

Review

## Perinatal Palliative Care and Ethical Issues

### Perinatal Palyatif Bakım ve Etik Konular

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#### ABSTRACT

Perinatal palliative care is a specialty that covers the fields of obstetrics, fetal medicine, pediatric palliative medicine and neonatal medicine. In this care, healthcare professionals offer an individualized care plan based on the needs of the fetus/newborn and family members in a multidimensional way with an interdisciplinary team approach. Unlike adult, neonatal and pediatric palliative care, the patient is not only a single person but a mother-fetus couple in perinatal palliative care; therefore this care type is based on family-centered care philosophy. Due to lack of information about preferences or requests of the fetus, families are expected to make the best medical decision for their baby considering their wishes and values. In this respect, it is important for the team members to inform the families during this process and for multidisciplinary healthcare professionals to support them for making the most appropriate decision. The aim of this review is to discuss some of the ethical issues encountered in perinatal palliative care and the roles and responsibilities of the nurse.

**Keywords:** Ethics, Fetal Abnormality, Nursing, Perinatal Palliative Care

#### ÖZ

Perinatal palyatif bakım, obstetrik, fetal tıp, pediatrik palyatif tıp ve yenidoğan tıbbi alanlarını kapsayan bir uzmanlık alanıdır. Bu bakımda, sağlık profesyonelleri disiplinler arası bir ekip yaklaşımı ile fetüs/yenidoğan ve aile bireylerinin ihtiyaçlarına göre çok boyutlu ve bireyselleştirilmiş bir bakım planı sunar. Erişkin, neonatal ve pediatrik palyatif bakımdan farklı olarak perinatal palyatif bakımda hasta sadece tek bir kişi değil, anne-fetus çiftidir; bu nedenle bu bakım türü aile merkezli bakım felsefesine dayanmaktadır. Fetüsün tercihleri veya istekleri hakkında bilgi eksikliği nedeniyle, ailelerin kendi istek ve değerlerini göz önünde bulundurarak bebekleri için en iyi tıbbi kararı vermeleri beklenmektedir. Bu açıdan ekip üyelerinin bu süreçte aileleri bilgilendirmesi ve multidisipliner sağlık profesyonellerinin aileleri destekleyerek en doğru kararı vermeleri önemlidir. Bu derlemenin amacı perinatal palyatif bakımda karşılaşılan bazı etik konular ve hemşirenin rol ve sorumluluklarını tartışmaktır.

**Anahtar Kelimeler:** Etik, Fetal Anomali, Hemşirelik, Perinatal Palyatif Bakım

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## INTRODUCTION

The recent advancements in prenatal diagnostic tests have made it possible to establish an early diagnosis in fetuses with life-limiting/severely debilitating/lethal fetal abnormalities. Life expectancy is low for infants with life-limiting chromosomal, renal, cardiac and neurological anomalies; some of these infants may live for seconds to hours after birth, some others are able to live for one week or longer after birth, or fetal death may occur (Cole et al., 2017). Parents come for pregnancy follow-ups with the expectation of learning healthy fetal findings such as seeing the movements of the fetus and listening to his/her heartbeat. The diagnosis of fetal abnormality established during these follow-ups is an emotionally traumatic life event as much as the pregnancy loss for the parents (Wool, 2011).

Healthcare professionals offer two options for parents diagnosed with life-limiting fetal anomalies; a) to keep the pregnancy until delivery and to prolong the life expectancy of the newborn as much as possible; b) to terminate the pregnancy. It is quite difficult for parents, who are given two options, to make the decision to terminate or keep the pregnancy. In the past, when the parents were diagnosed with fetal anomaly, the parents made the decision alone without support from health professionals. In the last 20 years, a new paradigm has emerged that emphasizes the importance of fetuses/newborns diagnosed as incompatible with life in the prenatal period to have a meaningful life with their families, regardless of the length of life expectancy. Perinatal palliative care service has been established in order to meet the needs of these parents and their newborns. (Rocha Catania et al., 2017).

Perinatal palliative care is a holistic and comprehensive care approach that starts as from the diagnosis of life-limiting/ lethal fetus/newborn anomaly diagnosis and continues during pregnancy, covers the process of birth, death and bereavement, and focuses on enhancing the quality of life by interdisciplinary team members (Kiman & Doumic, 2014). The care requirements for the perinatal period are different. Meeting these requirements requires interdisciplinary teamwork. Each team member is responsible for providing holistic services in cooperation on matters falling under their responsibilities.

