

PALLIATIVE CARE AND SPIRITUALITY IN NEONATAL NURSING: LITERATURE REVIEW

YENİDOĞAN HEMŞİRELİĞİNDE Palyatif Bakım ve Spiritüalite: LİERATÜR TARAMASI

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ABSTRACT

Aim: It is suggested to provide palliative care to newborns with life-threatening diseases and their families. The aim of this review article is to provide pediatric nurses with information on palliative care and newborn, palliative care and parents, role of nurse in palliative care, spirituality in palliative care, spirituality and neonatal nursing in order to manage palliative and spiritual care for newborns and their families effectively and efficiently.

Methods: In the literature review, full-text studies in English were examined in Pubmed, ProQuest, Science Direct and Google Scholar databases between 2015 and 2020. The search terms of 'palliative care', 'spirituality', 'neonatal', 'parent', 'nurse' and 'holistic care' and their combination were used in the review. Inclusion criteria for the studies were determined as follows: (a) published between 2015 and 2020, (b) focusing on palliative or spiritual care for the newborn and their parents, (c) written in English, and (d) published online full-text.

Results: As a result of the research, 588 articles were reached. The titles and abstracts of these articles were evaluated. 17 articles that met the criteria were identified. In this review, the findings obtained as a result of the literature review are discussed under five subheadings. These subtitles are palliative care and newborn, palliative care and parents, role of nurse in palliative care, spirituality in palliative care, spirituality and neonatal nursing.

Conclusion: Nurses can plan and implement palliative and spiritual care, using their roles of manager, caregiver, collaborator, leader, educator, researcher, and advocate. Palliative and spiritual care offered by nurses, who are in constant communication with the newborns and their parents, will improve the health outcomes, ensure that the parents have a healthier period of loss and grief, and support holistic, individualized, family-centered care.

Key words: palliative care, spirituality, newborn, nurse, parents

ÖZET

Amaç: Yaşamı tehdit eden hastalığı olan yenidoğanlara ve ailelerine palyatif bakım sağlanması önerilmektedir. Bu derleme makalesinin amacı, yenidoğan ve ailesine sunulacak palyatif ve spiritüel bakımın etkin ve etkili şekilde yönetilebilmesi için pediatri hemşirelerine palyatif bakım ve yenidoğan, palyatif bakım ve ebeveynler, palyatif bakımda hemşirenin rolü, palyatif bakımda maneviyat, maneviyat ve yenidoğan hemşireliği konularında bilgi vermektedir.

Yöntem: Bu literatür taramasında 2015-2020 yılları arasında Pubmed, ProQuest, Science Direct ve Google Scholar veri tabanlarında İngilizce tam metin yayınlanan çalışmalar incelenmiştir. İncelemede 'palyatif bakım', 'maneviyat', 'yenidoğan', 'ebeveyn', 'hemşire' ve 'bütüncül bakım' arama terimleri ve bunların kombinasyonu kullanılmıştır. Çalışmalar için dâhil edilme kriterleri (a) 2015-2020 yılları arasında yayınlanmış olmak, (b) yenidoğan ve ebeveynleri için palyatif veya manevi bakıma odaklanmak, (c) İngilizce yazılmış olmak ve (d) çevrimiçi tam metin olarak yayınlanmış olmaktadır.

Bulgular: Araştırma sonucunda 588 makaleye ulaşılmıştır. Bu makalelerin başlıkları ve özetleri değerlendirilmiştir. Kriterleri karşılayan 17 makale belirlenmiştir. Bu derlemede literatür taraması sonucunda elde edilen bulgular beş alt başlık altında ele alınmıştır. Bu alt başlıklar; palyatif bakım ve yenidoğan, palyatif bakım ve ebeveynler, palyatif bakımda hemşirenin rolü, palyatif bakımda maneviyat, maneviyat ve yenidoğan hemşireliğidir.

