Impact of neonatal palliative care on neonates, their parents, and nurses: a systematic review

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Arman Mohammadi, Mostafa Gholami, Mohammadamin Jandaghian-Bidgoli and Fatemeh Abdi

Abstract

Background: Neonatal palliative care (NPC) is a comprehensive approach that addresses the physical, mental, social, and spiritual well-being of neonates in need of palliative care.

Objective and design: The objective of this systematic review was to examine the impact of NPC on the management of symptoms and conditions in neonates admitted to the neonatal intensive care unit, as well as its effects on their parents and nurses.

Methods: This study was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. Five electronic databases, including Scopus, PubMed, Web of Science (WoS), Cumulative Index to Nursing and Allied Health Literature (CINAHL), and the Cochrane Library, were searched up to July 30, 2024. The quality of eligible studies was assessed using the Mixed Methods Appraisal Tool.

Results: A total of 10 studies that met the inclusion criteria were included in the review. The results indicated that the implementation of an NPC program led to an increased use of analgesic drugs, a reduction in invasive therapeutic and diagnostic procedures for newborns, an increase in withdrawal of life support, more do-not-resuscitate orders, and greater parental involvement in the care of newborns. These findings suggest that providing NPC can improve parents' quality of life, as well as enhance symptom management and pain relief in newborns.

Conclusion: The implementation of an NPC program can benefit both neonates and parents. It can improve the quality of life and reduce stress for parents, enhance the quality of newborn care, foster better inter-team collaboration, and prevent unnecessary invasive procedures, leading to greater comfort for newborns and improved pain and symptom management.

Keywords: end-of-life care, neonatal palliative care, neonate, NPC

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Background

Given the high hospitalization rates among newborns with congenital abnormalities who require palliative care and are admitted to the neonatal intensive care unit (NICU), there is an increasing emphasis on enhancing the health and quality of life (QOL) of these infants and their families.[1] Neonatal palliative care (NPC) involves comprehensive attention to the physical, mental, social, and spiritual well-being of newborns in need of palliative care.[2] The primary objectives of NPC are to control pain, manage symptoms, and improve the overall QOL for both the neonates and their parents. Importantly, NPC provides support throughout all stages of illness, including assisting families during the bereavement process following a child's death.[3] NPC is a dynamic approach that plays a crucial role in all stages of disease, including bereavement after a child's death for the family.[4] However, NPC remains a relatively underexplored area compared to other topics in neonatal care.[5] While this type of care was first described in the early 1980s, its widespread implementation has only become possible

Correspondence to:
Fatemeh Abdi
Nursing and Midwifery Care Research Center, Health Management Research Institute, Iran University of Medical Sciences, Shahid Hemmat Highway, Tehran 14496-14535, Iran
abdi.fh@iums.ac.ir

Arman Mohammadi
Mostafa Gholami
Student Research Committee, Iran University of Medical Sciences, Tehran, Iran

Mohammadamin Jandaghian-Bidgoli
Nursing Department, Faculty of Medical Sciences, Tarbiat Modares University, Tehran, Iran

in recent years due to advances in neonatal care technology and the growth of specialized neonatal care departments.[6]

The fundamental principles of NPC include compassion, dignity, respect, and collaboration with families.[7] Care strategies in NPC focus on interventions such as pain relief, symptom management, and the provision of psychosocial support to parents.[8] Unlike adult palliative care, NPC is tailored to the unique physiological and developmental characteristics of newborns.[9] In NPC, it is vital to involve and support parents, as they are the ones who establish a deep emotional bond with their infants.[10] Parents must be prepared to accept the fact that no effective treatment is available, and that symptom management and pain control for the infant are the primary priorities.[11] Although the exact criteria for which newborns qualify for palliative care are not universally defined, those who may be eligible include infants with significant abnormalities and syndromes incompatible with life, such as trisomy 18 and 13, anencephaly, hydrocephalus, bilateral renal agenesis, and severe conditions requiring dialysis. Additionally, infants weighing less than 600 g, neonates who have undergone cardiopulmonary resuscitation, those who have had extensive surgeries such as for omphalocele, and babies whose treatment has been prolonged with little response to interventions, are all considered candidates for palliative care.[12] Newborns who undergo major surgeries and either partially recover or are discharged early from the NICU due to uncertain treatment outcomes can also benefit from NPC.[13]

Providing NPC offers multiple benefits to infants, their families, healthcare providers, and the healthcare system as a whole.[14] For infants, it ensures appropriate symptom and pain management, reducing suffering. For families, NPC helps parents better cope with their infants' conditions, lowers stress levels, and ultimately improves their QOL. By actively involving parents in the care process, NPC empowers them, increases their sense of worth, and reduces their stress.[14,15] Furthermore, the involvement of parents in the care process enhances the overall quality of neonatal care.[16] The implementation of NPC fosters collaboration and cohesion among the various members of the healthcare team, enhancing their collective ability to provide effective care.[17] Despite numerous studies on the benefits of providing NPC worldwide, a comprehensive model of this care has not yet been established in many countries. Given that many studies have been done on the effect of providing the NPC. Given the extensive body of research on the effects of NPC, this study aimed to evaluate its impact on symptom management and clinical outcomes in neonates admitted to the NICU, as well as its influence on their parents and the nursing staff.

Materials and methods

Design and registration

This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines[18] (Supplemental File). Meanwhile, it was registered in the International Prospective Register of Systematic Reviews (PROSPERO;ID: CRD42024555292).

