

Prenatal Palliative Care and Perinatal Hospice – New Challenges in Caring for the Precious Gift of Life in its Fragility

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Abstract:

Prenatal diagnosis often brings information about serious illness of the child with unfavourable prognosis. Some consider termination of pregnancy; for others termination is unthinkable; others are not sure which path would be a more acceptable or more compassionate choice. In such a situation, to make the final decision, it is important to have a wide range of accurate sources of information at one's hand. Prenatal palliative care and perinatal hospice provide support to those parents who

choose to continue their pregnancy. The approach is based on strict scientific methods joined with thorough health care planning as well as empathy and compassion. The aim of the paper is to point out the innovative possibilities of professional medical assistance to an unborn child diagnosed with serious illness and to its parents, as well as to demonstrate the need for cooperation of health care professionals and helping professions in accompanying such couples.

Introduction

More and more parents owe the saving of their child's life and health to progress in neonatology. However, the expectations of parents, gynecologists, neonatologists and other specialists in certain situations exceed the limitations of what is possible to achieve while rescuing some children. Even those medical specialities that progress rapidly cannot always maintain the health and life of all children. Although pronouncing a serious diagnosis in the prenatal period, making an unfavorable prognosis, awaiting an expected death during pregnancy, before birth, at birth or even after birth is not too common, nevertheless, it does occur. Even today we are confronted with suffering and death. Medicine as a field offers highly qualified, professional, and comprehensive medical assistance in the form of prenatal palliative care and perinatal hospices. While around the world, there is a growing response to this trend, some countries, including Slovakia, remain passive, despite the theoretical principles and practical steps to the provision of palliative care to children in utero, or newborns with life-threatening and/or life-limiting diseases having been laid out (Fussiova, Bauer 2016).

Every dying is unique and there is no recipe for how it should be handled. The final processing of a loss of a child and the subsequent management of emotions by the family depends on many factors. We believe that accompanying the family through this process is currently a major challenge for healthcare professionals, as well as for other helping professions, and it needs to be addressed. Firstly, we find it instructive to explore how the surrounding countries in the central European region respond to the dissemination of the concept of a perinatal hospice. Secondly, we examine what trends and standards of operating procedures have been laid out in this respect in the world. Additionally, we outline how they have been applied in Slovakia. In this

text, we will emphasize the difference between the classic, established approach to dealing with prenatal diagnoses with life-limiting and/or life-threatening diseases through abortion, and the approach of prenatal palliative care and the perinatal hospice. The aim of this paper is to support the thesis that the perinatal hospice represents a sensitive and especially human approach to the conceived fragile life. Such an approach represents more than just organizational, institutional, and functional change or a specific place of treatment. It is a professional, clinical and interpersonal model of care and service based on a relationship where help consists of the use of strictly scientific medical methods that go hand in hand with healthcare planning, sincere interest, compassion and humanity.

Prenatal diagnosis and maternofetal therapy

Former Czechoslovakia was one of the countries that were one of the first in Europe to introduce *prenatal genetic diagnosis* into clinical practice in 1971. The integration of prenatal genetic diagnosis and obstetric non-invasive and invasive methods into clinical practice has enabled in-depth and increasingly detailed monitoring of the intrauterine development of the child from its early stages to the moment of birth (Hajek *et al.* 2000). Advanced technologies in the form of modern diagnostic techniques and devices, as well as the improvement and introduction of new laboratory methods, have led to a great development of prenatal diagnosis. Along with this development, the number of detectable genetic defects and diseases has been increasing. There has also been an increase in the number of situations where parents have been faced with information that their child is not and will never be healthy, and/or even more tragically, that their child is suffering from a life-limiting disease (LLD). Life-limiting and/or life-threatening diseases are those that cannot be treated curatively or in which cur-

ative treatment has failed (Kysel, Jasenkova 2018). The overall incidence of life-limiting and/or life-threatening diseases in childhood is 30 cases per 10,000 children in the population. A total of 57,717 children were born in Slovakia in 2016. Of those, 3,390 suffered from a life-limiting and/or life-threatening disease (Trizuljakova, Sitinova 2018).

