

Palliative Care in Neonatal Intensive Care Units: Challenges and Solutions

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ABSTRACT

Palliative care is a series of actions aiming to offer support to parents and their infants in order to improve their quality of life. Despite optimal outcomes, the provision of palliative care for infants and achieving these outcomes may be hardly feasible. The present study aimed to investigate the barriers to palliative care and gain insight into the solutions. Accordingly, the obstacles were identified and classified into three categories of parent-related barriers (parental request for continuing treatment, cultural background, and religious beliefs), barriers concerning healthcare providers (attitude toward palliative care, death, and life values, religious beliefs, knowledge and skills in palliative care, and ethical distress), and barriers within the healthcare system (unclear policies regarding the implementation of palliative care, inadequate support from caretakers, lack of educational programs, insufficient personnel, unprepared environment, lack of technological requirements, and lack of access to consultants). Each category was discussed, and relevant solutions were provided.

Keywords: Delivery of health care, Health personnel, Neonatal intensive care unit, Palliative care, Parents

Introduction

The highest mortality rates during childhood are reported in infancy, and most neonatal deaths occur in neonatal intensive care units (NICUs) (1, 2). In 2013, approximately 23,440 neonatal deaths were reported in the United States, two-thirds of which occurred among infants and in NICUs (3).

Despite the advancement in increasing the survival rate of premature neonates, low-birth-weight infants, and those with deficiencies (e.g., asphyxia and congenital anomalies) (4), NICU teams are faced with fatal anomalies in newborns, some of which are hardly cured by medical and surgical procedures due to factors such as the prematurity and low birth weight of neonates (5). Under such circumstances, it seems necessary to take account of some measures and procedures that could reduce pain in infants and enhance the quality of life of parents (6).

Palliative care is a series of actions

recommended in such settings to offer comfort for newborns at the end of life and protect both the infants and parents (7). Palliative care has progressed rapidly around the world owing to raising the awareness of healthcare providers regarding pain and other symptoms of spiritual, psychological, and social stress in patients and their family members (8). This care procedure mainly focuses on preventing pain and suffering and providing psychological, spiritual, social, and physical support to patients and their families, thereby improving their quality of life (9).

Planned and coordinated palliative care for infants was first developed by Catlin and Carter in 2000 (10), who provided holistic care to infants and their families, enabling parents and caregivers to make proper decisions for the life-threatening conditions affecting their newborns (11).

Decision-making about the provision of palliative care to a newborn less likely to survive

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is perceived as a significant challenging in terms of ethical, legal, and clinical concepts (6). It stands to reason that palliative care in NICUs has not been considered to be of essence yet. The significance of palliative care and its outcomes have been clarified in the adult population over the past two decades as globally demanding concept (12); as a result, this healthcare concept has recently been integrated into neonatal care (13). Moreover, palliative care is of paramount importance due to the high incidence of mortalities in NICUs and responsibilities of the healthcare staff to relieve pain in the infants and provide support to their parents (14).

Application of palliative care in clinical settings has been highlighted in the literature with growing evidence. Several studies have demonstrated the effectiveness of integrating palliative care into other healthcare domains (4). According to the literature, the provision of palliative care could be beneficial for infants, parents, and healthcare systems. The neonates receiving palliative care may have a short length of stay in NICUs and are less likely to undergo painful procedures, treatment with mechanical ventilation along with medication therapy, and resuscitation (7). Furthermore, these positive outcomes may result in other favorable outcomes for parents, such as less sorrow, better adaptation to suffering (15), greater satisfaction (16), better acceptance of the do-not-resuscitate (DNR) order, and less frequent visitation of the newborns receiving palliative care (17). On the other hand, palliative care could decrease the financial burden on healthcare systems, particularly the expenses on the painful end-of-life procedures that neither decrease the suffering of infants nor affect their survival (7).

Despite the favorable outcomes attributed to

palliative care, the integration of this care procedure into the agenda of the healthcare system for infants and achieving optimal outcomes may be hardly feasible.

The present study aimed to investigate the challenges concerning the implementation of palliative care and offer solutions for the underlying challenges in this regard.

Challenges Concerning the Implementation of Palliative Care

The first step to every paradigm shift is to identify the existing barriers and facilitators of the matter, which applied to the provision of palliative care for newborns as well (18). To date, So far, several studies (19-56) have been conducted in this regard, each identifying some of the barriers and facilitators associated with palliative care. According to these findings, the existing barriers to the implementation of palliative care could be classified into three main categories, including parent-related barriers, barriers concerning the healthcare providers, and barriers within the healthcare system (Table 1).

