna jest traumatycznym doświadczeniem dla rodziców oczekujących narodzin dziecka. Hospicyjna Opieka Perinatalna skierowana jest do rodzin, które doświadczają niepomyślnej diagnozy prenatalnej. Stanowi formę pomocy i wsparcia poprzez objęcie kobiety i jej najbliższych indywidualną opieką, dostosowaną do potrzeb i oczekiwań, pozwalającą na godne przeżywanie rodzicielskich doświadczeń. System perinatalnej opieki hospicyjnej nie jest uregulowany prawnie z tego powodu widoczny jest brak ujednoliconych standardów postępowania. Instytucje świadczące hospicyjną pomoc perinatalną opracowują własny model opieki, w wyniku czego pacjentka i jej rodzina nie mają możliwości doświadczenia ciągłości opieki. Konieczne jest zatem zwrócenie uwagi na problem niskiego poziomu świadomości personelu medycznego na temat celów i możliwości hospicjów perinatalnych oraz zasad prenatalnej opieki hospicyjnej. Jednym z członków hospicyjnego zespołu opieki perinatalnej jest położna. Celem artykułu jest przedstawienie roli

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[1] Artykuł w języku polskim: https://www.stowarzyszeniefidesetratio.pl/fer/2022-3-Porysz.pdf

położnej oraz zadań poszczególnych specjalistów w postępowaniu terapeutycznym w opiece nad ciężarną, u której prenatalnie stwierdzono wadę letalną u płodu. Rola i zadania położnej jako członka zespołu sprawującego opiekę nad ciężarną pacjentką z rozpoznaną wadą letalną u płodu polega przede wszystkim na towarzyszeniu kobiecie w tym trudnym okresie, udzieleniu wsparcia emocjonalnego i przygotowaniu rodziców do narodzin chorego dziecka oraz koncentrowaniu działań na realnych potrzebach rodziców i dostosowywaniu do ich oczekiwań. Włączenie położnej do zespołu hospicyjnej opieki perinatalnej pozwala na dopełnienie procesu pielęgnowania wobec rodziców dziecka z rozpoznaną wadą letalną. Obecnie brakuje standardów i wytycznych dotyczących organizacji opieki położniczej wobec pacjentek w sytuacji wykrycia wady rozwojowej w okresie prenatalnym. Z tego powodu istotne jest prowadzenie działań przygotowujących personel do udzielania profesjonalnej pomocy rodzinom doświadczającym niepomyślnej diagnozy prenatalnej.

Słowa kluczowe: diagnoza prenatalna, hospicjum prenatalne, położna, wada letalna

Introduction

For future parents pregnancy is the time of hope, dreams and expectations to welcome a new life. Visualization of the future is often accompanied by concerns about the health and life of the unborn child, but despite anxiety, in parents' hearts there are feelings unlike any previously known. Joy dominates, and a strong, uniting bond is established between them. Unsuccessful prenatal diagnosis ruins the current order, making the diagnosis of a congenital disease in a child one of the most tragic life experiences. How to help parents who feel completely helpless, which is caused by the diagnosis being definitive and irreversible? How does the preparation for the birth of a child with a congenital disease or defect look like? How can parents' suffering be reduced? Hospice perinatal care is one of the forms of help that allows to live parental experiences with dignity, praises life as a value and brings joy to every moment of its duration.

