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Perinatal experiences after a fetal/child lethal diagnosis (LFD) - a woman's perspective[1]

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Abstract: A lethal fetal diagnosis defines severe developmental disorders that lead to the death of the child either before birth or shortly after. In the global healthcare system, the issue of stillbirths has been overlooked, and care for this group of families has been neglected. As a result, the experiences of women during pregnancy following a prenatal diagnosis of a lethal prognosis for the fetus/child have not been sufficiently studied. However, in the last decade, increasing attention has been given to this issue, and the topic of caring for families who, despite a lethal diagnosis, choose to carry the pregnancy to term has become an important public health concern. Taking into account the needs of this group of women/parents, perinatal hospices have been established, providing multidisciplinary perinatal care tailored to the needs of these families. Research indicates that despite the anticipated loss of the child, parents can have positive experiences related to the period of waiting for the birth and the delivery of a lethally ill child. Through professional, empathetic medical care, parents can be provided with the space to experience prenatal parenthood, growth in personal strength, relationships with others, and an appreciation for life. Therefore, the aim of the article is to describe selected stages/issues of the pregnancy period in women following a prenatal diagnosis of a lethal prognosis for the fetus/child.

Keywords: pregnancy, lethal fetal diagnosis, LFD, perinatal palliative care, perinatal hospice, post-traumatic grow

Introduction

In recent years significant progress has been made in perinatal medical care. However, despite these advances malformations in the baby, especially those with a lethal prognosis, are still a serious challenge for medicine. A fatal fetal disease is defined as a condition that is likely to result in death in the mother's uterus or within the first hours or weeks of the baby's life after birth (Power et al., 2020). The Lancet devoted a series of articles to the problem of stillbirths, in which the authors highlighted that this is one of the most neglected areas of public health, omitted from global health programs (Flenady et al., 2011; Flenady et al., 2020; Frøen et al., 2011; Lawn et al., 2011). This problem is a challenge not only for medicine, but also for families who experience the devastating loss of a child.

More than 2.7 million babies are stillborn worldwide each year (Lawn et al., 2016). The perinatal period is characterized by the highest rates of morbidity and mortality among pediatric patients. In high-income countries, approximately 2-3% of women receive a diagnosis of a fatal fetal disease (Coleman, 2015).

In recent years, research has begun to be conducted on the needs of women/families who have continued pregnancy despite a fatal fetus/child di-

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[1] Article in polish language: https://www.stowarzyszeniefidesetratio.pl/fer/59P_TatP.pdf

agnosis (Cope et al., 2015; Côté-Arsenault & Denney-Koelsch, 2011; Denney-Koelsch et al., 2016).

Thanks to the enormous progress in prenatal diagnostics, both imaging (latest generation ultrasound machines, the possibility to perform fetal MRI), as well as invasive and non-invasive genetic tests (including testing of free fetal DNA in the mother's blood, based on the next generation sequencing technique -NGS), fetal defects, including those of a lethal nature, can be identified early in pregnancy (Breeze et al., 2007; Frates et al., 2004; Rutkowska & Szczepaniak, 2018).

Studies show that 3% of fetuses are diagnosed with life-threatening problems: Live Limiting Fetal Condition (LLFC), and 2% are considered fatal defects: Lethal Fetal Diagnosis (LFD) (Coleman, 2015). In such circumstances, 20-60% of parents decide to continue their pregnancy and give birth to a sick child (Breeze et al., 2007), motivating their decision with moral convictions, a sense of what is moral or right for them, views on abortion, religious beliefs (Sandelowski & Barroso, 2005; Wool, 2011). Also in countries where there is a legal possibility of terminating pregnancy, many mothers in the event of a severe and irreversible defect found during the prenatal life of the child decide to continue pregnancy for the above reasons.