Parent-related Barriers

Parents are considered an important part of the healthcare team and play a pivotal role in planning and implementing palliative care for infants. Various challenging conditions may arise during NICU stay, predisposing infants to predictable or unpredictable death and suffering of parents. Although the type of care and considerations largely vary depending on the situation, the common principles for both predictable and unpredictable deaths are family-centered care, empathy, individualized care, and involvement of parents in the decision-making process depending on their

Table 1. Barriers to Implementation of Palliative Care for Neonates

	Main Barriers	Type of Barriers
Barriers to Implementation of Palliative Care for Neonates	Barriers Attributed to Parents	Parental request for continuing treatment Parental cultural background and religious beliefs
	Barriers Attributed to Healthcare Providers	Attitude of healthcare providers toward palliative care, death, and life values Religious beliefs of healthcare providers Poor knowledge and skills in palliative care Ethical distress
	Barriers within Healthcare Systems	Unclear strategies and policies regarding the implementation of palliative care Inadequate support from caretakers Lack of education regarding palliative care Unprepared physical environment Insufficient personnel Technological imperatives Lack of access to consultants

willingness (4).

Parental request for continuing treatments (13, 19) and their subsequent struggles with the healthcare providers are among the challenging issues influenced by the cultural, religious, and spiritual background of families (21), as well as the differences in the attitudes toward palliative care (22). In other words, the perspectives of parents toward palliative care are rooted in their cultural background, religion, norms and beliefs, and perspectives (23, 24), which affect the perception of parents regarding the death of their infant and interventions that are carried out in the end-of-life stages (25).

In this regard, religion and spirituality have been proposed as significant influential factors in the parental decision-making. For instance, the acceptance of the DNR order for severely low-birth-weight infants may depend on the religious and spiritual beliefs of the parents rather than the provided information by the physician (26). In the viewpoint of Muslims, the survival or death of humans depends on God's will. Muslims believe that life is a test, and all difficulties of life serve a purpose. Based on these beliefs, Muslim parents may not be convinced easily by the physician to accept or reject palliative care since they believe that physicians are merely the means of help, and the death or survival of every individual is decided by God (27). Accordingly, the acceptance of assisted death for the sake of terminating their suffering is perceived as interference in God's will by many Muslim parents. On the other hand, some parents consider the illness of their newborn as a punishment for their lifelong sins and mistakes (28-31).

From the cultural perspective, the reactions of parents to palliative care may vary. For instance, some parents tend to keep a photograph or toy as a memento of their child, so that they would keep their memories alive. However, in some cultures, it is unacceptable to keep the mementos that belong to an infant who is less likely to survive (32). On the other hand, parents of other cultural backgrounds may hesitate to touch their infant upon the initiation of palliative care. Other examples in this regard are the parents who resist the healthcare attempts to detach a dying infant from life support devices, perceiving this possibility to be against their cultural beliefs and values (33).

Barriers Concerning Healthcare Providers

Barriers concerning healthcare providers in the context of palliative care need to be addressed

in parallel with family-related barriers. In addition, the attitude of healthcare providers toward palliative care is of paramount importance (19). Considering that healthcare team members expect the provided care to result in the survival and longevity of neonates (10), their attitudes toward accelerating the dying process (34), life values (35), and their religious beliefs (36) may influence the provision of neonatal palliative care. Attitude guides behavior (37), and negative or positive attitudes toward death could affect the behaviors of professional caregivers in the case of dying patients. In other words, negative attitudes reduce effective communication with dying patients in terms of truth-telling and discussions regarding the dying process (38). On the other hand, the fears and concerns of professional caregivers might affect the patients and their families as well (37).

On the same note, religious beliefs are also of great importance in the provision of palliative care for infants since Muslims believe that the preservation of human life is a meritorious deed (39), life is a God-sent gift that is expected to be preserved at any cost, and no one is entitled to terminating life directly or indirectly (39, 40).

In parallel with the effect of attitude on the implementation of palliative care, knowledge of healthcare providers is a significant determinant of the implementation of palliative care (19, 20). Palliative care requires the adequate knowledge of the strategies to inform parents about the health status, resuscitation procedures, and skills used for their infant (e.g., symptom management, empathic communication, and interdisciplinary cooperation) (41). Insufficient knowledge and skills could lead to ineffective communication, inappropriate evaluation of the current needs of newborns and parents, and failure in the implementation of palliative care (42) or the defective implementation of neonatal palliative care (26).