1. Prenatal diagnostics

Advances in prenatal diagnosis make it possible to identify developmental disorders of the fetus at an early stage of pregnancy. Detection of defects during prenatal examinations (including TTTS twin pregnancy steal syndrome, obstructive uropathies, adenocystic lung degeneration, non-immune fetal edema, hydrocephalus, fetal hemolytic disease, spinal hernia, teratomas, diaphragmatic hernia, oligohydramnios, or polyhydramnios) (Health Policy Programme, Journal of Laws, 2020 No 1398, as amended) allows for the implementation of intrauterine therapies supporting treatment after childbirth. However, there are still diseases in which the implementation of therapeutic measures is impossible, as no effective therapy has yet been developed. These disorders are described as lethal defects. "For the so-called a lethal defect (lat. Latali) in a fetus and a newborn, serious developmental abnormalities with uncertain or poor prognosis are considered. A lethal defect may be: 1) miscarriage of a dead fetus, 2) premature stillbirth, 3) death of the child immediately after birth or in early infancy, regardless of the treatment used (Krzeszowiak, Śmigiel, 2016, p. 58). Among such diseases there are, among others trisomy of the 18 and 13 pair chromosomes, chromosomal aberrations (e.g. monosomes of autosomal chromosomes), lethal monogenic diseases (bone dysplasia, some forms of Smith and Lemili syndrome), defects of the central nervous system (skullcap, cerebral hernias), critical heart defects with lung hypoplasia, some forms of conjoined twins (Szmyd, Śmigiel, Królak-Olejnik, 2014, p. 389). There are places created for children with a diagnosis of birth defects and their families. The aim of these places is providing specialized care. These institutions are known as perinatal hospices.

According to Małgorzata Grabska, paediatrician working in Fr. E. Dutkiewicz SAC in Gdańsk, "perinatal hospice is not a place, is a way of thinking (...) It is being next to the family in this path through the pregnancy, birth and death. Death with dignity. Such death, wich is not "for nothing". Such, which is leaving us with experience of welcoming and saying goodbye to a child, which is extremely tough but also full of love" (Małkowska, 2013, p. 12).

2. Hospices around the world

The idea of establishing perinatal hospices is related to the hospice movement supporting terminally ill adults. The first activities aimed at helping those in need struggling with a chronic disease appeared in ancient times.

The approach to people in need of special care has improved under the influence of the Gospel message that people should be treated subjectively, appreciating the dignity of their person, conscience and the value of life (Szot, 2009, p. 221). Christianity "brought a new justification for the need to care for the sick, a mercy that does not allow the sick to be left without help" (Szumowski, 1961, p. 100). In the ancient times care of those in need was considered as serving God (res sacra miser). The first institutions to help those in need were church institutions–religious orders, fraternities. After the Edict of Milan, in AD 313, charity centers were opened to help the sick. The person influencing the development of the hospice movement was the bishop of Caesarea Cappadocia, St. Basil. A man in the suburbs of the metropolis brought to life a new city whose task was to care for travelers and the sick, especially lepers. Monasteries founded by a clergyman had places for pilgrims, the sick and the abandoned. In 529, St. Benedict opened a Benedictine convent in Monte Cassino. One of the ideas in the rule of this assembly was to care for the sick. In 6th-7th century hermits provided social care in the deacons-hospices they ran. Shelters and hospitals were established at church institutions. They were called hospitals, hospitals, and infirmary. There, the spiritual and physical needs of the sick were taken care of. The Crusades, especially their significant increase in the years 1095-1270, contributed to the numerous emergence of new facilities of this type. Congregations influencing the development of care for the sick were the Basilians (Eastern Byzantine Church) and Benedictines (Western Church). The regular canons of the Holy Spirit were taking care of the unwanted children. The decree of the Council of Trent, issued in the years 1545-1563, by imposing on bishops the obligation to care for hospitals, significantly contributed to increasing the level of health services for the sick and dying. During this period, previously unknown types of institutions were established–for the incurably and mentally ill and convalescents. During this period, laymen also began to support the development of institutions caring for those in need. The Roman emperor Justinian (527-567) was a donor to many hospices and health centers. From the 10th century in Italy, France and Germany during the so-called In municipal communes, care for the sick and the poor was getting better and better (Szot, 2009, p. 221). In 1591 in Warsaw Fr. Piotr Skarga founded st. Lazarus Hospital, which idea was to support cancer patients. Medicine development in 19th century also affected standards improvememnt of care of patients with fatal diseases. In 1842 Jeanne Gardier opened a place only for dying people in Lyon – hospice and Calvary. Over time, similar facilities for people in the terminal state were opened in France. In Dublin, the Daughters of Charity opened Lady's Hospice in 1897 and in 1905 in London the St. Joseph. In the following years, under the care of the Church of England, the following were successively opened: Friedesheim Home of Rest (1885 r.), Hostel of God (1891 r.) i St. Luke Home for the Dying Poor (1893 r.) (Szot, 2009, p. 221).

