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## **Prenatal Palliative Care**

### **Prenatalna opieka paliatywna**

#### **Abstract:**

Twenty-first century society believes in the almost infinite power of medicine, therefore in the mentality of modern man there is often no acceptance of serious illness or death. Medicine today is constantly coming up with new methods to prolong the life of the patient, applying aggressive therapy in situations where there is no hope of recovery. In recent years, a new set of moral dilemmas has emerged in the case of children diagnosed with lethal abnormalities in the prenatal stage, which most often lead to the premature death of a child.

This article will discuss palliative care (including home care), based on an integrative vision of a human being, holistically treating all physical, emotional and spiritual needs. Presented in this paper is the concept behind perinatal (Gr. *peri* – around, Latin *nascor*- to give birth) hospices created to provide support to parents who decide to give birth, despite an unfavorable diagnosis. Palliative care includes the provision of complete care for terminally ill children, with the purpose of treating them with full dignity and protection from aggressive and ineffective therapy. Creating support for the family and child in the case of a troubling prenatal diagnosis involves full empowerment of both mother and child, the latter recognized as a patient in the prenatal phase with both the right to life and the right to a dignified death. The article also discusses the position of the Catholic Church on prenatal testing and the position of the Polish Pediatric Association on aggressive therapy.

Every human being, including a child in the prenatal stage and a newborn, deserves humane treatment throughout their entire life up until the very end. Perinatal hospices aim to help the patient die with dignity and raise awareness in society about the respect that should be bestowed during the final moments in life.

#### **Key words**

Palliative care, perinatal hospice, aggressive therapy, ethical dilemmas, dying.

### Abstrakt:

Spółczesność XXI wieku wierzy w prawie nieograniczone możliwości medycyny, stąd coraz częściej w mentalności współczesnego człowieka nie ma zgody na ciężką chorobę i śmierć. Dzisiejsza medycyna sięga po coraz nowsze środki i techniki, by przedłużyć życie chorego, stosując uporczywą terapię w sytuacjach, w których nie ma szansy na wyleczenie.

W ostatnich latach pojawiły się nowe dylematy moralne związane z dziećmi, u których w fazie prenatalnej zdiagnozowano wady letalne, które najczęściej są przyczyną przedwczesnej śmierci dziecka.

W artykule omówiona zostanie opieka paliatywna (w tym domowa), która uwzględnia integralną wizję człowieka, holistycznie traktuje jego potrzeby fizyczne, emocjonalne i duchowe. Przedstawiona zostanie istota działania hospicjów perinatalnych (gr. *peri* - wokół, łac. *nascor* - rodzić), których założeniem jest towarzyszenie i wspieranie rodziców, którzy decydują się na kontynuację swojego rodzicielstwa, pomimo niekorzystnej diagnozy dla dziecka. To koncepcja objęcia całościową opieką nieuleczalnie chorego dziecka, nastawiona na zapewnienie godnego traktowania i ochronę przed uporczywą, daremną terapią. Objęcie troską rodziny i dziecka w sytuacji uzyskania niepokojącej diagnozy prenatalnej, stanowi pełne upodmiotowienie matki oraz dziecka, będącego pacjentem w fazie prenatalnej, posiadającym prawo do życia i godnej śmierci. W artykule opisano również stanowisko Kościoła Katolickiego wobec badań prenatalnych oraz stanowisko Polskiego Towarzystwa Pediatrycznego wobec uporczywej terapii.

Każdy człowiek, również dziecko w fazie życia prenatalnego czy noworodek, zasługuje na godne traktowanie przez całe swoje życie, także u jego kresu. Hospicja perinatalne mają pomóc „umierać po ludzku”, mają uświadomić społeczeństwu, że ostatnie chwile życia człowieka zasługują na szacunek.

**Słowa kluczowe:** opieka paliatywna, hospicjum okołoporodowe, uporczywa terapia, dylematy etyczne, umieranie

### Introduction

Significant progress- better diagnostics, new methods of treatment- has caused modern man to believe in the nearly limitless powers of medicine and has drastically reduced our acceptance of severe illness and death. Although death is a natural stage of existence, modern culture relegates it to the area of taboo. Elisabeth Kubler-Ross pointed out that “the more progress we make in science, the more we seem to fear death and deny its existence” (from Guzowski et al., 2016, p. 18).

