Magdalena Różańska M. Sc. Midvife
Department of Obstetrics and Gynecology, General Hospital in Wołomin
Barbara Baranowska M. Sc. PhD
Urszula Tataj-Puzyna M. Sc. PhD
Grażyna Bączek M. Sc. PhD
Department of Didactics in Gynecology and Obstetrics, Medical University of Warsaw
Anna Kajdy MD, PhD
Department of Procreative Health Medical Center for Postgraduate Education Warsaw

Perinatal hospice care in the narratives of parents and caregivers – a qualitive survey

1. Introduction

Constant development and perfection of prenatal diagnostic techniques increases the precison of assessment of the fetal health (Frączek et al., 2013). There are no doubts regarding the role of prenatal diagnosis in cases that result in intrauterine or postnatal treatment of the child. Ethical controversies and public discussions begin in cases where the prognosis is poor, the defect is non compatible with life and the parents have to choose between termination or continuation of pregnancy (Frączek et al., 2013). The Polish law provides the option of termination of pregnancy before the child reaches viability in cases of lethal defects (Family Planning Act, 1993). Since 1999 in Poland women who have decided to continue their pregnancy are provided with paliative care by the Perinatal Hospice (Dangel, Szymkiewicz-Dangel, 2015).

The history of hospice care in Poland dates back to the seventies. At that time, a Group Study in Nowa Huta was formed, which provided assistance at the Stefan Żeromski Hospital. In 1977 Cracow decided to build a Stationary Hospice, and in 1981 the Friends of the Ill Society "Hospice" was established (Boulay, Rankin, 2009).

The precursors of perinatal hospices in Poland are prof. T. Dangel and prof. J. Szymkiewicz-Dangel. T. Dangel is the creator of pediatric palliative care. He plays a special role among the leaders of the hospice movement. He was inspired by Cicely Saunders and has undertaken the continuation of the difficult work of palliative care for children (Łuczak, 2004, p.8-16). In 1994 the Warsaw Hospice for Children (WHD) was established, the first in Central and Eastern Europe. In 1999, J. Szymkiewicz-Dangel presented the concept of perinatal hospice for the first time, during the European Palliative Care Course on Children in Budapest (Dangel, 1999).

T. Dangel and J. Szymkiewicz-Dangel believe that terminally ill children and their parents should be free to choose between hospital and home treatment of the child. The most common types of illnesses that qualify for hospice treatment are neurological damage, degenerative and demyelinating diseases, progressive genetic diseases, malignancies, metabolic diseases, congenital malformations, chromosome aberrations or extreme multi organ failure (Dangel , 2007, pp. 67-73).

Perinatal palliative care provides comprehensive support for parents in the perinatal and postnatal period of pregnancies affected by lethal defects. Hospice services include the symptomatic treatment of a terminal child, psychological, social and spiritual support for the parents, even after the child's death. Childcare can be carried out either in the prenatal phase, after delivery in the neonatal ward, at home by a parent or in the hospice, if the child survives and is discharged from the hospital (Dangel, 2008).

Perinatal Hospice is based on the idea of general hospice care. Its main goal is fullfillment of emotional and spiritual needs of the child and its family. Medical support is limited to pain relief, general improvement in the quality of life of the child until its natural death (Shabbat, 2013).

The regulations regarding hospice care are the Regulation of the Minister of Health of 29 October 2013 on guaranteed benefits for palliative and hospice care (Regulation of the Minister of Health, 2013). Unfortunately, in case of Perinatal Hospices, this care has not been financed so far by the National Health Fund (NFZ). Assistance in this area was organized within the statutory framework of the Hospice or Voluntary Foundation. It is only from 2017 that palliative perinatal care is included in the guaranteed benefits package (Kurzyńska, 2017, p. 8).

The motivation to take up this topic resulted from reflection on practical obstetrics and its confrontation with bioethical knowledge. Numerous problems in defining the boundries of life, concentrating on the ethical side of health care representatives, and finally the lack of knowledge among physicians and midwives regarding care for the family with an unsuccessful prenatal diagnosis of the child, prompted the authors to bring closer the idea of perinatal hospice and determine what is the role of midwives in these services.