The initiator of modern hospice care was an English scientist–a doctor, nurse, volunteer from the St. Lazarus Church in London–Cicley Saunders. The woman took care of people suffering from cancer. The experiences of the woman and the needs of her patients made her want to create a place where people would receive the necessary help and could wait for death in decent conditions. In 1967 Dr. Saunders was the initiator of the opening of the stationary Hospice of St. Christopher in London (Szot, 2009, p. 221). The facility motto were the words of its founder: „You matter, because you are who you are. You matter until the last moment of your life. We will do everything we can, not only helping you to die calmly but also to live until you die" (Doyle et al., 1998). This place has become a model unit providing hospice care and supporting terminally ill people and their relatives. Two years later, the scope of provided assistance was extended to include home hospice teams. In 1975, at St. Luke in Sheffield, the day care center for terminally ill people was the first to combine home and community care. This solution contributed to full-scale care and prevention of the isolation of the patient and support of the relatives in caring for the dying person. In 1975, a Palliative Care Unit was established at the Royal Victoria Hospital in Montreal. At that time, one of the main goals of the World Health Organization was to relieve pain and symptoms of terminal cancer (Szot, 2009, p. 221).

3. Hospice movement in Poland

Special needs of chronically ill were also noticed in Poland. Since 1964, Hanna Chrzanowska, the initiator of the Krakow home nursing centre, has taken care of people diagnosed with incurable diseases and in a terminal state. Dr Stanisław Kownacki, a specialist working in the infectious diseases ward of the hospital in Nowa Huta, was considered a precursor of the hospice movement in Poland because it significantly influenced its development. He believed that medical facilities should take care of chronically ill patients until death. Kownacki didn't support opening stationary hospices though. People with advanced neoplastic disease stayed in the hospital in Nowa Huta. There were special places in the facility–social beds, which were intended for units requiring care, called hospice. Kownacki expressed his approval for the frequent visits of patients by their families, friends and volunteers. In 1978 dr Cicely Saunders took part in Polish sitting of Medical Society and Oncological Institute in Cracow. During these events, she gave speeches in which she raised the issue of caring for terminally ill patients. In 1984 in Gdańsk, on the initiative of Fr. Eugeniusz Dutkiewicz and prof. Joanna Myszkowska-Penson, a place was opened to care for terminally ill people in their homes. In the following years in Poland more hospice teams have been founded. They had a stationary and home character. The first way of care took place in a specially adapted place–a hospice. On the other hand, according to the second model, care for the patient should take place in their home. An alternative to both projects is the day hospice, the purpose of which is to provide the patient with specialist care during their daily stay in a special facility. At the Department of Oncology of the Medical Academy in Poznań in 1988, on the initiative of prof. Jacek Łuczak, the first Palliative Care Unit in Poland was opened, which in 1990 was transformed into a Palliative Care Clinic. The establishment of the National Palliative and Hospice Care Council in 1993 by the Minister of Health and Social Welfare was a turning point in organizing care for terminally ill people. On September 1, 1994, the Pain Treatment Clinic for Children was established at the Institute of Mother and Child in Warsaw, which contributed to the establishment of the first Warsaw Hospice for Children (Szot, 2009, p. 221). At present, the United States is the country with the most extensive possibilities of perinatal help for children diagnosed with lethal defects and their parents. There are the most facilities of this type in the USA. Available data shows that nowadays every state has got at least one facility with hospice care. Perinatal hospices are most often a part of hospice for adults and children. There are also groups for parents with the similar experiences – for example Embracing Grace in Richmond, Virginia. Most facilities of this type is funded by private persons (Kmieciak, Szafrańska-Czajka, 2016; Informator dla Rodziców, Hospicjum perinatalne Fundacji Gajusz). In Central-East Europe there are not enough perinatal hospices. The available data show that there are two facilities of this type in Germany–in Bruck and in Berlin (Kmieciak, Szafrańska-Czajka, 2016). In the capital of this country there is Betereuung Und Begleitung von Neugeborenen Mit Unheilbaren Erkrankungen at the Neonatology Clinique of Charite University Hospital. The task of this facility is to care for unborn children and newborns diagnosed with incurable diseases. There is a stationary hospice in Prague and stationary and mobile hospice in Ostrava in the Czech Republic. Help and support in the country is also provided over the phone and the Internet by midwife Lenka Pazdera, who currently lives in Great Britain. She is the woman in charge of proper operation of Perinatální hospic- Perinatální hospicova a paliativní péči. The costs of care provided by the perinatal hospice in the Czech Republic are not covered by government funds. The services provided by the facility are free of charge. Caring for babies before birth is part of a wider program. In Bratislava, Slovakia, there is an organization that cares for people who have survived the loss of a loved one. There is also a home hospice Plamienok, which task is to take care of children of different age. This institution is funded by private persons. The main goal of this facility is not the help for parents and their unborn children, however it also supports women who ask for help. At the moment there is not enough information on perinatal hospices activity in Eastern Europe (Kmieciak, Szafrańska-Czajka, 2016).