Search strategy

The search strategy included various limiters, with some variations depending on the database: English language, publications up to July 30, 2024, human studies, palliative care studies, global studies, and journal or review articles (the latter to facilitate reference hand-searching; Figure 1). We conducted searches for systematic reviews across five electronic databases: PubMed/Medline (US National Library of Medicine), Scopus (Elsevier), CINAHL (Cumulative Index to Nursing and Allied Health Literature), Web of Science (WoS; Clarivate Analytics), and the Cochrane Library (Wiley & Sons, Inc.). The research librarian used EndNote to manage and automatically deduplicate the records. The search process was independently performed by two authors (A.M. and M.G.), and any disagreements were resolved through consensus. The descriptions of the screening processes, and the selection of appropriate Medical Subject Headings (MeSH) terms, tailored to fulfill the PICO criteria (participants, intervention, comparison, outcome, and study) were presented as follows: ((((Palliative Care[MeSH Terms]) OR (Palliative Treatment [Title/Abstract]) OR (Palliative Treatments[Title/Abstract]) OR (Palliative Therapy[Title/Abstract]) OR (Palliative Supportive Care[Title/Abstract]) OR (Palliative Surgery[Title/Abstract]) OR (Palliative Therapies[Title/Abstract]) OR (Palliative management[Title/Abstract]) OR (Palliative nursing Care[Title/Abstract])))) AND (((Neonate[Title/Abstract]) OR (newborn[Title/

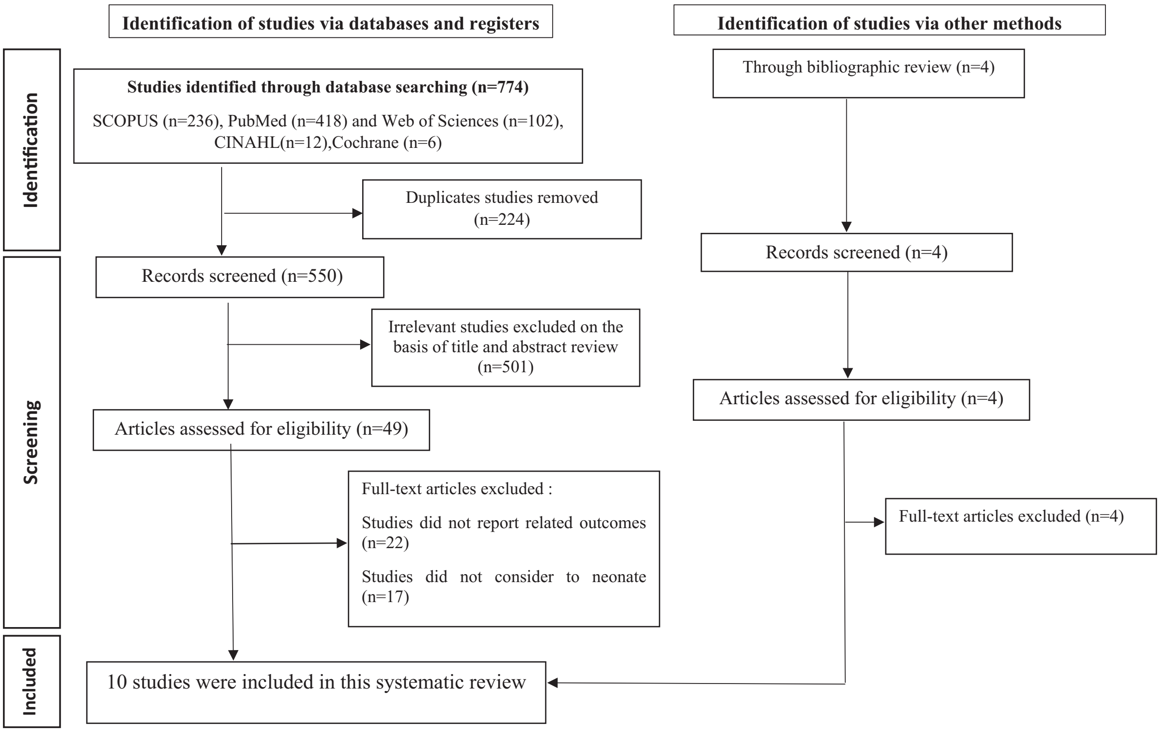

Figure 1. The literature search results and the screening process based on the PRISMA flowchart.

Abstract]) OR (infant[Title/Abstract]) OR (neonates[Title/Abstract]) OR Infants[Title/Abstract] OR (newborns[Title/Abstract]))) AND (((Care Planning, Patient[Title/Abstract]) OR (Planning, Patient Care[Title/Abstract]) OR (Nursing Care Plans[Title/Abstract]) OR (Care Plan, Nursing[Title/Abstract]) OR (Care Plans, Nursing[Title/Abstract]) OR (Nursing Care Plan[Title/Abstract]) OR (Plan, Nursing Care[Title/Abstract]) OR (Plans, Nursing Care[Title/Abstract]) OR (Goals of Care[Title/Abstract]) OR (Care Goal[Title/Abstract]) OR (Care Goals[Title/Abstract])))).

Eligibility criteria

The inclusion criteria for this study were determined using the PICOS framework. The following eligibility criteria were established:

Population. The study included neonates, their parents, and nurses involved in the care of newborns in the NICU.

Intervention. The intervention was the implementation of the NPC program, which encompassed biological, psychological, sociological, and spiritual care for neonates and their families. The program aimed to address the comprehensive needs of the neonate and support the family during the end-of-life (EOL) process.

Comparison. Comparisons were made between groups that received the NPC program and those that did not. Additionally, within-group comparisons were conducted before and after the implementation of the NPC program, specifically examining its impact on EOL management outcomes for neonates and their families. This approach enabled an assessment of how NPC influenced decision-making and symptom management during the EOL phase.

Outcomes. The primary outcome of the study focused on evaluating the effectiveness of NPC in EOL management, including the relief of pain and symptoms, as well as the decision-making processes related to life-sustaining treatment (LST). Secondary outcomes included the effect of NPC on the rate of diagnostic and therapeutic interventions, particularly those that might be deemed unnecessary or burdensome in the context of palliative care. The study aimed to assess how the NPC program influenced the overall quality of care, patient comfort, and family satisfaction.