In Poland, in October 2020, the Constitutional Court issued a ruling, the consequence of which is a ban on termination of pregnancy in the event of fetal birth defects (Judgment of the Constitutional Tribunal of 22 October 2020, Sygn. Act K 1/20). The situation in which the child in the prenatal phase of life is a full-fledged patient has brought a number of challenges to create professional, comprehensive perinatal care, adapted to the needs of women/families who, despite the prenatal diagnosis with a lethal prognosis for the life of the child, decide to continue the pregnancy and give birth to a terminally ill child. In response to the needs of this group of parents, perinatal hospices were created, which implement multidisciplinary perinatal care programs.

The purpose of this article is to describe the experiences of perinatal women who continue their pregnancies after a prenatal diagnosis of a lethal prognosis for the life of her child.

1. Pregnancy as a state of liminality – being "in between"

From an anthropological point of view, the gestation period is seen as a liminal space. The transition from pregnancy to parenthood is examined in a social context as a rite of passage. Pregnancy and childbirth are seen as a liminal phase (Côté-Arsenault et al., 2009).

Studies show that every woman during pregnancy experiences an important life transition from one social role to another. This state is referred to as "liminality" – being "in between". The perception of an important life transition as a liminal phase is not new. According to van Gennep's philosophy (1960) life is a successive transition from social group to group. This process concerns all areas of human life in which change takes place. Van Gennep described three phases of this process: separation – when the individual disconnects from previous social roles; liminality – when he transitions to new social roles; and integration – when new social roles are incorporated into the identity of the individual (ibid., see also: Ladge et al., 2012).

Recognizing pregnancy as a liminal state is crucial for a full understanding of what it means for women *to be pregnant* and what its inherent personal challenges and dilemmas are. This is similar to being in a certain type of undefined space (Côté-Arsenault et al., 2009).

2. The experience of pregnancy with a child's lethal defects

Particularly interesting is the contemporary study of liminality in relation to pregnancy, birth and loss of the child in the intrauterine or postnatal phase. In this field, research is used to explain major changes in the treatment of women by society, to recognize them or isolate them from the mainstream of society and to make them "invisible" during pregnancy, childbirth and the postpartum period (Côté-Arsenault et al., 2009).

The difficulty associated with the liminal state of women who continue a pregnancy after an unfavorable diagnosis with a lethal prognosis for the child is exacerbated by the lack of social acceptance regarding the delivery of a child who will die during or after birth. Although the philosophy and approach to caring for parents who have experienced the death of their unborn or newborn child has changed over the past 40 years, there is still a lack of social acceptance of stillbirth. The taboo associated with the perinatal death of a child increases parental suffering, loneliness and social isolation (Rådestad et al., 2011).

Information about a diagnosed congenital defect in a child in the prenatal phase is traumatic for parents. Many women face difficult decisions and choices influenced by many psychological, social and ethical factors (Blakeley et al., 2019). Research shows that parents who decide to continue their pregnancy experience ambiguous feelings (Cope et al., 2015; Côté-Arsenault & Denney-Koelsch 2016; Fonseca et al., 2011; McKechnie et al., 2015). On the one hand, women suffer from the perceived loss of their expected child and the loss of the chance for happy motherhood. On the other hand, they experience positive changes in personal development and the process of rebuilding life after trauma (Black & Sandelowski 2010; E. M. Denney-Koelsch et al., 2018; Lalor et al., 2009).

Research conducted in Ireland shows the characteristic „process of transforming hope" („Recasting hope") adaptation of women after receiving a tragic diagnosis. In this process mothers must face the loss of ideas about motherhood, „normal pregnancy" and their dream baby and go through four phases of adaptation: "Accept Normalcy", "Shock", "Gaining Meaning" and "Rebuilding Hope"". After an unsuccessful diagnosis mothers do not believe that their conceived child has been diagnosed with lethal defects. When the tragic diagnosis is confirmed by subsequent tests, they experience shock. Then begins the stage of giving meaning to this difficult stage of family life. The last phase concerns rebuilding hope, recovering from the trauma of accompanying a child through illness and dying, and in accepting the child's death. In this process, an important role is played by the acceptance of ideas about the unfulfilled expectations of a happy motherhood after the birth of this child (Lalor et al., 2009).