Review of the literature suggested that nurses and physicians have limited knowledge about the philosophy, nature, and principles of palliative care (43-48). Poor knowledge may lead to false perceptions regarding palliative care, such as the use of placebo for relieving pain in the patients undergoing end-of-life procedures or withdrawing emotional support from the dying patient in order to initiate palliative care (49). Additionally, poor knowledge regarding the implementation of palliative care could cause ethical distress within the healthcare team (50). Nurses may consider their care provision to be unsuccessful (29, 50)

when technology not only fails to guarantee the survival of an infant, but it also creates false hope for the parents (12, 51). Such circumstances may lead to ethical distress in nurses, acting as a hindrance to the implementation of palliative care (12, 50, 51).

Barriers within the Healthcare System

The barriers within the healthcare system were the third category of the identified barriers to palliative care, which contribute to the implementation of these procedures. In this regard, the main challenges associated with the provision of palliative care were the lack of clear and documented policies, particularly regarding the proper time for the discontinuation of treatment, legal and ethical frameworks in NICUs, training programs for caregivers, and physical environment for providing palliative care (19, 23, 30).

A review of the current literature demonstrated the insufficient training of healthcare providers in terms of implementing palliative care (12, 19, 20, 31, 52-54). In a study by Epstein, 74% of the nurses and 82% of the physicians received no formal training on palliative care (31). In another research, Botwinski has stated that 12-62% of the nurses in various studies reported that educational instructions about palliative care were unsatisfactory, and the average time allocated to palliative care instructions were less than 15 hours (52). Furthermore, evaluation of the available training curricula indicated the lack of educational guidelines and instructions regarding palliative care for neonatologists and pediatric nurses (55, 56). Few empirical surveys have focused on the provision of educational interventions for palliative care in NICUs (7, 51, 57).

Another barrier within healthcare systems is the absence of an appropriate physical environment for the provision of palliative care (13, 19). The open-ward design of NICUs could be an obstacle against meeting the emotional needs of parents, attachment to the infant, and receiving authentic medical information about the infant. In other words, open environments prevent parents from expressing their feelings and emotions to the healthcare team (58).

With respect to the barriers within the healthcare system, the shortage of human resources increases the workload of the healthcare staff, thereby limiting the opportunities for the provision of palliative care

by nurses (59). In this regard, Forouzi et al. investigated the barriers to the implementation of palliative care in the NICUs of a hospital in the southeast of Iran from the perspective of nurses, mentioning human resource shortage as the most significant barrier to the provision of palliative care. Currently, the NICU nurses in Iran are required to provide care to 4-5 infants simultaneously. For instance, in some cases, the nurse must provide simultaneous care to a newly born infant and a dying infant that struggles to survive. Such situations lead to confusion and fatigue in the nursing staff (60).

Technological requirements could be considered an obstacle to the provision of palliative care since the basic reason for utilizing technical devices is to maintain one's survival. Nonetheless, it might be perceived paradoxical and confusing by some individuals to utilize life-saving technologies to postpone imminent death and deliver palliative care simultaneously to ease the death of a dying infant (61). In the study by Forouzi et al., the nurses stated that the utilization of advanced devices with the aim of preserving life might become an excuse to avoid delivering palliative care. As a result, some nurses tended to convince parents to accept treatment using such devices for the sake of their infant (60).

Lack of access to counseling services was the last barrier in this category. In several studies, nurses have reported that there are no consultants for the parents of the neonates receiving palliative care in the hospitals. On the other hand, these professional caregivers lacked sufficient competence and proficiency in communicating with parents efficiently. Therefore, lack of access to consultants was perceived as a barrier to palliative care (13, 19). According to our findings, parents of the infants receiving palliative care require religious and spiritual counseling in order to achieve positive outcomes, such as proper coping responses, low ethical distress, and improved decision-making (62).

Solutions for the Provision of Palliative Care

Implementation of palliative care in the current context of NICUs is numerous challenges, which arise from a series of factors relating to parents, healthcare providers, and healthcare system. Therefore, it seems necessary to identify and implement appropriate solutions for the existing barriers in this regard for effective

palliative care.

Considering that parental consent is the primary step to the initiation of palliative care and their resistance against the provision of palliative care, it seems important to assign a multidisciplinary team consisting of experts in the fields of psychology, social work, and pediatrics in order to overcome the reluctance of families toward the implementation of palliative care (57).

Communication is considered an inherent element in dealing with the family members that are expected to make decisions about the status of their ill infant. However, communicating with the parents of the infants who are at the risk of death and require palliative care is a difficult task; it becomes even more difficult when it comes to announcing the bad news to the families considering the diversities in their values, beliefs, and knowledge (63). Poor communication might exert long-lasting negative effects on the perception of parents toward the quality of care (64). Therefore, parents of the neonates requiring palliative care need empathic, timely, and honest interactions, so that they would gain a stronger sense of control over the hardships (65).