Contemporary medical care for those afflicted with a chronic, incurable illness consists of prolonging their life with modern techniques and therapy. Aggressive therapy neglects the true nature of the treatment of a terminally ill patient, namely, the decrease of physical and spiritual suffering, the ensuring of a relatively good quality of life and humanitarian care (Buss, Lichodziejewska-Niemierko, 2008). The questioning of an anthropological, integrative vision of man, who struggles not only with bodily illness, but also existential dilemmas, leads to ethical problems that must be faced by twenty-first-century society.

Modern man avoids the recognition of death as an inevitable consequence of, and end to, life. Contemporary medicine reaches for ever newer means and techniques of prolonging the life of the patient, using aggressive therapy in

regardless of its effectiveness. The needs of the terminally ill are addressed by hospices, created for the ill who need emotional and spiritual comfort in addition to medical care. (Bomber, Komornicka-Jędrzejewska, 2016). Every human being has the right to a dignified and natural death<sup>1</sup>.

The enhancement of medical knowledge and medical diagnostics, especially ultrasound, led to the rise in prenatal testing, which provides a glimpse of the child's development already in the early stages of fetal life. Consequently, new moral dilemmas have arisen in recent years related to children who have been diagnosed with lethal abnormalities. Women, who find out in early pregnancy that their unborn child has no chance of survival, need comprehensive medical, psychological and spiritual care. Perinatal hospices attempt to meet those needs, as their aim is to accompany and support parents who have received an unfavorable prenatal diagnosis. The influence of the environment surrounding the parents, both familial and medical, largely determines the attitudes of parents faced with a terminal disease of their unborn child (Cobb, 2016).

In this article, the authors describe the beginnings of residential and home hospices, the philosophy of care and the nature of work in a perinatal hospice. They present the position of the Catholic Church on prenatal testing as well as the position of the Polish Pediatric Association on terminating life-sustaining treatment of children.

### **1. Palliative care**

Palliative care, according to the definition of the World Health Organization<sup>2</sup>, is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. The hospice movement developed in the 1960s, conceived and led by Elisabeth Kubler-Ross. Dr. Kubler-Ross' clinical research on human attitudes to impending death helped break the wall of silence between medical personnel and the dying patient, making the former aware of the problems of the dying and their families. Kubler-Ross created a classification of the phases of dying, which forms the basis for palliative psychology still today (Guzowski et al, 2016).

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<sup>1</sup> W. Bołoz, *Prawa człowieka umierającego*

[https://www.mp.pl/etyka/kres\\_zycia/41127,prawa-czlowieka-umierajacego](https://www.mp.pl/etyka/kres_zycia/41127,prawa-czlowieka-umierajacego) (05.10.2018).

<sup>2</sup> WHO Definition of Palliative Care, <http://www.who.int/cancer/palliative/definition/en/> (27.09.2018).

One of the first propagators of palliative medicine in the 20<sup>th</sup> century was the British nurse and doctor Cicely Sanders, who, in 1967, founded the first modern (by the standards of the day) hospice in London, St. Christopher's Hospice. At the time, there were already homes for the dying, mostly run by convents. Cicely Sanders introduced effective pain treatment, debunking the principle whereby curing the patient is the only task of medicine. Dr. Sanders was convinced that not all patients can be cured, and that dying people need, compassion, respect as well as respect of their dignity. She insisted that the inability to cure does not indicate the inefficiency of therapy and that patients should not be deceived in the case of an unfavorable diagnosis<sup>3</sup>.

Sanders was inspired to create a home for dying people by a meeting with a forty-year-old Polish-Jewish immigrant diagnosed with terminal cancer. They formed a spiritual bond and discussed the idea of creating a home for dying people to provide them with peace in their last days. Dawid Taśma uttered prophetic words before his death: „I will be the window in your home”. The St. Christopher Hospice, a home for the dying where scientific expertise is combined with love and care, still contains a window dedicated to the memory of David Tasma<sup>4</sup>.

