



Neonatal palliative care

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Purpose of review

A significant number of newborns are affected by life-limiting or life-threatening conditions. When prolongation of survival is no longer a goal, or prognosis is uncertain, a plan of care focused on the infant's comfort is essential. The aim of this article is to review the most recent and relevant literature regarding neonatal palliative care (NPC).

Recent findings

A variety of perinatal and NPC programs are described, but most programs focus exclusively on end-of-life care. Moreover, there is a great need to standardize practices and obtain follow-up quality measures. Guidelines to address infants' basic needs, to achieve a state of comfort, are proposed. A multidisciplinary team addressing the infants' medical and nonmedical needs, parental grieving process, and providers' distress is recommended.

Summary

NPC is a unique multidisciplinary approach for the care of newborns affected by life-limiting or complex medical conditions with uncertain prognosis. Standardized guidelines should be implemented with the goal of achieving a state of comfort for newborns throughout the course of illness. Further studies are warranted to assess whether NPC effectively promotes newborns' comfort and parents and providers' satisfaction.

Keywords

life-limiting condition, neonatal comfort care, neonatal end-of-life care, neonatal palliative care, perinatal palliative care

INTRODUCTION

The infant mortality rate in the United State is approximately 6/1000 live births and prematurity and congenital anomalies are the two leading causes of neonatal deaths [1].

Prenatal detection of congenital anomalies leads to identification of infants who are affected by life-limiting conditions with short life expectancy. Moreover, a significant number of newborns admitted to the neonatal ICU (NICU) in critical condition face potentially adverse prognoses. Neonatal palliative care (NPC) offers a plan of choice for improving quality of life when the patient's prolongation of life is no longer the goal of care or the complexity of the medical condition is associated with uncertain prognosis. However, there is no current evidence-based standard of palliative care for this population [2,3]. This article reviews the most recent experiences of NPC and provides recommendations for implementation of guidelines focused on baby's comfort and on parental and providers' satisfaction with the care.

CANDIDATES

Candidates for NPC include newborns prenatally or postnatally diagnosed with life-limiting conditions. Some of these conditions are not compatible with life beyond hours or days with or without life support and early demise is expected (i.e., anencephaly, renal agenesis), whereas in others the burden of intensive care may exceed the benefits in terms of length of survival (i.e., trisomy 13 and 18) [4,5,6]. NPC may also be the treatment of choice for terminally ill babies after failure of intensive care [7] or extremely premature babies born at the cusp of viability [8,9]. A comprehensive but not necessarily

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KEY POINTS

- There are a significant number of newborns diagnosed with life-limiting conditions and diseases with uncertain prognoses.
- When length of life is limited or prognosis uncertain, focusing on the infant's comfort is essential.
- A state of comfort is achieved when some basic needs (bonding, maintenance of body temperature, relief of hunger/thirst, alleviation of pain/discomfort) are met.
- Perinatal and neonatal palliative care programs are present in most states; however, standardized guidelines and quality measures are needed.
- Only a multidisciplinary team can address the infant's medical and nonmedical needs, and support parents' grieving process and providers' distress.

all inclusive list of conditions appropriate for comfort care measures is shown in Table 1.

Last, NPC should also be offered to infants affected by complex medical conditions with uncertain or potential adverse prognoses, combined with intensive care and with the goal of improving quality of life [10].

PERINATAL PALLIATIVE CARE

In many cases, NPC starts before delivery [9,11¹²]. Because of advances in prenatal diagnosis, most life-limiting conditions are identified during pregnancy. A small but increasing number of women choose to continue pregnancy after detection of severe fetal anomalies and this increase seems to be associated with the availability of a postnatal plan of NPC [12].

Prenatal counseling

The American College of Obstetricians and Gynecologists and the American Academy of Pediatrics recommend parental informed consent and discussion of all available options, including NPC, in cases of potential life-limiting fetal anomalies [13]. Models of care have been proposed [14], but these recommendations are not yet standard practice [15].

A survey with questions related to prenatal communication and proposal for plan of care for fetal adverse diagnoses was sent to 434 perinatologists at 48 centers for prenatal diagnosis. The participation rate was about 50% and revealed a wide range of practice, with 30% of obstetricians and 10% of neonatologists not mentioning the option for birth support, including perinatal palliative care [16]. Kukora *et al.* [17] performed a retrospective medical record analysis of a population of pregnant women carrying fetuses with either a 'nonsurvivable' or 'uncertain, likely poor' prognosis and showed that only a minority of mothers (17%) received prenatal palliative counseling.