We included both quantitative and qualitative studies. For this publication, we reported findings from descriptive and interventional studies. Additionally, the results from qualitative studies were also included. We excluded studies that lacked access to full texts, letters to the editor, conference papers, and posters, especially when the main article was inaccessible or lacked methodological details. Studies published in non-English languages were also excluded.

Data collection

To improve the efficiency of managing search results and screening for relevant studies, the studies were imported into EndNote, version 20.2.1; Clarivate Analytics. This process involved removing duplicates and ensuring proper referencing. Initially, two independent researchers (M.J., A.M., and M.G.) screened the titles and abstracts to identify studies that addressed the research questions. The same researchers then carefully evaluated the full-text articles to select those that met the inclusion criteria. Articles that met the eligibility criteria were included in the study, while those that did not were excluded. To maintain consistency, inter-rater reliability between the researchers was assessed. Any discrepancies were resolved through discussion or consultation with a third researcher (F.A.). The three evaluators reached a consensus, with a high Kendall's coefficient of agreement ($r=0.92$; $p<0.001$). The final search results were presented in a flow diagram in accordance with the PRISMA 2020 guidelines.

Data extraction

Two researchers (F.A. and A.M.) independently reviewed the full texts of all eligible studies and extracted the data using a pre-established checklist, which was then recorded in an electronic file. The obtained data included the first author's name, year of publication, study design, the study location, sample size, the study population, study period, gestational age at birth, intervention, instrument, and main finding. Any uncertainties or disagreements between the two researchers were resolved through discussion and consensus with a third researcher (Table 1).

Quality assessment

The methodological quality of the included studies in this study was conducted by the Mixed Methods Appraisal Tool (MMAT).[19] The quality assessment was conducted independently by two authors. The MMAT was developed to evaluate the different empirical studies categorized into five categories, including qualitative, randomized controlled trial, nonrandomized, quantitative descriptive, and mixed methods studies. This tool consists of five items for each category, each of which could be marked as Yes or No. Based on the scoring system, score 1 is assigned to Yes and score 0 to All other answers. In other words, the total score would be the percentage of affirmative responses. To evaluate the final scores qualitatively, scores above half (more than 50%) were considered as high quality (Table 2).

Results

Description of studies

Our initial search across the Scopus, PubMed/Medline, and WoS databases yielded a total of 774 articles. After removing duplicates and screening full texts, we assessed 10 full-text articles for the eligibility (Figure 1). Table 1 shows the baseline characteristics of the included studies. The reviewed studies were conducted in different areas, including the United States ($n=4$), Australia ($n=2$), Canada ($n=1$), Georgia ($n=1$), Spain ($n=1$), and Iran ($n=1$). The majority of included studies were quantitative design ($n=8$) and qualitative study ($n=2$). A total of 1103 participants were included in the study. In the majority of studies, the babies were examined as the central recipient of services. Two qualitative studies were selected that reached similar themes. These studies were conducted in different countries of the world, showing the importance of the topic and the universality of NPC. Countries that had a more advanced health system were the leaders in the field of implementing and examining the consequences of this care, including United States, Australia, and Spain. The limited number of studies in this field suggests that NPC is still a relatively new concept, particularly in the context of neonatal care, and has not yet been comprehensively defined across all countries. Given that this concept was first introduced in 1989 in the United States, it is not surprising that the highest number of studies ($n=4$) have been conducted in this country.

Palliative care for neonates

To carry out this study and investigate the impact of the NPC program, it was carefully examined.

Table 1. An overview of included studies in the systematic review.

References	Year	Country	Design	Study population (*n*)	Study period	GA at birth	Intervention	Measurement	Main finding
Palomo et al.[20]	2024	Spain	Retrospective observational	Neonates who received palliative care (*n*: 256) Males: 58% Females: 42%	2009–2019	34 + 1 weeks	- Parental presence - Tack photography by parents - Prepare private room - Analgesia use during dying process - Offer of baptism or ritual - Performance of ritual or ceremony	Medical record document	- The presence of parents during the dying process was different: (90.9% vs 98.5%; $p < 0.05$) - Take photography was different: (75% vs 91.7%; $p < 0.05$) - The place of death was different: (15% vs 48.6%; $p < 0.05$) - Analgesia use: (97.5% vs 96.97%; $p > 0.05$) - Offer of baptism or ritual: (91.7% vs 86.6%; $p > 0.05$) - Performance of ritual: (34.4% vs 48/8%; $p > 0.05$) - Implementation of a NPC protocol helped to improve the family-centered end-of-life care There was an increase in the number of babies transferred from NICU to single rooms to favor the intimacy of the baby's family in the end-of-life period ($p = 0.0001$)
Sadeghi et al.[30]	2021	Iran	Qualitative content analysis	Female nurses who experienced caring for the newborn and their family at end of life (*n*: 12)	During the year of 2020	Less than 37 weeks	(A) NPC for the newborn (compassionate and spiritual end-of-life care) (B) NPC of the family, before and after the death of the newborn	Semi-structured interviews	NPC are used to improve the care of infants and families at the end of life and death for officials and nurses of NICU
McLaughlin et al.[25]	2020	Georgia	Retrospective cohort	Infants who admitted to NICU (level IV) and received *NPC* consultation and who did not (*n*: 64) Male: 34 Female: 30	2015–2016	34.2 weeks	Palliative care constellation: (A) Clarify goals of care, (B) Symptom management (C) Support family and care team	Medical record document	- Order for DNR: OR: 1.3 (0.4–4.2; $p > 0.05$) - WLS: OR: 0.6 (0.2–1.6; $p > 0.05$) - Cardiopulmonary resuscitation: OR: 0.3 (0.1–1.7; $p > 0.05$) - Time from DNR to death: OR: 1.2 (1.0–1.5; $p > 0.05$) - Time from WLS to death: OR: 1.0 (1.0–1.0; $p > 0.05$) - Arterial or central line placement: RR: 0.4 (0.1–1.9; $p > 0.05$) - Infants with NPC received fewer laboratory blood draws and fewer blood product transfusions - Infants with *NPC* had 40 days longer hospitalization ($p = 0.06$)