As much as the progress of medicine has made the treatment of pain and other somatic ailments more effective, the assuaging of psychological suffering and fulfilling patients' psycho-social and spiritual needs remains a challenge for the medical personnel caring for the terminally ill. Care focused on the terminally ill patient's human dignity is extremely important to patients and significantly impacts their well-being (Cyzowska, 2018).

The aim of palliative care is the mitigation of physical suffering, providing the patient with the necessary psychological and spiritual comfort, when in a state of anxiety, fear, depression or guilt. Palliative care stems from an integrative vision of a person, holistically treating all physical, emotional and spiritual needs. The core of the support lies in expressing compassion for the patient, offering company and help in finding meaning in suffering and dying (Bomber, Komarnicka-Jędrzejewska, 2016, p. 58). Hanna Chrzanowska (1902-1973), founder of home care for the terminally ill in Poland and teacher of many generations of nurses, understood this very well. In 1922, while still a student in nursing school, Ms Chrzanowska wrote: “In lectures and in practice we learned about social nursing only in the context of social medicine and preventive hygiene. I was not aware that it included severely ill people confined to

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<sup>3</sup> Dame Cicely Saunders, founder of the modern hospice movement, dies, <https://www.bmj.com/content/suppl/2005/07/18/331.7509.DC1> (01.10.2018).

<sup>4</sup> T. Dangel, *Cicely Saunders (1918-2005)*, [http://www.hospicjum.waw.pl/pliki/Artykul/1142\\_cicelysaunders.pdf](http://www.hospicjum.waw.pl/pliki/Artykul/1142_cicelysaunders.pdf) (05.10.2018).

their homes, a type of work I grew to love so much in the future” (from: Rumun, 1978, p. 353).

### 2. Palliative home care according to Hanna Chrzanowska

Ms Chrzanowska became interested in home nursing and home care for the terminally ill while in the United States in 1946. She became acquainted with New York home nursing through a “wise black woman” who visited the ill in their homes with her. This experience, in addition to the knowledge received, reinforced her belief in home nursing as a very important and demanding vocation, requiring, in addition to sensitivity to the needs of the patient and empathy, extensive medical knowledge. It also required just as high qualifications as in other branches of nursing (Florkowska, 2018).

In 1947, Hanna Chrzanowska, as a nursing teacher, initiated the creation of new branches of learning at the University School of Nursing and Hygiene in Cracow: home nursing and subsidiary hospital care. However, the medical community at the time did not understand the idea behind the home care for the terminally ill, considering hospitals the best environment for that.

She wrote: “The right of a human being to her own space, here in the world of the ill, finds its categorical expression. One’s own space, not limited to a bed, night table and chair, like in institutions. We want something more, some freedom. Without the discipline, imposed order of the day, turning off lights. At home, I do indeed institute an order of the day, but it is my own” (Rumun, 1978, p. 361).

Hanna Chrzanowska led the training facilities of open nursing in Cracow, and, on the commission of the Health Ministry, lectured in other cities in Poland. She described her knowledge and experience in the textbook *Nursing in Open Healthcare*, published in 1960<sup>5</sup>. The medical community did not understand the nature of home care of terminally ill patients properly; it was not undertaken at all, and people were sent to hospitals. The impetus for home care, provided by Chrzanowska was merely the activity of ‘schoolgirls’, who under her leadership, practiced home hospice care during their traineeships (Florkowska, 2018).

The tireless nurse decided to involve the Church in the care of her patients and find a priest who would understand the idea behind palliative home care. In 1957, she reached out to Father Karol Wojtyła, to whom she presented the situation of patients and the absence of home care within the healthcare system. She found an influential ally in Father Wojtyła, who later became bishop of Cracow. Karol Wojtyła

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<sup>5</sup> H. Chrzanowska H., K. Skobyłko (1960), *Pielęgniarstwo w Otwartej Opiece Zdrowotnej*, Kraków: PZWL.

