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Models of Supportive Care for Parents of Infants in Neonatal Intensive Care Units: A Systematic Review of Their Characteristics and Outcome

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Systematic Review

Keywords: Neonatal ICU, Parental stress, Parental support programs, Preterm infants

Posted Date: October 30th, 2026

DOI: https://doi.org/10.21203/rs.3.rs-11543035/v1

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Additional Declarations: The authors declare no competing interests.

Abstract

Background: Prematurity is a dire situation for both parents and infants. Neonatal Intensive Care Unit (NICU) hospitalizations for premature infants increases stress for parents, affecting negatively their emotional well-being. Supportive care models aim to relieve parental stress and improve family outcomes. There are only a few studies in Greece , regarding supportive models for parents with babies hospitalized in NICUS. The new information might improve the development of such supportive models and empower parents.

Method: A comprehensive search of databases such as ApaPsychNet, Scopus, PubMed and Google Scholar was conducted through 1/4/2025-1/9/2025. The chosen studies focused on various supportive care models and they were included only if they registered interventions, experiences and outcomes related to parental support in the NICUS. Data extraction followed PRISMA guidelines.

Results: From the 17 studies that were thoroughly screened, two were of high quality, three of moderate to high quality and eleven studies were of moderate quality. The studies reported 6 possible supportive care models for parents with premature infants, which differed in type: 1) Family Centered Care (FCC), 2) Family Integrated Care (FI Care- AB FI Care) , 3) Kangaroo Mother Care (KMC), 4) Peer Support, 5) Psychosocial Interventions with support tools and 6) Specialized Father Support.

Conclusions: We identified that supporting care models show great promise in reducing parental stress, increasing parental engagement and parental efficacy and introducing better health outcomes for parents. The need of special health personnel training and the implementation of a homogeneity in support model combined with institutional and organizational alterations in NICUS is considered necessary. Furthermore, the need of consistent supportive programs for fathers with preterm infants is imminent.

1. Introduction

The definition ”preterm” characterizes an infant that is born before 37 weeks of gestation. The definition ”extremely preterm” characterizes an infant born before 28 weeks of gestation. In this day and age the number of preterm infants is disturbingly high (approximately 13.4 million worldwide), which means that 1 newborn out of 10 births is preterm [1, 2]. Premature infants are plagued by organic immaturity and problems with their immune system which puts their life in danger [2]. Many researches dictate that in developed countries 1 out of 10 preterm infants die, whereas in underdeveloped countries 9 out of 10 preterm infants die. Prematurity has a high morbidity percentage, including deaths in children aged below 5 [1].

The Neonatal Intensive Care Units (NICUS) are situated in a complex hospital environment, where the preterm infants struggle to survive. NICUS possess a wide range of specialized incubators and personnel that try to tend to the complex needs of the infants [4]. Although the NICU personnel try their best to keep the preterm infants to life, the obligatory use of sensors and machinery, can hinder the

neurological and emotional development of the infants, especially when they have no contact whatsoever with their parents [5].

From the parental point of view, the combination of the NICU environment and the acute situation of their infant can cause a huge emotional distress. Many researches indicate that parents with preterm neonates treated in the NICUS can develop depression, stress and PTSD disorder [6, 7]. There are also parents that have feelings of guilt, uncertainty and fear, especially when they visit their infant and see the machinery and cables attached to it, unable to care for it. The parental emotional distress is sometimes combined with other physical symptoms, like insomnia and fatigue [8].

The parental emotional distress has a repetitive pattern, which follows home after the discharge of a preterm NICU patient. Mothers especially,report negative emotions and feelings of uncertainty, when discharged with seriously ill babies [9]. The majority of them express fear and disappointment, when considering their parenting duties, although they have instructions given from NICU personnel [9]. The discharge of a NICU patient can also challenge the parental bonding and family balance [10]. A cross sectional study revealed that parents with NICU babies altered their daily routine, which they recovered after approximately 11 months [10].