Sonuç: Hemşireler; danışmanlık, bakım verici, işbirlikçi, lider, eğitici, araştırmacı ve savunucu rollerini kullanarak, yenidoğan ve ebeveynlerinin gereksinimlerini düşünerek, palyatif ve spiritüel bakımı planlayabilir, uygulayabilirler. Gelişen sağlık sistemi içinde, yenidoğan ve ebeveyniyle sürekli iletişimde olan ve en değerli dokunuşları yapabilecek olan sağlık profesyonellerinden olan hemşireler tarafından sunulan palyatif ve spiritüel bakım, yenidoğan ve ebeveynin sağlık çıktılarını iyileştirecek, ebeveynlerin kayıp ve yas sürecini daha sağlıklı geçirmesini sağlayacak, bakım kalitesini arttıracak ve bütüncül, bireyselleştirilmiş, aile merkezli bakımı destekleyecektir.

Key points

- Palliative care of newborns includes a family-centered, professional, multidisciplinary, dynamic, individual, and holistic approach covering newborns and their parents during prenatal, natal, postnatal, and bereavement periods.
- Palliative and spiritual care are important both newborns and their families. Newborns and their families should be considered together.
- Nurses should be aware that they play a critical role in spiritual care, which should be involved in palliative care and should improve themselves in this area for family-centered and holistic care.
- Nurses can plan and implement palliative and spiritual care, using their roles of manager, caregiver, collaborator, leader, educator, researcher, and advocate.

Continuing professional development: reflective questions

How could be the nursing palliative care programs for newborn and their families in neonatal intensive care unit (NICU)?

What could be considered in the training of nurses so that the spiritual dimension of palliative care is not ignored?

Why should be developed palliative care guidelines for nursing practices in NICUs?

INTRODUCTION

Medical and technological developments in prenatal and neonatal care have increased the survival rates of newborns. However, a large proportion of childhood deaths still occur in the neonatal period. Although the care given to newborns treated in the neonatal intensive care unit (NICU) is mainly focused on saving lives, some of these infants die as a result of advanced prematurity, congenital anomalies, and multifaceted medical problems (Anspacher et al., 2017; Esenay, 2018; Viillard & Moriette, 2017). In this case, it is important to approach the newborn at the end of her short life, as well as parents with complex emotions, sensitively, and to provide appropriate physical, psychological, social, and spiritual support with a holistic perspective (Anspacher et al., 2017; Viillard & Moriette, 2017; Zuniga-Villanueva et al., 2021).

A holistic perspective can support us to recognize and meet the spiritual needs of the newborn and her family. The holistic approach can be used to evaluate the meaning, balance, and harmony of life along with physical, mental, psychological, and spiritual well-being (Kilicarslan

Toruner et al, 2020). In this reason, palliative and spiritual care should not be ignored and has to be available at all levels of care. Palliative care is a crucial part of integrated, people-centered health services. On the other hand, it is a global and ethical responsibility to relieve serious health-related suffering at physical, psychological, social, or spiritual level (WHO, 2020). Palliative care includes spiritual care. Spiritual care is essential for an individual's wellbeing and health. Therefore, spiritual care and meeting the spiritual needs are one of the most important responsibilities of the nurse (Rachel et al., 2019). Nursing care, which includes physical, social, psychological and spiritual care, is an integrative part of the health system (Zamanzadeh et al., 2015).