understood the nature of the problem; hence he financially and spiritually supported the initiative of home care. In 1960, he began visiting the terminally ill at their homes, including this as a ritual during bishop visits in the entire diocese. In 1957, there were 25 home patients, and in 1970 this number rose to 563. Hanna Chrzanowska was a pioneer of social nursing, also described as open nursing, of which home care was one of the forms. She believed that chronically ill patients with no chance of being cured should be entrusted to professional home care. She had very high expectations of nurses working in the homes. They were not only to ensure the personal hygiene of the ill, bandaging their bedsores, but also ease their existential sufferings. Chrzanowska believed that a nurse should be able to carry on an interesting conversation with their patients, giving them a sense of value as a human being, drawing their attention away from the illness. Her intuitive approach was very close to the idea of palliative care and in her home nursing one should see the onset of the practice of home hospices. On April 28, 2018 the beatification of Hanna Chrzanowska took place in the Divine Mercy Sanctuary in Lagiewniki<sup>6</sup>.

### 3. Perinatal hospices

Perinatal hospices (Greek: *peri*-around, Latin: *nascor*- to give birth) are a new site of care for pregnant women who receive an unfavorable diagnosis of their unborn child. Although medical literature has begun to devote more attention to these practices, systematic philosophical reflection on perinatal hospices is still relatively unknown in the medical community (Cobb, 2016).

The progress that has been made in recent years in genetics and medical diagnostics, especially ultrasonography, has contributed to the expansion and development of prenatal testing. Due to technological development of the medical sciences and increasing knowledge and experience, doctors can diagnose malfunctions in fetal growth already in the early stages of pregnancy. Modern practice enables not only the formulation of an accurate and precise diagnosis, but also the inception of treatment still in the uterus, or immediately after birth (Węgrzyn, Borowski, Wielgoś, 2015).

More advanced prenatal diagnostics allows for the detection of many lethal abnormalities. This situation has created new ethical and social dilemmas related to the aims of prenatal testing and the use of the results (Różyńska, 2013). In ethical

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<sup>6</sup> Jabłońska K. (2018), *Błogosławiona Hanna Chrzanowska i jej kompleks wyższości*, <http://wiesz.com.pl/2018/04/28/blogoslawiona-hanna-chrzanowska-i-jej-kompleks-wyzszosci/> (07.10.2018).

discussions, the question is often linked with eugenics. Authors insist that genetic tests are not always performed in order to treat the child, but, rather, lead to the termination of pregnancy. This points to a strong social inclination to perform abortions, mainly due to lethal abnormalities of the fetus (Frączek, Jabłońska, Pawlikowski, 2013).

From data submitted by the Health Ministry it appears that, in 2016, 1098 legal abortions were performed in Polish hospitals. Most abortions were performed as a result of prenatal testing- 1042; 55 were caused by a threat to the health or life of the mother, and one abortion resulted from a crime<sup>7</sup>.

The circumstances in which women/parents find out about the improper course of fetus development have a great influence on the perception of the problem and decisions taken by parents. The role of the doctor, who is the first to communicate the unfavorable diagnosis to the parents is crucial for further decisions (Łuczak-Wawrzyniak, Czarnecka-Iwańczuk, Bukowska, 2012, p. 171).

The choice of the parents is strongly related to the mindset of the people surrounding them. Family, friends and doctors are active participants in the choices considered by parents. This closeness and dependence on loved ones and medical authorities can be a source of courage, love, hope and the moral principles guiding the parents' choices. Parents, in the case of an unfavourable prenatal diagnosis need the support of family and friends who will help them see the meaning in accompanying their child until natural death, who will consider the child an awaited and loved member of the family for whom they are especially responsible, and make them realize that this activity reflects the values of a life well lived. The parents want confirmation that their love for a terminally ill child is neither pointless nor wasted (Cobb, 2016).

A child in the prenatal stage with developmental dysfunctions has the same right to live as any other person, who has been diagnosed after birth. Personalism gives the right for full inclusion of disabled people into society (Sipowicz, Pietras, 2017), which is why killing ill children in the mother's womb is unacceptable, since every disabled person is a full member of society (George, Tollefsen, 2011). The rising frequency of lethal abnormalities in children requires an entirely new approach. The pregnant woman must be provided with medical, psychological and spiritual care, as well support and guidance for the entire family (Thornicroft, Tansella, 2010).