Except the problems previously described, the parental situation seems also complicated regarding the support they receive. A vast number of parents declare dissatisfaction with the support and care provided to them in the NICUS worldwide [11, 12, 13, 14, 15]. Especially in Greece, there is a registered high percentage of moral distress and intense internal conflict in parents that have a premature baby hospitalized in a NICU [16]. In order to alleviate the emotional gap between parents, NICU personnel and NICU infants, the need to examine the literature for supportive parental care models arises.

2. Methods

This review used the PRISMA [17, 18] guidelines for reporting and it was registered with PROSPERO (1132580) [19]. Previously published studies were used for the data analysis and did not require patient consent and ethical approval.

2.1 Search strategy

A systematic literature research was conducted in databases such as Apa Psych Net, Google Scholar, PubMed and Scopus from September 2000 until September 2025.Keywords, Medical Subject Headings (MeSH), other index terms and combinations of the terms and correct synonyms were used. The search terms focused on “Neonatal Intensive Crae Unit”, “NICU”, “Parent Support”, “Integrated Family Care”, “Support Program”, “Parental Education”, “Psychosocial Intervention”, “Parental Stress”, “Parental Anxiety”, “Parental Depression”, “Parental Satisfaction”, “Parental empowerment”, “Parental Coping”, Predictors and their synonyms (supplementary material BOOLENS). All the reference list of the studies selected were searched manually for any supplementary studies that meet the criteria.

2.2 Inclusion Criteria

- Studies published in English
- Late preterm or extremely preterm infants
- NICUS from every part of the globe and their personnel, including low-income countries
- Mothers and Fathers from all socioeconomic backgrounds and races
- Articles from 2000 onwards
- Randomized Controlled Trials
- Intervention Studies
- Qualitative Studies
- Mixed Methods Studies
- Comparative Quantitative Studies

2.3 Exclusion Criteria

- Full term infants hospitalized in NICUS
- Low birth weight full term infants
- NICU hospitalizations during COVID-19
- Wrong study outcomes such as hospitalization costs
- Death of the preterm infant
- Articles referring exclusively to the medical treatment given to the preterm infant
- Articles before 2000
- Conference proceedings, editorials, review articles and letters
- The original article could not be found in any way
- Articles not written in English

2.4 Data Extraction

The extraction of the data was materialized by two reviewers that used a Microsoft Excel 2019 spreadsheet. The data was extracted independently and a third senior reviewer intervened resolving disagreements when necessary. For each article the data were organized on the following characteristics: 1) basic information about the article, authors, country and year of publication and 2) basic information on the research outcomes based on exclusion criteria.

2.5 Synthesis of results

A narrative synthesis was chosen, due to the vast heterogeneity of supportive care models and outcomes.

3. Results

Initially, a comprehensive research from the aforementioned databases evaluated a total of potentially 1604 relevant articles to be screened for title and abstract. After rigorous screening, a total of 1.252 articles were excluded due to duplication and non adherence to inclusion criteria issues. This process left 252 articles adherent to the inclusion criteria that were also thoroughly screened. The process of this screening resulted in only 37 articles that had available free full text in which a full text search was conducted.

Upon final examination, 17 articles were chosen, based on the predefined criteria. The types of articles chosen were, two RTC's (1, 15), one Mixed method study (16) and fourteen Qualitative studies (2,3,4,5,6,7,8,9,10,11,12,13,14,17). Five of the studies examined were prospective(1,6,7,15,16) and twelve retrospective (2,3,4,5,8,9,10,11,12,13,14,17).

Regarding the articles containing RCT's, we have a simple RCT (15) and a Cluster RCT (1).

Regarding the Qualitative articles we have:

- Two Qualitative articles using the Grounded theory (5,10)
- Four Qualitative articles using the Content Analysis (6,7,8,13)
- Eight Qualitative- interpretive descriptive articles (2,4 9,11,12,13,15,17)

3.1 Study populations

In the articles examined, the sample size ranged in parent population from 2 to 765. Furthermore, regarding the parent population, it is worth mentioning that mother population ranged from 3 to 765 and the father population ranged from 2 to 74. Some articles included exclusively mothers of preterm infants (1,5,6,7,12), some articles included fathers of preterm infants (14,16) and some articles included both mothers and fathers of preterm infants (8,15,17). Additionally, there were some articles that included both NICU personnel and parent population (8, 9, 13).