There are models and approaches that can guide nurses who aim to provide care with a holistic approach. Some of the most commonly used models in nursing are the Roy Adaptation Model, Health Belief Model, Orem Self-Care Model, Pender Health Promotion Model. One of the most suitable models that can guide nurses aiming to provide care using a holistic approach is Watson's Theory of Human

Caring. According to this model, nursing care is a scientific, ethical, aesthetic, and professional process in which two people interact in physical, mental, spiritual, and socio-cultural ways. Watson's Theory of Human Caring is a holistic care model that allows the nurse to address the individual she cares for not only physically, but also socially, psychologically, culturally, and spiritually (Watson & Woodward, 2020). The Model emphasizes that each part is essential and in harmony with each other without compromising the whole (Korhan, 2019; Şentürk et al., 2017). Watson states that the basic concepts of nursing care are love, compassion, empathy, ethics, comfort, and aesthetics (Korhan, 2019; Watson & Woodward, 2020). With these concepts, planning nursing care suitable for spiritual care will be able to guide nurses. Planning nursing care per spiritual care using these concepts will guide nurses. The healthcare team can carry out palliative care concurrently with curative care to alleviate the physical pain of infants who cannot recover and support their families (Catlin et al., 2015).

It is a requirement of holistic, comprehensive, and high-quality nursing to assist an individual in protecting,

developing, and maintaining her health condition in all dimensions. However, there are important obstacles to the development of the spiritual dimension in palliative care and nursing (Kain et al., 2009; Victor & Treschuk, 2020). These obstacles can be listed as follows: inadequate legislation on palliative care services, lack of appropriate environmental regulations, insufficient information provided to health care recipients, lack of process preparation, deficiencies of palliative care training programs, communication problems among the healthcare team, and a limited number of studies on palliative care nursing (Beckstrand et al., 2019). This review article aims to provide a perspective on palliative care for newborns and their families in neonatal nursing, spiritual care that constitutes an important part of palliative care, and the effective management of this process. In this context, the subject will be covered under the following headings: palliative care and the newborn, palliative care and parents, the role of the nurse in palliative care, spirituality in palliative care, and spirituality and nursing.

A Theoretical Framework

It is estimated that 40 million people need palliative care each year. 78% of them live in low and middle-income countries. Only 14% of people needing palliative care worldwide have the chance to receive this care (WHO, 2020). According to 2014 WHO data, the proportion of children who need palliative care was 23 per hundred thousand in Turkey where the rate of children whose palliative care needs were met was 2.9 per hundred thousand (WHO, Global Atlas of Palliative Care at the End of Life, 2014). The development of palliative care varies from country to country. While palliative care services are provided widely in developed countries such as the United States, Sweden, Germany, Canada, Japan, and Australia, developing countries are still in the planning stage of palliative care services (Cimete, 2018).

There are many models used in Nursing Research. One of the most appropriate models that can be used to guide the care to be provided by nurses within the scope of palliative care and spiritual care is Watson's Theory of Human Caring. Watson addressed three main themes in the model he developed between 1975 and

1979. These are creative factors, a caring relationship, and caring moments (Alharbi & Baker, 2020). Watson's Theory of Human Caring (THC) suggests that human beings are a whole consisting of mind, body, and soul, and mentions the importance of each part and their harmony with each other, without compromising the whole (Korhan, 2019; Watson & Woodward, 2020). This approach is very suitable for palliative and spiritual care provided with a holistic understanding. Therefore, this article discusses the roles of nurses in palliative and spiritual care for newborns and their families within the framework of Watson's Theory of Human Care. In this article, we argue that nursing interventions within the framework of this model will guide nurses with a modern nursing vision.

METHODOLOGY

This literature review article aims to explain the roles and functions of nurses to meet the needs of newborns and their parents in palliative and spiritual care. In the literature review, full-text studies in English were examined in Pubmed, ProQuest, Science Direct and Google Scholar databases between 2015 and 2020, in order to provide current information.

The search terms of 'palliative care', 'spirituality', 'neonatal', 'parent', 'nurse' and 'holistic care' and their combination were used in the review. Inclusion criteria for the studies were determined as follows: (a) published between 2015 and 2020, (b) focusing on palliative or spiritual care for the newborn and their parents, (c) written in English, and (d) published online full-text. As a result of the research, 588 articles were reached. The titles and abstracts of these articles were evaluated. 17 articles that met the criteria were identified. In the light of the data obtained from these articles, this review was created. The main themes discussed in this review are the palliative and spiritual care needs of newborns and their parents, and the role of nurses in practices within the framework of Watson's Theory of Human Care.