The main aim of this paper was to present a multi-faceted perspective on the aspects of hospice care. The secondary aim was sharing the experiences of persons providing help in hospice care and those benefiting from such assistance. In addition, attempts were made to assess the care provided and to discuss the presence of midwives in perinatal hospices.

2. **Materials and methods**

The research method was based on semi-structured interviews conducted with persons that experienced perinatal hospice care. The interviews where based on a questionnaire prepared specifically for this project.

The study group included:

[Ps] - two psychologists
[L] - doctor
[N] - neonatologist
[P] - midwife
[K] - Catholic priest
[R] - parents who used hospice care.

All respondents asked for full anonymity. Therefore, the characteristics of the examined group refer only to the role they played in hospice care, and therefore the exact place of work of the examined persons is not given.

An analysis of organizational forms related to the work of perinatal hospices operating in Poland was performed. The talks were held between November 2016 and March 2017. The interviews were usually conducted in the place of residence of the interviewees, as they allowed for a frank and open conversation about their experiences, observations and conclusions.

3. Results

3.1. Functional analysis of the prenatal hospice in the legal, medical, psychological and ethical aspects

From a legal point of view, perinatal hospices usually function on the basis of the Foundation or an Association. The scope of services is usually determined individually by a given team, creating its own model of perinatal hospice care. An interesting solution has been implemented by the hospice in Wrocław. It is based on the cooperation of an Association, Foundation, hospital clinic and the out patient clinic, which provides comprehensive care for families who have decided to continue their pregnancy despite the diagnosis of a lethal defect in their child. As a result of the agreement of these institutions, a Consultation Card has been created. It is a summary of specialist consultations and parents' expectations and decisions regarding further proceedings.

The Warsaw Children's Hospice Foundation has proposed a program of life protection in the case of prenatal diagnosis of a lethal defect. The Ministry of Health has granted the Foundation an Accreditation in Pediatric and Perinatal Palliative Care. They are authorized in training of physicians and psychologists in the field of perinatal palliative care, issuing of certificates, consulting difficult cases and making binding decisions as well as supervision of other palliative care centers and developing standards (Dangel, Szymkiewicz - Dangel, 2016).

An important aspect of prenatal hospice care is the medical aspect. The basis and condition of palliative care is to determine unequivocally the diagnosis (ex. the statement of the so-called lethal defect). This is done by a consultant and is based on ultrasound, echocardiography and genetic testing. Additional medical services include: consultation with specialists - neonatologist, gynecologist-obstetrician, geneticist, cardiologist, additional ultrasound examinations and individual midwife care. These activities are mostly informative, and parent consultations with the medical community allow them to work out an individual plan for the length of pregnancy, birth plan, and follow-up and care for the family after the baby's birth.

The functional aspect of supporting the needs of the family through hospice care is described by the psychologist (taking part in the study):

> *"Psychological support is needed at the decision-making stage whether to continue the pregnancy or not, while waiting for the baby, especially after childbirth and after the child's death. Medical support is also needed - the physician and midwife in our team answer questions and dilemmas of the parents, help create a plan of labor. If the parent wishes, the doctor/midwife is present during the birth. If necessary, we help them with the necessary research. We also work with a genetic concultant to help them understand their baby's diagnosis and make decisions future parenting decisions. Spiritual support from our chaplain is available. If necessary we provide social support. "[Ps]*

According to the interviewers of the parents supported by Hospice services, the care consisted primarily of arranging visits to specialists who prepared them for the birth of their daughter: a geneticist, a midwife, an obstetrician, a neonatologist. Parents discussed with each member of the interdisciplinary team the medical, psychological and spiritual aspects of care in the perinatal period. A gynecologist who worked at the hospice provided care for the pregnancy from the unsuccessful diagnosis of the condition of the child until it was resolved. Regular meetings with midwives were aimed at preparing the mother for the birth of the child. The midwife listened to the baby's heartbeat and discussed the details of the baby's birth. In the case of intrauterine death, the woman was provided with medical care and accompanied by the midwife during the difficult period of waiting for the baby.

