

DOI: <https://doi.org/10.36489/saudecoletiva.2021v11i66p6519-6528>

Permanent education in Neonatal Screening: an integrative review

Educaç o permanente em cribado neonatal: uma revis o integradora

Educa o permanente na Triagem Neonatal: uma revis o integrativa

ABSTRACT

Objective: To investigate studies on education / permanent training related to neonatal screening (NS), identifying strategies that favor future actions related to the theme. **Methods:** This is a descriptive study through an integrative review, conducted in August 2019, in the databases "LILACS", "MEDLINE", "IBECs" and "SciELO", through the terms: "Triagem Neonatal", "Teste do Pezinho", "Capacita o" and "Educa o em Sa de". **Results:** The final sample consisted of 12 studies, the majority from the Medline database (n = 11). Among the articles analyzed, three were published in national journals and nine in international journals. Considering the modalities of NS, seven studies addressed biological NS, while hearing and heart screening were mentioned by four and one articles, respectively. The most studied population was nurses and parents. **Conclusion:** The importance of implementing permanent education and training programs is ratified, addressing effective strategies for the improvement of Universal Neonatal Screening.

DESCRIPTORS: Permanent Education; Neonatal Screening; Children Health.

RESUMEN

Objetivo: Investigar estudios sobre educaci n / formaci n permanente relacionados con el cribado neonatal, identificando estrategias que favorezcan acciones futuras relacionadas con la tem tica. **M todos:** Se trata de un estudio descriptivo mediante revisi n integradora, realizada en agosto de 2019, en las bases de datos "LILACS", "MEDLINE", "IBECs" y "SciELO", atr vies de los t rminos: "Triagem Neonatal", "Teste do Pezinho", "Capacita o" y "Educa o em Sa de". **Resultados:** La muestra final consisti  en 12 estudios, la mayor a de la base de datos Medline (n = 11). Entre los art culos analizados, tres fueron publicados en revistas nacionales y nueve en revistas internacionales. Teniendo en cuenta las modalidades de la cribado neonatal, siete estudios abordaron la cribado neonatal biol gica, mientras que cuatro y un art culo mencionaron la detecci n auditiva y card aca, respectivamente. La poblaci n m s estudiada fueron enfermeras y padres. **Conclusi n:** Se ratifica la importancia de implementar programas de educaci n y capacitaci n permanente, abordando estrategias efectivas para el mejoramiento del Cribado Neonatal Universal.

DESCRIPTORES: Educaci n Permanente; Cribado neonatal; Salud infantil.

RESUMO

Objetivo: Investigar estudos sobre educa o/capacita o permanente relacionados a triagem neonatal (TN) e/ou teste do pezinho, identificando estrat gias que favore am futuras a oes relativas ao tema. **M todos:** Trata-se de um estudo descritivo por meio de revis o integrativa, realizado em agosto de 2019, nas bases de dados "LILACS", "MEDLINE", "IBECs" e "SciELO", atr vies dos termos: "Triagem Neonatal", "Teste do Pezinho", "Capacita o" e "Educa o em Sa de". **Resultados:** A amostra final foi composta por 12 estudos, a maioria da base de dados Medline (n=11). Dentre os artigos analisados, tr s foram publicados em peri dicos nacionais e nove em peri dicos internacionais. Considerando as modalidades de TN, sete estudos abordaram a TN biol gica, enquanto as triagens auditiva e de cardiopatias foram referidas por quatro e um artigos, respectivamente. A popula o mais estudada foi de enfermeiros e pais. **Conclus o:** Ratifica-se a import ncia de implantar programas de educa o permanente e capacitaci o, abordando estrat gias eficazes para melhorar a Triagem Neonatal Universal.

DESCRITORES: Educa o Permanente; Triagem Neonatal; Sa de Infantil.

