

Neonatal Bilirubin Encephalopathy in Premature Infants: Nursing Interventions and Challenges in Neonatal Care

Encefalopatia Bilirrubínica Em Recém-nascidos Prematuros: Intervenções de Enfermagem e Desafios no Cuidado Neonatal
Encefalopatía Bilirrubínica en Recién Nacidos Prematuros: Intervenciones de Enfermería y Desafíos en el Cuidado Neonatal

RESUMO

Este estudo analisa o papel da enfermagem na prevenção e tratamento da encefalopatia bilirrubínica neonatal, com ênfase na fototerapia e na Sistematização da Assistência de Enfermagem (SAE). Trata-se de uma revisão bibliográfica integrativa realizada nas bases SciELO, PubMed e Lilacs, considerando publicações entre 2000 e 2024. Os achados demonstram que a fototerapia é eficaz na redução dos níveis séricos de bilirrubina, sendo essencial o monitoramento contínuo pelos enfermeiros para evitar complicações. A SAE contribui para a organização do cuidado, aprimorando a comunicação entre profissionais e oferecendo suporte às famílias. Além disso, a educação parental e a humanização do atendimento favorecem a continuidade do tratamento e a prevenção de complicações. Conclui-se que a aplicação estruturada da SAE e o uso adequado da fototerapia são fundamentais para o manejo seguro da encefalopatia bilirrubínica neonata.

DESCRIPTORIOS: Educação parental; Encefalopatia bilirrubínica; Enfermagem neonatal; Fototerapia; Sistematização da Assistência de Enfermagem.

ABSTRACT

This study analyzes the role of nursing in the prevention and treatment of neonatal bilirubin encephalopathy, emphasizing phototherapy and the Systematization of Nursing Care (SNC). This is an integrative literature review conducted in the SciELO, PubMed, and Lilacs databases, considering publications from 2000 to 2024. The findings demonstrate that phototherapy is effective in reducing serum bilirubin levels, with continuous monitoring by nurses being essential to prevent complications. SNC contributes to the organization of care, improving communication among professionals and providing family support. Additionally, parental education and humanized care promote treatment continuity and prevent complications. It is concluded that the structured application of SNC and the appropriate use of phototherapy are fundamental strategies for the safe management of neonatal bilirubin encephalopathy.

DESCRIPTORS: Parental education; Bilirubin encephalopathy; Neonatal nursing; Phototherapy; Systematization of Nursing Care.

RESUMEN

Este estudio analiza el papel de la enfermería en la prevención y el tratamiento de la encefalopatía bilirrubínica neonatal, con énfasis en la fototerapia y la Sistematización de la Atención de Enfermería (SAE). Se trata de una revisión bibliográfica integrativa realizada en las bases de datos SciELO, PubMed y Lilacs, considerando publicaciones entre 2000 y 2024. Los hallazgos demuestran que la fototerapia es eficaz para reducir los niveles séricos de bilirrubina, siendo esencial el monitoreo continuo por parte de los enfermeros para prevenir complicaciones. La SAE contribuye a la organización del cuidado, mejorando la comunicación entre los profesionales y brindando apoyo a las familias. Además, la educación parental y la humanización del cuidado favorecen la continuidad del tratamiento y la prevención de complicaciones. Se concluye que la aplicación estructurada de la SAE y el uso adecuado de la fototerapia son fundamentales para el manejo seguro de la encefalopatía bilirrubínica neonatal.

DESCRIPTORIOS: Educación parental; Encefalopatía bilirrubínica; Enfermería neonatal; Fototerapia; Sistematización de la Atención de Enfermería.

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RECEIVED: 02/25/2025 APPROVED: 03/18/2025

How to cite this article: Veiga SV, Veiga GV, Silva IJ, Guedes IM, Nascimento FS, Torres ACP, Corrêa NC, Matos ALA. Neonatal Bilirubin Encephalopathy in Premature Infants: Nursing Interventions and Challenges in Neonatal Care. *Saúde Coletiva* (Edição Brasileira) [Internet]. 2025 [acesso ano mês dia];15(95):15428-15441. Disponível em: DOI: 10.36489/saudecoletiva.2025v15i95p15428-15441