Attention to the possible approaches to enhance communication with the parents whose child is dying is a complex task when it comes to discussing palliative care. Every individual perceives death and life differently and shows different reactions to bereavement. As such, the needs of individuals may vary during the process of palliative care (66). Under such circumstances, one of the main requirements is meeting the need for religious and spiritual counseling. It is critical to allocate adequate time to the provision of counseling sessions compatible with the religious and spiritual beliefs of parents prior to the implementation of palliative care (67).

Special attention must be paid to the cultural differences of parents (68). For instance, it is recommended that NICUs recruit interpreters for non-native clients, and the cultural differences of parents be taken into account by making eye and physical contacts (10, 69). Moreover, the cultural and religious preferences of families should be respected through allowing the performance of rituals and making them memorable for patients and their family (70). These considerations can encourage parents to participate in the decision-making processes regarding palliative care and affect their perceptions toward death (25, 71).

Considering the barriers associated with caregivers and offering proper solutions could facilitate the implementation of the provided recommendations. As mentioned earlier, the attitude of healthcare providers toward palliative care, death, life values, religious beliefs, knowledge, skills, and ethical distress play a key role in the effective implementation of palliative care. To tackle these barriers, it is recommended that professional caregivers be instructed on palliative care. Training interventions could raise their awareness, alter their perspectives about palliative care (72-74), and enhance their skills (75, 76).

On the other hand, training may facilitate the implementation of this care approach by reducing stress, the fatigue caused by empathy, burnout, and post-traumatic stress syndrome in healthcare providers. Therefore, training programs containing instructions about the philosophy and advantages of palliative care, principles of multidisciplinary and collaborative work, symptom management using pharmacological and non-pharmacological methods, communication skills, religious and spiritual sensitivities, ethical and legal principles regarding the discontinuation of treatment, coping mechanisms, and supportive resources seem to be essential (77-79). To provide instructions, various approaches could be adopted, such as workshops (1), online educational courses (80), E-learning, and forums to share professional experiences (77).

Ethical distress in the healthcare providers of palliative care could be addressed by providing the opportunities to reflect and discuss the critical thinking outputs regarding values, beliefs, and ethics, especially when different aspects of care are in contrast with the personal values of the caregivers (42). Furthermore, ethical decision-making is a learned skill and an effective measure to eliminate ethical distress. However, it demands clear executive policies regarding the implementation of palliative care (36).

Clear policies and protocols are considered to be the main requisite to the implementation of palliative care in every setting and system (13, 19, 66). Therefore, it seems necessary that every system providing palliative care possess their own written policies concerning these procedures in order to improve the quality of palliative care and make caregivers feel supported (81, 82). Additionally, healthcare providers should have freedom of speech in

order to express their values and beliefs (13, 19, 66). All members of the healthcare team should participate in the provision of palliative care, so that the challenges between the healthcare team and families would be minimized and successful implementation of palliative care would be achieved. It is noteworthy that the policies in this regard need to be revised constantly so as to facilitate evidence-based care and exchange experiences and perceptions by healthcare providers (81).

One of the concepts that has recently been discussed is the open-ward design of NICUs, which is considered an obstacle to the implementation of palliative care. To address this issue, it is suggested that the separate rooms for parents and infants be replaced with the former design of open-space NICUs in order to improve the quality of family-based care and parent-infant interactions, preserve the privacy of mothers and infants, and increase parental satisfaction (83, 84). Meanwhile, alteration of the design of NICUs may help parents feel that their infant receives treatment as a human (85) is continuously monitored by the medical staff. If parents are assured of receiving continuous care for their terminally ill infants, they will perceive palliative care as a high-quality approach and hold stronger faith in this care procedure (86-88).

Regarding lack of human resources, the most effective solution can be to standardize the number of nursing staff in the NICUs and to keep the nurse-patient ratio of 1: 2-3. Also, a special attention should be paid to the severity of infants' health status when tasks are being assigned to the nurses fairly. Implementation of these recommendations can pave the path to improve the quality of cares for the patients (89). In addition, the provision of counseling services to the parents whose infant is receiving palliative care could reduce the workload of nurses and facilitate the implementation of palliative care. Counselors can direct their activities toward four main areas of advanced guided planning (e.g., stopping nutrition and fluid therapy), primary follow-ups for the resuscitation status, organ donation, and discontinuation of treatments. Counselors are also expected to be available to parents at any given time and assure them that their questions will be answered in order to assist them in their decision-making (90).