One of the interviewed women described the essence and importance of care during the waiting time for birth:

> *"In this care for us it was extremely important to set appointments so that we were waiting for the next meeting, without thinking that the time of labor was approaching, because for us that was synonymous with the death of our child. But the most important was the availability of the two midwives with whom we had contact, because they were people with*

> *whom we could talk quietly about our feelings, fears, complain about the system, and finally at night when the birth began to call at. 2.00 and hear a familiar voice in the handset assuring that everything will be ok and waiting for us in the delivery room. This gave us the confidence that we are in good hands. "[R]*

Ethical controversies in the area of hospice care may relate to the issue of prenatal diagnosis, which could result in termination of pregnancy or futile therapy. Perinatal Hospice provides and facilitates access to prenatal diagnostic services for parents. They refrain from futile therapy in favor of creating an oportunity to say farwells to the child in a dignified and familiar setting.

The position of the Church in regard to futile therapy is unequivocal. In the Catechism of the Catholic Church (KKK) we read: Discontinuing medical procedures […] does not will to cause death; one's inability to impede it is merely accepted" (CCC, 2278). The Church calls for palliative care, where it is possible to administer painkillers even if they are expected to shorten the life of the patient. Death in this case is not wanted, but only predicted and approved (CCC, 2279). "Even if death is thought imminent, the ordinary care owed to a sick person cannot be legitimately interrupted. The use of painkillers to alleviate the sufferings of the dying, even at the risk of shortening their days, can be morally in conformity with human dignity if death is not willed as either an end or a means, but only foreseen and tolerated as inevitable Palliative care is a special form of disinterested charity. As such it should be encouraged "(CCC, 2279).

Catholic ethics is of the opinion that there should be defined limits to the obligation to sustain human life. The document of the Pontifical Council for Health Care Services reads as follows: "The distinction between 'proportional' measures that can never be rejected to not prevent and induce death, and disproportionate measures, which should be rejected in order not to fall into futile therapy are a decisive ethical criterion in defining these boundaries (Pontifical Council Cor Unum, 1981).

John Paul II emphasizes that there is a moral obligation to heal and to undergo treatment. This should be defined in specific situations. First of all, it is important to assess whether the medicinal products used are objectively proportionate to the expected improvement in health. Disqualification of extraordinary and exaggerated means is not equivalent to suicide or euthanasia, rather expresses acceptance of human condition in the face of death (EV, 77).

Resignation from futile therapy is an expression of respect and appreciation of human dignity, rather than the lack of perception of values in mortal life. It is compatible with God's will and accepts the restriction of human existence. Declaration Iura et Bona specifies that in making such a decision, the righteous desire of the patient and his household and the opinions of the truly competent doctors must be taken into account. The latter will, in fact, be able to make a fair assessment of when the cost of resources and the workforce is not proportionate to the expected effects and when the medication is administered to the patient with pain or discomfort greater than the expected benefit (Congregation for the Doctrine of the Faith, 1980).

The documents of the Church do not specify what is an extraordinary measure, leaving it to the discretion of the doctors to respect the patients' decision, provided that they are capable of making that decision competently (CCC 2279). As the interviewees pointed out in the research, it is often the case that members of the perinatal hospice should be informed of the principles of withdrawal from futile therapy in a child with an unfavorable diagnosis. Prenatal medical procedures, that involve the mother and child must be preceded by a competent informed consent.

3.2. The specificity of the work of the Perinatal Hospice

Perinatal Hospice is not only an institution but, above all, a philosophy of life and conduct. The surveyed women see the Perinatal Hospice to be the place where parental resources are taken into consideration and supported to fullfil the need to continue the pregnancy and accept a child with an incurable illness, who is most likely to die after birth. The work of the hospice staff is described by the investigators as engaging, demanding, but also carrying deep sense and giving a lot of personal satisfaction. Team spirit is mentioned as a particularly positive aspect of the action force.

According to the psychologist, the core of hospice care is the psychological impact, directed at getting the parents through a difficult experience.

> *"It's a job with a variety of emotions from fear, anger to hope and powerlessness; feeling of guilt and harm, but also love for the child and the desire to protect it; from fight to acceptance. This is accompanying the parents through mourning for the loss of dreams and plans of having a healthy child and mourning the loss of a child. "[Ps] Employees describe their work as" accompanying the family, taking into account the different aspects that they are needed for by the parents. " [PS]*

As the neonatologist points out, hospice care aids the entire family, not just the child and its parents.