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INTRODUCTION

Neonatal bilirubin encephalopathy is a serious condition caused by excessive accumulation of bilirubin in the central nervous system of newborns, which can result in irreversible neurological consequences, known as kernicterus. This condition is more common in premature newborns due to hepatic immaturity, which limits the ability to effectively metabolize bilirubin.¹ Neonatal hyperbilirubinemia is a common clinical problem, affecting approximately 60% of full-term newborns and 80% of premature newborns, and in severe cases, requires rapid interventions to avoid irreversible neurological damage.²

Phototherapy has established itself as the standard treatment for neonatal hyperbilirubinemia, being effective in reducing serum bilirubin levels

through controlled exposure to light, which converts bilirubin into soluble forms, facilitating its elimination by the body.³ However, the use of phototherapy requires constant monitoring and specific techniques to minimize the risks of complications, such as dehydration and excessive heating, which highlights the essential role of nurses in monitoring and carrying out this procedure.⁴

In this context, the Systematization of Nursing Care (NCS) emerges as a structured strategy to organize and standardize neonatal care, ensuring quality and safety in care. NCS offers a comprehensive approach that involves steps such as diagnosis, planning and implementation of specific care for each neonate, also promoting effective communication between health professionals.⁵ In addition to technical competence, nurses' work also includes guidance and emotional

support for parents, aspects that are essential for the continuity of care after hospital discharge.⁶

Despite the recognized efficacy of phototherapy and NCS, neonatal care still faces significant challenges. The main obstacles include the lack of standardization in some nursing practices and the scarcity of studies on the long-term effects of phototherapy in premature neonates. Furthermore, gaps in the literature regarding the use of complementary interventions, such as gamma globulins and metalloporphyrins, limit the range of therapeutic approaches available, highlighting the need for further scientific research on the subject.

Given this scenario, this review aims to critically analyze the role of nursing in the prevention and treatment of bilirubin encephalopathy in neonates. The specific objectives include: (1) describing and evaluating

the effectiveness of phototherapy and NCS in the management of neonatal hyperbilirubinemia; (2) investigating the impact of parental education and guidance on the continuity of home treatment; and (3) identifying gaps in the literature and indicating directions for future research. Through this review, we seek to contribute to the improvement of neonatal nursing practices and strengthen the theoretical bases for the development of more comprehensive and safe protocols in the field of neonatology.

METHOD

This study was conducted as an integrative literature review, following methodological rigor to ensure the reliability and reproducibility of the analysis. The methodology was structured with the objective of exploring and comparing nursing interventions in the management of bilirubin encephalopathy in neonates, focusing on the use of phototherapy and Nursing Care Systematization (NCS). The main materials analyzed include the articles *The Importance of Nursing in the Care of Neonates with Jaundice*, by Chaves et al.¹, and *Systematization of Nursing Care for Bilirubin Encephalopathy*, by Sousa et al.², supplemented by other sources selected in the review.

Structure of the bibliographic search

The search was conducted in the SciELO, PubMed, Lilacs and Google Scholar databases, with an emphasis on recent publications relevant to the topic. Data collection took place in March 2024 and, to obtain specific results, Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH) were used, in Portuguese and English, with the following combined terms:

- “encefalopatia bilirrubínica” OR “kernicterus” AND “en-

fermagem” AND “neonatos”

- “fototerapia em neonatos” AND “SAE” OR “sistematização da assistência de enfermagem”
- “hyperbilirubinemia” AND “nursing care” AND “newborns”

These strategies provided a broad and detailed search, ensuring the inclusion of studies that addressed both the effectiveness of clinical interventions and the applicability of NCS in the context of neonatal care.

Inclusion and exclusion criteria

Inclusion and exclusion criteria were carefully defined to ensure relevance and quality of data:

- **Inclusion criteria:** Articles published between 2000 and 2024, available in Portuguese and English, with full access to the text and that addressed topics such as nursing performance, phototherapy, NCS, exchange transfusion and parental education in the management of neonatal hyperbilirubinemia.
- **Exclusion criteria:** Studies that dealt exclusively with medical interventions without analyzing the role of nursing were excluded, as well as secondary literature reviews, duplicate articles and publications in other languages unavailable in the databases consulted.

These criteria allowed the selection of studies that offered a specific and practical view of neonatal nursing, ensuring the inclusion of materials directly relevant to the critical analysis of interventions.