Parents' satisfaction

A group of 30 parents who decided to continue the pregnancy with a lethal fetal diagnosis were interviewed regarding their experience at different stages of their pregnancy. Although parents' overall goal was to 'have no regrets' as an opportunity to fully live their experience of parenthood, mothers and fathers showed different needs at different steps of the journey. These data should inform healthcare professionals of the need to provide timely support to each parent [18].

Table 1. Conditions appropriate for neonatal palliative care

Life-limiting conditions

Anencephaly, hydranencephaly, severe cases of holoprosencephaly, or other complex CNS anomalies associated with short life expectancy

Lethal lung hypoplasia primary or secondary to bilateral CDH, skeletal anomalies, severe hydrops, bilateral renal agenesis, or dysplasia

Complex cardiac anomalies inoperable or requiring single ventricle repair with poor prognosis

Structural anomalies such as inoperable conjoined twins, limb-body wall complex

Trisomy 13, 18, and others genetic conditions, especially when associated with severe structural anomalies

Metabolic conditions with short life expectancy despite treatment

Terminal conditions

Extremely premature infants not viable or at the threshold of viability

Newborns not responding to cardiopulmonary resuscitation

Newborns with central apnea associated with severe HIE or severe brain injury secondary to IVH or PVL

Neonates at end-of-life stage because of pulmonary, cardiac, and/or multiorgan failure

CDH, congenital diaphragmatic hernia; CNS, central nervous system; HIE, hypoxic-ischemic encephalopathy; IVH, intraventricular hemorrhage; PVL, periventricular leukomalacia.

Parental satisfaction with care after a life-limiting fetal diagnosis was measured using a web-based platform with 37 quality indicators. The sample included 405 parents who opted to continue their pregnancy despite the grim fetal prognosis. Overall family satisfaction with care was 76% and key quality indicators were provision of consistent care, compassionate care, and resources to cope with the emotional experience [19].

Programs' quality of care

According to a recent multicenter survey obtained from 75 perinatal palliative care programs in 30 United States, there are significant differences in services provided, formal professional training, and methods to assure continuity of care. Although 100% of the programs addressed spiritual and bereavement needs and more than 90% of the families received assistance with developing goals of care, only 43% of the programs established follow-up with families to measure outcomes and only 38% documented assessment of quality of care [20**].

NEONATAL ICU PALLIATIVE CARE

A significant number of newborns admitted to the NICU in critical condition face an unfavorable prognosis. Some of these babies will undergo redirection of care with limitation or withdrawal of life-sustaining treatment after failure of intensive care.

A literature search of three large databases (Cumulative Index of Nursing and Allied Health Literature, PubMed, and Cochrane Library) aimed at identifying evidence for implementation of NPC yielded 17 articles. Review of these articles suggests that NPC is still a growing field with many challenging aspects. Although there are several reports of NPC protocols, teams, or educational interventions, implementation and utilization are low. Moreover, the main focus of existing NPC programs is almost exclusively end-of-life care, whereas integration with life-prolonging measures, advanced care planning, infant's state of comfort and psychosocial support for parents and staff are not adequately addressed [21**].

Palliative care consultation

NPC is a holistic approach to care not only for newborns at the end-of-life, but also for those with complex medical conditions with an uncertain prognosis. NPC can be integrated with intensive care at any stage of the illness with the goal of delivering consistent, comprehensive and individualized care for babies

and their families with potential benefits for health-care professionals as well.

The needs of families for NICU palliative care have been identified through interviews with mothers of infants affected by life-threatening conditions. Participants emphasized the need for transparent communication, family meetings to facilitate the decision-making process, support of mothers' emotional well being, and continuity of care [22].

For the parents of a critically ill infant with an adverse prognosis, the proposal of 'palliative care' has been sometimes associated with 'giving up' and losing hope. However, a descriptive, qualitative study of NICU parents who received palliative care consultations revealed that families found the support of such services as beneficial within the medical care context [23]. Moreover, while parental stress is present whether or not NPC is provided, parents of babies who have received palliative services are more likely to be satisfied with the care compared with parents whose infant did not receive it [24].