RESULTS

In this review, the findings obtained as a result of the literature review are discussed under five subheadings. These subtitles are palliative care and newborn, palliative care and parents, role of nurse in palliative care, spirituality in palliative care, spirituality and neonatal nursing.

PALLIATIVE CARE AND NEWBORN

Palliative care begins with the diagnosis of a life-limiting or threatening disease of the newborn. Palliative care includes an effective and comprehensive approach to life, death, and aftercare. This approach is family-centered, individual, multidisciplinary, and holistic, and aims to maximize the quality of life of newborns and their parents by helping them (Anspacher et al., 2017; Quinn et al., 2020; Silva et al., 2019). According to the WHO, palliative care is an approach that aims to identify, evaluate and treat pain and other physical, psychosocial, and spiritual problems of patients with life-threatening problems and their families at an early stage and improve their quality of life (WHO, 2020). Components of palliative care are pain management, symptom management, social, psychosocial, emotional support, and caregiver support (Dalcalı, 2019). Palliative care is concerned with quality rather than the length of life and focuses on quality of life. Palliative care considers life and death as normal processes. Death is neither delayed nor accelerated (Marlow &Gallagher, 2020; Zamani et al., 2019).

In the past, palliative care was considered in terms of the adult patient population with cancer, HIV / AIDS, and neurological diseases. Nowadays, it has started to be applied for newborns as well (Marçola et al., 2017; The British Association of Perinatal Medicine, Palliative Care, 2010). Palliative care of newborns includes a family-centered, professional, multidisciplinary, dynamic, individual, and holistic approach covering newborns with life-threatening diseases and their parents during prenatal, natal, postnatal, and bereavement periods. Palliative care aims to improve the quality of life of newborns and their families. Neonatal nurses are an indispensable part of palliative care (Anspacher et al., 2017; Esenay, 2018; Silva et al., 2019). Palliative care can be offered along with therapeutic care to relieve the suffering of newborns with life-threatening diseases and their families and to improve their quality of life (Kain et al., 2009).

PALLIATIVE CARE AND PARENTS

The loss of an infant can have a much greater impact on families than the loss of an adult family member. When they find out that they will have a baby, parents experience hope and happiness, with the

excitement of a new individual joining their lives. The illness or loss of a newborn causes terrible sadness and mourning for the parents. In this process, it is vital for newborns and their parents to integrate palliative care into therapeutic care (Almeida et al., 2016; Marc-Aurele & English, 2017; Özel et al., 2018; Parravicini, 2017). The time parents spend with their babies is very short and therefore very valuable. If this opportunity is missed, the regret caused by this situation can last forever. The process of dealing with this loss is quite difficult for the family (Falck et al., 2016). Newborns and their parents should be evaluated as soon as possible after the palliative care decision. Problems should be identified, the pain of the baby should be alleviated in the early period and psychosocial-spiritual support should be provided to the family (Özel et al., 2018; Viallard & Moriette, 2017). Research on parents with babies receiving treatment in the neonatal intensive care unit reveal that the families of newborns receiving palliative care find this care beneficial and their stress is significantly reduced compared to parents who do not receive this service (Currie et al., 2016; Petteys et al., 2015). Within the scope of palliative

care, newborn parents want to be informed about symptom management, education, communication, and emotional support, to take part in decisions about the patient, to spend more time with their babies, and to receive care in institutions with better facilities (Kıvanç, 2017). Zuniga-Villanueva et al. (2021) evaluated the effect of pediatric palliative care compared to standard care for newborns in their systematic review. The results are synthesized qualitatively. In the study organized outcomes into eight different categories: psychological, social and spiritual support; communication, place of care, symptom management, grief care, predicted versus actual neonatal outcomes, parental coping, stress, satisfaction (Zuniga-Villanueva et al., 2021). Nurses should continually evaluate their care goals and adopt a holistic and family-centered approach to pain relief, comfort, quality of life, emotional and spiritual care rather than a treatment-oriented approach.