(Continued)

Table 1. (Continued)

References	Year	Country	Design	Study population (*n*)	Study period	GA at birth	Intervention	Measurement	Main finding
Hancock et al.[28]	2018	USA	Randomized clinical trial	Mothers of infants with prenatal single-ventricle diagnoses at prenatal visit and neonatal discharge (*n*: 38)	2013–2015	Less than 37 weeks	- Early pediatric palliative care intervention - Palliative constellation for *mothers* - Symptom management for *newborn*	- Beck Depression Inventory-II - STAI - BCI - PedsQL Family Impact Module	Early NPC resulted in: - Decreased maternal anxiety (−7.6 vs 0.3; $p = 0.02$) - Improved maternal positive reframing - Improved communication and family relationships (effect size: 0.46 and 0.41). -Hospital and ICU length of stay, total length of intubation, cardiac re-operation, tracheostomy, and seizure were insignificant between groups
Kilcullen and Ireland[29]	2017	Australia	Interpretative phenomenological analysis/thematic analyses	Neonatal nurses who had experience providing NPC in the neonatal context (*N*: 8)	During the year of 2015	Less than 37 weeks	Delivery of palliative care (perceptions of neonatal nurses about facilitators and barriers that impact upon the delivery of *NPC*)	Semi-structured interviews	- Family support factors that were perceived to support the provision of quality *NPC*, including: • Emotional support • Communication • Practices within the unit - Staff factors included: • Leadership • Clinical knowledge • Morals, values, and beliefs - Five themes emerged that were perceived to be barriers to providing quality *NPC*: • Staff perceived education • Lack of privacy • Isolation • Staff characteristics • Policy and procedure factors
Gilmour et al.[21]	2016	Australia	Retrospective cohort	Infants who received NPC consultations additional to usual neonatal care Total = 46 NICU care and NPC consult group (*N* = 4) NICU care group (*N* = 42)	2012–2014	31 (5.6) weeks	- Communication - Resuscitation planning - Preferred location of death - Symptom management plan - Multidisciplinary team meetings - Caring for carers - Memory making - Spiritual support - Bereavement care	Medical record document	- Very high proportions of infants and families had family meetings (100%), social worker involvement (100%), and memory-making opportunities (100%). - Autopsy discussion: 25% - Redirection of care discussion:75% - Discussion and preferred location of death: 75% - Preferred location of death discussion: 75% - Symptom management medications: 25% - Written symptom management plan: 75% - Informal symptom management plan: 25%

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Table 1. (Continued)

References	Year	Country	Design	Study population (*n*)	Study period	GA at birth	Intervention	Measurement	Main finding
									- Multidisciplinary team meeting: 100% - Sibling support: 100% - Discussion of beliefs and spiritual support: 75% - Spiritual support: 75% - Specialized bereavement service: 75% - Individualized lactation cessation advice: 50%
Lam et al.[22]	2016	Canada	Retrospective cohort	Infants who died under tertiary neonatal intensive care/*N*: 227 Male: 53.7% Female: 46.3%	2009–2013	29.7 weeks	- Spiritual care - Clinical ethics - Psychology care to withdrawal of LST - Use of comfort Medications (Analgesic and Sedative) - Use of a private, parent room - Withdrawal of mechanical ventilation - Use of medical technologies (Use of neonatal monitor after withdrawal) - Holding of baby by parents or hospital staff (Held by family after withdrawal)	Medical record document, hospital databases (web-based application designed to support validated data capture and collection for research studies)	- Participation of family members to take care of the baby in EOL: 88.9% - Death most frequently followed an active decision to withdraw LST: 81% - Use of analgesic medications: 75.1% - Most of withdrawal occurred in parent room: 64.6% - Most dying infants were held by their family members during or after withdrawal of mechanical ventilation - Analgesic and sedative were variably given and not associated with a hastening of death - Most commonly death occurred following elective withdrawal of LST after family meetings with counseling - Basis for withdrawal of LST: • Anticipated poor developmental outcome or perceived QOL • Lack of treatment option or improvement despite ongoing treatment • Deteriorating clinical course despite ongoing treatment • Clinically deteriorating or moribund
Younge et al.[23]	2015	USA	Retrospective cohort	Era 1 (2003–2005): infants who died before initiation of a NPC Program	2003–2009	28 + 8 weeks	- Doing palliative care protocol for neonate - Implement an individualize electronic order - Do nursing plan of car for neonate - Staff education	Medical record document	- *Era1 vs Era 2*: WLS incidence (73% vs 63%; $p=0.17$) DNR incidence (46% vs 53%; $p=0.42$) Number of EOL family meetings, median (range), (1 (0, 5) vs 2 (0, 5); $p=0.13$) Time to death after WLS (h): (1 vs 1; $p=0.17$)

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Table 1. (Continued)