RECEIVED ON: 11/28/2020 APPROVED ON: 24/2021



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INTRODUCTION

Neonatal Screening (NS) is a population screening program that aims to identify disorders and diseases in the newborn, ensuring treatment and continuous monitoring for those with a positive diagnosis. In Brazil, this program is supported by Ordinance GM / MS n° 822, of June 6, 2001, and carried out in the biological, auditory, ocular and critical congenital heart diseases, in addition to the evaluation of the lingual frenulum. Biological NS, popularly known as the "heel prick test", uses laboratory tests as a strategy to identify possible diseases in the newborn, with the diagnosis of Phenylketonuria, Cystic Fibrosis, Congenital Adrenal Hyperplasia, Biotinidase Deficiency, Sickle Cell Anemia and Congenital Hypothyroidism^(1,2,3), all of them available in the Unified Health System.

The reach of 100% coverage of newborns in the National Neonatal Screening Program is hampered by several factors that hinder access to the test, highlighting the failures in guidance during prenatal care by health professionals.^(4,5)

The development of strategies for the education of parents about NS has been a challenge, generating uncertainties about the appropriate content to be presented to this audience. In this context, the importance of the health professional in interacting with the parents is also highlighted, establishing a sense of security and guiding them towards promoting support for the newborn's health.^(6,7)

Research has pointed to an insufficient knowledge of neonatal screening by the health team. This gap could be filled with continuing and continuing education actions. However, despite the relevance of the subject, there is a shortage of scientific productions that deal with the performance and educational promotion of health teams in relation to NS.^(8,9)

This research aimed to investigate studies on education/training in health related to neonatal screening and/or heel prick, in order to identify strategies that may favor the development of future educational actions related to the theme.

METHODS

It is a descriptive study of integrative review, elaborated in six stages: (1) identification of the theme and selection of hypothesis; (2) establishment of criteria for inclusion and exclusion of studies and choice of the sample; (3) definition of the information to be extracted from the selected articles; (4) evaluation of studies included in the integrative review; (5) interpretation of results and discussions; (6) synthesis and presentation of the review.⁽¹⁰⁾

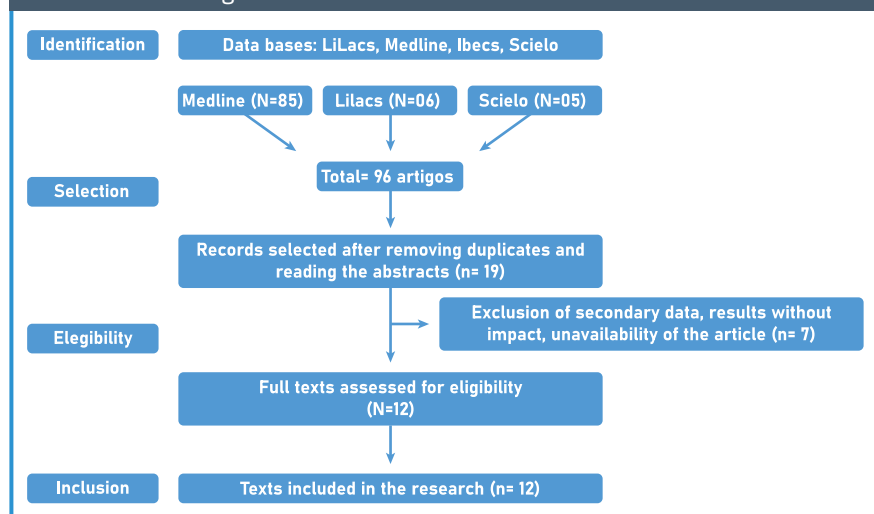
The search for the articles was carried out in August 2019. The following terms were used as a strategic selection for article searches: "Triagem Neonatal", "Teste do Pezinho", "Capacitação" and "Educação em Saúde", with the intention of encompassing the theme, allowing a broad search, however, in a targeted manner.