Conclusion

As a progressive requisite in NICUs, palliative

care has been associated with challenges that stem from various factors, including parents, healthcare providers, and healthcare system. Therefore, it is essential to address these challenges in order to properly implement palliative care in NICUs. The next steps are clarifying the policies and protocols in this regard and planning educational programs that are compatible with the cultural, religious, and spiritual preferences of the families, as well as the principles of family-centered care. Furthermore, healthcare systems should modify the physical environment of NICUs and provide the necessary facilities for the provision of palliative care.

Conflicts of interests

None declared.

References

1. Twamley K, Kelly P, Moss R, Mancini A, Craig F, Koh M, et al. Palliative care education in neonatal units: impact on knowledge and attitudes. *BMJ Support Palliat Care*. 2013; 3(2):213-20.
2. Leuthner SR, Pierucci R. Experience with neonatal palliative care consultation at the Medical College of Wisconsin-Children's Hospital of Wisconsin. *J Palliat Med*. 2001; 4(1):39-47.
3. Hamilton BE, Hoyert DL, Martin JA, Strobino DM, Guyer B. Annual summary of vital statistics: 2010-2011. *Pediatrics*. 2013; 131(3):548-58.
4. Stephens BE, Tucker R, Vohr BR. Special health care needs of infants born at the limits of viability. *Pediatrics*. 2010; 125(6):1152-8.
5. Bhatia J. Palliative care in the fetus and newborn. *J Perinatol*. 2006; 26(Suppl 1):S24-6.
6. de Rooy L, Aladangady N, Aidoo E. Palliative care for the newborn in the United Kingdom. *Early Hum Dev*. 2012; 88(2):73-7.
7. Pierucci RL, Kirby RS, Leuthner SR. End-of-life care for neonates and infants: the experience and effects of a palliative care consultation service. *Pediatrics*. 2001; 108(3):653-60.
8. Rassouli M, Sajjadi M. Palliative care in Iran: moving toward the development of palliative care for cancer. *Am J Hosp Palliat Med*. 2016; 33(3):240-4.
9. Kenner C, Press J, Ryan D. Recommendations for palliative and bereavement care in the NICU: a family-centered integrative approach. *J Perinatol*. 2015; 35:S19-23.
10. Catlin A, Armigo C, Volat D, Hadley MA, Bassir R, Valle E, et al. Conscientious objection: a potential neonatal nursing response to care orders that cause suffering at the end of life? Study of a concept. *Neonatal Netw*. 2008; 27(2):101-8.
11. Williams-Reade J, Lamson AL, Knight SM, White MB, Ballard SM, Desai PP. The clinical, operational, and financial worlds of neonatal palliative care: a focused ethnography. *Palliat Support Care*. 2015;