3. Professional medical care

3.1. Empathic medical care adapted to the woman's worldview and philosophy of life

Empathetic medical care, acceptance and support by medical personnel of the decision to continue the pregnancy, despite the lethal prenatal defect found in the child, are an important factor for women, influencing the passage through the difficult time of pregnancy. Many studies show that women in this situation expect that their needs will not be marginalized, that they will be treated like other pregnant women, and that the unborn child will be "given" patient status by medical personnel. They also expect that their pregnancy will not be considered less important and valuable, and that their prenatal child will be treated with respect. These studies also found that women, upon receiving a prenatal diagnosis of a lethal prognosis for the fetus/baby, often faced a lack of understanding from medical personnel, who suggested that they terminate the pregnancy (Guon et al., 2014; Horning & Braun, 2006; Sandelowski & Barroso, 2005; Tataj-Puzyna et al., 2022).

The turning point for this group of women was finding a gynecologist who provided them with medical care that was tailored to their individual needs consistent with their worldview, philosophy of life and principles. Women considered professional, empathetic care and indication/direction to perinatal hospices where they could receive perinatal, multidisciplinary care to be particularly important (Guon et al., 2014; Horning & Braun, 2006; Sandelowski & Barroso, 2005; Tataj-Puzyna et al., 2022).

Tosello et al., (2017) showed that more than half of specialists (52.9%) took the initiative of informing women about options for support in childbirth (including perinatal palliative care), while 32.7% of obstetrician-gynecologists did not take this initiative compared to 10.2% of neonatologists ($p < 0.01$). The results of these studies indicate an urgent need for training in POP for specialists and standardization of its practices (ibidem)[2].

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[2] Studies conducted in France show that not all doctors give women information about the possibility of care in perinatal hospices (Tosello et al., 2017).

Similar results were obtained in a Polish study in the area of perinatal palliative care, medical caregivers have insufficient knowledge about the essence of care for women with lethal fetal diagnosis (Gruszka et al., 2019). This demonstrates the urgent need for more training for healthcare professionals in this area.

Psychological studies indicate that it is better for a woman's mental health to continue pregnancy with a lethal perinatal diagnosis than to remove the pregnancy (cf. Ryś, 2020). A study conducted at Duke University Medical Center in a group of 158 women and 109 men who lost their pregnancies due to lethal defects (anencephaly, a fatal neural tube defect) showed that women who terminated their pregnancies were significantly more likely to report problems related to despair and depression than women who continued their pregnancies. On the other hand, men whose partner continued the pregnancy after an unsuccessful diagnosis were much more likely to report difficulties in coping with emotions than men whose partner terminated the pregnancy (Cope et al., 2015).

Other studies show that for many women, the continuation of pregnancy after an unfavorable diagnosis of a lethal prognosis for the fetus/child was an important and significant experience, enabling the survival of a short, prenatal motherhood. Women consciously tried to make the most of the time to establish contact with the child in the prenatal phase of its development. In this situation, they described the prenatal relationship with the child as "accelerated parenting", during which they compressed the time to establish a close relationship with the child in the phase of its prenatal life and experience parental behavior in the shortest possible time (Côté-Arsenault & Denney-Koelsch, 2011; Guon et al., 2014; Lathrop & VandeVusse, 2011; Tataj-Puzyna et al., 2022).

3.2. Helping to survive anticipatory grief

Modern theorists believe that mourning is a process to adjust to life without a loved one. The grieving process is a way of dealing with loss. Grieving individuals cope by moving from confronting the reality of loss at certain times and avoiding confrontation at other times (Côté-Arsenault, 2020).

An unsuccessful prenatal diagnosis causes a significant increase in the level of anxiety associated with the imagined prospect of losing a child. Each family member experiences an individual reaction related to the future loss of a child's death. This individual response to a potential loss is referred to as anticipatory grief or anticipatory grief. Anticipation is the ability to predict. Through experience and knowledge the family acquires the ability to imagine their emotions and reactions and prepare for the situation that will occur. This is especially important from the perspective of self-control and stress management. It is the experience of mourning before the loss occurs. This experience performs a protective function – it allows you to prepare for difficult emotions that will come later. Some researchers consider this phenomenon as a process that begins from the moment of unsuccessful diagnosis and includes phenomena such as changes in the family system interactions coping methods and psychosocial transformations (cf. Majid & Akande 2022; Rogalla, 2020).