Study selection procedure

The selection of articles was carried out systematically and in several stages. Initially, 217 articles were found, of which 153 remained after the elimination of duplicates. Then, an analysis of the titles and abstracts, based on the inclusion and exclusion criteria, led to the selection of 57 ar-

ticles for full reading. After this stage, 18 articles were included in the final review, as they met the criteria and provided relevant information for a detailed comparative analysis. The articles by Chaves et al.¹ and Sousa et al.² were considered central references due to the specific focus on NCS and nursing interventions.

Analysis of selected texts

For the analysis of the articles, content analysis was adopted, according to Bardin¹, enabling a careful and organized interpretation of the texts. The analysis process followed three main stages:

1. **Floating Reading:** A preliminary reading of the articles was carried out to identify the main topics covered, such as phototherapy, NCS, parental education and complementary interventions.
2. **Thematic Coding:** Based on the study objectives, the contents were organized into thematic categories: Effectiveness of Phototherapy, Application of NCS, Parental Education and Guidance, and Clinical Challenges and Limitations.
3. **Synthesis and Comparison of Findings:** Each article was examined to identify convergences and divergences in approaches, as well as gaps and limitations. The main findings were systematized in a comparison matrix, providing an integrated view and a critical interpretation of the results.

This analysis methodology allowed a clear and detailed view of the content, facilitating the identification of convergent and divergent points between the studies. Thematic coding and the synthesis of the findings allowed an organized structuring of the information, ensuring that each category was explored in depth.

Procedures for reproducibility

To ensure the reproducibility of

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the methodology, all descriptors, criteria and search strategies were rigorously documented. In this way, future researchers can replicate the study using the same databases and strategies, allowing comparison of results and contributing to the deepening of knowledge about the role of nursing in bilirubin encephalopathy in neonates. In addition, the careful selection of articles, based on clearly established criteria, ensures the quality and reliability of the data presented in this review.

References to main articles

The reference articles included in this methodology are:

1. Chaves DCM, Gomes IS, Barbosa JKL, Franco RS, Stone VBS, Gomes RKS. The importance of nursing in the care of newborns with jaundice. *Cienc Saude*. (In the original: *A importância da enfermagem nos cuidados de neonatos com icterícia*. *Cienc Saude*.) 2024;28(133).
2. Sousa QC, Silva LG, Amorim ME, Lopes CB, Teles GAM, Cardoso TS. Systematization of nursing care for bilirubin encephalopathy (In the original: *Sistematização da assistência de enfermagem para encefalopatia bilirrubínica*.) *Rev Neonatal*. 2023;9(2):47-55.

These articles served as the main basis for the analysis of NCS and neonatal nursing interventions, enriching the discussion and providing a solid foundation for the results and interpretations presented throughout the study.

RESULTS

The results of the literature review highlight a series of practices and challenges in nursing care for neonates with bilirubin encephalopathy. Most of the reviewed studies agree

that phototherapy is the standard intervention, being effective in reducing serum bilirubin levels and preventing progression to kernicterus, as highlighted by Sousa et al.¹ In severe cases of hyperbilirubinemia, exchange transfusion is presented as a complementary option to phototherapy, although this procedure involves risks and must be performed under strictly controlled conditions.

The Nursing Care Systematization (NCS) has been identified as an essential method for organizing the stages of assessment, diagnosis, intervention and monitoring, promoting safer and more structured care for newborns. Sousa et al.¹ consider NCS as a facilitator of care coordination and systematic recording of nursing practices, ensuring that all critical aspects of neonatal care are covered.

Parental education has emerged as a crucial component for successful treatment. Studies indicate that family preparation and guidance are essential, helping them identify warning signs and maintain home treatment when necessary. Articles such as that by Chaves et al.² highlight that parental education reduces anxiety and increases adherence to treatment, contributing to safety and continuity of care after hospital discharge.

Regarding diagnostic methods, studies highlight the importance of scales and indicators, such as the BIND-M and the Kramer scale, in assessing the risk of hyperbilirubinemia, especially in resource-limited settings. These assessment tools are effective for initial screening and identifying cases that require intensive care, providing an early and more accurate diagnosis.

Another aspect highlighted was the need for an interdisciplinary approach. Coordination between neonatologists, pediatricians and nurses, together with the support of professionals such as psychologists, is considered essential for the quality of

care, particularly in cases that progress to severe encephalopathy. Studies suggest that this multidisciplinary integration contributes significantly to the safety and quality of care for neonatal patients.