Communications related to withholding or withdrawing of life-sustaining interventions can be challenging for both parents and providers. Janvier *et al.* [25] provide recommendations to facilitate successful decision-making process by focusing on the infant's medical situation and potential options, and by identifying parental emotions, needs, and hopes.

Recommendations for professionals involved in the care of newborns with complex medical conditions have been offered by a group of 25 NICU providers who experienced being parents or grandparents of NICU babies, some of whom died or lived with disabilities. A variety of learned lessons are listed, including a sense of gratitude and a new perspective of what perfection is. They learned the limitations of probabilities and predictions. They experienced the importance of connections, the need to be humble about the power of science, an unexpected resilience, and a renewed dedication to excellence in clinical care [26].

End-of-life care

A retrospective chart review of end-of-life care practices for NICU patients after withdrawal of life-sustaining treatment was performed. The study population included 227 newborns who died over the course of 5 years in two tertiary NICUs. Wide variability in end-of-life practices after withdrawal of life support, including use of private rooms, discontinuation of cardiorespiratory monitors, and administration of analgesics was noted [27].

The process of end-of-life decision-making has been studied through the use of questionnaires and interviews completed by NICU providers. Diverse

observations were reported. Although some providers stated feeling comfortable discussing withdrawal of life-sustaining treatment [28], others advocated the implementation of a NPC team to improve quality of care and to address the need for staff support and debriefing [29]. Moreover, health-care providers confronted with a newborn's death in the delivery room reported having experienced more emotional stress with family communication than with the medical care of dying newborns [30]. Last, it has been reported that difficulties with implementation of NPC programs may be associated not only with poor communication and conflicts among providers, but also with policy discrepancies and lack of administrative support and financial resources [31].

Perceptions of families regarding end-of-life care obtained through questionnaires showed that parents perceived inconsistencies in care practices among providers. Only slightly over a half of parents felt that comfort was achieved for their babies [29].

Outcomes after implementation of guidelines for end-of-life care was studied in three groups of infants ($N=106$): those who died before, during, or after the establishment of a NPC program. A significant increase in redirection of care (34 vs. 73%), use of analgesics and anxiolytics (36 vs. 64%), and a decrease in variability of interventions were noted when comparing end-of-life process before and after the implementation of the NPC initiative [32]. Similar results were found by Younge *et al.* [33], who compared two populations of infants ($N=150$) treated with end-of-life care before and after the implementation of a program of NPC. Mortality and use of morphine were similar in the two epochs; however, there was a significant increased use of benzodiazepines (26 vs. 43%) after implementation of guidelines.

These studies provide evidence of change of practice after implementation of guidelines, presumably for the better. However, the outcome of interest for the effectiveness of NPC programs should be the infant's comfort and parents and providers' satisfaction.

ACHIEVING A STATE OF COMFORT

Scientific evidence related to the achievement of a state of comfort for neonates is provided in a policy statement by the American Academy of Pediatrics [34]. The document lists a large number of studies demonstrating the effectiveness of nonpharmacological strategies such as holding, swaddling, massaging, skin-to-skin care, sucking, breastfeeding, and administration of oral glucose in reducing stress or pain secondary to invasive procedures. Although

utilized to promote comfort during painful procedures, these strategies identify specific basic needs of the neonate (bonding, maintenance of body temperature, relief of hunger/thirst, and alleviation of discomfort) that should be addressed even when the newborn is not in pain. Parravicini and Lorenz [11¹¹] proposed and implemented guidelines that address these basic needs (Table 2). Postnatal outcomes of 49 infants followed in the program over the course of 4 years demonstrated that infants receiving comfort care measures had a length of life similar to that of infants affected by the same conditions who were treated with standard intensive care, but without the burden of suffering [11¹¹]. Moreover, preliminary data of a self-report study of 42 parents, who elected comfort measures for their infants in the above-mentioned program, showed that parents greatly appreciated the opportunity to bond and participate in the care of their baby (skin-to-skin care and feedings). When these parents were asked 'Do you think that overall your baby received comfort?' the mode answer was 'always' (Parravicini *et al.* unpublished data).

Certainly, pain management remains a key aspect to promote comfort. In a comprehensive review, focused on end-of-life care, Carter and Jones [3] stress the complexity of quantifying the nonprocedural pain and reviews the effectiveness of pain scales to quantify pain and the use of pharmacological treatment in this population. Another review focuses on palliative care in newborns with neurological injury and suggests nonpharmacological and pharmacological strategies for irritability, seizure disorder, and shivering for babies undergoing therapeutic hypothermia [35].