References	Year	Country	Design	Study population (*n*)	Study period	GA at birth	Intervention	Measurement	Main finding
				Era 2 (2008–2009): infants who died following the program's implementation. And infants weighing <1500 g *N*: 150 Male: 58% Female: 42%			- Doing medication guidelines for palliative		Patients receiving opioids last 4 days: (88% vs 81%; $p=0.17$) Morphine dose last 24 h (µg/kg): (480 vs 179; $p=0.17$) Benzodiazepines used last 4 days: (26% vs 43%; $p=0.03$) Neuromuscular blocker use last 24 h: (17% vs 18%; $p=0.95$) - *Active NPC vs non-active NPC in Era 2:* WLS incidence (65% vs 62%; $p=0.8$) DNR incidence (85% vs 38%; $p<0.01$) Number of EOL family meetings, median (range), (2 (1, 4) vs 1 (0, 5); $p<0.01$) Time to death after WLS (h): (7 vs 1; $p=0.02$) Patients receiving opioids last 4 days: (90% vs 77%; $p=0.32$) Morphine dose last 24 h (µg/kg): (302 vs 92; $p=0.15$) Benzodiazepines used last 4 days: (62% vs 34%; $p=0.03$) Neuromuscular blocker use last 24 h: (5% vs 23%; $p=0.06$) - *VLBW Era 1 vs Era 2:* WLS incidence (75% vs 59%; $p=0.10$) DNR incidence (45% vs 43%; $p=0.83$) Morphine dose last 24 h: (88% vs 81%; $p=0.36$) Benzodiazepines used last 4 days: (20% vs 36%; $p=0.08$) Neuromuscular blocker use last 24 h: (20% vs 19%; $p=0.95$) - *VLBW active NPC vs non-active NPC:* WLS incidence (56% vs 59%; $p=0.84$) DNR incidence (80% vs 31%; $p=0.007$) Morphine dose last 24 h (v=0.11) Benzodiazepines used last 4 days: (50% vs 31%; $p=0.28$) Neuromuscular blocker use last 24 h: (10% vs 22%; $p=0.44$)
Samsel and Lechner[24]	2015	USA	Retrospective and prospective chart review	Care provider and neonate *N*: 106 Male: 54% Female:46%	2008–2013	32.4 weeks	- Communication skills training - Development formal practice guideline for neonate - Education NPC provider	Medical record document	- There was an increase in redirection of care (34% vs 45%; $p=0.01$) - There was an increase in palliative medication usage (37% vs 64%; $p=0.02$) - Ancillary service consultation was not significant (70% vs 91%; $p=0.16$)

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Table 1. (Continued)

References	Year	Country	Design	Study population (*n*)	Study period	GA at birth	Intervention	Measurement	Main finding
									- Occurrence of outcome expectation meetings was not significant (54% vs 77%; $p = 0.13$) - There was an decrease in variability of use of EOL interventions ($p < 0.001$)
Pierucci et al.[26]	2001	USA	Retrospective chart review	Neonate (all infants who were younger than 1 year at the time of their death in the hospital.) and care provider *N*: 196 Male: 60% Female: 40% Group 1: 25 infants and their families received NPC consultation Group 2: 171 did not NPC	1994–1997	36.1 weeks	Recommendations that the palliative care staff: - Advance directive planning - Advance medical intervention - Optimal environment for supporting neonatal death - Comfort and medical care - Psychosocial support	Medical record document (modified version of the EOL Chart Review)	*There was a significant increase in following items*: - Refer to chaplains service (64% vs 23%) - Receive social service (80% vs 30%) - Documented emotional need of family by the care provider (92% vs 64%) - Number of NPC consolation (5% vs 38%) - NPC physician team (2% vs 16%) - Withheld cardiac drug (56% vs 12%) *There was not significant different in:* - Withhold iv flued (0% vs 0%) - Withdraw iv flued (20% vs 9%) - Withdraw cardiac medication (28% vs 26%) - *Withdraw mechanical ventilation (56% vs 42%)* - *Use iv flued: (92% vs 95%)* - *Use iv nutrition :(28% vs 34%)* - *Use antibiotics: (56% vs 71%)* - *Use narcotic:(68% vs 79%)* *There was a significant decreased in following items:* - Use of specific intervention after NPC - Doing CPR (29% vs 8%) - Fewer blood draws (SD: 6 vs 8) - Fewer blood test in 48 h EOL (44% vs 7%) - Fewer receive blood product: (36% vs 64%): - Fewer use (64% vs 90%) - Fewer use X-ray: (40% vs 89%) - Fewer use paralysis drug (8% vs 43%) - Fewer use feeding tube (64% vs 95%) - Fewer use of ETT (60% vs 94%) - Fewer days stay in ICU - Withhold mechanical ventilation (28% vs 4%)

BCI, Brief Cope Inventory; CPR: Cardiopulmonary resuscitation; CV: central venous; DNR, do-not-resuscitate; EOL, end of life; ETT, endotracheal tube; GA, gestational age; LST, life-sustaining treatment; NICU, neonatal intensive care unit; NPC, neonatal palliative care; *p*, *p* value; QOL, quality of life; RR, rate ratio; SD, standard deviation; STAI, State-Trait Anxiety Index; USA, United States; VLBW, very low birth weight; WLS, withdrawal life support.

Table 2. Mixed Methods Appraisal Tool for quality assessment.

Design	**Methodological quality criteria**	**Hayley, 2018**						
Quantitative RCT	1. Is randomization appropriately performed?	C						
	2. Are the groups comparable at baseline?	Y						
	3. Are there complete outcome data?	Y						
	4. Are outcome assessors blinded to the intervention provided?	N						
	5. Did the participants adhere to the assigned intervention?	Y						
	Quality assessment score	High						
Study ID		**Pierucci, 2001**	**Samsel, 2015**	**Young, 2015**	**Lam, 2016**	**Gilmor, 2016**	**Nicol, 2020**	**Palomo, 2023**
Quantitative descriptive	1. Is the sampling strategy relevant to address the research question?	Y	Y	Y	Y	Y	Y	Y
	2. Is the sample representative of the target population?	Y	Y	Y	Y	Y	Y	Y
	3. Are the measurements appropriate?	Y	Y	Y	Y	Y	Y	Y
	4. Is the risk of nonresponse bias low?	C	C	C	C	C	C	C
	5. Is the statistical analysis appropriate to answer the research question?	Y	Y	Y	Y	Y	Y	Y
	Quality assessment score	High	High	High	High	High	High	High
Study ID		**Kilcullen, 2017**	**Sadeghi, 2021**					
Qualitative	1. Is the qualitative approach appropriate to answer the research question?	Y	Y					
	2. Are the qualitative data collection methods adequate to address the research question?	Y	Y					
	3. Are the findings adequately derived from the data?	Y	Y					
	4. Is the interpretation of results sufficiently substantiated by data?	C	C					
	5. Is there coherence between qualitative data sources, collection, analysis, and interpretation?	C	C					
	Quality assessment score	High	High					

Judgment: Y, yes; N, no; C, can't tell.