4. The specificity of the palliative care model on the example of the Warsaw Hospice for Children

Currently, there are fourteen institutions in Poland for the care of parents whose children have been diagnosed with lethal defects: Gajusz Foundation in Łódź, Fr. E. Dudkiewicz hospice in Gdańsk, w Łodzi, Warsaw Hospice for Children Foundation, Silesia Perinatal Hospice in Katowice, "Pomóż mi" Foundation ("Help me") for Children with cancer diseases and Children Hospice in Białystok, Lesser Poland Children Hospice in Cracow, Cracow Fr. Józef Tischner Hospice for Children in Cracow, Greater Poland Perinatal Hospice "RAZEM" Hospice for Children in Poznań, Little Prince Hospice for Children in Lublin, Home Hospice Foundation for Children in Opole, Outer Subcarpathia Hoscpice for Children in Rzeszów, Silesia Children Hospice Foundation in Tychy, Alma Spei Children Hospice in Cracow, Hospice for Children of Lower Silesia in Wrocław (Kmieciak, Szafrańska-Czajka, 2016). People who have contributed in a special way to the development of perinatal hospices in Poland are prof. Joanna Szymkiewicz-Dangel (specialist in paediatrics and cardiology) and Tomasz Dangel PhD (specialist in anaesthesiology and resuscitation, palliative medicine). In 1995, at the Children's Memorial Health Institute, Tomasz Dangel MD, created the idea of home palliative care for children and founded the Warsaw Hospice for Children. The first patient of the hospice was looked after at the turn of 1998-1999. In 2006, an ultrasound clinic was opened at Agatowa Street in Warsaw, thanks to which specialists can provide comprehensive care combining prenatal diagnostics and care in a home hospice for children. It is a unique model of caring for children with lethal defects. In addition, in 2016, a support group was established at the hospice for couples whose child did not have a chance to stay at home. According to the law in force, perinatal palliative care is directed to the families of a child who has been diagnosed with an incurable disease, regardless of the manner and date of delivery. Therefore the help of hospices is available for couples in the case of miscarriage, stillbirth or death after childbirth, birth of a living child with a lethal defect. (Szymkiewicz-Dangel, 2016; Dangel, Szymkiewicz-Dangel, 2016a; Dangel, 2015; Journal of Laws 2017 No. 236). The care provided by perinatal hospices is continuous. It provides pre-contraceptive, antenatal, intra-natal, postpartum and interconceptual care as well as care for the obstetrician and newborn. According to the Standards of the Polish Pediatric Society, perinatal palliative care consists in providing comprehensive support to parents of children in the intrauterine life phase and newborns with lethal defects (...) as well as care of newborns with such defects focused on providing comfort and protection against persistent therapy. It includes symptomatic treatment for the child and psychological, social and spiritual support as well as support for parents in grief. Child care can be carried out in the neonatology ward or at home by parents and the hospice, if the child survives the delivery and is discharged from the hospital" (Bednarska et al., 2019). Among the patients who found out about their child's disease before 24 weeks, 79% of women who obtained information at the Agatowa Clinic decided to continue their pregnancy (conference materials from 2015–5th scientific symposium in the cycle "Prevention of reproductive health disorders" entitled " Early reproductive failures–etiology, prevention and management in an interdisciplinary approach). Dangel thinks that "perinatal hospice is not a facility (for example hospice or clinique), but perinatal medicine model based on respect for life and dignity of terminally ill child (fetus and newborn). It provides comprehensive care for a pregnant woman after prenatal diagnosis of a lethal fetal defect, which has been verified in a reference center. Before childbirth, it includes comprehensive medical, psychological and spiritual care for a pregnant woman, as well as support in mourning, regardless of the period of the child's loss. Postpartum care includes palliative neonatal care, home palliative care and long-term care. It is an alternative to eugenic abortion and persistent therapy" (Dangel, 2015; Dangel, Szymkiewicz-Dangel, 2016b).