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<sup>7</sup> Komunikat PAP MZ: *W 2016 r. w szpitalach wykonano 1098 legalnych zabiegów przerwania ciąży, w zdecydowanej w większości w wyniku badań prenatalnych*, Rynek Zdrowia, źródło: <http://www.rynekzdrowia.pl/Serwis-Ginekologia-i-poloznictwo/MZ-w-2016-r-wykonano-1098-zabiegow-przerwania-ciazy,175825,209.html> (03.09.2018).

Perinatal hospices meet the expectations of families who discover that their child has lethal abnormalities which most often cause the death of the child before or directly after birth. The idea of providing all-encompassing care to the child in the prenatal stage and the entire family has at its core the ensuring of dignified treatment of every human being, but also the protection of terminally ill children from futile, aggressive therapy. Perinatal palliative care involves symptomatic treatment in children and providing psychological, social and spiritual comfort to the parents, also in mourning. The care for the child can be conducted in the newborn ward, at home by the parents, or in a hospice, if the child survives birth and leaves the hospital (Boszko, Dangel, Grenda et al. 2015).

Home palliative care for children in Poland- as a separate specialty in pediatrics - began in 1994, when the Warsaw Hospice for Children began operating at the Institute for Mother and Child. This Polish model of perinatal hospice, with its idea of providing comprehensive medical, psychological and spiritual care for the family awaiting the birth of a terminally ill child is unique in Europe and the entire world. In the literature available, one cannot find any institution described that would combine prenatal diagnostics with palliative home care for children (Szymkiewicz-Dangel, 2016). Currently in Poland there are more than ten perinatal hospices. New institutions constantly appear, in Warsaw, Lodz, Gdansk, Wroclaw, Cracow, Opole, Poznan, Rzeszow and Lublin (Kmiecik, Szafrńska-Czajka, 2016).

News of the illness of an unborn child always brings great stress and pain to the parents, who are often left alone to decide what to do next.

In the case of diagnosis of an incurable prenatal pathology of their child, the parents have the right to choose one of three options:

- 1) Termination of pregnancy (Polish law allows for termination of pregnancy when lethal abnormalities have been diagnosed; (ref. Ślipko, Starowieyski, Muszala, 2010; Parliament Act, 1993).
- 2) Cessation of treatment of the fetus and/ or newborn in the hospital, followed by perinatal home palliative care;
- 3) Reanimation -intensive therapy, described as persistent therapy (Dangel, Szymkiewicz-Dangel, 2005).

Prenatal hospice care provides the opportunity of expert psychological support as well as the acceptance for the parents' decision not to terminate the pregnancy. The continuation of pregnancy with a child burdened by genetic defect often meets with social disapproval. The clash between practical obstetrics and bioethical knowledge, problems in defining the onset of life as well as the inability of doctors and midwives to support families struggling with a negative prenatal

diagnosis are all challenges for healthcare workers in promoting perinatal hospices (Różańska, Baranowska, Tataj-Puzyna et al., 2017).

One cannot fully prepare for the death of one's child. Parents have difficulty accepting that their conceived child is terminally ill, that it could die before birth or right after. However, parents often find meaning in this tragic situation, discovering the dignity of the child and their own, without forsaking their humanity and parenthood. The suffering caused by the death of a child is extremely painful. Meanwhile, death is an essentially human experience, and participating in it can teach us a great deal. A dying person can show the people around them, above all, how to live (Bomber, Komarnicka-Jędrzejewska, 2016).

Studies show that women who terminated pregnancies because of lethal abnormalities of the fetus have experienced many more episodes of despair, avoidance and depression than women who continued with their pregnancy. Hence, doctors point to the psychological benefits women can gain from the continuation of pregnancy despite an unfavorable prenatal diagnosis (Cope, Garrett, Gregory, et al., 2015).

Literature on the subject indicates unequivocally that, in order to prevent postpartum depression, the mother is encouraged to have physical, skin-to-skin contact with the newborn directly after birth, also in the case of a stillbirth (de Graaff, Honig, van Pampus et al., 2018).