ROLE OF NURSE IN PALLIATIVE CARE

When parents receive devastating news about their babies before or after birth, the care and support they receive from nurses or other healthcare professionals is

invaluable during this intense and complex period of their lives and their babies during their short life. Recent studies in the literature have revealed that newborn babies and their parents need palliative care. Developing palliative care specific to both the perinatal and neonatal periods of babies is a necessity (Hasanpour et al., 2016; Mancini et al., 2020; Ünal & Zenciroğlu, 2016). The American Academy of Pediatrics recommends the initiation of pediatric palliative care in diagnosis and integration throughout the prognosis of the disease to alleviate pain, improve quality of life, and facilitate informed decision making (AAP, 2000).

The palliative care approach for newborns ensures that the baby continues to receive intensive care, but the level of technological care that is painful and reduces the quality of life is reduced as much as possible. It also means that families spend time with their babies and build memories (Kain et al., 2009). Silva et al. (2019) conducted a qualitative study to determine healthcare professionals' perceptions about neonatal palliative care. According to the study, healthcare professionals are sensitive to care in cases of serious illness and death, but they

encounter difficulties and insufficiency in providing care (Silva et al., 2019). Nurses are one of the health professionals who are in constant communication with newborns and their parents in this process and can make the most valuable touches. Nurses should establish open, reliable, and honest communication with their parents as well as the newborns they care for. Counseling should be provided to parents on healthcare and treatment planning, procedures and practices, management, team, and process. During this counseling, nurses, with their scientific knowledge and clinical expertise, identify the parents' religious, cultural, and spiritual desires, their preferred care and/or death, their feelings and thoughts, their hopes and fears, their strengths and weaknesses. Thus, they play a key role in planning the best care for parents and newborns. Nurses should aim to optimize the quality of life, preserve parental autonomy, and active parental involvement in the counseling they provide (Black et al., 2020; Mancini et al., 2020). In this context, the roles of the nurses are as follows:

- They provide ongoing emotional support to the newborns and their families.

- They evaluate and manage the pain and other symptoms of the newborns, and raise the awareness of the individuals and their families to be able to check symptoms at home.
- They provide the necessary information about reaching the hospital and emergency services.
- They improve the quality of life of families by helping them to maintain independence and control and make choices during daily care.
- They identify the social support available to newborns and their families and help them get support.
- They provide information to the families of newborns about the economic dimension of the disease and the economic support they can receive (Nursing Regulation, 2011).
- They apply palliative care in newborns along with individualized developmental care strategies.
- They help the newborns and parents understand the changes with the help of regular and detailed evaluations and discuss with parents about the goals of care and how these changes might affect future treatment.
- Palliative care should be provided in all settings where healthcare is provided, and it should be accessible to all newborns and

their families in need (Kenner, 2016; Ünal & Zenciroğlu, 2016).

- They create opportunities for newborns and their families to say goodbye.
- They support parents to create memories (such as photos, hair, hand-foot print) of the newborn (Butcher, Bulechek, Dochterman & Wagner, 2018).
- They allow parents to practice religious or cultural practices.
- They accept the newborns as individuals and ensure their privacy.
- They empathize.
- They accept the parents' beliefs as they are and act objectively.
- They allow parents to express the meanings they attribute to illness and death (Dalcalı, 2019).
- Palliative care of newborns includes physical, emotional, social, cultural, religious, and spiritual care elements.
- Care planning is based on effective communication and nurses need to develop and apply communication skills to support decision-making within the family.
- They provide family-centered care to achieve optimum results for newborns and their families (Kenner, 2016; Marc-Aurele & English, 2017).