The members of the interdisciplinary team taking care of the couple and their child are: doctors (including neonatologist, gynecologist, ultrasound doctor, geneticist), midwives, psychologist, clergyman, social worker, language translator, volunteers, physiotherapist, doula and funeral service provider (Madetko, Kowalczyk, 2018; Informator dla lekarzy Fundacji Gajusz). It is very important to provide the woman and the child's father a comprehensive care that will allow them to feel safe. In this critical period for the pregnant woman, but also during the further course of pregnancy, labour and the puerperium, the person who should provide the greatest support for the pregnant woman is the midwife. This role results from her constant presence at this time with the pregnant woman, and later with the woman giving birth and the midwife, creating a bond with her and providing emotional and informational support. It is the midwife who, as a result of the unfavourable diagnosis received by the parents from the doctor, has the task of strengthening the emotional bonds which have developed between mother and child, supporting and preparing the mother to care for the child with disabilities. The midwife can also act as a confidant for the mother when she needs it. The most important thing is for the pregnant woman to feel that there is someone who will always help her, answer her questions related to understanding the nature of the disability and support her in moments of crisis. (Sak, Łozińska-Czerniak, 2020).

The overriding goal of the perinatal hospice is to provide very detailed information on the child's disease, treatment options, possible medical procedures and their consequences for the child and mother. If parents need to meet other people with similar experiences, hospice can enable them such a meeting. Institutions providing the couple with reliable information and support enable rational decisions regarding further proceedings. The possibility of consulting a psychologist, talking to couples with similar experiences and the clergy gives the parents a chance to get used to the fate of their child–intrauterine or postpartum death, disability. Hospice helps them with dealing with emotions which occur with disturbing prenatal diagnosis–thoughts, stress, anxiety (Krzeszowiak, Śmigiel, 2016, p. 57; Szmyd, 2014, p. 389). If, after delivery, the condition of the newborn allows to discharge them from the medical facility, the hospice helps the family to provide comprehensive care and appropriate conditions for the child's stay at home. In such situations, the facility helps to organize the necessary equipment for this, and arranges home visits of doctors and midwives. The help of specialists who will support the woman and her relatives in this difficult period is very important. Visits should take place regularly with a frequency adjusted to the needs of parents and the condition of the newborn. During the visit medical staff should check if the couple is dealing well with the situation they are in and help them to solve any difficulties (Krzeszowiak, Śmigiel, 2016, p. 57; Szmyd, 2014, p. 389). If the child dies, the hospice supports couples in their mourning. Consultations with a psychologist and enabling contact with people from support groups may be helpful in this period (Kozik, 2014, p. 28).The activities of perinatal hospices have not been financed from public funds so far. These institutions obtained funds for their activities from private persons. According to the Regulation