- 13(2):179-86.
12. Romesberg T. Building a case for neonatal palliative care. *Neonatal Netw.* 2007; 26(2):111-5.
 13. Kain V, Gardner G, Yates P. Neonatal palliative care attitude scale: development of an instrument to measure the barriers to and facilitators of palliative care in neonatal nursing. *Pediatrics.* 2009; 123(2):e207-13.
 14. Ghoshal A, Damani A, Muckaden M. Palliative care in the neonatal intensive care unit: An Indian experience. *J Neonatal Nurs.* 2017; 23(2):75-81.
 15. Guimaraes HJ. The importance of parents in the neonatal intensive care units. *J Pediatr Neonat Individual Med.* 2015; 4(2):e040244.
 16. Petteys AR, Goebel JR, Wallace JD, Singh-Carlson S. Palliative care in neonatal intensive care, effects on parent stress and satisfaction: a feasibility study. *Am J Hosp Palliat Med.* 2015; 32(8):869-75.
 17. Younge N, Smith PB, Goldberg RN, Brandon DH, Simmons C, Cotten CM, et al. Impact of a palliative care program on end-of-life care in a neonatal intensive care unit. *J Perinatol.* 2015; 35(3):218-22.
 18. Kilcullen M, Ireland S. Palliative care in the neonatal unit: neonatal nursing staff perceptions of facilitators and barriers in a regional tertiary nursery. *BMC Palliat Care.* 2017; 16(1):32.
 19. Wright V, Prasun MA, Hilgenberg C. Why is end-of-life care delivery sporadic? A quantitative look at the barriers to and facilitators of providing end-of-life care in the neonatal intensive care unit. *Adv Neonatal Care.* 2011; 11(1):17-36.
 20. Martin M. Missed opportunities: a case study of barriers to the delivery of palliative care on neonatal intensive care units. *Int J Palliat Nurs.* 2013; 19(5):251-6.
 21. McHaffie HE, Lyon AJ, Hume R. Deciding on treatment limitation for neonates: the parents' perspective. *Eur J Pediatr.* 2001; 160(6):339-44.
 22. Poncet MC, Toullic P, Papazian L, Kentish-Barnes N, Timsit JF, Pochard F, et al. Burnout syndrome in critical care nursing staff. *Am J Respir Crit Care Med.* 2007; 175(7):698-704.
 23. Cuttini M, Casotto V, de Vonderweid U, Garel M, Kollée LA, Saracci R, et al. Neonatal end-of-life decisions and bioethical perspectives. *Early Hum Dev.* 2009; 85(10):S21-5.
 24. Oetzel J, Simpson M, Berryman K, Iti T, Reddy R. Managing communication tensions and challenges during the end-of-life journey: perspectives of Māori kaumātua and their whānau. *Health Commun.* 2015; 30(4):350-60.
 25. Chen CH, Huang LC, Liu HL, Lee HY, Wu SY, Chang YC, et al. To explore the neonatal nurses' beliefs and attitudes towards caring for dying neonates in Taiwan. *Matern Child Health J.* 2013; 17(10):1793-801.
 26. Boss RD. Palliative care for extremely premature infants and their families. *Dev Disabil Res Rev.* 2010; 16(4):296-301.
 27. Al-Alaiyan S, Al-Hazzani F. The need for hospital-based neonatal palliative care programs in Saudi Arabia. *Ann Saudi Med.* 2009; 29(5):337-41.
 28. Baergen R. How hopeful is too hopeful? Responding to unreasonably optimistic parents. *Pediatr Nurs.* 2006; 32(5):482-6.
 29. Rogers S, Babgi A, Gomez C. Educational interventions in end-of-life care: part I: an educational intervention responding to the moral distress of NICU nurses provided by an ethics consultation team. *Adv Neonatal Care.* 2008; 8(1):56-65.
 30. Maginnes E. Palliative care in the neonatal population. *Neonatal Netw.* 2002; 21(4):77-8.
 31. Epstein E. End-of-life experiences of nurses and physicians in the newborn intensive care unit. *J Perinatol.* 2008; 28(11):771-8.
 32. Kain VJ, Wilkinson DJ. Neonatal palliative care in action: moving beyond the rhetoric and influencing policy. *J Res Nurs.* 2013; 18(5):459-68.
 33. Catlin A, Carter B. Creation of a neonatal end-of-life palliative care protocol. *J Perinatol.* 2002; 22(3):1895.
 34. Barr P. Relationship of neonatologists' end-of-life decisions to their personal fear of death. *Arch Dis Child Fetal Neonatal Ed.* 2007; 92(2):F104-7.
 35. Inghelbrecht E, Bilsen J, Pereth H, Ramet J, Deliens L. Medical end-of-life decisions: experiences and attitudes of Belgian pediatric intensive care nurses. *Am J Crit Care.* 2009; 18(2):160-8.
 36. Lee MC, Chen YC, Chen CH, Lu FL, Hsiao CC, Peng NH. Comparison of the educational needs of neonatologists and neonatal nurses regarding palliative care in Taiwan. *Am J Hosp Palliat Med.* 2016; 33(3):264-71.
 37. Corner J, Bailey CD. *Cancer nursing: care in context.* New Jersey: John Wiley & Sons; 2009.
 38. Hinkle JL, Cheever KH. *Brunner & Suddarth's textbook of medical-surgical nursing.* Philadelphia: Lippincott Williams & Wilkins; 2013.
 39. Hedayat KM, Pirzadeh R. Issues in Islamic biomedical ethics: a primer for the pediatrician. *Pediatrics.* 2001; 108(4):965-71.
 40. Sachedina A. End-of-life: the Islamic view. *Lancet.* 2005; 366(9487):774-9.
 41. Quill TE, Abernethy AP. Generalist plus specialist palliative care--creating a more sustainable model. *N Engl J Med.* 2013; 368(13):1173-5.
 42. Mendel TR. The use of neonatal palliative care: Reducing moral distress in NICU nurses. *J Neonatal Nurs.* 2014; 20(6):290-3.
 43. Prem V, Karvannan H, Kumar SP, Karthikbabu S, Syed N, Sisodia V, et al. Study of nurses' knowledge about palliative care: a quantitative cross-sectional survey. *Indian J Palliat Care.* 2012; 18(2):122-7.
 44. Abu-Saad Huijer H, Abboud S, Dimassi H. Palliative care in Lebanon: knowledge, attitudes and practices of nurses. *Int J Palliat Nurs.* 2009; 15(7):346-53.
 45. Knapp CA, Madden V, Wang H, Kassing K, Curtis C, Sloyer P, et al. Paediatric nurses' knowledge of palliative care in Florida: a quantitative study. *Int J Palliat Nurs.* 2009; 15(9):432-9.
 46. Ronaldson S, Hayes L, Carey M, Aggar C. A study of