- They take into account the impact on all family members (parents, siblings, grandparents, and extended family) of having a baby in a life-threatening/restrictive situation.
- They help the family how to explain the situation to the siblings of the newborns.
- They protect and advocate the best interests of the newborns in practices and decisions (Mancini et al., 2020; Marc-Aurele & English, 2017).
- Nurses are an important part of the multidisciplinary palliative care team. Therefore, they improve themselves within the scope of knowledge, skills, and approach in palliative care and take an active role in team dynamics. It should be ensured that the team uses a common language.
- The nurse and the newborn team provide parents with newborn care options. They provide the best possible support for parents to make the right decision.
- They make care planning together with their parents.
- They evaluate the process and results for quality health care (Kenner, 2016; Kyc et al., 2020).
- They ensure continuity of care before and after death or loss.

- Nurses provide well-informed answers to parents' questions or concerns about autopsy/post-mortem.
- They should be able to discuss with the family the current practices of the physical care of the baby's body after death and the importance of continuing to care for or be with their baby after death.
- The baby is also cared for after death and the parents and other family members are supported after the baby dies (Black et al., 2020; Bloomer et al., 2015).

SPIRITUALITY IN PALLIATIVE CARE

Diseases, losses, and deaths are situations that disrupt existing balances and make reintegration difficult. Being faced with these situations may cause some reactions and some needs in individuals. One of these needs has a spiritual dimension (Edwards et al., 2010; Mancini et al., 2020). It is recognized that providing spiritual care is necessary to alleviate the suffering of life, illness, and death of newborns and their parents who are faced with a life-limiting disease (Walker & Waterworth, 2017). The spiritual dimension is as important as the physical, emotional, and social dimensions. The

spiritual dimension that exists in human life from the moment of birth is a part of the individual's identity (Çınar & Aslan, 2017). Spiritual care is an essential component of health care. Because meeting the spiritual needs of patients and parents is significantly related to their physical, psychological, social, and mental well-being and satisfaction with the quality of care. Individuals' spiritual needs arise in times of crisis such as stress, illness, loss, and death, when they have difficulty in finding answers about the meaning and purpose of life and when hopes are lost (Hu et al., 2019). It is important to identify, meet, and evaluate spiritual needs that arise in crises. Spiritual care provided by nurses who are competent in their field can positively contribute to the acceptance of the disease, future planning, quality of life, and recovery processes of the patient and their family (Çınar & Aslan, 2017; Paul Victor & Treschuk, 2020). Spiritual needs can be defined as trust, hope, love, self-worth development, righteousness, desire to find the meaning and purpose of life, relationships, forgiveness, experience, sensuality, self-expression, consolation, rituals, and faith support (Hu et al., 2019; Mancini et al., 2020) (Figure 1.).