Most literature on anticipatory grief describes the process in adults experiencing the loss of a close adult. There are few reports that concern the death of children and the impact of anticipatory grief on their parents (Rini & Loriz, 2007).

In the case of a prenatally diagnosed defect with a lethal prognosis for the child, the long period of waiting for birth increases the stress during pregnancy, while at the same time it gives parents time to experience anticipatory grief, the possibility of taming the tragic diagnosis. This is the time when parents bond with a child in the prenatal phase of his life, experience prenatal parenthood, at the same time prepare for childbirth, welcome the child, make a decision about saying goodbye to the child and preparing souvenirs related to him (Côté-Arsenault & Denney-Koelsch, 2016). Anticipatory grief allows a family to come to terms with the loss of a child. The support of professionals and immediate family can help the family experience difficult emotional states, but also plan and create meaningful memories already during the waiting period for the birth of a child with lethal defects and give meaning to one's own life without the expected child (Cortezzo et al., 2019, 2020; Pinkeney, 2020).

Understanding some of the main theories of grief and their roots can provide medical caregivers with knowledge about various forms of grief, such as anticipatory grief or complicated grief. These theories may contribute to the ability to distinguish normal grief responses from problematic responses (Côté-Arsenault & Denney-Koelsch, 2016).

3.3. Preparation of parents for birth of a child with a lethal prognosis

The literature devoted to preparing parents for childbirth mostly concerns antenatal education for mothers/fathers who are expecting the birth of a healthy child, not burdened with lethal defects. Few scientific studies have been devoted to how parents, after an adverse prenatal diagnosis, prepare for the birth and probable death of a child (English & Hessler, 2013; Wool, 2013). Research shows that this group of parents is looking for professional tips and information that they can expect during childbirth (Denney-Koelsch et al., 2016).

Parents after an unfavorable diagnosis with a lethal prognosis for the child have the opportunity to prepare for childbirth in in-hospital and out-of-hospital hospices and during individual meetings with a midwife (Dangel, 2015; Dangel & Szymkiewicz-Dangel, 2016; Jalowska et al., 2019; Tataj-Puzyna et al., 2023)[3].

Parents who have decided to continue their pregnancy despite prenatal diagnosis of lethal prognosis for the fetus/child present different styles of handling this situation. Some are looking intensely for information on the stage of child development, diagnosed defects and further proceedings. Others, on the contrary, avoid information related to difficult diagnosis (Lalor et al., 2009).

According to Polish research, some parents sought 'normality', they used prenatal education (birth classes), dedicated to parents awaiting the birth of a healthy child. They did not reveal the child's lethal diagnosis to feel like other parents. Others sought families in a similar situation, so they attended a parenting school dedicated to parents after LFD and LLFD. In a community with other parents who faced the situation of tragic diagnosis for the child, they experienced prenatal parenting. Belonging to some group of parents awaiting the birth of a child made them "visible" to society as parents (Tataj-Puzyna et al., 2023)

According to researchers from other countries, searching for communitas was a need for women, related to the rite of pregnancy transition (Côté-Arsenault & Denney-Koelsch, 2011).

There were also parents who postponed thinking about the moment of birth of a sick child and did not take any activity to prepare for childbirth. They displaced the lethal fetal diagnosis of a child born without having personal resources to confront difficult reality (Tataj-Puzyna et al., 2023).

As part of antenatal education (birth school) parents prepare a birth plan. Writing a birth plan provides an important therapeutic element giving parents a sense of control time to enjoy the baby in the prenatal phase celebrate the birth and experience grief appropriately (Cortezzo et al., 2019 2020; Horning & Braun 2006). Birth planning is not just a written document but a process during which parents can develop trusting relationships with the interdisciplinary team of perinatal palliative care midwife doctor psychologist. Working on setting goals and planning for the future accustoms parents to the difficult inevitable future of their child. This process helps them fulfill parental roles develop parenting skills (prenatal parenting) and regain control over the child's future. Birth planning is a process that takes place over time not just the technical completion of a document (Lamberg Jones & Leuthner 2020).