- nurses' knowledge of a palliative approach in residential aged care facilities. *Int J Older People Nurs.* 2008; 3(4):258-67.
47. Morita T, Miyashita M, Shibagaki M, Hirai K, Ashiya T, Ishihara T, et al. Knowledge and beliefs about end-of-life care and the effects of specialized palliative care: a population-based survey in Japan. *J Pain Symptom Manage.* 2006; 31(4):306-16.
 48. Whittaker E, Kernohan WG, Hasson F, Howard V, McLaughlin D. The palliative care education needs of nursing home staff. *Nurse Educ Today.* 2006; 26(6):501-10.
 49. Al Qadire M. Nurses' knowledge about palliative care: a cross-sectional survey. *J Hosp Palliat Nurs.* 2014; 16(1):23-30.
 50. Yam BM, Rossiter JC, Cheung K. Caring for dying infants: experiences of neonatal intensive care nurses in Hong Kong. *J Clin Nurs.* 2001; 10(5):651-9.
 51. Carter BS, Guthrie SO. Utility of morbidity and mortality conference in end-of-life education in the neonatal intensive care unit. *J Palliat Med.* 2007; 10(2):375-80.
 52. Botwinski C. NNP education in neonatal end-of-life care: a needs assessment. *MCN Am J Matern Child Nurs.* 2010; 35(5):286-92.
 53. Rassouli M, Sajjadi M. Cancer care in countries in transition: the Islamic Republic of Iran. *Cancer Care in Countries and Societies in Transition.* New York: Springer; 2016. P. 317-36.
 54. Rassouli M, Sajjadi M. Palliative care in the Islamic Republic of Iran. *Palliat Care Cancer Patient.* 2014; 9:39.
 55. Baker JN, Torkildson C, Baillargeon JG, Olney CA, Kane JR. National survey of pediatric residency program directors and residents regarding education in palliative medicine and end-of-life care. *J Palliat Med.* 2007; 10(2):420-9.
 56. Kolarik RC, Walker G, Arnold RM. Pediatric resident education in palliative care: a needs assessment. *Pediatrics.* 2006; 117(6):1949-54.
 57. Knapp C, Thompson L. Factors associated with perceived barriers to pediatric palliative care: a survey of pediatricians in Florida and California. *Palliat Med.* 2012; 26(3):268-74.
 58. Falck AJ, Moorthy S, Hussey-Gardner B. Perceptions of palliative care in the NICU. *Adv Neonatal Care.* 2016; 16(3):191-200.
 59. Kain V. Exploring the barriers to palliative care practice in neonatal nursing: a focus group study. *Neonatal Paediatr Child Health Nurs.* 2011; 14(1):9.
 60. Azzizadeh Forouzi M, Banazadeh M, Ahmadi JS, Razban F. Barriers of palliative care in neonatal intensive care units. *Am J Hosp Palliat Med.* 2017; 34(3):205-11.
 61. Wilder MA. Ethical issues in the delivery room: resuscitation of extremely low birth weight infants. *J Perinat Neonatal Nurs.* 2000; 14(2):44-57.
 62. Guthrie M. A health care chaplain's pastoral response to moral distress. *J Health Care Chaplain.* 2014; 20(1):3-15.
 63. Price J, McNeilly P, Surgenor M. Breaking bad news to parents: the children's nurse's role. *Int J Palliat Nurs.* 2006; 12(3):115-20.
 64. Kang T, Hoehn KS, Licht DJ, Mayer OH, Santucci G, Carroll JM, et al. Pediatric palliative, end-of-life, and bereavement care. *Pediatr Clin North Am.* 2005; 52(4):1029-46.
 65. Branchett K, Stretton J. Neonatal palliative and end of life care: what parents want from professionals. *J Neonatal Nurs.* 2012; 18(2):40-4.
 66. Lewis SL. Palliative care in the neonatal intensive care setting: our past and our future. *J Hosp Palliat Nurs.* 2012; 14(2):149-57.
 67. Kodadek MP, Feeg VD. Using vignettes to explore how parents approach end-of-life decision making for terminally ill infants. *Pediatr Nurs.* 2002; 28(4):333-40.
 68. Moro TT, Kavanaugh K, Savage TA, Reyes MR, Kimura RE, Bhat R. Parent decision making for life support decisions for extremely premature infants: from the prenatal through end-of-life period. *J Perinat Neonatal Nurs.* 2011; 25(1):52-60.
 69. Gale G, Brooks A. Implementing a palliative care program in a newborn intensive care unit. *Adv Neonatal Care.* 2006; 6(1):37-53.
 70. Stringer M, Shaw VD, Savani RC. Comfort care of neonates at the end of life. *Neonatal Netw.* 2004; 23(5):41-6.
 71. Maddocks I, Rayner RG. Issues in palliative care for Indigenous communities. *Med J Aust.* 2003; 179(6):S17-9.
 72. Frommelt KH. Attitudes toward care of the terminally ill: an educational intervention. *Am J Hosp Palliat Med.* 2003; 20(1):13-22.
 73. Kane JR, Hellsten MB, Coldsmith RA. Human suffering: the need for relationship-based research in pediatric end-of-life care. *J Pediatr Oncol Nurs.* 2004; 21(3):180-5.
 74. Lange M, Thom B, Kline NE. Assessing nurses' attitudes toward death and caring for dying patients in a comprehensive cancer center. *Oncol Nurs Forum.* 2008; 35(6):955-9.
 75. Field D, Wee B. Preparation for palliative care: teaching about death, dying and bereavement in UK medical schools 2000-2001. *Med Educ.* 2002; 36(6):561-7.
 76. Robinson R. End-of-life education in undergraduate nursing curricula. *Dimens Crit Care Nurs.* 2004; 23(2):89-92.
 77. Mancini A, Kelly P, Bluebond-Langner M. Training neonatal staff for the future in neonatal palliative care. *Semin Fetal Neonatal Med.* 2013; 18(2):111-5.
 78. Meadors P, Lamson A. Compassion fatigue and secondary traumatization: provider self care on intensive care units for children. *J Pediatr Health Care.* 2008; 22(1):24-34.
 79. Czaja AS, Moss M, Mealer M. Symptoms of posttraumatic stress disorder among pediatric acute care nurses. *J Pediatr Nurs.* 2012; 27(4):357-65.
 80. Goodyear HM, Hatton S, Cuddeford L, Wallis M, Kruse S, Blackwell N. Developing an e learning module in paediatric palliative care. *Arch Dis*