> *"My job is to provide multidirectional, medical, psychological, spiritual and social support to parents, grandparents, and siblings of an incurable child before and after childbirth." The statement from the midwife shows that the task of people working in the Hospice is to provide multidimensional care, which is based primarily on meetings, conversations and parental support during a difficult period of waiting for an incurable child. "The specificity of work lies in being honest in what we communicate to our parents. This assumption was from the beginning, even if the parents choose termination, then let it be their choice, not the only option imposed. Let them know between what they choose. Often when we ask our parents (...) how they remember the first meeting, they emphasize that it was again a conversation about "the child and the parents" and not the "pregnancy with the problem". We emphasize the importance that we are waiting for a new human, we encourage them to*

give the child a name. We talk about a specific person with specific needs. And we try to get to know this person and his needs. We try to adress these needs. His and his whole family". [P]

A hospice psychologist has a particularly positive view of work with parents:

"It is most valuable to be able to accompany parents in their gradual discovery of what their resources are in dealing with an extremely difficult situation, and in supporting actions that allow them to end up knowing that they have done everything that is possible for their child. "[P]

As stated in the doctor's interview, the work of members of the prenatal hospice team refers to all aspects of what is happening around an unfavorable diagnosis. Taking care of parents at the time when the diagnosis is not yet final is mainly about the experiences and emotions that emerge from them. Hospice care can be divided into three stages. The first one is before stating the diagnosis. During that time it mainly relates to parental anxiety, and this is the time devoted mainly to conversation. The next step is to make the final diagnosis and the last step – is the decision regarding further management.

The Catholic priest described the work in the hospice as:

(...) a direct encounter with the value of respect for the human being, the encounter with the life that we welcome to say goodbye to, often short of passing from the joy of meeting to the painful farewell. "[K]

The respondents emphasized the importance of working with families in understanding the various constraints, accepting powerlessness and accompanying families without judging their attitudes and decisions. Interviewers found work extremely difficult especially in situations where the proposed by th Hospice model of care proposed was not available to the parents, and *"... the inability to break through information about this form of care by the medical community, particularly gynecologists".[P]*

3.3. The role of midwife in hospice care

A midwife is usually the first person to accompany the parents, both in the prenatal stage, at the time of childbirth and during the postnatal period. Very often she is present at the time of death of the child, which sometimes occurs immediately after birth. Regardless of the decision regarding postnatal management, parents should be able to benefit from reliable, individual preparation by a midwife. This direct contact with midwives is also an important element of mental support for a family facing the birth of a terminal child. In the opinion of the surveyed midwives, *"... it is also someone who binds all the other people involved in hospice care". [Ps]*

Of all the members of the interdisciplinary team, the midwife is believed to have the closest relationship with the parents.

> *"I see midwives as the closest to the family that we are dealing with, they are irreplaceable." [K]*

She accompanies the parents throughout their hospice care experience. It is the midwives who make sure that parents can see and say goodbye to their children, to keep memories of their children. According to the investigators her role in the team is priceless. According to the psychologist:

> *"It is of great value to meet parents with midwives so that they can discuss the plan of childbirth, adapt it to a specific place where the birth will take place. This gives the possibility to discuss the doubts and concerns about the course of childbirth. Above all, there is a relationship of trust that can be developed in such a meeting, and which in the most difficult time, when the birth takes place, can bear fruit".[Ps]*

3.4. Suggestions for improving prenatal hospice care

Patients who were asked to indicate the direction of improvement in the system of prenatal hospice care referred primarily to the lack of funding.

> *"So far, no one pays for such care. Everyone works voluntarily, and some of our research is paid for by people of good will." [N]*

None of the respondents have indicated any malfunctioning or defects in the current palliative care system for children with lethal defects. The proposals for improvement concerned the dissemination, standardization and introduction of such care into the basket of services offered by the National Health Fund.

> *"I dream of a time when it will formally work, when it is a finished product, that will be presented to the NFZ as a specific service. I would like the standard to incorporate a special information card, which will record the needs of parents about preparation for childbirth, taking into account the role of the midwife, individual birth school, then we can say that there is an alternative. Only then are possible conscientious choices. With this thinking you have to reach all of Poland, not only the largest hospitals. [L]*

The respondents emphasized the need for education of the whole society as well as the specialists.