The birth plan is an expression of the personal goals of the parents the decision of preferences for childbirth the birth of the baby and the initial care of the newborn. Preparing a birth plan gives parents space to reflect and summarize expectations they were afraid to express (Côté-Arsenault & Denney-Koelsch, 2011; Sandelowski & Barroso, 2005; Denney-Koelsch, 2016).

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[3] In 2019, the Parenting School was established at the Warsaw Hospice for Children Foundation, dedicated to parents after prenatal lethal fetal diagnosis (LFD) and life-limiting fetal diagnosis (LLFD). As part of the classes, parents have the opportunity to meet in groups with an interdisciplinary medical team: an anesthesiologist, neonatologist, gynecologist, midwife, psychologist, physiotherapist (Tataj-Puzyna et al., 2023).

As parents adjust to the imminent loss of a child they experience anticipatory grief. The support of the care team can help them begin to grieve plan and create meaningful memories already during pregnancy. Research shows that for parents planning care in advance has a therapeutic impact. Discussing different aspects of pregnancy care approximating the different possible scenarios and actions during childbirth gives them a sense of control and preparation for unexpected events (Cortezzo et al., 2019, 2020).

There is no one right form of pre-natal education for this group of families. Research shows that in a situation of severe stress people adopt different coping strategies resulting from the preferred style: avoidance confrontational or cognitive (Ryś & Trzęsowska-Greszta, 2018). Therefore, health care providers should adapt their care to the individual needs of parents in such a difficult situation.

4. Perinatal Palliative Care

Perinatal palliative care (PPC) is comprehensive care in the perinatal period for this group of parents who, after receiving information about the lethal fetal diagnosis of the fetus/child, decide to continue the pregnancy, give birth and accompany the child until his natural death (Buczek, 2015; Latos-Bieleńska et al., 2010). Doctors of various specialties (gynecologists, neonatologists, geneticists, psychiatrists), and psychologists, nurses, clergy, surround the whole family with medical, psychological and, if necessary, spiritual care (Martín-Ancel et al., 2022). The goal of perinatal palliative care is to comprehensively provide an adequate quality of life for families awaiting the birth of a child with a life-limiting diagnosis. Care is coordinated with inpatient treatment, specialist advice in the field of obstetrics, gynecology or neonatology, cooperation with prenatal diagnosis centers and home hospices in the situation of the possibility of discharge of the child from the hospital (Côté-Arsenault & Denney-Koelsch, 2016)[4]. After birth, the care of the still-living child is taken over by a home hospice, focusing on protecting the infant from persistent therapy and providing him with the right conditions for a dignified life and a dignified death (Jalowska et al., 2019).

Multidisciplinary care also includes a period of bereavement to help parents adjust to life without a child (Côté-Arsenault & Denney-Koelsch, 2016).

Guaranteed benefits in the field of perinatal palliative care are financed in Poland from public funds and may be implemented under agreements concluded between the National Health Fund and prenatal diagnostic centers, prenatal cardiology centers, genetics departments, palliative medicine clinics and home hospices for children or inpatient hospices (Ciałkowska-Rysz, 2019; Dzierżanowski, 2020; Rozporządzenie Ministra Zdrowia z Dnia 31 Stycznia 2017 r. Zmieniające Rozporządzenie w Sprawie Świadczeń Gwarantowanych z Zakresu Opieki Paliatywnej i Hospicyjnej, 2017). In Poland, these services are provided in seventeen perinatal hospices, in 13 voivodships. Midwives are not employed in these facilities, which means that in preparation for childbirth, a woman diagnosed with a lethal fetal defect can only benefit from the care of a primary care midwife (POZ) or a hospital outpatient clinic that does not cooperate with perinatal hospices. Inclusion of a midwife in the palliative care team in the perinatal period would fill the gap in the process of caring for women who continue pregnancy after an unsuccessful diagnosis of a lethal fetal defect, would ensure continuity of care for women from the moment of receiving an unsuccessful diagnosis, through professional preparation for childbirth, survival of the postnatal period, death of the child until the mental balance is restored (Tataj-Puzyna et al., 2023).