The sample size in NICU staff ranged from 10 to 67. Some articles included exclusively NICU personnel (3, 23, 11), whereas some other articles included both NICU staff and parent population (8, 9, 13).

3.2 Quality of the studies

The methodological quality of the studies was assessed using the Critical Appraisal Skills Program (CASP) checklist for systematic reviews (17-item version) [20, 21]. The review demonstrated high quality in methodology, clear research questions, appropriate study designs and transparency in the studies examined. Two of the included studies were of high quality (11, 15), three studies moderate to high quality (1,12,14), eleven studies were of moderate quality (2,3,4,5,6,7,8,9,10,13,16) and one study was moderate to low quality (17).

There were a few issues detected regarding the quality of the studies: Initially, the studies are characterized by very high heterogeneity of designs (many qualitative and less RCT's). This can lead mainly to narrative/thematic synthesis instead of strong quantitative comparison. Additionally, small samples and monocentricity in several qualitative studies is detected, which can possibly lead to limited transferability (5,7,8,10,13,14,16).

Another issue that possibly can arise is the "unit culture" that can affect the results of the implementation of a support model (3,4,8,9,11,13). Furthermore, there is a possibility of selection bias- especially when the participants recruitment is through social media (2) and reporting bias, especially in self- reported outcomes (15). Moreover, there were results from studies that included specific populations that have equity value but have ambiguous generalizability in other countries (5). Ultimately, we have detected studies with limited to none representation from fathers (8,10,13,14,15), whereas in the majority of the studies the mother population appears exclusively or is dominant (1,2,5,6,7,8,10,12,13,15,17).

3.3 Supportive Models of care for parents

The 17 included studies described 6 main supportive models of care for parents with preterm or extremely preterm infants. The supportive models described were: 1) Family Centered Care (FCC), 2) Family Integrated Care (FI Care- AB FI Care), 3) Kangaroo Mother Care (KMC), 4) Peer Support, 5) Psychosocial Interventions with support tools and 6) Specialized Father Support.

The majority of the studies accounted that supportive care models for parents with preterm infants have a positive effect in their mental well being and enhance parental confidence and engagement. Examining the articles, The Family Centered Care model appears dominant in the studies and recognizes the parents of the premature infant as equal members of the NICU expert team [24, 28, 30, 34].

Another supportive model of care that is suggested rigorously through the studies is the Family Integrated Care model that educates the parents to become active caregivers, tending to the needs of their premature infant [25, 33, 35]. In addition, Kangaroo Mother Care, is considered optimal for the enhancement of maternal self confidence, emotional stability and parental attachment [38].

Furthermore, psychosocial intervention with support tools (e.g. the NICU diaries), can help the premature infant's parents to process and accept the hospitalization experience in order to alleviate the emotional trauma [29, 31]. Moreover, specialized father support involving their interactions with their preterm infants after NICU personnel encouragement has shown great promise in improving parental stress and anxiety levels [16]. Finally, peer support [32, 36] can potentially prove useful for the parental mental well being, whereas social media groups can dictate the support needs of the premature infant parents and the issues to be addressed from NICU personnel [23, 26].

4. Discussion

This systematic review examined potential support models of care for parents with preterm or extremely preterm infants hospitalized in NICUS worldwide. Among the 17 studies that we included, Family Centered Care (FCC), Family Integrated Care (FI Care- AB FI Care), Kangaroo Mother Care (KMC), Peer Support, Psychosocial Interventions with support tools and Specialized Father Support, were the support models most widely studied and consistently associated with supporting parents with premature or extremely premature infants.

The results of our systematic review can provide an up-to-date comprehensive summary of the latest evidence. They will inform over interventions and supportive programs that can improve the emotional well-being and reduce the stress of parents with preterm infants that can be applied in Greek NICUS. Our findings indicate that parental support in the NICUS is more effective when supported by multicomponent models of care that are family centered and encourage the active participation of the premature infant's parents.