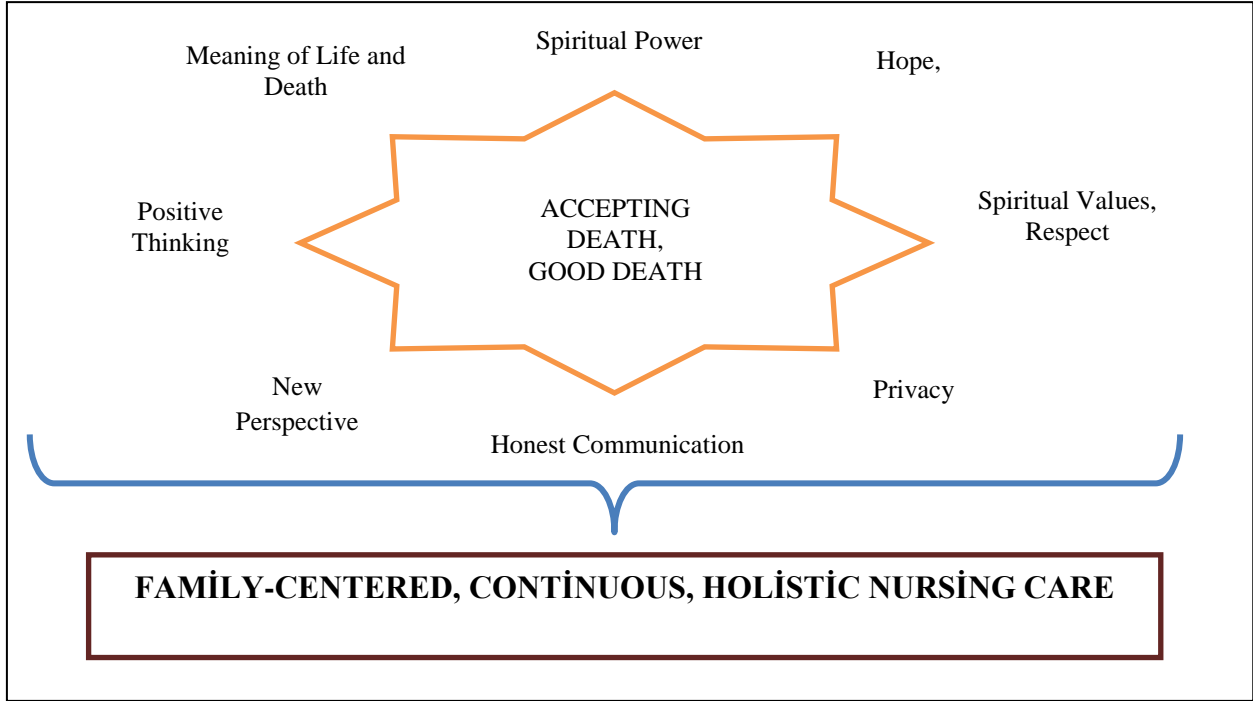


Figure 1. Spiritual care and nursing care

Spiritual care requirements associated with the disease in individuals are described as follows.

- 1) The need to attribute meaning to life or disease
- 2) To have a sense of purpose, mission, or desire to live
- 3) The need for spiritual values to be accepted, respected, and supported
- 4) The need of the mind to focus on issues other than illness
- 5) Accepting death and dealing with it
- 6) The need for forgiveness
- 7) The need to feel hope and trust (Center for Spirituality, Theology and Health, 2023; Mamier et al., 2019).

SPIRITUALITY AND NEONATAL NURSING

Nurses must carefully manage this period, which is very valuable at the end of life for both newborns and parents in palliative care. Studies show that palliative care needs are quite wide and cover many areas of the lives of newborns and their families. One of these is the spiritual area (Dalcalı, 2019; Walker & Waterworth, 2017). Spiritual care is an intrinsic and essential component of palliative care (Gijsberts et al., 2019). Problems experienced in the spiritual area can prevent physical symptoms in palliative care patients and their families. Problems related to the spiritual sphere can even take precedence over physical symptoms in palliative care patients and their families (Edwards et al., 2010; Mamier et al., 2019; Mancini et al., 2020). In a qualitative study by Hasanpour et al. (2016), it has identified six themes; human dignity for newborn; need to comfort the soul; spiritual belief in supernatural power; supportive and preparation needs in the infant's death; reliance on information and communication needs; spiritual and compassionate care needs for infant and

their family (Hasanpour et al., 2016). Spiritual care provides less stress, lower costs, a safe environment, high satisfaction, and improved quality of life for newborns receiving palliative care and their families (Gijsberts et al., 2019; Mamier et al., 2019; Pearce et al., 2012; Steinhauser et al., 2017). Nurses who are constantly in contact with newborns and aim to provide holistic nursing care, should also comprehensively evaluate newborns and their parents spiritually and provide care (Dalcalı, 2019). Competence in spiritual care determines the effectiveness of care and is considered one of the primary professional skills of nurses (Hu et al., 2019). Spiritual care, which is part of quality care, is the responsibility of nurses (Çınar & Aslan, 2017). In this regard;

- They should ensure that newborns spend time with their families and other important people in their lives.
- They should help the newborns and their parents build memories.
- They should support parents in creating meaning and purpose for life, illness, and death.
- Mutually open, respectful, empathic, and reassuring therapeutic communication is essential for spiritual care.