- Childhood. 2011; 96(Suppl 1):A79-80.
81. Kumaran VS, Bray Y. Palliative care for newborn infants—the current scene in New Zealand and the way forward. *Sites*. 2011; 7(2):113-29.
 82. Zargham-Boroujeni A, Zoafa A, Marofi M, Badiee Z. Compilation of the neonatal palliative care clinical guideline in neonatal intensive care unit. *Iran J Nurs Midwifery Res*. 2015; 20(3):309-14.
 83. Swanson JR, Peters C, Lee BH. NICU redesign from open ward to private room: a longitudinal study of parent and staff perceptions. *J Perinatol*. 2013; 33(6):466-9.
 84. Stevens DC, Helseth CC, Thompson PA, Pottala JV, Khan MA, Munson DP. A comprehensive comparison of open-bay and single-family-room neonatal intensive care units at Sanford Children's Hospital. *HERD*. 2012; 5(4):23-39.
 85. van der Geest IM, Darlington AS, Streng IC, Michiels EM, Pieters R, van den Heuvel-Eibrink MM. Parents' experiences of pediatric palliative care and the impact on long-term parental grief. *J Pain Symptom Manage*. 2014; 47(6):1043-53.
 86. Browning DM. Microethical and relational insights from pediatric palliative care. *Virtual Mentor*. 2010; 12(7):540-7.
 87. Melin-Johansson C, Axelsson I, Jonsson Grundberg M, Hallqvist F. When a child dies: parents' experiences of palliative care-an integrative literature review. *J Pediatr Nurs*. 2014; 29(6):660-9.
 88. Heller KS, Solomon MZ; Initiative for Pediatric Palliative Care (IPPC) Investigator Team. Continuity of care and caring: what matters to parents of children with life-threatening conditions. *J Pediatr Nurs*. 2005; 20(5):335-46.
 89. Rogowski JA, Staiger DO, Patrick TE, Horbar JD, Kenny MJ, Lake ET. Nurse staffing in neonatal intensive care units in the United States. *Res Nurs Health*. 2015; 38(5):333-41.
 90. Leuthner SR, Pierucci R. Experience with neonatal palliative care consultation at the Medical College of Wisconsin-Children's Hospital of Wisconsin. *J Palliat Med*. 2001; 4(1):39-47.