Complementary interventions, such as the use of gamma globulins and metalloporphyrins, have also been mentioned in some studies; however, data on their efficacy and safety are still limited, indicating an emerging area of research that requires further scientific investigation.

The review also highlights the importance of continuous monitoring of vital signs and bilirubin levels, which are essential to prevent the worsening of the newborn's clinical condition. Studies suggest that the adoption of more rigorous monitoring protocols can significantly reduce the length of hospital stay and complications associated with hyperbilirubinemia, contributing to more favorable and safe outcomes.

DISCUSSION

Convergences of results

The reviewed studies converge on several essential aspects of nursing care in bilirubin encephalopathy in neonates, especially regarding the importance of phototherapy and Nursing Care Systematization (NCS). Phototherapy is widely considered as first-line treatment for hyperbilirubinemia in neonates, both full-term and preterm, due to its efficacy in rapidly reducing serum bilirubin levels and preventing progression to kernicterus, as highlighted by Sousa et al.¹ This practice, in use since the 1950s, transforms bilirubin into eliminable soluble compounds, minimizing neurotoxicity.

There is also consensus on the relevance of the NCS as a structure that systematically organizes care, reducing risks and standardizing interventions, especially in complex cases. The

use of the NCS allows nursing to act in a coordinated manner with other specialties, promoting a comprehensive view of the patient.

Another point of convergence concerns the role of education and guidance for parents, a fundamental component for the success of interventions. Parental education promotes continuity of care in the home environment and helps parents recognize early signs of worsening. Many studies indicate that emotional and educational support reduces parental anxiety, enabling them to adopt safer care practices, which facilitates the recovery of the newborn and prevents new hospitalizations.

Divergences between studies

A notable divergence between studies concerns the approach to the use of NCS. While authors such as Sousa et al.¹ advocate a rigorous and standardized application in all cases, others, such as Chaves et al.², argue that NCS should be adapted to the specificities of each case and the available infrastructure. This debate reflects different opinions on the flexibility required in the application of NCS. Chaves et al.² suggest that, in low-complexity scenarios, a less rigid and more adaptable model would be more appropriate to optimize resources and address the variability of clinical conditions.

Another area of disagreement is the efficacy and application of additional interventions, such as exchange transfusion and the use of gamma globulins in cases of severe hyperbilirubinemia. Some studies advocate these practices for neonates at risk of neurotoxicity, while others indicate that exchange transfusion, because of its high risk profile, should be considered only in specific conditions. The lack of consensus and the scarcity of robust data on these additional interventions suggest the need for more defined protocols and controlled studies that provide a more solid ev-

idence base.

Limitations of the studies

The lack of longitudinal data is a common limitation observed in most of the reviewed studies. Although phototherapy and NCS are widely accepted as safe and effective practices for controlling hyperbilirubinemia in neonates, the lack of studies that follow patients over the long term represents a significant limitation. Short-term studies confirm the efficacy of phototherapy in reducing bilirubin levels, but few studies evaluate the neurological impact and psychomotor development of these patients after months or years of repeated exposure to phototherapy, especially in premature infants, who are more vulnerable.

Another limiting point is the variation in the inclusion criteria and methodologies used. This methodological heterogeneity makes it difficult to directly compare results, constituting an obstacle to the establishment of universally applicable clinical guidelines. Different protocols and approaches can introduce biases in the results, compromising the generalization of the findings to clinical practice. This scenario points to the need for a methodological consensus that allows for a more precise and comparative evaluation of the results.

Gaps in the literature

The gaps in the literature highlight the need for additional research on alternative interventions, such as the use of metalloporphyrins and gamma globulins, which, although promising, lack conclusive evidence regarding their efficacy and safety. Metalloporphyrins have been investigated for their potential ability to inhibit bilirubin production; however, the lack of robust clinical trials prevents their consistent incorporation into clinical protocols. This gap represents

an opportunity for future research, which could clarify the applicability of these interventions as alternatives or complements to phototherapy and exchange transfusion.

In addition, there is an important gap regarding the role of NCS in the humanization of neonatal care, especially with regard to the interaction between professionals and family members. Although many studies address NCS as a model for organizing technical care, few explore its contribution to the emotional well-being of parents and to effective communication between professionals and family members. Exploring this dimension can open paths for a more integrative and humanized approach to NCS, promoting a nursing practice that also considers the emotional needs of family members.