Taking care of the family and the child in the case of a troublesome prenatal diagnosis involves giving full agency to the mother and child, who is a patient in the prenatal stage, with the right to life and as well as the right to a dignified death. For this reason, care in a perinatal hospice cannot be treated merely as an alternative to eugenic abortion. The significance of perinatal hospices is much broader (Kmiecik, Szafrńska-Czajka, 2016). From the report by Alastair McIntyre, one can observe that perinatal hospices foster virtues and attitudes towards the terminally ill and defenseless, which are indispensable to a noble life. Therefore, perinatal hospices deserve broad support in society, which should promote a civilization of life, but also a civilization of dying (Cobb, 2016).

Every human being, including a child in the prenatal stage or shortly after birth, deserves humane treatment during the entirety of its life, also at its end. Perinatal hospices are supposed to assist "dignified dying", raising awareness on the respect owed to the final moments of life. At a time when life inevitably fades away and there is no hope of prolonging it, doctors should not desperately fight to prolong life, but make space for peace, silence and intimacy with the dying (Guzowski et al., 2016, p. 26).

In 2011, the Polish Pediatric Association published guidelines for doctors entitled *Cessation and Limitation of Aggressive Life Sustaining Treatment of Children*, which form the ethical basis of a pediatrician's actions (Boszko, Dangel, Grenda et al. 2015). Aggressive therapy is a series of medical actions which may significantly escalate the suffering of the patient, and the effectiveness of which is incomparable to the intensity of the measures taken (Cepuch, Domańska, Dębska, 2013).

The Commissioner for Human Rights wrote in the *Bill of Rights of the Terminally Ill Child* that "every terminally ill child, regardless of the illness, and the psychological and physical state, has the right to dignity, respect and intimacy in a home environment (...). These children should be protected from pain, suffering and unnecessary medical tests and procedures" (Boszko, Dangel, Grenda et al. 2015, p. 33).

The system of caring for a family awaiting the birth of a child with a congenital or developmental abnormality should be integrated and comprehensive. The fundamental task of a mature civil society is to guarantee the right to a dignified life and dignified death. Every woman and every family in Poland who struggle with the risk of giving birth to a child with a congenital or developmental defect, including lethal abnormalities, should have the right to medical, psychological and spiritual care.

Perinatal hospices play a very important role in the education of society, according to the paradigm of respect for all forms of human life, from conception to natural death (Sipowicz, Pietras, 2018).

In 1999, the Institute of Mother and Child published *Standards of Home Palliative Care for Children* for the Ministry of Health. The document states, among other points, that "home care should be promoted as a form of care that is the most appropriate for the needs of parents and children, and moreover, one that is less costly than institutional care. In large cities, it is justifiable to create centers for the exclusive care of terminally ill children. In other towns, where home care centers for children do not exist, the most appropriate solution is a small team trained in child care collaborating with existing adult hospices and a pediatric ward (for instance, oncology)" (Dangel, 2006, p. 9). Palliative home care for children in Poland is developing more and more each year (Dangel, 2015).

#### **4. The position of the Catholic Church on prenatal testing**

The position of the Catholic Church on prenatal testing and the status of a conceived child is clear and has been included in the Catechism of the Catholic Church "Prenatal diagnosis is morally licit, if it respects the life and integrity of the

embryo and the human fetus and is directed toward its safe guarding or healing as an individual... It is gravely opposed to the moral law when this is done with the thought of possibly inducing an abortion, depending upon the results: a diagnosis must not be the equivalent of a death sentence" (KKK, 2274). Further: "One must hold as licit procedures carried out on the human embryo which respect the life and integrity of the embryo and do not involve disproportionate risks for it, but are directed toward its healing the improvement of its condition of health, or its individual survival" (KKK, 2275).

In the *Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation* we read that prenatal testing is morally permissible "if the methods employed safeguard the life and integrity of the embryo and the mother, without subjecting them to disproportionate risks"(DF/I/2).

The conducting of prenatal testing can be justified only by the true necessity of urgent diagnosis and the importance of medical procedures crucial to the child's well-being. Pope John Paul II insisted that diagnostic methods that pose a danger to the life or health of the conceived child should be avoided. The moral acceptability and justness of prenatal testing is dependent primarily on the assessment of the risk placed on the conceived child (John Paul II, 1982).