of the Minister of Health of January 31, 2017, No 236 amending the regulation on guaranteed services in the field of palliative and hospice care, it is possible to cover the costs of services provided by the National Health Fund (NFZ). In accordance with the Regulation "the services financed under the general health insurance include, support for the parents of the child, including those in the prenatal phase, the care focuses on providing comfort and protection against persistent therapy for newborns–with severe and irreversible disability or life-threatening incurable disease that arose in the prenatal phase during the child's development or during childbirth". According to the Regulation, services guaranteed to pregnant women may be provided by centers providing perinatal palliative care–in a prenatal diagnosis center, prenatal cardiology center, genetics unit, palliative medicine clinic, home hospice for children or in an inpatient hospice. The guaranteed services include medical and psychological advice and consultations in hospices and palliative medicine clinics. These services will be financed by the public payer in the units that will contract the services from the National Health Fund. Services guaranteed under the conditions of palliative care are provided until the 28th day after the birth (Journal of Laws 2017 No. 236).

5. Midwives role in hospice perinatal care

An unsuccessful obstetric diagnosis is a traumatic experience for parents who are expecting a baby. Such a situation requires the implementation of specialist care for couples awaiting the birth of an terminally ill child (Kornas-Biela, 2008). One of the members of the hospice perinatal care team is a midwife. Midwife supervises the family awaiting the birth of a child with a lethal defect. In such case midwife faces many very important tasks that will help future parents prepare and survive the period of pregnancy, childbirth, puerperium and mourning. (Krzeszowiak, Śmigiel, 2016, p. 57). The midwife is the only member of the medical staff who is present with the patient and the family throughout this period. The fact that there is no time limit, as in the case of the doctor or the psychologist, allows the midwife to undertake supportive or complementary actions to those begun by them. She takes part in all therapeutic procedures, either by herself or by assisting in them. During these procedures she gets to know the reaction of the pregnant woman which enables her to take appropriate actions (Jalowska et al., 2019).

The midwife should take care of the patient according to the biopsychosocial model. Care should take into account the biological, psychological and social area. From the very beginning of cooperation between medical staff and parents, there should be a thread of understanding that will facilitate further work. The basis of such a relationship is active listening, empathy, a willingness to understand and help. Acceptance by the midwife and the couple will have a positive impact on the undertaken actions. Patients may react in different ways to an unsuccessful prenatal diagnosis. This event may be accompanied by extreme behaviors and emotions (fear, helplessness, anger, guilt). The midwife must show great care and patience. It is the midwife who, at various stages of the diagnostic procedure, will often explain information provided by other members of the therapeutic team that is incomprehensible to the pregnant woman. This allows for a gradual familiarisation with the new situation.