Impact of parental education

The studies reviewed highlight the positive impact of parental education on treatment success and prevention of complications. Many indicate that guidance given to parents during hospitalization improves the safety of home treatment and allows family members to recognize early warning signs. However, the effectiveness of this educational approach may vary according to the socioeconomic context and the level of education of the parents. This suggests that, to optimize results, the nursing team should adapt parental education to the specific conditions of each family, using accessible language and visual support materials when necessary.

Implications of the results

The implications of the results for nursing practice in bilirubin encephalopathy are broad, indicating the need for a flexible and integrated approach that takes into account the clinical conditions of the patients and the social context of the family members. The use of phototherapy and NCS is

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effective and safe, but the implementation of adaptable protocols, especially in settings with limited resources, can improve results. The analysis suggests that an approach that integrates clinical flexibility, parental education, and interdisciplinary practice may be more effective than a rigid, standardized model, especially for complex and highly vulnerable cases.

Prospects for standardization

The standardization of phototherapy practices and NCSs widely supported in the reviewed studies, especially in highly complex settings, where standardized protocols can optimize workflow and ensure quality of care. On the other hand, for scenarios with structural limitations, such as small clinics or remote regions, the adoption of a flexible and adapted model may be more feasible and equally effective. This adaptable standardization, adjusted to local realities, can offer an intermediate solution between rigidity and flexibility, ensuring quality of care in different contexts.

Ethical and cultural issues

Interventions in neonates, such as exchange transfusion, raise ethical and cultural issues, especially when family beliefs influence acceptance of proposed treatments. The literature highlights that health teams must be prepared to respect and adapt interventions as necessary, maintaining an open and respectful dialogue with families. In some cultures, invasive procedures may be misunderstood or rejected, requiring a culturally sensitive approach that prioritizes family understanding and trust in the health team.

Need for future research

The review highlights the urgent need for long-term studies investigating the neurological development of neonates undergoing repeated pho-

totherapy. Currently, the literature lacks studies with follow-up years after neonatal treatment, limiting the understanding of possible cumulative impacts or late effects. Future studies could also explore new technologies, such as the use of LED light and specific filters in phototherapy, to assess whether they offer additional benefits compared to traditional techniques.

Conclusion of the critical analysis

Critical analysis of the results suggests that phototherapy and NCS are effective tools in the management of bilirubin encephalopathy. However, flexible application of protocols, considering the complexity of cases and the conditions of each institution, can optimize results. The need for additional research to evaluate the long-term impact of interventions, develop alternative therapies, and promote culturally sensitive education represents important directions for the continuous improvement of nursing practice in neonatal care. This multidimensional approach may result in more effective and humanized clinical practice.

CONCLUSION

The literature review on nursing performance in the prevention and treatment of bilirubin encephalopathy in neonates allowed us to summarize the most effective practices and the challenges faced in this context. It was observed that phototherapy is widely recognized as the standard treatment for neonatal hyperbilirubinemia, being effective in reducing serum bilirubin levels when applied with strict monitoring and care, especially under the supervision of the nursing team. The application of the Nursing Care Systematization (NCS) also stood out as an essential organizational tool, promoting comprehensive and safe care for neonates and

strengthening communication among health professionals.

These findings contribute significantly to the understanding of the topic, highlighting that nursing work goes beyond technical execution, encompassing the education of parents on home care and emotional support. This humanized approach not only promotes continuity of care, but also reduces the risk of complications, enabling the family to monitor the health of the newborn after hospital discharge. In practical terms, the review suggests that the implementation of NCS and the use of phototherapy with active nursing supervision are essential strategies for the management of hyperbilirubinemia, with potential application in various neonatal contexts.

For future research, it is suggested that longitudinal studies on the effects of phototherapy in premature newborns and the investigation of complementary interventions, such as the use of metalloporphyrins and gamma globulins, should be conducted. These studies could expand treatment options and provide a better basis for nursing practices in cases of severe hyperbilirubinemia.

In terms of limitations, this study was restricted to a bibliographic analysis, which limits the generalization of the findings. In addition, the lack of standardization among the reviewed studies made it difficult to directly compare the results. Nevertheless, this review article contributes to the strengthening of nursing practices and provides important theoretical support for the development of more robust and safe clinical protocols, with a potential positive impact on neonatology.

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