The effect of the NPC program on two groups was studied: the first group consisted of babies who required NPC, and the second group comprised parents of babies who needed NPC. Various studies have examined the effect of providing NPC, including cohort studies and Randomized controlled trials (RCTs) that focused on its impact on both neonates and parents. For parents, the impact of the NPC program on compliance and participation in neonate care, which was consistent across studies, was examined. For neonates, the study investigated several factors, including the impact of the NPC program on rates of invasive diagnostic and therapeutic procedures at the EOL, the use of do-not-resuscitate (DNR) orders, withdrawal of life support (WLS), invasive diagnostic and therapeutic measures, length of stay in the ICU at EOL, symptom and pain control, and the use of analgesics. Several cohort studies have analyzed the effect of the NPC program by examining hospital records, typically comparing groups that did not receive this care with those that received it before and after the intervention. The results related to the physiological aspects of receiving NPC were directly investigated, taking into account the various dimensions of NPC and the physiological and developmental conditions of newborns.

The use of analgesics. Six studies addressed the use of analgesics (such as narcotics, benzodiazepines, neuromuscular blockers, and other pain management drugs). The analyses produced varying results regarding the amount of analgesics used before and after the implementation of the NPC program. In general, the use of analgesics increased after the program was implemented. In the NICU, analgesics and painkillers are primarily used to control pain and manage symptoms, with different drugs and doses being administered. For example, some studies used narcotics like morphine, while others used midazolam and sedatives.

In some studies, no significant difference was observed in the use of analgesics before and after the NPC program. A study conducted in Spain found that while analgesic use increased, the change was not statistically significant.[20] In another study, the use of symptom management drugs increased by 25% for all neonates.[21] In Canada, one study showed a 75% increase in the use of analgesics, with both analgesics and sedatives being variably administered, though not associated with hastening death.[22] A study conducted in the United States found that the use of opioids in the last 4 days of an infant's life increased, though the increase was not statistically significant. The morphine dose used to control pain in the last 24 h of life increased, as did the use of benzodiazepines in the final 4 days (24%–43%). Our results showed an increased use of analgesic drugs in active palliative care compared to non-active palliative care, particularly in very low birth weight neonates.[23] A study on the use of subcutaneous morphine and midazolam for symptom management demonstrated a significant increase in the use of these drugs.[21] Some studies reported an increase in pain medication use after the NPC program was implemented. For example, in one study, the use of these drugs increased from 36% before the program to 64% after implementation.[24] Another study reported a 1.75% increase in the use of painkillers, including narcotics, benzodiazepines, and chloral hydrate, from 6 h before LST withdrawal until death.[22] Considering that the dose of use of painkillers and analgesics in different studies is different, it can be said that depending on the purpose of prescribing these drugs, different results can be achieved.

Withdrawal life support. Four studies were referred to WLS, and in general, the rate of WLS was increased after implementation of NPC program. Two studies did not find a significant relationship before and after the implementation of NPC program. In this regard, in a study conducted in Georgia, the increase in the rate of WLS before and after the implementation of palliative NPC program care[25] and in the study conducted in Canada, the rate of WLS in the parents' room was 64% and no statistically significant difference was found.[22] In a study, the rate of WLS was generally (65% vs 62%) that no significant relationship was found between before and after the implementation of NPC program, but the survival time of the baby after WLS was longer.[23] However, the average time of death did not have a significant difference.[23] But another study conducted in America showed that the rate of WLS before and after the implementation of NPC program was 28% vs 4%, indicating a significant relationship.[26] But in general, these declared values were only WLS in the continuation of lifesaving measures, but we also had WLS in various aspects, for example, in Pierucci's study, WLS was examined in terms of the use of vasopressor drugs, mechanical ventilation, and IV-fluid. The results of this study showed that there was a significant correlation between vasopressor and mechanical ventilation before and after WLS palliative care.[26] According to the different results, it can indicate the different levels and conditions of babies from each other. WLS is a very difficult decision and must be made with the participation of a group of disciplines related to the treatment of the newborn, including doctors, nurses, family, psychologists, and religious experts, so that all the biological, psychosocial, and spiritual needs of the newborn and his/her family are seen. And for these needs, proper planning should be done.

A do-not-resuscitate order. Overall, three studies have examined DNR order. This order means that if the baby needs CPR, this cannot done. This order can be due to poor prognosis or low hope of the baby's survival. DNR order is a very important and challenging issue and is not acceptable in some society. For example, in an Islamic country, or in violation of the law, one must defend a person's life, even if it is a baby, until the last moment with all their power and equipment, and perform CPR carefully, completely, and correctly. These studies are conducted in Australia, America, and Georgia, for which DNR order has been accepted in this country. In a study conducted in Georgia, the rate of DNR order was slightly increased, and this rate did not differ significantly after the implementation of NPC program, but in the same study, the number of CPRs performed went from 10% arrives. The 25% increase in these results could be due to the fact that the infants who underwent CPR program were not suitable candidates for NPC.[27] However, in another study, the rate of talking to parents for autopsy before and after NPC was increased and discussed resuscitation during pregnancy with parents before and after care was infant palliatives have increased by 10%. DNR research falls under the category of palliative biologic care, and other studies did not address other palliative care.