Family Centered Care (FCC) and Family Integrated Care (FIC) proved to be the most influential and comprehensive support care models in the studies included in this systematic review. The Alberta FI care model proved that parental engagement in neonatal care after structured support can positively influence parental engagement [22, 35]. The qualitative studies within or aligned with the FIC and FCC models demonstrated parental increased confidence, self -efficacy and higher quotes of collaboration with NICU personnel [24, 25, 28, 33, 34, 35]. However, the successful implementation of the FCC/FIC models seems to be dependent on personnel attitudes and organizational culture. Studies that include personnel perspectives on supportive models for parents indicate that workload, hierarchy issues and role ambiguity can hinder the parental participation in neonatal care [24, 25, 30, 32]. It is also detected that in low-income countries with restricted sources, the implementation of FCC/FIC is challenged because of strict institutional and organizational restrictions [30]. Based on the information given, the need of more concrete interventions regarding institutional reorganization and personnel commitment arises, regarding the FCC/FIC models. This means that FCC/FIC are not simple clinical interventions and they need concrete support from the health systems and their representatives.

As another alternative supportive model, Kangaroo Mother Care (KMC) is emerging as a practice that encourages parent-infant closeness and active parental involvement in the NICU, especially when combined with family-centered structures and consistent, practical support from personnel. However, its implementation is vulnerable to organizational and environmental factors, variable personnel attitudes/availability, as well as practical difficulties. After discharge, the continuation of KMC is often limited by time constraints support at home, leading many parents to maintain closeness in alternative ways [38].

As a non-autonomous supportive model that emerged from the studies, peer support is considered a valuable component that if combined with FCC/FIC, can validate emotionally and socially connect the parents of premature infants hospitalized in NICUS. Parents considered peer support as an important shared living experience that differentiated from professional support. The connection among parents

with hospitalized preterm infants reduced the feelings of anxiety and isolation and fostered hope [23,35,36,]. Although the supportive care models included in this systematic review emphasize on FCC or FIC, peer support appears to be limited and non-systematic [33, 34, 35, 38]. Only a few studies incorporate structured peer-to-peer interventions, such as parent mentors or peer navigators [23, 35, 36], while most focus on support from health professionals or from the parents' broader social network (family and friends) [32, 33, 34, 38]. Although parents, and especially fathers, express a need for emotional understanding from people with shared lived experience, this need remains largely unmet [35, 37, 38]. Findings from peer support interventions show mixed results, particularly when implemented after discharge, suggesting that their effectiveness may depend on the timing, structure, and integration into the overall care model [35, 36]. Furthermore, peer support is not experienced the same way for all cultures and races. For example, black mothers of premature babies declared the need for culturally similar peer support groups [26]. These findings suggest that peer support interventions need to implement intentional design and representation. In conclusion, the limited presence of peer support and social network groups in the support models examined, highlighted a significant gap in the care of parents in the NICU and support the need for further development and evaluation of structured peer support interventions. It is also important that peer support programs are adequately designed and implemented based on the cultural and structural context.

Specialized father support is deemed necessary, given the fact that fathers experience the hospitalization of their newborn in the NICU as a particularly stressful experience, characterized by intense anxiety, fear of loss and uncertainty about the paternal role, often combined with limited emotional expression and a feeling of exclusion from care [35, 36, 37, 38]. Interventions that actively involve fathers in the care appear to improve paternal self-confidence, enhance sense of role, and reduce feelings of helplessness and fear during hospitalization. These findings suggest that systematic participation in care and quality communication with staff are key support mechanisms for fathers [25, 35, 37, 38]. Furthermore, early physical contact with the premature infant, combined with support from NICU personnel emerges as an important protective factor for paternal involvement and emotional connection with the newborn, especially in cases where fathers display fear of physical contact or feelings of insecurity [35, 37, 38]. One major drawback that was detected, is that despite the fact that FCC/FIC models theoretically recognize the role of both parents, data shows that fathers still receive less systematic support compared to mothers [22, 23, 26, 27, 28, 31, 33, 38]. Moreover, the heterogeneity in paternal experiences, mainly related to gestational age and the severity of the newborn's condition, highlights the need for personalized support and avoidance of homogenized interventions [35, 37]. Overall, the data suggest that support for fathers should not be limited to the duration of hospitalization, as their needs often intensify during the transition home [37, 38]. Finally, the findings demonstrate a significant gap in the development and evaluation of father-centered support models, which requires further investigation.