> *"It is also important to include all social activities in making society aware of the perinatal hospice (social campaigns, conferences, articles). At the crucial moment when the family learns that their child has a lethal defect, the "environment" can be appropriately direct them towards perinatal care."[Ps]*

The parents stressed there was no information from the medical staff at the time of the unsuccessful diagnosis if they rejected the possibility of termination of pregnancy.

> *"There is no publicity for such care. Because a woman who does not agree to termination of pregnancy is sent home without any help, "we have proposed a solution to the situation, you do not agree, so let yourself be worried now."*

There is no understanding among physicians that one can see the meaning of a small man's life in his belly, whether he will live a few decades after childbirth, die shortly after birth, or may not be able to survive. Doctors (unless they are the only ones) are convinced that if someone does not use the termination proposal, it is only because it does not reach him that the child is ill and will not survive.

Discussion

The research is a synthesis of the available research data regarding hospice care. We present the statements of persons directly related to hospice care, both on the professional side and of families receiving this kind of care. Perinatal Hospices are perceived, by parents and health professionals as a complex, multi-specialty care for a family of a child with an unfavorable diagnosis. They have the opportunity to take advantage of psychological care, medical consultations and support from the midwife. Such a model of care has already been described in foreign-language literature. In Polish-language studies there are few reports analyzing this kind of care, most of them appear in the form of interviews or are published in the quarterly Warsaw's Children Hospice (Dangel, Szymkiewicz-Dangel, 2015; Others, 2003; Korzeniewska-Eksterowicz, 2013, Mixer et al., 2015; Cobb, 2016; Ramer-Chrastek, Thygeson, 2015; Krzeszowiak, Śmigiel 2016).

The hospice is part of the pediatric palliative care model described by Dangel, "which aims to protect the dignity of the child, improve the quality of his life, protect against persistent therapy and iatrogenic activities. It includes symptomatic treatment and psychological, social and spiritual support for the whole family, also during time of mourning" (Dangel, Szymkiewicz-Dangel, 2016).

In spite of the various forms of organization and ways of providing help, the prenatal hospice activity can be described as a support network for parents experiencing difficult, rather than a stationary medical care facility for pregnant woman. As noted by the people working in the hospice, this is not a place, but rather a model of care, according to which it is supposed to be provided to families of sick children.

This is in line with the idea of the first modern hospice of St. Christopher, founded in London in 1967 by the English nurse Ceicily Saunders (Rogiewicz, Krajnik 1998, p. 11). Saunders believed that the idea of working in a hospice is to accompany people suffering, sick and dying, and laid the groundwork for palliative care. (Du Boulay, Rankin, 2009). "*Hospice is not a place, but an idea that each of us carries within us*" (Chmiel-Baranowska, 2016, p. 18).

All respondents emphasized that hospice work has deep meaning and is a kind of distinction, an opportunity to accompany a person in suffering. In addition, for many years, the functioning of prenatal hospices in Poland was based on voluntary work. For that reason, the interdisciplinary teams were made up of people devoted and convinced to the idea.

All respondents agreed that this model of hospice care was optimal, and the only changes needed were better public awareness about hospice care. The existing standard of care is informing the parents about the option of termination of pregnancy in cases of children with a diagnosed incurable defect. The option perinatal hospice care is often omitted in the consultation process. It is therefore essential to build awareness of the medical community in particular about prenatal hospice care. In 2007, T. Dangel at the meeting of the Parliament Committee on the Family and Women's Rights showed that obstetricians more often suggest abortion than childbirth followed by palliative care, and that these parents should be offered consultation in a prenatal care.

Information about the unfavorable diagnosis of the child is a source of great stress and pain for the parents. They are often left to deal with these feelings all alone. Continuing a pregnancy, where the child is affected by a genetic disease, quite often results social disapproval. Prenatal hospice care gives the parents an opportunity to receive both psychological and substantive support as well as so much needed feeling of acceptance during a difficult time.