The midwife must show great care and patience. She should try to get involved in all activities related to the course of pregnancy, childbirth, both the future mother and the father of the sick child. Thanks to this, they will have the opportunity to establish a bond with the child, which may turn out to be very important in mourning in the event of the death of the newborn. Medical personnel should be tolerant of the couple and the decisions they make. In no way should you exert pressure, impose your decisions on your parents. The midwife's task is to provide comprehensive answers to questions bothering parents, to determine the further course of action, to calm down, support and comfort them. The couple may need to talk about the baby, their feelings, or the opposite – they will avoid these topics, wanting to reduce their suffering. The midwife should follow the parents' needs in this regard. Due to this, it will be possible to build a therapeutic atmosphere, thanks to which a woman and a man will feel safe (Motyka, 2011). The midwife in this situation should make use of the skills developed in the course of her education and professional work, such as patience, empathy, understanding, commitment, which constitute her unique role in the team as well as being of great value to the supported parents. Parents awaiting the birth of a child with a lethal defect should be provided with specialist care already in the perinatal period. It is worth getting to know the midwife who will care for them before the birth. Thanks to this, both parties can know each other, accept and discuss all important issues. The midwife who is caring for the couple should give them full information about the course of pregnancy, delivery and the puerperium. This will enable preparation for upcoming events in some way. It is also important to establish a birth plan. An important element of preparation for termination of pregnancy is educating a woman in the field of labor pain relief, proper breathing techniques, and postpartum lactation management. Before the due date of delivery, parents should be able to find out about the hospital where their care will be provided. Medical staff should follow the patient's wishes, according to the existing possibilities. It is also worth discussing with the couple the possibility of carrying out religious ceremonies according to their faith. In addition, you can offer parents to prepare souvenirs related to their child – for example photos, footprint, birth certificate (Krzeszowiak, Śmigiel, 2016, p. 57;

Szmyd, 2017). During the patient's stay in the hospital, it is very important to choose the appropriate room for the woman. The best solution is to provide an individual room, away from the delivery path and in the maternity ward. This will keep the couple intimate and calm. Choosing the right place will limit their negative emotions that may arise in contact with other families waiting for the birth of a healthy child. Moreover, the above-described solution will enable the presence of the child's father or other relatives of the woman with whom she would like to be at the moment, in comfortable conditions that do not increase stress for the patient. Inappropriate selection of the room may adversely affect the mental state of a woman and her recovery both physically and mentally (Krzeszowiak, Śmigiel, 2016, p. 57; Szmyd, 2017; Niekorzystne zakończenie ciąży. Rekomendacje postępowania z pacjentkami dla personelu medycznego oddziałów położniczo-ginekologicznych województwa mazowieckiego, 2019). During labor, parents should decide for themselves whether they want the fetal heart function to be monitored regularly. The decision on how to terminate the pregnancy is made by doctors taking into account the current obstetric condition, with particular emphasis on the health situation of the mother. After birth, the baby should undergo standard neonatal examination. The midwife's task is to ensure thermal comfort and food for the newborn. It is unjustified to use persistent therapy in a patient diagnosed with a lethal defect. Parents should have unlimited contact with the child, also in the event of its transfer to the Neonatal Intensive Care Unit. If they wish for other family members to be present in the room, hospital staff should not prevent them from making such visits. The midwife, may offer the woman and the man to bathe and dress the newborn baby together, if their condition allows it. Medical personnel should cover the child in such a way as not to emphasize anatomical abnormalities. Hospital staff should ensure the presence of a clergyman in the room, if parents express such a need. If a newborn is born dead or dies while in hospital, parents should be able to say goodbye to them and give them a hug. This is important to the mourning process (Krzeszowiak, Śmigiel, 2016, p. 57; Szmyd, 2017). If the condition of the newborn allows his discharge from the hospital, the midwife should, in accordance with applicable law, make at least 4 patronage visits at the patient's home. The purpose of the above-mentioned procedure is the observation and assessment of the child's condition. It is also important to evaluate the relationship between parents and the child. The medical worker should provide the couple with information on the care and nutrition of the child, lactation, and pro-health behavior. The perinatal hospice also supports parents in caring for a child with a lethal defect staying at home.

6. Situation of the parents of a child with a lethal defect

Unsuccessful prenatal diagnosis destroys the current world of parents who are expecting a child to be born.They do not take into account the possibility of complications during pregnancy. Nobody is able to prepare for such a message. Such situations force couples to make very difficult decisions that will affect their future and the fate of the unborn child. There are no standards of conduct in the case of a diagnosed lethal defect, therefore parents and members of the medical staff face difficult ethical dilemmas.

Parents should also determine what procedures will be performed on the child in the event of a live birth. Surgery to extend and improve the life of the newborn, resuscitation, perinatal or intensive care care, and hospital / home treatment should be considered.