In the case of testing positive for prenatal diagnosis and the discovery of fetal pathology, it is a common solution to propose to parents a medically indicated termination of pregnancy (Decree of the Ministry of Health No. 74/1986 Coll.). As a rule, women are only offered this one solution, as it is believed that ending a pregnancy is less traumatic for a woman than giving birth to a child that subsequently dies. There is an effort in the world to re-evaluate this solution and substitute it with an alternative offer of tangible assistance (Noia 2019). Taking the alternative route requires shifting focus to maternal-fetal medicine and prenatal palliative care. Additionally, such shift fundamentally changes the goal of prenatal diagnosis: from the decision to terminate the pregnancy prematurely to trying to treat a child causally or symptomatically already in the womb. The present state of the fetus determines the goal of the treatment: whether it is to cure the child; to improve its long-term outlook; to manage the most burdensome symptoms (provide relief); or to provide palliative (prenatal or perinatal) care. The way forward is proving to be possible due to the constant developments in fetal medicine. Thus, both non-invasive pharmacological and surgical therapy of the fetus have become an important option in the present management of several fetal problems (Noia 2019). Trisomy 13 and 18, metabolic diseases, anatomical malformations of the brain and kidneys, congenital developmental heart defects, congenital diaphragmatic hernia constitute some of the most frequent intrauterine pathological conditions of the fetus. Prenatal invasive fetal surgery may also be recommended in strictly selected cases (Ferianec 2014). Although fetal therapy, due to its specific conditions and limitations, constitutes only a small part of the possibilities and postnatal interventions, increasingly more impressive, ambitious and complex procedures are emerging and are thus becoming more accessible (Noia 2019; Dráb *et al.*, 2017;

Ferianec 2014; Tworetzky, Marschall 2003; Noia *et al.*, 1992).

In the case of a child whose death is expected, the parents' original wishes and dreams are collapsing. In Slovakia, of all the deaths of children between 2011 and 2016, 70-75% were unexpected and 30-35% of the deaths were so-called 'expected deaths' (Trizuljaková, Sitinova 2018). However, the parents' hope may be given new meaning and direction, knowing that their child will live a short but dignified life with the utmost professional and comprehensive medical assistance.

Prenatal palliative care and perinatal hospice around the world

Palliative care is an approach that improves the quality of life of patients and their families against life-threatening illness by early identification, urgent diagnosis and treatment of pain and other physical, psychosocial, and spiritual problems, and thereby prevents and alleviates suffering. Palliative care includes: healthcare provided by doctors (diagnosis and treatment); nursing care; rehabilitation; psychological care; curative education in children; spiritual care; social care. Palliative care focuses on life, improves the quality of life of the patient and the whole family, and alleviates the process of grief. The basic principles of palliative care in adults and children are the same. However, the decision-making process, treatment, and communication all have their specifics (Kysel, Jasenkova 2018).

Palliative care for children is the provision of palliative care to children with life-limiting and/or life-threatening illnesses. It begins on the first day when a serious diagnosis is made and continues regardless of whether the child is being treated by another potentially curative or life-prolonging treatment for life-limiting and/or life-threatening illnesses. It requires a multidisciplinary approach of professionals from various medical and non-medical professions.

Home palliative care for children born with life-limiting and/or life-threatening disease fulfils the basic need and desire of children to be and live at home. To illustrate, four children's mobile hospices have been providing home palliative care in Slovakia: *Plamienok* (Little Flame) hospice in Bratislava since 2002; *Svetielko pomoci* (Light of Help) hospice in Košice since 2011,

Svetielko nádeje (Light of Hope) hospice in Banská Bystrica since 2015; *Pod krídlami Dominiky* (Under the Wings of Dominika) hospice in Nitra since 2017 (Kysel, Jasenkova 2018).

In 2014, the WHO Global Resolution called on its member states to improve access to palliative care and integrate it into their health systems with an emphasis on primary care and home care. This effort should be fortified by the development and implementation of palliative care guidelines within each country. In Slovakia, experts are currently developing standard operating procedures of palliative care in perinatology within a multidisciplinary team (Chovancova 2019). This initiative's target group consists of the child, its parents, and the family. Health professionals such as obstetricians, midwives, obstetrics and gynecology nurses, neonatologists and pediatric nurses, psychologists, and hospital social workers are the potential everyday beneficiaries of these standard operating procedures. These aim to optimize the quality of life of a child with life-limiting and/or life-threatening illness and to support the family in the decision-making process and enable it to provide care that is in the best interest of the child. Emphasis is placed on: interdisciplinary support of the family; on optimal palliative care for the child; on building a relationship of trust between the family and the medical team. It is difficult to predict the child's clinical condition and quality of life before birth. The child's death may occur during pregnancy, during childbirth, and in the period immediately thereafter. In the case of a stillbirth, standard operating procedures recommend that parents are allowed contact with the child. Touches, as well as farewell rituals, are encouraged, all in an intimate setting and in accordance with the parents' preferences. The implementation of these standards in practice supposes: minimizing of suffering (e.g. pain) and discomfort of children; strengthening of the doctor-patient relationship (parents acting as the child-patient's representatives); reinforcing parents' support of and trust in palliative care; improving awareness and increasing support for health care providers as palliative care providers (Chovancova 2019).