The study revealed the important role of a midwife as a member of the interdisciplinary team. Krzeszowiak and Szmigla's described the midwife an important member of the therapeutic team. According to them she takes care of the whole family that is expecting the birth of child with a poor prognosis (Krzeszowiak, Śmigiel, 2016, pp. 57-61). In interviews with women and doctors, the midwife is referred to as a link between the medical community and the parents. She is seen as being closest to the family, accompanying the pregnant woman, during and after giving birth to a termminally ill child. She is someone who is closest, who often is the first to greet this child in the world. Parents appreciate the safety they receive from their midwife in difficult times. The position of a physician, a medical authority, can create a type of distance in relation to the parents. Kędzierska, a psychologist, psychotherapist and psycho-oncologist who has worked in hospice care for over a dozen years, training staff in the psychological aspects of working with dying children, notes that doctors have more difficulties dealing with hospice care. As a cause, she explains, is the specificity of the profession. The doctor is meant to the fight death, rather than be an idle bystander approving its inevitability. Significant differences are seen in the psychological approach of midwives. She admits that the group is better suited to the difficult tasks posed by work in the prenatal hospice. She appreciates the sensitivity and empathy that often characterizes this profession. Kędzierska also points to the important aspect of cooperation in the midwifery team, as its quality often reflects on the way the patients are treated (Marshall, 2016, pp. 24-27).

The legal basis of functioning of Perinatal Hospices in Poland is defined by the Regulation of the Minister of Health of 29 October 2013 (*Journal of Laws* of 2013, 1347). This document defines the list of palliative care benefits, the conditions under which they are provided (stationary, home and outpatient) and professionals who are entitled to perform the services. These are mainly medical consultations, psychological counseling and nursing care. The Regulation describes the scope of care primarily for adult Hospice Care and Child Hospices. Guidelines for Perinatal Hospice are not included in this document.

A Resolution of the Council of Ministers of 20 December 2016 on the Comprehensive Family Support Program "For Life" has highlighted palliative and hospice care for families with lethal defects of the fetus. This care is to be provided by increasing access to palliative care services and by providing the mother with psychological care during pregnancy and childbirth, which also falls within the scope of the Perinatal Hospice. Financing of these benefits is to be obtained from the Ministry of Health Resolution of the Council of Ministers, 2016, No. 160).

During the study period, the perinatal Hospices were financed primarily by funds donated to charity organizations thanks to "1 % tax "and private donations.

The ethical challenges described by the respondents mainly refer to the proposition of prenatal diagnosis and the refusal to apply to children with persistent therapy. The Code of Ethics is a set of rules that a physician should follow when practicing his profession. In Article 38 pt. 1 there are detailed rules regarding dissemination of information about availability of genetic testing and prenatal therapeutic interventions. The physician is also required to provide information about the degree of risk associated with the intervention, both for the child and for the mother (Code of Ethics, Articles 38-39). Futile therapy is a collection of medical actions that are to a large extent burdensome to the patient, can exacerbate the suffering of the patient, and the benefit of their application is not commensurate with the measures taken (Cepuch et al., 2013, pp. 163-169).

Clinical situations in which withdrawal and / or abandonment of life supportive therapies are permitted are so-called "No chance" situations (*Royal College of Paediatrics and Child Health*, 1999, p. 821-837). T. Dangel in his reflections on the dignity of the child believes that treatment in such a situation does not improve the quality of life of the patient and can only delay the death of the child. Unnecessary prolonged treatment turns out to be unsuccessful, cumbersome and contrary to the best interests of the patient. Therefore, the doctor has no legal duty to lead them (Dangel, 2007, p. 15-21).

Futile therapy, according to John Paul II, consists of the use of particularly destructive and cumbersome measures for the patient, condemning him to artificially extension of agony. Such conduct is contrary to the dignity of the dying person, so the moral task is to accept death, to allow it to proceed naturally (ibid.).

In this treatment it is not more important to prolong the time of death, but improve the quality of life of the dying person. From the point of view of ethics, it is justified to discontinue life support when they are a source of pain and suffering that are incomparably greater than the achievable benefits (*WHO Expert Committee Report*, 1990).

In the final declaration of the V General Assembly of the Pontifical Provita University we read: "When a doctor realizes that he can no longer prevent a patient from dying and that the only effect of intensive therapy is to multiply his sufferings, he must acknowledge the limitations of medical knowledge and his own actions, a death that can not be avoided.

Respect for the dying person requires avoiding all forms of "futile therapy" and helping the patient to accept death "(*V General Assembly of Pontifical Provita Academy*, 2005).