Therefore, a very important aspect in ethical judgment is the purpose of prenatal testing. In the *Evangelium Vitae* encyclical, John Paul II points out that "prenatal diagnosis, which presents no moral objections if carried out in order to identify the medical treatment which may be needed by the child in the womb" (EV, 14). A moral aim considered licit is also "to favour a serene and informed acceptance of the child not yet born" (EV, 63).

Pope John Paul II firmly condemns the use of prenatal testing for potential abortions. In this case, they become unjust, as they are performed with the willingness to kill the child, if it turned out to be burdened by genetic defects. Such eugenic abortion, as the Pope points out, is an element of a mentality, that "accepts life only under certain conditions and rejects it when it is affected by any limitation, handicap or illness" (EV, 14) and "presumes to measure the value of a human life only within the parameters of 'normality' and physical well-being, thus opening the way to legitimizing infanticide and euthanasia as well" (EV, 63).

John Paul II referred also to the concept of 'aggressive therapy' and the possibility of stopping it. In the *Evangelium Vitae* encyclical he wrote "when death is clearly imminent and inevitable, one can in conscience refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted .... To forego extraordinary or disproportionate means is not the equivalent of suicide or

euthanasia; it rather expresses acceptance of the human condition in the face of death" (EV, 65).

### 5. Guidelines of the Polish Pediatric Association for Physicians

M. Korzon in her introduction to *Guidelines for Physicians of the Polish Pediatric Association*, concerning the cessation and withdrawal of aggressive sustaining therapy of children wrote: "Most doctors graduating from medical school practice their profession with the goal of maintaining the life of the patient in every case and at all cost. Especially in pediatrics the acceptance of the right of the child to a dignified death and cessation of treatment is extremely difficult. The currently formulated statement that a doctor in a hopeless situation should resign from life-sustaining therapy that prolongs the suffering of the child, is often not fully understood or practiced. Aggressive therapy, which ethically prevents the "acceptance of death", is a moral and legal transgression. Furthermore, it is often said that keeping a child in the hospital, rather than in the more psychologically comfortable home environment, as well as the resort to treatment which increases and prolongs suffering constitutes a misdemeanor in the light of current law" (ref. Dangel, 2011, p. 9).

### Conclusion

The death of a child in the prenatal stage is incomparable with other losses since a child at that stage, regardless of age, constitutes a specific person in the eyes of the parents. When faced with the loss of a child, parents simultaneously lose the ability to take on the role of parent. A source of pain also lies in the lack of memories or souvenirs of the child deceased before birth and mourning concerns largely what did not happen. Along with the child, parents lose dreams, plans and a sense of self-worth (Łuczak-Wawrzyniak, Czarnecka-Iwańczuk, Bukowska, 2012, p. 164).

A perinatal hospice is not merely a place, but a concept of providing families with comprehensive care when they find out that their unborn child will die before birth, during or after labor. After the initial, prenatal diagnosis parents' perceptions of a happy parenthood are crushed. At such a time, they seek help in various places. They expect confirmation of the diagnosis, accurate medical information, and, above all, comfort in this difficult and painful experience of being a parent and witnessing the death of a child. Hospice workers offer parents authentic support and confirmation that a bond with the terminally ill child in the prenatal stage is crucial for building the value of their parenthood. The love of a parent for an ill child is

neither futile nor wasted; it forms the core of the humanity of the parent. The fundamental biological, emotional and spiritual bond cultivated by the parents in the prenatal stage develops their humanity.

The actions and support of hospice workers can strengthen the conviction of parents that their sick child is a difficult gift, which should be accepted. Through this approach, parents understand the value of parenthood, while accompanying the ill child in the prenatal stage and after birth. It impacts their assessment of a well lived, though short, parenthood. Love for the child enables the development of feelings of a higher order in the parent. In order to build a 'civilization of life' it is imperative to build a 'civilization of dying', the ability to accompany every human being, including a child, in the face of the inevitability of death.

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