The inclusion criteria defined for the selection were: (a) original article, published in Portuguese, English or Spanish, (b) between 2009 and 2019, in the databases "LILACS", "MEDLINE", "IBECs" and "SciELO". To be included, the studies should have developed some action on health education and/or training, addressing the theme of neonatal screening and/or heel prick test. Dissertations and theses, publications referring to conference abstracts, annals, editorials, comments and opinions, reflection articles, projects, reports and technical reports were excluded.

The choice of articles was made in four stages, illustrated in Figure 1: identification phase, in which strategic terms were searched; selection phase, in which inclusion and exclusion criteria were used; eligibility phase, containing necessary assumptions for the choice of articles; and the inclusion phase, which defined which articles would be included in the study.

This review included 12 studies, shown in Chart 1, with 11 articles found in the "Medline" database and 1 identified in the "SciELO" database. Among

Figure 1. Flowchart of identification and selection of articles for the integrative review in the approach of continuing education and training on neonatal screening.



the 12 articles analyzed, three were published in national journals, written in Portuguese, and nine were published in international journals, eight of which in English and one in Portuguese.

RESULTS AND DISCUSSIONS

Universal Neonatal Screening is part of the National Policy for Comprehensive Child Health Care (PNAISC - Política Nacional de Atenção Integral à Saúde da Criança) (Ordinance GM/MS No. 1,130 of August 5th, 2015) described in Strategic Axis 1, whose objective is to promote and protect the child health and breastfeeding. For this, according to the Ministry of Health, available human resources are needed and in a constant process of permanent education, for articulated and timely access at all levels of care considering individual care, education and collective health actions.⁽²⁾

In this integrative review, articles related to the importance of health education in the approach to neonatal screening

were selected, with a focus on continuing education and health training.

Among the 12 articles analyzed in this review, seven studies addressed biological NS^(7,11-16), while hearing screening was referred to by four articles^(10,17,18,20) and only one article presented data on NS of heart disease.⁽¹⁹⁾

In studies 1, 4, 5, 6, 7, 8 and 10^(7,11-16) (Table 1) the importance of health education in relation to biological screening was approached, from different perspectives.

In articles 1, 5 and 8^(11,12,15) health education was directed towards the diagnosis of cystic fibrosis, while in article 6⁽¹³⁾ the focus was on sickle cell disease, both diagnosed by the "heel prick test". In the research carried out in study 8⁽¹⁵⁾, all 12 families interviewed reported having received information about NS during pregnancy or shortly after birth, either verbally or in writing. However, the parents reported not having read the material on NS made available, as they felt falsely reassured by the health professionals,

who reported on the low probability of a positive result. The information presented in this study shows that continuing education about NS, directed at parents, is not standardized and this generates inaccurate and subjective information from the health team itself.

The difficulty in communicating between parents and the health team about NS was also discussed in studies 1, 5 and 6⁽¹¹⁻¹³⁾, in which parents emphasize the need to improve communication about NS during the perinatal period, and suggest clarifying the purpose of NS and which diseases are included in the test.

The lack of knowledge about NS also has an impact on the life expectancy of children with a positive diagnosis of NS. The research of article 6⁽¹³⁾ analyzed the occurrence of deaths in children with sickle cell disease, and concluded that the lack of knowledge about the disease by health professionals were aggravating factors in the patients' clinical condition.

In Brazil, Ministry NS should be brought to parents by the health team,

Chart 1- Description of the articles included in the integrative review on the approach of continuing education and training on neonatal screening.