- They should encourage parents to evaluate their spiritual values and beliefs.
- They should provide private and quiet environments for spiritual activities that the individual determines (Butcher et al., 2018).
- They should evaluate the spiritual well-being of the parents. They should plan and manage the care needed (Black et al., 2020).
- Nurses should be available to support parents in times of pain.
- They should provide support regarding the use of spiritual resources and care providers.
- They should provide guidance for parents to consult spiritually based programs and support groups.
- They should provide additional physical, mental, and spiritual-based guidance and support as needed (Butcher et al., 2018).
- Individualized nursing practices should be shaped based on the spiritual needs of newborns and parents.
- Nurses should take an active role in the creation and implementation of guidelines for meeting their spiritual needs and performing care practices.
- They should give opportunities for new perspectives (Black et al., 2020; Dalcalı, 2019).

NURSING IMPLICATION

Systematic delivery of nursing care with a care-specific model facilitates the identification of problems in practice, the

planning of comprehensive care and the development of solutions, and enables the nurse to focus on care. In this way, a professional communication is ensured, a common language of care, a way of thinking about care is developed and the quality of care is improved. Nurses who will provide palliative care services in the NICU can plan care based on the Watson human care model. With this model, the nurse's care behaviors can be listed as being patient-centered, being compassionate, providing and maintaining the patient's comfort, preserving hope, approaching with love and kindness, active listening, taking into account cultural differences in care, being emotionally open and accessible, protecting the patient's dignity, trustworthiness, touch, consistency, respectfulness, physical and mental readiness, providing a healing environment (a physically, emotionally and spiritually comfortable, beautiful, peaceful environment etc) (Kabasakal & Kitiş, 2021; Pajnkihar, McKenna, Štiglic & Vrbnjak, 2017; Watson & Woodward, 2020). All these behaviors are very important in providing palliative care. Nurses should be aware of the person(s) they care for and their own beliefs or

judgments at the time of care. The pediatric palliative care team should be increasingly integrated into the NICU to ensure a smooth transition from curative care to palliative care when appropriate (Jackson & Vasudevan, 2020). However, spiritual care is an essential part of this care. It is observed that nurses have problems in applying spiritual care. These problems generally appear as follows: Nurses' thinking that they do not have sufficient knowledge and application skills on the subject, their inability to comprehend the distinction between spirituality and religion, lack of time, absence of palliative care teams and guides in clinics, and low visibility of spiritual care than the physical one (American Holistic Nurses Association, 2013; Dalcalı, 2019; Mamier et al., 2019; Paul Victor & Treschuk, 2020; Selman et al., 2018). It has been observed that palliative and spiritual care is insufficient in the field of pediatrics. Nurses should be aware that they play a critical role in spiritual care, which should be involved in palliative care and should improve themselves in this area for family-centered and holistic care. They should integrate it into nursing care without ignoring the spiritual dimension.

CONCLUSION

The roles of the NICU health professionals are both to care for the newborn, providing comfort, minimising the distress and managing symptoms and also to support the parents in the difficult decisions. Nurses should provide holistic, family-centered, and individualized care for newborns and their parents. In parallel with the developing healthcare system, it is considered that palliative care provided within the scope of neonatal intensive care services in our country will improve the health of newborns and their parents. Thus, it will be ensured that the parents overcome the loss and bereavement process more healthily, the quality of care will increase and holistic, individualized, and family-centered care will be supported.

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Contributions

RÇ and EKT wrote the manuscript. All authors read and approved the final manuscript.

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