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[4] In Poland, guaranteed benefits in the field of perinatal palliative care were first specified in the Regulation of the Minister of Health of 31 January 2017 (Regulation of the Minister of Health of 31 January 2017 Amending the Regulation on Guaranteed Benefits in the Scope of Palliative and Hospice Care, 2017) (Journal of Laws of 2017, item 236). According to the regulation, services in the field of perinatal palliative care may be provided in prenatal diagnostic centers, prenatal cardiology centers, genetics departments, palliative medicine clinics and in home hospices for children or inpatient hospices. The care is dedicated to the parents of a child, including a child in the prenatal phase, with severe and irreversible impairment or an incurable life-threatening disease that arose in the prenatal period of development or during childbirth (Communication of the President of the National Health Fund of 6 July 2022 on Perinatal Palliative Care, n.d.). Rozporządzenie Ministra Zdrowia z Dnia 31 Stycznia 2017 r. Zmieniające Rozporządzenie w Sprawie Świadczeń Gwarantowanych z Zakresu Opieki Paliatywnej i Hospicyjnej, Dz. U. z 2017 (2017)

Among the various forms of organization and ways of providing assistance, the activity of perinatal hospices can be described as a support network for parents experiencing difficulties, and not as a stationary medical facility for pregnant women. As the employees of the hospice claim, it is not just a place, but rather a model based on providing care in accordance with the preferences of the parents of sick children. Perinatal Hospice is not only an institution, but above all a philosophy of life and conduct. Research shows that women perceive the Perinatal Hospice as a place where their own parental resources are taken into account. Employees support families who want to satisfy the need to continue pregnancy and accept a lethally ill child who is most likely to die in the prenatal period or shortly after birth (Różańska et al., 2017).

The dissonance between obstetric practice and the state of bioethical knowledge, problems with defining the beginning of life and the lack of skills of doctors and midwives to effectively support families struggling with a negative prenatal diagnosis are challenges for health care workers in promoting perinatal hospices.

5. Post-traumatic growth

In recent decades, researchers have begun to see the positive effects of traumatic experiences, which has led them to treat trauma as an important existential experience. Research shows that in addition to the negative effects of trauma, such as disorganization of mental life, it is possible to experience positive changes resulting from these difficult experiences (Ogińska-Bulik, 2013).

The positive change resulting from struggling with traumatic life events is referred to as posttraumatic growth (PTG) (Tedeschi & Calhoun, 2004).

The extent of posttraumatic growth depends on the type of traumatic event, the individual characteristics of the person and the support they received. The research shows that approx. 50-60% of people experiencing trauma notice positive changes resulting from these experiences (Popielski & Mamcarz, 2015).

It is emphasized that PTG is expressed in increased empathy for others, in greater respect for life, appreciation of relationships, in engaging in altruistic activities and in increased strength to cope in difficult situations and in greater competences[5] (Meyerson et al., 2011).

N. Ogińska-Bulik (2009) analyzed the mechanisms by which difficult experiences can bring benefits. She paid particular attention to eustress, which is a positive response to stressors. She described it as a beneficial effect of a stress transaction. In order for eustress to be activated, a person must perceive difficulties as a challenge and take specific actions to cope with the situation ((Ogińska-Bulik, 2009). As a result of a positive trauma, significant changes in life may occur, such as a change or deepening of life philosophy or spiritual development (cf. e.g. Frankl, 2019)[6].

Researchers analyzing the perinatal experiences of women after an unsuccessful prenatal diagnosis (LFD – fatal fetal defects) challenge the popular opinion that continuing pregnancy in such a situation is an exclusively negative experience for women and their families. Research also indicates important, positive changes – personal growth of parents, appreciation of the importance of life values, respect for the child (Alvarez-Calle & Chaves, 2023; Black & Sandelowski, 2010; Jarzębińska, 2017).