Nº	JOURNAL/TYPE/YEAR	OBJECTIVES	KIND OF STUDY
1	J Perinat Neonat Nurs 2009 ⁽¹¹⁾	Investigate the provision of information about NS to parents	Qualitative
2	Adv in Neonatal Care 2014 ⁽¹⁹⁾	Assess nurses' knowledge about screening for congenital heart disease	Almost experimental
3	Revista CEFAC 2014 ⁽¹⁰⁾	To evaluate nurses' knowledge in educational actions in child hearing health.	Integrative review
4	J Genetic Counsel 2015 ⁽⁷⁾	Explore models of health education for parents.	Systematic review
5	J Genetic Counsel 2015 ⁽¹²⁾	Assess parents' knowledge about cystic fibrosis	Prospective and randomized
6	Jornal de Pediatria 2015 ⁽¹³⁾	Characterize deaths of children with sickle cell disease	Clinical and epidemiological research.
7	JAMA Pediatrics 2016 ⁽¹⁴⁾	Analyze the effect of prenatal education on neonatal screening	Randomized clinical trial
8	J Genet Counsel 2016 ⁽¹⁵⁾	Explore parents' experiences after a positive result for cystic fibrosis or sickle cell disease.	Qualitative
9	J Midwifery Womens Health 2016 ⁽¹⁷⁾	Analyze the hearing screening approach in the medical curriculum	Data survey
10	Rev. Paul. Pediatr. 2017 ⁽¹⁶⁾	Evaluate the knowledge of puerperal women about the heel prick test.	Descriptive and quantitative
11	Int J Pediatr Otorhinolaryngol 2017 ⁽²⁰⁾	Assess the provision of information about NS to parents	Data survey
12	Braz J Otorhinolaryngol 2013 ⁽¹⁹⁾	Investigate studies on education in hearing screening	Almost experimental

with no details on how and when to carry out this approach, nor on essential information that should be considered.^(1,2) In time, it is important to reinforce that health education actions point to three segments of priority actors: health professionals, working in disease prevention, health promotion and curative practices; managers, providing support to these professionals; and the population that needs to build their knowledge and increase their autonomy in care, individually and collectively.⁽²¹⁾

The research carried out in study 5⁽¹²⁾ concluded that educational videos about NS can, in addition to increasing the parents' adherence to take the test, improve understanding and reduce anxiety of parents who may receive a positive result in the NS exam.

Article 10⁽¹⁶⁾ concluded that the knowledge of postpartum women about NS is superficial and may reflect the fragility of the health team's performance, and emphasized the need to prioritize permanent education actions in health services that focus on NS.

It is necessary to train the professionals involved, evaluate the dissemination of information and evaluate such educational interventions, in order to document the local needs for neonatal screening and the obstacles of this process, for later adoption of strategies.⁽¹⁰⁾ It is worth mentioning that, if we consider biological NS, which involves the diagnosis of six diseases, each with its pathology and distinct and complex consequences, the difficulty in producing a concise and easy to understand material is notorious.

The author of Article 9⁽¹⁷⁾ interviewed directors of Midwifery Education Programs in the USA (Medical Residency Program) and, although all respondents confirmed the inclusion of auditory NS in the curriculum, it is noted that deeper issues about NS are not debated, such as parental counseling about possible positive results and the monitoring of children not screened at birth.

Other studies on auditory NS^(10,18,20) they also point to the need for more

accurate information on the subject to parents. In an integrative review of auditory NS, study 3⁽¹⁰⁾ affirms the need to expand the knowledge of health professionals through permanent education.

Proposals for educational actions to health professionals have also been presented by other studies.^(10,18,19) In the articles 3:12^(10,18), the authors carried out educational actions aimed at children's hearing health and considered them positive in order to modify the professionals' knowledge.

The need for health institutions to provide sufficient instruction and education before the implementation of new protocols or changes in clinical practice was also evidenced in the study 2⁽¹⁹⁾, when evaluating how efficient the online education of nurses was in the diagnosis of heart disease in NS.