A birth plan and neonatal care plan are prepared in accordance with the needs of the parents. While preparing the birth and neonatal care plan, the family and the team members decide together concerning mode of delivery, where and how the delivery will take place, measurements to be made after the delivery, and spending meaningful time with the infant (Kiman & Doumic, 2014; Kobler & Limbo, 2011). Team members should endeavor to do whatever is culturally and spiritually meaningful for the family-infant relationship (Thornton et al., 2019). If the birth/death of the infant occurs in the hospital, the place offering perinatal care or home, his/her care should be planned in accordance with this setting. Providing the baby with a comfortable and dignified death helps reduce the burden of bereavement for parents. After the death of the infant, the families are referred to the genetic specialist about the situations they may encounter in their next pregnancies and the tests to be done and to the bereavement therapist for grief support along with the discharge recommendations suitable for their needs. Families are informed about the resources from which they receive support (Cole et al., 2017).

Perinatal palliative care programs are implemented in Australia and in some countries of Europe, especially in the United States of America (Kobler & Limbo, 2011). Perinatal palliative care programs have been established in response to the unmet needs of parents (Kiman & Doumic, 2014).

It has been determined that in these programs, the parents' satisfaction levels are high in terms of communicating compassionately with team members, seeing their infants as an individual, supporting spiritual traditions, helping them cope with their emotions, creating a comfortable care setting, helping them make decisions, and receiving a consistent and safe medical care (Wool, 2011). Although the importance of perinatal palliative care programs has been defined, there are no

studies with sufficient evidence level. It is recommended to provide financing for the structuring, implementation, and development of perinatal palliative care programs and to establish mechanisms that evaluate the quality of care (Balaguer et al., 2012; Rocha Catania et al., 2017). There is no perinatal palliative care service in Turkey. Palliative care is a service provided mostly to adult and oncology patients in Turkey (Can, 2015).

Perinatal palliative care team members help families in the decision-making process, provide them with care and treatment options in accordance with cultural and religious values in management of childbirth process and neonatal care, and provide support to them in the postpartum period (Thornton et al., 2019). Team members consist of those working in different disciplines such as obstetrician, perinatology nurse, midwife, genetic counselor, neonatal physician, neonatal intensive care nurse, psychologist, social worker and religious officer (Cole et al., 2017). It is important to determine the care coordinator in managing complex and uncertain situations during pregnancy, childbirth, and postpartum period, continuing care and providing an effective communication between team members. Nurses serve as care coordinators or case managers in the perinatal palliative care team (Rocha Catania et al., 2017).

Perinatal palliative care is a complex condition involving ethically controversial issues from the diagnosis of fetal anomaly to the postnatal period. The aim of this review is to discuss some of the ethical issues encountered in perinatal palliative care.

## **Ethical Issues in Perinatal Palliative Care**

### **Obscure Terminology**

Although it is possible to determine the diagnosis and prognosis of life-limiting fetal abnormality in routine pregnancy follow-ups in the antenatal period through technological developments, sometimes the diagnosis may not be determined until the postpartum period (Bourdens et al., 2017).

Team members should communicate with parents in an ethically realistic, moderate, compassionate, and sensitivity while informing parents about well-defined syndromes (Kiman & Doumic, 2014). It is necessary to pay attention to the language and terminology that determine the prognosis in communicating. Parents may misunderstand the prognosis, live with hope rather than accepting prognostic information, choose palliative care or request aggressive intensive care measurements. Parents can agree to keep the pregnancy to give their baby a chance (Cole et al., 2017). Because sometimes fetuses/newborns diagnosed with abnormality are able to live unexpectedly longer, emotionally charged borderline terms such as "lethal malformation", "lethal" or "incompatible with life" increase obscurity and can be understood as a hopeful prognosis (Lantos, 2016; Wilkinson et al., 2014). The concept of "medical futility" creates a deficiency in identifying cases and assessing the problem, limits parental autonomy, and restricts the desired treatment (Wilkinson et al., 2014). The use of unclear and inconsistent language when planning curative/palliative interventions for the fetus/newborn may result in multiple interpretations in the parents. Thus, parents can feel distrust and dissatisfaction concerning the healthcare system (Sidgwick et al., 2017; Wilkinson et al., 2014;).

In the informed consent, it is recommended that "The benefits and risks to both the fetus and the pregnant woman need to be comprehensively discussed. All options should be discussed, including fetal intervention, postnatal treatment, palliative care or termination of pregnancy" (ACOG, 2011). This "comprehensive discussion" relies on professionals' knowledge in difficult issues and their ability to reveal parents' beliefs and values in informing them (Sidgwick et al., 2017). The mother is an autonomous individual having the right of informed consent about the benefits and harms of tests for her own health. The fetus is also a single individual but lacks decision-making autonomy. The best decision for the fetus is the decision his/her mother makes. Parents and surrogate decision makers make decisions based on their personal beliefs and

values. Knowing these conditions before birth is beneficial for the newborn in taking precautions such as choosing the hospital for the delivery or providing the equipment (Harrison, 2008).