The aim of deciding on the medical actions mentioned above is to ensure child's well-being and reduce their suffering. The choices made by the woman and the child's father should be independent, the best in their opinion. The only exception is the decision to use life extension methods, which is at the discretion of the doctor. No one in the medical staff is allowed to put pressure on the couple. Before making a decision, the woman and the child's father should have the opportunity to consult other specialists in the field of obstetrics and genetics, a psychologist, priest, and parents with similar experiences. Independent opinions may be helpful (Szmyd, Śmigiel, Królak-Olejnik, 2014, p. 389; Dangel, 2012; Dangel, Szymkiewicz-Dangel, 2005).

A very important task is to provide the couple with information about their child's condition–the course of the disease, treatment methods, possible complications and genetic issues. In addition to the substantive value of the explanations provided, the very way of talking to the parents is extremely significant. A person responding to parents' questions should be full of empathy and understanding. It is worth to remember, that the factor that may influence the decisions made is the way of passing the poorly prognostic diagnosis to the parents. The couple should obtain this information from a specialist with current medical knowledge who is confident of the diagnosis. The best solution is to talk to both parents at the same time. The woman and the man should be able to ask questions. It is the doctor's responsibility to explain all options for further action. The conversation should take place in a quiet, secluded place that gives a sense of comfort and security. When making a diagnosis, it is advisable for the specialist to use vocabulary that is understandable to the couple. After the diagnosis is made, the woman and her husband should be able to consult a psychologist, priest or parents with similar experiences. (Szmyd, Śmigiel, Królak-Olejnik, 2014, p. 389; Dangel, Szymkiewicz-Dangel, 2005). If a decision is made to withdraw from persistent therapy after childbirth, the couple may benefit from the care of a perinatal hospice. This institution cares for the parents and the child from the diagnosis of the lethal defect to the end of mourning. Persons using the care of the above-mentioned unit are provided with specialist medical, psychological and spiritual care. It is very important to take care of such families. They cannot be alone or without specialist care. Helping you survive such a difficult life event is to enlist the help of support groups that connect people with similar experiences (Szmyd, Śmigiel, Królak-Olejnik, 2014, p. 389; Dangel, Szymkiewicz-Dangel, 2005). In case of unsuccessful diagnosis woman should be provided with particular care. Future mother could feel responsible for her child's state and their disease. The emotional instability accompanying the period of pregnancy will probably further intensify the negative emotions in the patient.

7. Summary

Hospice Perinatal Care is aimed at families who experience unsuccessful prenatal diagnosis. It is a form of help and support by providing a woman and her relatives with individual care, tailored to the needs and expectations. The perinatal hospice care system is not regulated by law. There is a visible lack of unified standards of conduct. Each institution in Poland providing hospice perinatal assistance develops its own model of care, as a result of which the patient and her family do not have the opportunity to experience continuity of care. It is crucial to consider the problem of low level of medical staff consciousness on the aims, possibility of perinatal hospices and principles of prenatal hospice care. In the medical community, there is a lack of preparation of staff to provide professional help to families experiencing unsuccessful prenatal diagnosis. Due to the fact that an unsuccessful prenatal diagnosis is a trauma not only for families but also for the healthcare personnel, it is important to provide psychological and emotional support to the members of the therapeutic team, as well as education in coping with difficult situations. Daily contact with illness, suffering and death makes medical personnel particularly vulnerable to the occurrence of burnout syndrome.

Conclusions

1. In current reality role and tasks of midwife as a member of a team that takes care of a pregnant patient with diagnosis of a lethal defect of a fetus, is first and foremost about accompanying woman in this hard period, emotional support and preparing parents for birth of a sick child.
2. It is important to concentrate actions on real needs of parents of children with lethal defect and adjust individual care to their expectations.
3. Including a midwife to perinatal care team in hospice allows to completes the process of taking care of parents of a child with a lethal defect.

Translation: mgr Justyna Zydek

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