Health education practices are inherent to health work, but are often relegated to a second place in the organization of services and in the management itself.⁽²¹⁾ This scenario is not unique to Brazil, where education in NS is often not prioritized, with low or non-existent budgets, requiring programs to be effective with little funding. In this context, North American researchers developed a document entitled "Model of Best Education Practices for Neonatal Screening", in which a flowchart helps to identify the difficulties involved in the process of neonatal screening, and also points to practical issues in the implementation of educational actions, as well as its feasibility in different situations. According to the authors, the sharing of successful strategies between NS programs mitigates the scarcity of resources and reduces the workload.⁽²²⁾

The article 4 research⁽⁷⁾ discusses four different models of Neonatal Screening Programs in different countries, and shows their impacts on parents' knowledge on the topic. According to the authors, meeting the expectations and preferences of parents about the types of approaches to implement health education is an important objective, and they

point out that the type of continuing education to be offered depends on the degree of parental involvement in the decision to participate or not in NS.

The importance of adapting the material to be used in continuing education was also evident in works 3 and 4.^(7,10) For this reason, the investigation to whom the educational material will be destined, having socioeconomic and demographic factors as parameters, is fundamental for the preservation of the intelligibility and ease of use of the material.⁽¹⁰⁾

Upon realizing the difficulties in monitoring actions implemented in the auditory NS, a Logical Model of the Auditory NS Program was elaborated and validated in Brazil.⁽²³⁾ The Logical Model is defined as a visual scheme that facilitates the planning of actions and the management of a program, and in this case education in hearing screening was one of the dimensions worked on. Corroborating with previous studies^(12,18), guidance actions through conversation circles were suggested in environments where parents and health professionals are habitually inserted: waiting rooms, clinical meetings, among others, so that the exchange of information is more effective. This approach envisions the parental responsibility, since one of the biggest obstacles to the success of auditory NS, according to the authors, is precisely the non-adherence of parents and family to the referrals made.⁽²³⁾

In the research of study 7⁽¹⁴⁾, carried out in the United States (USA), the parents' knowledge and attitudes towards NS had a specific focus in addition to NS: the retention and use of biological material from the newborn for research. An interesting aspect mentioned in this research is that the postpartum activity can contribute to low efficacy of the current educational approaches carried out in this late phase.

Finally, the need for more research to evaluate best practices for implementing NS education during routine obstetric practice is emphasized. According to data from a technical report that summa-

rizes the situation of the PNTN, published in 2013, educational activities are restricted, in most states, to the training of technicians responsible for collecting samples. In this sense, the document points out that the permanent education actions in NS can count on specific resources transferred by the Ministry of Health for this purpose, requested in the

bipartite negotiation spaces (Bipartite Intergovernmental Commission and Regional Intergovernmental Commission), becoming part of the State Plans for Permanent Education.⁽²⁾

CONCLUSION

In this integrative review, there was

a shortage in national and international literature regarding health education programs in NS, especially for health professionals. Effective methods were reviewed to guide future elaborations of permanent education programs in NS, presenting interventions through educational actions with concrete and updated suggestions. ■