MULTIDISCIPLINARY PLAN OF CARE

When comfort becomes the exclusive or a relevant goal of treatment, multidisciplinary care is essential, given the complex needs of these infants and their families.

NPC programs treat newborns with a wide range of conditions, from stable babies with a life expectancy of weeks, months, or even years, to terminally ill infants and others with an uncertain prognosis. Creativity, availability, expertise, and teamwork are needed to implement the best practices.

The medical/nursing team, in collaboration with speech pathologists, breastfeeding specialists, and occupational/physical therapists, can address the infant's physical, basic needs. However, other professional figures such as social workers, psychologists, child life specialists, and chaplains need to be actively involved in the care to address

Table 2. Guidelines to achieve a state of comfort for newborns treated with neonatal palliative care

Bonding
Holding, skin-to-skin care
Provide parents the opportunity to take care of their baby's needs (breast/bottle feeding, nutrition via NG/OG/G-tube, diaper change, bath, dressing, etc.)
Provide parents the opportunity to help with their baby's medical needs (taking temperature, suctioning, help with medical dressing, etc.)
Bonding is promoted in delivery room, on the postpartum floor while the baby rooms-in with the mother or in the NICU. A private space should be provided. If no family members are available, the baby is held by healthcare personnel or trained volunteers
Maintenance of body temperature
Skin-to-skin care, holding
Warmer, heat lamps, isolette, swaddled in blankets in bassinet
Relief of hunger/thirst
Breast/bottle feeds (breastfeeding/lactation consultant/speech pathologist support)
Special nipples or devices (speech pathologist support)
Use of NG/OG/G-tube as appropriate
Infant NPO or end-of-life care: nonnutritive strategies (speech pathologist support)
Alleviation of discomfort/pain
Assessment of respiratory distress (air hunger, agitation, increased work of breathing, gasping) and use of nonpharmacological strategies (i.e., gentle suctioning upper airways, positioning) or pharmacological treatment (morphine sulfate PO/IV; fentanyl IN)
Assessment of pain by validated clinical scores (NIPS or PIPP) and use of nonpharmacological strategies (meet the baby's basic needs as listed above) or pharmacological treatment (acetaminophen PO/PR; morphine sulfate PO/IV; fentanyl IN; lorazepam PO/IV; midazolam IN)

G-tube, gastric tube; IN, intranasal; IV, intravenous; NG, nasogastric; NIPS, neonatal infant pain scale; NICU; neonatal ICU; NPO, nil per os; OG, orogastric; PIPP, premature infant pain profile; PO, per os. Adapted with permission from [11[■]].

psychosocial, emotional, practical, and spiritual needs of the family [10].

A spiritual assessment includes reviewing family's hopes, dreams, and the role of prayer and rituals. Thus, chaplains need to be involved in the care to provide spiritual and emotional support. Moreover, clinicians need to be familiar with the concept of viability and the moral status of fetus and newborn according to different religious denominations to provide proper support to families confronting difficult decisions [36].

Bereavement support starts during pregnancy at the moment of the diagnosis, when parents experience the 'loss of a healthy baby', and continues with the celebration of the baby's birth (even if stillborn) following family preferences. Providing families concrete mementos (photographs, hands/feet imprints, and tridimensional casts) can be invaluable in the mourning process, which is a life-long journey. For this reason, long-term family follow-up is strongly recommended [28]. Because of a wide range of familial social, cultural, and spiritual backgrounds, family centered and culturally driven strategies are recommended [37[■]].

Last, NPC programs can provide support to medical, nursing, and allied professionals involved in the care by case discussions, debriefing, and psychological help [10,37[■]].

CONCLUSION

NPC is a multidisciplinary approach for the care of newborns with life-limiting or life-threatening conditions. The goal of care is achievement of a state of comfort by satisfaction of the infant's basic needs. In addition, NPC addresses needs and expectations of families and provides support for professionals. Because of the unique needs and medical conditions of neonates, specific guidelines should be established.

Although a variety of perinatal and NPC programs are currently available, there is an urgency to standardize practice and obtain follow-up quality measures. Further studies are warranted to assess whether neonatal palliative services meet the need for comfort of the newborn and address parental grieving experience and providers' stress.

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Conflicts of interest

There are no conflicts of interest.

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