Prenatal palliative care and perinatal hospices are a practical response to pathological findings discovered during prenatal examinations of children (literature includes the use of the

terms prenatal and perinatal as synonyms). It focuses on the perinatal period of the child and its parents. According to the WHO, the perinatal period begins upon completion of 22nd gestational week or upon the child achieving the weight of 500 grams until the completion of 7th day after birth (in some countries the limit varies from 22nd to 24th or 28th week of gestation) (Chovancova 2019). It is a compassionate model of support for parents who decide to continue their child's pregnancy after prenatal diagnosis with a life-limiting and/or life-threatening disease. The idea of a 'hospice in the womb of the mother' helps parents to accept any life their child may potentially have. Additionally, it supports them: in childbirth planning; provides emotional support and support in grief; promotes respect for parents' preferences; enables preliminary medical decisions before the baby is born; as well as endorses more traditional hospice and palliative care provided after birth in the institution or at home. Perinatal palliative care, therefore, includes basic care for the newborn such as warmth, comfort and nutrition, and all other means that can improve or make life easier for the child (www.perinatalhospice.org).

The American gynecologist and obstetrician B.C. Calhoun was among the first to use the term 'perinatal hospice' and became a pioneer in this area (Calhoun *et al.*, 1997). Subsequently, it was two women, a developmental psychologist Deborah Davis (2011) and journalist Amy Kuebelbeck (2003) who brought attention to this topic and the new approach. Kuebelbeck is a freelance journalist and former reporter, editor of *The Associated Press*, and author of the book *The Gift of Time – Continuing Your Pregnancy When Your Baby's Life is Expected to Be Brief*. In this book, she describes her own experience with pregnancy and perinatal loss. She is the initiator and editor of the website, which has continuously provided information on prenatal palliative care from around the world since 2006 (www.perinatalhospice.org). Today, the site provides information on more than 300 specialized programs running worldwide. These are diverse, varying in the scope of support, assistance and services offered to the parents and the child. Some are established directly in hospitals, integrated into the overall management of a pregnant woman, others are applied in perinatal hospices. There are civic asso-

ciations which operate independently, for example through raising awareness of the subject. Countries, where the program has expanded, include the US (Alabama, Alaska, California, Florida, Illinois, Maryland, Massachusetts, New York, Pennsylvania, Washington, and dozens of other states), Canada, Argentina, Uruguay, Chile, Nicaragua, Australia and New Zealand. In Europe the concept of prenatal palliative care has made its way into practice in the United Kingdom (Scotland, Wales), Germany, Norway, Spain, Hungary and Poland (Korzeniewska-Eksterowicz *et al.*, 2013). Ukraine has also opened its first perinatal hospice by a clinical psychologist and bioethicist sr. Guistina Olha Holubets. She focuses mainly on accompanying parents who have experienced perinatal loss.

Italy is of particular importance in the European context due to the *Center of Prenatal Palliative Care* named after Mother Teresa of Calcutta and the *Perinatal Hospice* at the Faculty of Medicine and Surgery of A. Gemelli at the Sacred Heart University in Rome. Its director, Professor Giuseppe Noia, is also involved in a non-profit organization *Il Cuore in una Goccia* (The Heart in a Drop) aimed at protecting the life and health of the unborn child, with special regard to cases of prenatal pathologies of different natures and severities, and the life and health of the mother. In May 2019, Professor Noia hosted almost four hundred participants at an international conference called *‘Yes to life! Caring for the precious gift of life in its frailness’*. At this event, world experts spoke about the importance of delivering proper and complete information to parents about the real risks of fetal disease as well as about the new approaches to prenatal diseases and the news in fetal medicine (Noia 2019).