Very important ethical reflections are also provided by words of T. Dangel, who has accompanied families in saying "farewell" to terminally ill children: "Accepting the death of a terminally ill child by a doctor and parents is a necessary condition to ensure a dignified life - as long as it results from the natural course of the disease. Medical and other interventions – which are part of the holistic palliative care model based on the concept of total pain, should aim to improve the quality of life, not to extend it. In practice, this means the ability to distinguish between proportional and disproportionate means and the application of the first in the best interests of the child"(Dangel, 2007, p. 17).

Lack of consent for the natural occurrence and course of incurable diseases in fetuses and newborns leads to inhuman activities in the field of eugenic abortion or infanticide, an example of which may be euthanasia of newborns according to the protocol from Groningen in the Netherlands "(Verhagen, 2005, pp. 959-962) . T. Dangel proposed palliative care for the first time as an alternative to the Groningen protocol (Dangel, 2009, pp. 137-144). D. Kornas - Biela believes that as diagnostic techniques develop, the number of early prenatal diagnosis of defects in children will increase. This will be followed by an increase in selective abortions which may lead to a gradual decrease of social tolerance for birth defects (Kornas - Biela, 2009, p. 430).

The medical community may contribute greatly to the dissemination of knowledge about perinatal Hospice care enabling a decent life until natural death. The doctor and midwife are the first people who are with the parents when they learn the unsuccessful diagnosis of their conceived child. That first conversation often has the greatest influence on the parent's decision about further management of the pregnancy. Parents start to look at their child through the eyes of the medical personnel and it becomes basis of their acceptance or rejection of the unborn child. Prenatal hospices are an indispensable element of palliative pediatric care and are crucial in supporting the family and increasing the chances of reevaluating their decisions.

Bibliography:

Calhoun B.C., Napolitano P., Terry M., Bussey C., Hoeldtke N.J. (2003), Perinatal hospice. Comprehensive care for the family of the fetus with a lethal condition. *The Journal of Reproductive Medicine*, 48, p. 343–348.

Cepuch G., Domańska D., Dębska G. (2013), Ból i cierpienie a godność i prawa dziecka chorego w aspekcie uporczywej terapii, *Psychoonkologia*, 4, s. 163–169.

Chmiel-Baranowska A. (2016), Hospicjum perinatalne to nie miejsce, ale idea, którą każdy z nas nosi w sobie, *Hospicjum,* nr 2 (76), s. 18.

Cobb A.D. (2016), Acknowledged Dependence and the Virtues of Perinatal Hospice. *The Journal of Medicine and Philosophy,* 1(41), p. 25-40.

Dangel J., (1999), *Ethical problems in perinatal medicine*. I European Course on Palliative Care for Children. Budapest, Abstract.

Dangel T. (2007), *Godność dziecka – refleksja lekarza,* Opieka Paliatywna nad Dziećmi, Tom XV, s. 15-21.

Dangel T. (2007), *Zalecenia (standardy) dotyczące domowej opieki paliatywnej (hospicyjnej) nad dziećmi – projekt dla Ministerstwa Zdrowia,* Opieka Paliatywna nad Dziećmi, Tom XV, str. 67-73.

Dangel T., (2008), *Wady letalne u noworodków – opieka paliatywna jako alternatywa wobec eugenicznej aborcji, eugenicznego dzieciobójstwa i uporczywej terapii,* (w:) *Dziecko – studium interdyscyplinarne,* E. Sowińska, E. Szczurko, T. Guz, P. Marzec (red.), s. 443-460, Lublin: Redakcja Wydawnictw KUL.

Dangel T. (2009), *Lethal defects in foetuses and neonates: palliative care as an alternative to eugenic abortion, eugenic infanticide, and therapeutic obstinacy, Obsteric Anaesthesia and Perinatal Medicine,* s. 137-144.

Dangel T., Szymkiewicz-Dangel J. (2015), *Hospicjum perinatalne – polski model.* Informator Fundacji Warszawskie Hospicjum dla Dzieci, nr 1 (71), s. 37-40.

Dangel T., Szymkiewicz-Dangel J. *Propozycja programu ochrony życia w przypadku rozpoznania wady letalnej w badaniach prenatalnych,* http://perinatalne.pl/pliki/Artykul/1034_propozycja-programu-ochrony-zycia-13-10-2016.pdf (28.10.2017)

Du Boulay S., Rankin M., (2009), *Okno nadziei. Cicely Saunders – założycielka ruchu hospicyjnego,* Kraków: ZNAK.