Despite the uncertainty of diagnosis, there are some prognoses that can have relatively precision. Stories of babies who survive against all possibilities can be told while counseling (Blumenthal-Barby et al., 2016). Parents have stated that professionals communicate poorly in informing options about prenatal diagnosis, "withdraw" in ensuring continuity of care, and are too fatalistic and prejudiced (Wool, 2013). For these reasons, it is the professional responsibility of healthcare professionals serving in the perinatal field to provide up-to-date, objective and accurate information to parents (Marty & Carter, 2017).

After the diagnosis of fetal abnormality is established, negative communication and interactions between parents and healthcare professionals may prevent the process from progressing in a healthy way (Berry et al., 2021). Parents may experience emotional turmoil during the test or examination due to the devastating news. Lack of sensitivity and empathy of healthcare team members can cause parents to experience more intense emotions such as distress, shock, anger, and sadness (Mills et al., 2014).

Setting ethical boundaries for severe fetal abnormalities or developmental disorders is beneficial for both parents and healthcare professionals. The patient diagnosed with fetal abnormality should be considered as a patient who may die. Therefore, a more active management can be offered instead of fetal aggressive treatment (Wilkinson et al., 2014). Parents may have personal or organizational conflicts with healthcare professionals, social workers, and other services. It may be beneficial to resolve conflicts by establishing a qualified communication with the parents, and to consult decision-making mechanisms such as the ethics committee if necessary (Marty & Carter, 2017).

### **Clarifying Parent Values and Goals**

Healthcare professionals respect hospital authorities in making decisions after medical information about diagnosis and prognosis of fetal abnormality. Even when patients do not have the capacity to make their own decisions, healthcare staff can make decisions as surrogates in line with the patient's wishes, values and goals. In this process, the standard decision-making model in health care plays the best role (Opel, 2017). This model is used for the physician-patient relationship as medicine moves away from paternalism. In the model, the decision is made to create a consensus on the treatment to be applied by sharing information on both sides. In the perinatal area, however, the relationship between the best interests of the fetus and the best interests of the mother can be complicated. Prognostic uncertainties often create areas that create ethical tensions and therefore require the use of alternative thinking approaches such as relational and narrative ethics. While taking anamnesis from parents, they are allowed to share their fetus-newborn stories and it is decided based on this "big picture". It is important to reveal the values and goals of parents in the decision-making process. (Blumenthal-Barby, 2016). It should be tried to determine what the diagnosis of fetal abnormality means for the fetus and his/her family.

Care during the perinatal period should generally be established when preparing the birth plan. While creating a care plan, it is tried to be informed about the values and expectations of the parents and aims of care. Obstetricians should value the mother's views on mode of delivery, anesthesia options, and fetal monitorization levels in childbirth and postpartum care (Sidgwick et al., 2017).

### **Decision Making in Transition from Aggressive Medical Care to Comfortable Measurements**

Perinatal palliative care is one of the aggressive, life-prolonging, treatment-oriented medical interventions for the newborn in intensive care and should ensure the transition to comfortable and quality-of-life-based measurements. These transitions

require mechanical ventilator support, artificial circulatory support, artificial feeding and deciding whether to continue hydration. The health care team and family generally agree on providing the best benefit for the infant in alleviating pain and discomfort. In some cases, ethical conflicts may arise about “inappropriate, heavy, futile, and physiologically unnecessary care”. Parents can delegate decision-making authority to team members. The ethical duty of the team members is non-maleficence, endeavoring to learn the best interests for the infants with their families and adherence to the practices realized in line with professional ethical codes (ACOG, 2011; Bosslet et al., 2015).

Many institutions have policies that guide care or identify medical/physiological futile conditions. These policies are usually determined together with ethical consultants. Team members should share the decision by dealing honestly with the parents. The healthcare team in the hospital ethics committee helps parents evaluating alternative options with open communication and transparency. Unresolved disagreements cause problems between family and team members. It is also recommended to consult with bioethics consultants in resolving conflicts (ACOG, 2011; Wilkinson et al., 2014).

### **Differences in Grief Support**

When parents are diagnosed with life-limiting fetal abnormality and decide to terminate the pregnancy, palliative care should continue during the bereavement period. The World Health Organization has reported that in palliative care, life is affirmed, death is seen as a normal bereavement process, and palliative care is neither accelerating death nor delaying death (World Health Organization, 2013). Termination of pregnancy through medical or surgical procedures by removing the fetus from the uterine cavity can be regarded as speeding up death (ACOG, 2011). Perinatal palliative care aims to enhance the quality of life by reducing the discomfort of the fetus or newborn. It is not known whether or not fetal abnormality diagnoses cause discomfort or pain in uterus. In some diagnoses, the fetus may die due to natural causes in the uterus; in other cases, a live birth can occur by allowing the fetus to develop. For live-born newborns, palliative care interventions appropriate for their medical condition should be initiated. Parents and palliative care professionals plan treatments to prolong life expectancy on the one hand and develop care plans that include possible scenarios from sudden death to home discharge, on the other hand. Treatment plans include interventions such as symptom control, oxygen, antiepileptic drugs, and care plans include options for parents to feed their babies and create memories. In arrangement of a well-structured treatment plan and care in neonatal intensive care, home or hospice, resuscitation and invasive measurements are among controversial issues (Marty & Carter, 2017; Mendes et al., 2017).