In this systematic review, NICU diaries emerged as significant psychosocial interventions to support parents, appearing in more than one article, mainly through studies of the experiences of parents and health professionals [29, 31, 36]. Evidence indicates that NICU diaries function as meaning-making and

coping interventions, allowing parents to mentally negotiate their experiences, understand the premature newborn's journey, and restore continuity of parental presence in an environment that is often experienced as chaotic and traumatic [29, 31, 36]. It is reported that diaries reduce the sense of depersonalization of the NICU and enhance emotional closeness with the premature newborn, even during periods of physical absence from the unit [31]. From the point of view of healthcare professionals, NICU diaries are recognized as tools that can enhance parental role, support understanding of events, and introduce elements of hope into the NICU [29] .

The utilization of the NICU diaries presented some knowledge gaps in specific areas that need to be addressed. An important finding of the studies is that, although NICU diaries appear to support both parents, literature rarely systematically examines the differentiated experiences of mothers and fathers. For mothers, diaries are mainly associated with emotional expression, stress management, and processing the premature infant’s hospitalization and the difficult experience of motherhood [29, 31]. For fathers, who prove to be a group with feelings of exclusion and limited availability regarding support interventions, NICU diaries offered an alternative connection with the newborn or held a more pragmatic role (e.g. documentation about what happened during their absence) [31] However, fathers remain underrepresented in the samples, and analyses are rarely separated by gender, highlighting a clear knowledge gap. From the NICU professional’s perspective regarding the NICU diaries, significant challenges are noted, such as lack of time, emotional burden from reading parental records, and the absence of clear guidelines for the use of diaries [29]. The development of standardized guidelines and protocols for the use of the NICU diaries, with clear identification of goals, roles, and boundaries for parents and personnel, should be investigated and implemented more, so that they can integrate with other support models, like FCC or FIC .

5. Conclusion

This systematic review has some limitations. First of all, although the search strategy was comprehensive, it may still have been missed including some studies. In addition, it is difficult to perform a meta-analysis, especially due to the diversity of studies included. Finally, because most of the studies were retrospective in nature, casual assertions cannot be made about other possible support models for parents with preterm or extremely preterm infants.

In conclusion, we have identified 6 possible supportive models of care for parents with preterm or extremely preterm infants : 1) Family Centered Care (FCC), 2) Family Integrated Care (FI Care- AB FI Care), 3) Kangaroo Mother Care (KMC), 4) Peer Support, 5) Psychosocial Interventions with support tools and 6) Specialized Father Support Programs. Although the findings of the studies were interesting, more well-designed and extensive prospective studies investigating support models of care for parents with preterm or extremely preterm infants hospitalized in NICUS are needed in the future. It is worth mentioning that the results of this systematic review regarding the changes needed to be made in the support models of care confirm the results of other systematic reviews. A good example is a case-based communication course for the NICU personnel that can help establish better trusting relationships and

successful cooperation with the parents [39]. Regarding the caregiving paternal role in the NICUS, evidence from other systematic reviews demonstrated that is yet to be recognized and supported, so new research regarding supportive guidelines and paternal training programs should be introduced [40, 41]. As far as Kangaroo Mother Care (KMC) is considered, most of the systematic reviews suggest that educational programs should be implemented in order to overcome institutional and organizational barriers [42, 43, 44]. Finally, FCC/FIC is implemented but partially and in order to achieve reliable integrated application, changes in the hospital culture and suitable training procedures must be made [45, 46, 47].

Declarations

Ethical aspects and Conflict of interest Statement

No ethical issues or conflicts of interest were declared by the authors.

Data availability statement

The original contributions presented in this systematic review are included in the Supplementary material, further inquiries can be directed to the corresponding author.

Funding

No funding was received to conduct this systematic review

Author contributions

Christina Angeli, Zoe Konstanti, Mary Gouva and Nektaria Zagoriannakou contributed to the conception and design of the study, data collection, and drafting of the manuscript.

All authors read and approved the final version of the manuscript.

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