Frączek P., Jabłońska M., Pawlikowski J. (2013), Medyczne, etyczne, prawne i społeczne aspekty badań prenatalnych w Polsce. *Medycyna Ogólna i Nauki o Zdrowiu*, nr 19(2), s. 103–109.

Jan Paweł II, Encyklika *Evangelium vitae,* (25.03.1995).

Katechizm Kościoła Katolickiego (11.10.1992), Poznań 1994.

Kodeks Etyki Lekarskiej (1991).

Kongregacja Nauki Wiary (1980), Deklaracja o eutanazji, Iura et bona, AAS 72, 542-552.

Kornas-Biela D., (2009), *Pedagogika prenatalna, nowy obszar nauk o wychowaniu,* Lublin: Wydawnictwo KUL.

Korzeniewska-Eksterowicz A., Respondek-Liberska M., Przysło Ł., Fendler W., Młynarski W., Gulczyńska E. (2013), Perinatal palliative care: barriers and attitudes of neonatologists and nurses in Poland. *The Scientific World Journal*, Volume.

Krzeszowiak J., Śmigiel R. (2016), *Rola i zadania położnej jako członka zespołu sprawującego opiekę nad ciężarną pacjentką z rozpoznaną wadą letalną u płodu, Pielęgniarstwo i Zdrowie Publiczne,* nr 6(1), s. 57–61.

Kurzyńska E. (2017), Paliatywna opieka perinatalna w koszyku świadczeń gwarantowanych, *Puls Medycyny,* nr 14(345), s. 8

Łuczak J., (2004), *Geneza działalności Warszawskiego Hospicjum dla Dzieci na tle ruchu hospicyjnego w Polsce i Europie*, Opieka Paliatywna nad Dziećmi, Wyd. XII, s. 8-16.

Marszałek M. (2016), Dotknąć kresu i iść dalej. *W Czepku Urodzone,* Nr 3(5), s. 24-27.

Mixer S.J., Lindley L., Wallace H., Fornehed M.L., Wool C. (2015), The relationship between the nursing environment and delivering culturally sensitive perinatal hospice care. *International Journal of Palliative Nursing*, Nr 21(9), s. 423-429.

Papieska Rada „Cor Unum": Alcune questioni etiche relative ai malati gravi e ai morenti (27 lipca 1981). Za: Karta Pracowników Służby Zdrowia. Papieska Rada ds. Duszpasterstwa Służby Zdrowia. Watykan 1995, s.100.

Ramer-Chrastek J., Thygeson M.V., (2005), A perinatal hospice for an unborn child with a life-limiting condition. *International Journal of Palliative Nursing*, nr 11(6), s. 274-6.

Raport Komisji Ekspertów Światowej Organizacji Zdrowia: *Leczenie bólu w chorobach nowotworowych i opieka paliatywna.* WHO. Genewa 1990.

Rogiewicz M., Krajnik M., (red.), (1998), *Opieka Paliatywna,* Akademia Medyczna: Bydgoszcz.

Royal College of Paediatrics and Child Health (1999). Zaniechanie i wycofanie się z leczenia przedłużającego życie u dzieci. Zarys praktyki medycznej. *Pediatria Polska*, nr 8, s. 821-837.

Rozporządzenie Ministra Zdrowia z dnia 29 października 2013 r. w sprawie świadczeń gwarantowanych z zakresu opieki paliatywnej i hospicyjnej, Dz. U. 2013 poz. 1347.

Szabat M., (2013), *Elementy filozofii opieki paliatywnej a zagadnienie śmierci.* Warszawa: SEMPER.

Uchwała nr 160 Rady Ministrów w sprawie programu kompleksowego wsparcia dla rodzin „Za życiem" z dnia 20 grudnia 2016 roku.

Ustawa z dn. 7 stycznia 1993r o planowaniu rodziny, ochronie płodu ludzkiego i warunkach dopuszczalności przerywania ciąży, art. 4.

V Zgromadzenie Papieskie Akademia Provita (2005), Deklaracja końcowa.

Verhagen E., Sauer P.J.J. (2005), The Groningen protocol – euthanasia in severely ill newborns. *The New England Journal of Medicine,* nr 352(10), p. 959-962.