### **Organ Donation**

Parents may sometimes consider donating or transplanting the cornea, heart valves, tissues, and organs of a newborn who dies during or shortly after birth to other neonatal, pediatric, and adult patients. Websites and companies can help raise awareness among parents about choosing organ donation. Organ donation has always caused ethical debates such as the procurement, sharing, and management of transplanted human organs. In the world of perinatal and neonatal medicine, the situation is more complex. Parents who were diagnosed with fetal abnormality, started to think about organ donation while waiting for the death of their newborns. After cardiac death, neonatal organ donation can be initiated with the consent of the parents. This altruistic behavior can help many families cope with loss or may be an option to give families a gift. Parents consider that their terminated genetic inheritance will save other children and affect their families' lives (Sarnaik, 2015). There are limits to the size of organs to be transplanted anatomically in pediatric patients, but organs of newborns can overcome these limitations (Mendes et al., 2017).

Non-maleficence is an ethical principle in neonatal organ donation. When making decisions about their infants, parents are reminded to consider that newborns are a vulnerable population due to their vulnerability and lack of autonomy (Mendes et al., 2017). Another ethical consideration is the parents' intention and motivation in the decision to keep the pregnancy. Is keeping the pregnancy only for the donation of the organs or is the pregnancy continued regardless of the donation? Every child needs a respectful and dignified care. If organ transplantation has no benefit to the donor, the importance of non-harmful purpose is debated (Global Atlas of Palliative Care at the End of Life, 2020). If parents choose to keep the pregnancy and receive palliative care for organ donation, complicated processes can occur when near-death symptoms occur. An important goal of having a life-limiting child is meeting the newborn, embracing and creating memories. Bereavement professionals encourage parent involvement in applying spiritual and cultural rituals such as caring for, hugging, dressing, and bathing the baby (Thornton et al., 2019). Parents often find time spent with their newborn comfortable and meaningful. The time for newborns to supply their organs is a sensitive time. Families may grieve during organ donation despite their desires to donate organs (Harrison, 2008).

### **Neonatal Freezing After Death**

As a result of new developments in the field of technology, neonatal freezing after death has come to the fore. Previously the hurdles of environmental needs to maintain the integrity of the child's body have limited the opportunity to provide this extended service to families of children older than one (Cooling in Death Care, 2024). In the hospital or home environment, a system of freezing equipment may be used in conjunction with a small cooling unit, such as a small crib, baby carriage. For family members of newborns who die in the hospital, this system can be used instead of freezing their babies in the morgue. These equipments gives parents the opportunity to spend time with their child after death to create memories or conduct special rituals with newborns. Parents get the opportunity to prepare to say goodbye and goodbye to their baby. Nurses may need additional time using equipment to bring memories to families. In shock, deep mourning or difficult labor, which are the emotions experienced after loss, mothers may want time to heal and rest before saying goodbye. Parents may also be offered the option to invite other family members to see the newborn's natural changes. Cooling system prevents postmortem physical changes in newborn (Mendes et al., 2017).

### **The Roles and Responsibilities of the Nurses**

Perinatal palliative care programs are coordinated by nurses or by a team including mostly nurses. Nurses as care coordinators, ensure the continuity of care in cooperation with other team members in perinatal palliative care. Nurses are key persons with whom families will communicate by providing the basic coordination of case management (Cortezzo et al., 2020). Nurses have the professional and ethical responsibility to provide nonjudgmental nursing care to all patients (ACOG, 2019). Nurses should be educated on best practices to optimally support pregnant persons and families with perinatal palliative care strategies during pregnancy, birth, and the postpartum period. Nurses should lead the perinatal palliative care team in care management while incorporating cultural, religious, and familial needs.

### **CONCLUSION**

Perinatal palliative care programs make it possible to meet the holistic needs of parents diagnosed with fetal abnormality incompatible with life from pregnancy to postpartum period. Clinical ethics committees can be established to clarify ethical issues for both parents and team members. Creating perinatal palliative care models is an opportunity for nurses to

determine the needs of families and to discover how to give the best care and how to apply it effectively to community policies. In perinatal palliative care, nurses can provide basic coordination of case management as care coordinators.

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