Prenatal palliative care and perinatal hospices in Czechia and Slovakia

In the Czech Republic, perinatal hospices have also gained attention. In her research, Katerina Rastislavova points out that insecurity and enormous psychological stress are experienced not only by parents but also by health care professionals who witness a perinatal loss of the child. As a solution, she recommends that health care professionals and cooperating helping professions attend educational courses and training

with a special focus on communication and mourning therapy (Rastislavova 2016). Some of these recommendations have already become a reality. The course *“Care for Parents after Perinatal Loss”* is run under the auspices of the Faculty of Health Care Studies of the University of West Bohemia in Pilsen twice a year, both as a distance and full-time program with all places filled, leaving many applicants on a waiting list each year (Trizuljakova, Sitinova 2018). Additionally, several websites about perinatal hospices have emerged, being mostly informative in nature. The perinatal hospice *Dite v srdci* (Child in the Heart) began to operate in the Ceske Budejovice and Hradec Kralove regions with a team consisting of a gynecologist, psychiatrist, social worker, midwife, doula and a priest. The *Dlouha cesta* (Long Road) Society started a program called *Prazdna kolebka* (Empty Cradle), which aims at assisting parents in dealing with the loss of their child. Moreover, parents who have endured perinatal loss are offered counselling by a Prague mobile hospice *Cesta domu* (A Way Home), originally specialized solely on adult patients, and by a perinatal hospice *Duha* (Rainbow). Concepts, ideas, and the philosophy behind providing prenatal palliative care are spreading around the Czech Republic and reaching the public thanks to education provided by non-profit organizations, as well as through various charity and cultural events (www.perinatalnihospic, www.ditevsrdci).

In Slovakia, we are not aware of an institution, non-profit organization, or civic association that would specify, disseminate and implement the program and its activities as a systemic provision of prenatal, perinatal palliative care, or would function as a perinatal hospice. Palliative care in our country is usually commenced after the birth of a child and provided in perinatal and neonatological centers. Unsuccessful pregnancies with the expected prenatal and perinatal loss of the child are, nevertheless, a pressing issue.

Perinatal loss

Perinatal loss is the loss of a child (fetus, newborn) who dies during the perinatal period. The ability to accept and cope with such loss is determined highly individually and the response remains subjective on the part of each person. It

is the type of loss and experience that can both reinforce interpersonal relationships, but also disrupt them. The effects on for example the physical and psychological balance of parents or family relationships can be detrimental and the event can act as a devastating experience in the lives of those concerned.

Sadness and grief are natural reactions to the loss of a loved one. Parental grief is a deep, cruel, long-lasting and complicated symptom that changes over time. Active, functional, or uncomplicated sadness is a natural, painful, but necessary adaptive response to loss and it includes the emotional, physical, spiritual, social, and intellectual responses of the individual, family, and community. Perinatal loss can turn into dysfunctional sadness at any stage. Research suggests that termination of pregnancy due to a child's congenital developmental defect may subsequently be associated with the woman's psychological distress (Zeanah *et al.*, 1993; Kersting *et al.*, 2004).

Those health professionals who are involved with the effected women and parents the most (especially doctors, nurses, midwives, clinical psychologists, and hospital social workers), play an important role in the adaptation process and in promoting healthy grieving. Helping the parents who grief and addressing their needs enables anticipation and prevention of some of the problems. In their research, Mazuchova and Zaludkova (2014) outline what these needs, expectations, or difficulties may be. They investigated how women who had suffered perinatal loss experienced the provided health care. According to their findings, health care workers focused primarily on the physical aspects and on meeting the mother's physical needs. The women reported unsatisfactory experiences with learning where and to whom they should go for support, with obtaining assistance from a psychologist, with disinterested attitudes of the staff, with no interest in how the family members were dealing with the situation, and with absence of information about the possibility of having a mourning ceremony or burying the child. Health care professionals neither provided nor suggested any commemorative items for the baby, or, at times did not allow such action to be taken. Other findings suggest that parents were not given the opportunity to say goodbye to their child, to see,

touch, or give the child a name. These findings are surprising as the presence of professional psychological and spiritual support according to individual requirements should always be available to these women and families. The authors considered it interesting that several respondents suggested that health professionals should be trained for such situations in advance, for example when obtaining higher education and that they should undergo psychological training for helping women with perinatal loss. The authors considered these suggestions of educational and training activities for health professionals especially well-founded (Mazuchova, Zaludkova 2014).

Conclusion

When a life-limiting and/or life-threatening disease of a child is discovered during prenatal diagnosis, some parents decide to continue their pregnancy. They should not be left alone under these specific and unique circumstances. The Czech Republic is already responding to their needs through education, courses, lectures, and charity events. In Slovakia, systematic attention to the topic has been lacking and papers on this topic are only sporadically found in the literature. Even so, Slovakia should not be left aside. We are confident that in the beginning very little is needed, a mere first step. The effort can consist of: targeted management of families; of building systematic communication channels; of connecting networks of experienced professionals who are enthusiastic about the concept of perinatal hospices. Such professionals may include geneticists, gynecologists and obstetricians, neonatologists, psychologists, or midwives.

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