Jarzębińska (2017) describes the dilemmas and suffering that woman, after the unsuccessful lethal diagnosis of their children, experienced at different stages of the struggle with the child's illness. Studies have shown that trauma has become for some mothers

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[5] The PTG construct has gained prominence and recognition in adult populations, and there is emerging evidence for its generalisability to adolescents (Meyerson et al., 2011).

[6] The pioneer of the idea of transformative role of suffering that can give meaning to life was V.E. Frankl (2019), the creator of logotherapy, the science of the meaning of life. The task of logotherapy is to treat sense. (When you understand "why", you will find each "how"). He deals mainly with problems such as existential voidness, frustration, existential crisis, noogenic neurosis.

an impetus to personal development and change their lives for the better, and the presence of a sick child brought them unique, positive experiences.

The prenatal diagnosis and illness of a child in the context of pediatric palliative care is an extremely complex experience for parents. Cadell (2010) describes that although the stress of caring for a sick child is enormous, many parents experience growth. This growth was measured using the Post-Traumatic Development Inventory, which helps to understand its determinants (Ogińska-Bulik & Juczyński, 2010). Personal resources, such as parental well-being, are crucial in the process of making sense of difficult experiences, which in turn promotes growth (Cadell et al., 2014).

Research shows that the onset of post-traumatic development is favored by the subjective characteristics of the individual and, above all, psychological resilience and integrated personality. The more integrated an individual's personality is, the more likely they are to cope with the traumatic event. Cognitive involvement related to trauma processing also plays an important role in effective coping with trauma (Ogińska-Bulik & Juczyński, 2010).

The style of cognitive functioning, based on the search and processing of information and its creative structuring, increases the chances of the occurrence of post-traumatic development. The ability to find the meaning and meaning of experienced traumatic situations also seems important. Helgeson et al., (2006) point to the role of optimism and religiosity in post-traumatic growth. Reaping the benefits of traumatic events is related to the spiritual development of the individual (ibidem). It is also important to discover the meaning of difficult events and social support (Alvarez-Calle & Chaves, 2023).

The results of the Black & Sandelowski (2010) study also suggest that positive growth may follow an unfavorable prenatal diagnosis. These findings may help create models of perinatal palliative care that support coping with grief and bereavement. Properly prepared medical personnel can help develop strategies to support the further development of parents experiencing the death of their own child.

However, the personal development of parents after prenatal diagnosis of severe fetal anomaly still requires more careful examination. More detailed research on this group of parents needs to be done to better understand the processes that can affect the coping and well-being of this group of parents.

Summary

The diagnosis of lethal fetal prognosis for a child to be born is a traumatic experience for parents, a paradoxical coincidence of life and death. However, research shows that continuing pregnancy after an unsuccessful diagnosis and giving birth to a child with a lethal prognosis is not just a negative experience. Thanks to professional, empathetic medical care, parents can have positive experiences related to the waiting period for the birth and delivery of a terminally ill child.

Despite the high involvement of hospice teams, there is still a lack of public awareness and sufficient institutional support to provide comprehensive care, taking into account the role of the midwife for families expecting a child with an unfavorable diagnosis. The social lack of awareness and stigma associated with the perinatal loss of a child makes mothers feel marginalized and „invisible" in society. This difficult experience of short motherhood means that mothers are more dependent on their own psychological and emotional resources and on the empathetic support of medical caregivers and loved ones to cope with an unfavorable diagnosis and loss of a child. Many parents suffer not only from a devastating loss, mainly in silence, but from the persistent stigma and social taboo still common in society.

Compassionate care tailored to the individual needs of parents, the ability to give meaning to loss, honor the importance of the life of a stillborn child, the opportunity to experience anticipatory grief and mourning for loss, can be an incentive for women/parents to develop personally and change their lives, and thus to be open to further life plans, including procreation plans.

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