REFERENCES

1. Brasil. Ministério da Saúde. Secretaria de Atenção a Saúde. Departamento de Atenção Especializada e Temática. Triagem neonatal biológica: manual técnico. Brasília: Ministério da Saúde, 2016. 80 p.: il.
2. Núcleo de Ações e Pesquisa em Apoio Diagnóstico-NUPAD Diagnóstico situacional do Programa Nacional de Triagem Neonatal nos estados brasileiros: relatório técnico / Núcleo de Ações e Pesquisa em Apoio Diagnóstico – NUPAD. Belo Horizonte: NUPAD, 2013. 34 p.: il.
3. Carvalho DCSN, Macêdo TCC, Moreno M, et al. Evolução do programa de Triagem Neonatal em hospital de referência no Ceará: 11 anos de observação. *Arq Bras Ciências da Saúde*. 2017;42(3):143–6.
4. Oliveira EF, Souza AP. A importância da realização precoce do teste do pezinho: o papel do enfermeiro na orientação da Triagem Neonatal. *Id Line Rev Psicol*. 2017;11(35):361–78.
5. Botler J, Camacho LAB, da Cruz MM, George P. Neonatal screening - the challenge of an universal and effective coverage. *Cien Saude Colet*. 2010;15(2):493–508.
6. Mendes LC, Santos TT, Bringel FA. Evolução do programa de triagem neonatal no estado do Tocantins. *Arq Bras Endocrinol Metabol*. 2013;57(2):112–9.
7. Potter BK, Etchegary H, Nicholls SG et al. Education and Parental Involvement in Decision-Making About Newborn Screening: Understanding Goals to Clarify Content. *J Genet Counsel*. 2015;24:400–8.
8. Mesquita APHR, Marqui ABT de, Silva-Grecco RL, Balarin MAS. Profissionais de Unidades Básicas de Saúde sobre a triagem neonatal. *Rev Ciências Médicas*. 2017;26(1):1.
9. Servidoni MF, Gomez CCS, Marson FAL, et al. Teste do suor e fibrose cística: Panorama da realização do teste em centros públicos e privados do estado de São Paulo. *J Bras Pneumol*. 2017;43(2):121–8.
10. Barbosa CP, Griz SMS. Educação em saúde com vistas à triagem neonatal e audição: uma revisão integrativa. *Rev CEFAC*. 2014;16(2):643–50.
11. Tluczek A, Orland KM, Nick SW, Brown RL. Newborn Screening: an appeal for improved parent education. *J Perinat Neonat Nurs*. 2009;23(4):326–34.
12. Temme R, Gruber A, Johnson M, et al. Assessment of parental understanding of positive newborn screening results and carrier status for cystic fibrosis with the use of a short educational video. *J Genet Counsel*. 2015;24:473–81.
13. Sabarense AP, Lima GO, Silva LML, Viana MB. Characterization of mortality in children with sickle cell disease diagnosed through the Newborn Screening Program. *J Pediatr*. 2015;91(3):242–7.
14. Botkin JR, Rothwell E, Anderson RA, Rose NC, et al. Prenatal education of parents about newborn screening and residual dried blood spots a randomized clinical trial. *JAMA Pediatr*. 2016;170(6):543–9.
15. Chudleigh J, Buckingham S, Dignan J, et al. Parents' Experiences of receiving the initial positive Newborn Screening (NBS) result for cystic fibrosis and sickle cell disease. *J Genet Couns*. 2016;25(6):1215–26.
16. Arduini GAO, Balarin MAS, Da Silva-Grecco RL, De Marqui ABT. Knowledge of puerperal mothers about the Guthrie test. *Rev Paul Pediatr*. 2017;35(2):151–7.
17. Palmer SB, Bednarz SE, Dilaj KA, et al. Universal newborn hearing screening in midwifery education: a survey. *J Midwifery Women's Heal*. 2016;61(4):435–41.
18. Barbosa CP, Aires JB, Yasmin I, et al. Newborn and infant hearing health education for nursing professionals. *Braz J Otorrinolaryngol*. 2013;79(2):226–32.
19. Ryan DJ, Mikula EB, Germana S, et al. Screening for critical congenital heart disease in newborns. *Adv. Neonatal Care*. 2014;14(2):119–28.
20. Krishnan LA, Lawler B, Van Hyfte S. Parent educational materials regarding the newborn hearing screening process. *Int J Pediatr Otorrinolaryngol*. 2017;95:34–8.
21. Falkenberg MB, Mendes TPL, Moraes EP, et al. Educação em saúde e educação na saúde: conceitos e implicações para a saúde coletiva. *Ciência & Saúde Coletiva*. 2014; 19(3):847–852.
22. Evans A, LeBlanc K, Bonhomme N, Shone SM, et al. A Newborn Screening Education Best Practices Framework: Development and Adoption. *Int. J. Neonatal Screen*. 2019;5(2):22. DOI: 10.3390/ijns5020022.
23. Pimentel MCR, Figueiredo N, Lima MLLT. Construção e validação do Modelo Lógico do Programa de Triagem Auditiva Neonatal. *Rev CEFAC*. 2020;22(4):e14019