Invasive diagnostic and therapeutic procedures. Regarding less invasive care for infants at EOL, five studies have worked extensively on this topic. In general, the results of the studies showed that the implementation of NPC program reduces invasive diagnostic and treatment procedures.[25,26] Due to the condition of infants at the EOL, caregivers are forced to perform care and treatment measures, some of which are invasive. A study conducted in Georgia showed that after the implementation of NPC program, invasive procedures for babies decreased, but specifically, the results of this study showed that after the implementation of this care, the rate of needling of the baby for laboratory tests of the newborn, transfer of blood products, the rate of central venous catheter placement, intubation and use of tracheal tube, the use of nasogastric tube for feeding dramatically decreased, and even the rate of surgery after the implementation of NPC program reached zero.[25] The results of this study demonstrated that the implementation of NPC program led to more comfort and less invasive procedures in infants at the EOL. However, in a study conducted in America in 2001, it was found that after the implementation of NPC program, the rate of blood sampling obtained from the patient was lower, the rate of transfusion of blood products decreased, the use of central venous access decreased, but between the rate of receiving IV-fluids, the rate of receiving IV-nutrition increased, and the rate of receiving antibiotics decreased, but no significant relationship was observed between soothing for infants.[26] The results of the studies showed that the implementation of NPC program led to a reduction in invasive procedures. This provides great comfort for babies.

Palliative care for parents

Moreover, this study aimed to investigate the impact of the NPC program on parents. Few studies have focused on this aspect, as most have primarily discussed the physiological components of this care for neonates. Providing NPC through a multidisciplinary approach and teamwork is crucial to strengthening the neonatal care support network.[21] NPC can enhance parental involvement in the caregiving process, the patient's death, and the grieving process.[20] It has also been shown to reduce maternal anxiety.[28] Emotional support from the family and their collaboration with the palliative care team are important factors in the effectiveness of care for newborns.[29] In addition, the parents' communication with the care team improves and can help them share important information, ultimately increasing their satisfaction with their baby's care.[27] In a study, palliative care for the family was obtained as a main theme. In this study, according to the main themes, there is a special emphasis on the two main recipients of NPC, that is, the baby and the family, and it indicated that spiritual care should be implemented for the babies and their family in the final stages of life.[30]

Participation in care. Our results showed that the implementation of NPC program can increase involvement of the family in the process of caring for the newborn and increase QOL by reducing anxiety levels in parents. Three studies investigated the effect of NPC on parents. In a study conducted in Spain, the number of parents presenting with their babies increased. Then, a dedicated room for parents of babies was created, and the practice of taking pictures of parents with their babies was increased. There was a significant relationship before and after the implementation of the NPC program.[20] In another study, meetings with family were not significantly different before and after the implementation of NPC program, which was 100%. Talking with parents and preferences for the place of death of the baby increased significantly. There was a 40% increase in the support of siblings of the baby in this care, and the support of the family before and after the study was 100% and there was no change.[21] In the qualitative studies, one of the main themes extracted was palliative care for the family, which consisted of the sub-themes of palliative care for the family before the death of the baby and palliative care after the death of the baby.[30] In palliative care for the family, it starts from the identification of the need for NPC of the baby and continues until death and beyond. Part of the burden of illness and discomfort for the family continued after the death of the baby, and as mentioned previously, the aim of providing this care was to improve the QOL of the parents.[9] In another study, one of the main themes is family support, consisting of sub-themes of emotional support, communication, and participation in baby care.[29] In this study, other dimensions of NPC are well mentioned, which are less addressed in quantitative studies. Qualitative studies investigate in depth the fundamental concepts of a subject that need to be addressed in quantitative research.[30]

Palliative care for nurses

The primary focus of the studies was on the effectiveness of palliative care in improving the symptoms and conditions of newborns. However, some studies also highlighted the impact of palliative care on caregivers. Specifically, providing palliative care can enhance and transform neonatal care practices, fostering critical thinking among nurses. It also strengthens communication skills, promotes a holistic approach to care, and encourages interprofessional collaboration.[24] Furthermore, palliative care helps expand nurses' competence in addressing the psychological and spiritual needs of patients and enhances their ability to apply care technologies.[22]

Other variables

This section presents other variables examined in previous studies but not shared across all articles. In a study conducted in Spain, parents of newborns were offered rituals and ceremonies, and the results showed no significant difference before and after the implementation of the NPC program.[20] Another study found no significant differences in the length of hospital and ICU stays, the rate of seizures, the incidence of kidney failure, or the duration of intubation before and after the NPC program was implemented.[28] In a separate study, there was a significant increase in discussions about care redirection, the creation of symptom management plans, and the frequency of interdisciplinary meetings for newborn care.[21] These improvements suggest that palliative care can foster collaboration among the treatment team, leading to better outcomes and an improved QOL for both the baby and their family. One of the key aspects of palliative care highlighted in this study was spiritual care. This area showed a slight increase in its provision before and after the NPC program's implementation, with special religious services and spiritual ceremonies for the family and baby notably increasing.[21] The only study that directly assessed family involvement in EOL care found that 88.9% of families participated, underscoring the family-centered approach of the NPC program.[22] Additionally, the study reported a 73% increase in care redirection after the implementation of the NPC program, alongside a reduction in EOL interventions such as ancillary service consultations.[24] Some barriers were identified in studies that affect the provision of NPC: these include barriers related to the family, barriers related to palliative care providers, and barriers related to the system and policies of the centers.[29] In one study, barriers to providing quality NPC were staff-perceived education, lack of privacy, isolation, staff characteristics, and policy and procedure factors.[29]

Discussion

This systematic review synthesizes findings from both qualitative and quantitative studies, summarizing current knowledge on the impact of neonatal NPC on managing neonates in the NICU as well as its effects on their parents.

Most studies on NPC have primarily focused on the use and effectiveness of analgesics and sedatives. The type and dosage of medication administered depend on the diagnosis and the neonate's condition. The primary aim of NPC is to alleviate pain and symptoms[31] while supporting the family by taking into account the values and needs of both the infant and the family.[32] Providing relief from pain and symptoms during the dying process is standard medical practice. Research has shown that the use of opioids and sedatives in appropriate doses to alleviate symptoms at the end of life does not hasten death, carries only a small risk of respiratory depression, and increases comfort during the dying process.[33] Non-pharmacological interventions can often relieve certain symptoms experienced by neonates at the end of life, though they may not address all discomforts. However, the reviewed studies did not specifically explore these interventions.

The results of the studies indicate that the decision to withdraw life support may increase in some cases and remain unchanged in others when NPC is introduced in certain countries. Withdrawing life support can reduce the infant's suffering, but it is important to remember that the goal of NPC is to provide comfort, not merely to prolong life. It also helps to alleviate the suffering of the parents.[34] This decision is challenging and complex for both the infant's family and the care team and should be made through an interdisciplinary approach, with collaboration between the family and the medical providers involved in the infant's care.[32] This collaborative approach ensures that all the biological, psychological, spiritual, and social needs of the newborn and their family are addressed. It is crucial to involve parents in deciding how, when, and where to discontinue life-prolonging measures and what wishes or activities they would like to share with their infant before death.

Spiritual EOL care is a crucial component of NPC and has been utilized in studies to support infants in the NICU. Spirituality serves various functions for families, helping them navigate complex situations, such as making life-and-death decisions related to advanced care planning or withdrawal of care during acute deterioration.[35] Religion and spirituality are considered significant factors influencing parental decision-making. Furthermore, parents of infants receiving NPC may benefit from religious and spiritual counseling, which can lead to positive outcomes, such as better coping strategies, reduced ethical distress, and improved decision-making.[36]

DNR orders are one aspect of the biological dimension of NPC that has been studied. While DNR is accepted and legally recognized in some countries, it remains a difficult practice for many. Data suggest that DNR decisions in the NICUs vary by geographic location, with some NICUs issuing the directive later in the course of illness, often when death is imminent.[37] Effective communication between healthcare providers and families is essential to ensure compassionate palliative care during the loss of an infant. The timing of these discussions is crucial. Parents appear to be most reassured by empathetic, compassionate healthcare providers who demonstrate both expertise and knowledge in delivering medical, nursing, and palliative care. Key elements for providing quality palliative care include compassion, a commitment to NPC, dignity, integrity, respect, transparent communication, family involvement in decision-making, and collaboration. According to the findings of the reviewed studies, the implementation of NPC reduces the need for invasive diagnostic and treatment procedures. Since these procedures are painful and stressful for the infant without leading to beneficial or effective outcomes in the final stages of life, their continued use only diminishes the baby's comfort and heightens family concerns. The decision to provide palliative care instead of pursuing aggressive medical interventions can be extremely stressful for both the family and the medical team. However, an interdisciplinary, family-centered approach, with collaboration in decision-making, can minimize both the pain and suffering of the child and the family. Thus, it is essential that palliative care is implemented appropriately.[38] According to the World Health Organization guidelines, hospitals providing invasive LSTs should also offer palliative care by specialized palliative care physicians. This care aims to alleviate the discomfort of intensive care, provide an alternative to LSTs with limited benefits, and ensure the comfort of infants when LSTs are withdrawn.[39]

The use of NPC for newborns has a significant impact on parents. It can enhance family satisfaction, provide emotional support, and improve communication and involvement in the baby's care. Additionally, it gives parents a sense of efficacy.[29] One of the key outcomes identified in the studies was increased family involvement as a result of NPC.[22] According to all guidelines, it is crucial that parents fully understand the implications of a doctor's prognosis regarding their baby (especially when the prognosis is poor), so they can play an active and informed role in making decisions about future care; in some cases, this future may be limited.[34] Implementing NPC program for newborns aids families in coping with the physical challenges and complications that arise as the newborn's illness progresses.[31] Furthermore, NPC helps parents and families adjust to the baby's condition, illness, and death, and it can reduce the intense grief following the loss of a child.[20,31]

Although most studies have focused on EOL care in using NPC in NICU, some studies have indicated the impact of implementing NPC on reducing the length of hospital stay.[26,28] Some survivors of the NICU may develop chronic critical illnesses, meaning that their condition stabilizes but can take a long time to improve. In such cases, important decisions need to be made regarding what the infant requires to thrive outside the hospital. Involving pediatric palliative care in the NICU for infants with chronic critical illnesses can help with managing complex symptoms effectively.[40]

Several methodological limitations in these studies must be considered. First, the number of studies on NPC in the NICUs remains small, and many of the studies had limited sample sizes. The diversity of research methods used in the selected studies, along with their varying focuses, may have influenced the synthesis and integration of the findings. Additionally, the studies were restricted to the English language. However, by using a broad range of keywords and international databases, we were able to gather a comprehensive overview of current global knowledge on the impact of NPC on neonates hospitalized in NICUs and their families. Furthermore, bias in data collection and synthesis was minimized through close collaboration and discussion between the authors.

Conclusion

The results of this study showed that the implementation of NPC is useful and beneficial for neonates and parents. For parents, it could improve the QOL and reduce their stress and discomfort in dealing with existing conditions. Parental involvement in care increased, leading to improved quality of neonatal care and enhanced collaboration among healthcare team members. For babies who are hospitalized in the neonatal visa care department, the implementation of NPC could prevent invasive diagnostic and therapeutic measures, resulting in more comfort for the babies and better management of their pain and symptoms.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Author contributions

Arman Mohammadi: Data curation; Methodology; Writing – original draft; Writing – review & editing.

Mostafa Gholami: Data curation; Methodology; Writing – original draft.

Mohammadamin Jandaghian-Bidgoli: Methodology; Writing – review & editing.

Fatemeh Abdi: Conceptualization; Data curation; Methodology; Project administration; Writing – original draft; Writing – review & editing.

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The authors declare that there is no conflict of interest.

Availability of data and materials

All the data analyzed during this study are included in this study.

ORCID iD

Fatemeh Abdi https://orcid.org/0000-0001-8338-166X

Supplemental material

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