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INTEGRATIVE LITERATURE REVIEW

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EDUCAÇÃO EM SAÚDE DE PAIS E CUIDADORES PARA PREVENÇÃO DA SÍNDROME DA MORTE SÚBITA EM LACTENTES

Health education for parents and caregivers to prevent sudden infant death syndrome

Educación para la salud de padres y cuidadores para prevenir la muerte súbita del lactente

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ABSTRACT

Objectives: to identify publications that address health education regarding the prevention of Sudden Infant Death Syndrome.

Method: integrative review carried out in PubMed, Portal Periódicos da Coordenação de Aperfeiçoamento de Pessoal de Nível Superior, Cochrane Reviews, Scientific Electronic Library Online and the Biblioteca Virtual em Saúde. Publications in english, spanish and portuguese were included, without time frame, available for free, that addressed health education on sudden infant death syndrome, regardless of design. Those whose population was premature, duplicity, gray literature and editorials were excluded.

Results: two categories of analysis were identified, namely: topics of health education and barriers and facilitators of adherence to prevention recommendations. The health professional should encourage good health practices, identifying barriers and facilitators for adherence to recommendations. The approach must be done in a collaborative and in accessible language to facilitate communication and bonding between the parties. **Conclusion:** the professional must be sensitive to the idea that every baby may be at potential risk and, therefore, must use the tools and strategies available to take this individual out of a situation of vulnerability- if any.

DESCRIPTORS: Sudden infant death; Prevention; Health education.

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RESUMO

Objetivo: identificar publicações que abordam a educação em saúde relacionada à prevenção da Síndrome da Morte Súbita em Lactentes. **Método:** revisão integrativa realizada no PubMed, Portal Periódicos da Coordenação de Aperfeiçoamento de Pessoal de Nível Superior, Cochrane Reviews, Scientific Electronic Library Online e a Biblioteca Virtual em Saúde. Incluíram-se aquelas nas línguas inglesa, espanhola e portuguesa, sem recorte temporal, disponíveis gratuitamente, independentemente do delineamento. Excluíram-se duplicidades, literatura cinzenta, editoriais e cuja população eram prematuros. **Resultados:** identificou-se duas categorias de análise: temas para educação em saúde e barreiras e facilitadores de aderência às recomendações de prevenção. O profissional de saúde deve estimular as boas práticas de saúde, identificando barreiras e facilitadores para a adesão às recomendações. **Conclusão:** o profissional deve trazer a ideia de que todo bebê tem risco potencial para a síndrome da morte súbita e utilizar as estratégias disponíveis para tirá-lo da situação de vulnerabilidade.

DESCRITORES: Morte súbita do lactente; Prevenção; Educação em saúde.

RESUMEN

Objetivos: identificar publicaciones que aborden la educación para la salud sobre la prevención del Síndrome de Muerte Súbita del Lactente. **Método:** revisión integrativa realizada en PubMed, Portal Periódicos da Coordenação de Aperfeiçoamento de Pessoal de Nível Superior, Cochrane Reviews, Scientific Electronic Library Online y lá Biblioteca Virtual em Saúde. Se incluyeron publicaciones en inglés, español y portugués, sin límite de tiempo, disponibles de forma gratuita, que abordarán la educación en salud sobre síndrome de muerte súbita del lactente, independientemente del diseño. Se excluyeron aquellos cuya población fue prematura, duplicidad, literatura gris y editoriales. **Resultados:** se identificaron dos categorías de análisis, a saber: temas de educación para la salud y barreras y facilitadores de la adhesión a las recomendaciones de prevención. El profesional de la salud debe incentivar las buenas prácticas de salud, identificando barreras y facilitadores para la adherencia a las recomendaciones. El acercamiento debe hacerse de forma colaborativa y en un lenguaje accesible para facilitar la comunicación y el vínculo entre las partes. **Conclusión:** el profesional debe ser sensible a la idea de que todo bebé puede estar en riesgo potencial y, por lo tanto, debe utilizar las herramientas y estrategias disponibles para sacar a ese individuo de una situación de vulnerabilidad, si la hay.

PALABRAS CLAVE: Muerte súbita del lactente; Prevención; Educación en salud.

INTRODUCTION

Sleep is essential to human life and, especially in the newborn, it is characteristic of this intense moment of brain activity, with the development of cognitive and psychomotor areas.¹ In this sense, parents or caregivers should be aware of the baby's environment and positioning, since certain behaviors can offer risks of aggravation such as suffocation, strangulation, and the Sudden Death Syndrome in Infants (SIDS), subject of this review.²

SIDS is any sleep-related death that is sudden and unexpected, occurs during the first year of life, and for which the cause of death is not clear after a review of the clinical history, physical examination, necropsy, and examination of the site of death.³ In developed countries, SIDS is the leading cause of death in infants, with the highest risk between the second and fifth months of life, with more than 3,500 cases per year in the United States.⁴ In Brazil, there is no official data on the incidence of SIDS.³

SIDS rates declined by 45 percent between 1980 and 1988, coinciding with the American Academy of Pediatrics (AAP) recommendation, "The ABCs of Safe Sleep," that babies should sleep alone, on their backs, and in a crib.⁴ In addition, the "Back to Sleep: Now Safe to Sleep" campaign of the National Institutes of Health in the United States has played an important role in promoting other sleep-related protective measures, such as sleeping on a firm surface, away from soft objects, sharing a room with parents, and others.⁴

Despite these measures, studies have shown that the prevalence of sleep-related risk behaviors remains high and stable.^{5,6} There-

fore, this study aimed to identify publications that address health education for parents and caregivers regarding SIDS prevention.

METHOD

This is an integrative review adapted to the recommendations of the Preferred Reporting Items for Systematic Reviews (PRISMA-ScR). Integrative reviews facilitate the identification of knowledge on a specific topic to identify, analyze and synthesize the results of independent studies on the same topic.⁷

The review question was developed using the PIC strategy, with the following mnemonic elements as basic elements P- population/medical condition; I- the phenomenon of interest; Co-context. To search for results, the following were defined as P- sudden infant death syndrome; I- prevention; Co- health education. The review question adopted was: What has been published about parent/caregiver health education for the prevention of SIDS?

We considered eligible studies, freely available, dealing with the prevention of SIDS with an emphasis on health education, regardless of design and without a time frame, until the date of selection (May 2022). Those in which the population was pre-term infants were excluded, as were duplicates, grey literature, or editorials.

The databases consulted were PubMed, Portal Periódicos da Coordenação de Aperfeiçoamento de Pessoal de Nível Superior

(CAPES), and Cochrane Reviews. In addition, the Scientific Electronic Library Online (SciELO) and the Virtual Health Library (VHL) were used. In the search strategies for each electronic database, descriptors controlled according to the Health Sciences Descriptors (DeCS/MeSH) were used with the Boolean operator "and": ("sudden infant death syndrome" AND "health education" AND "sleep" AND "prevention"); ("sudden infant death syndrome" AND "health education" AND "sleep" AND "prevention"); ("muerte súbita del lactente" AND "educación para la salud" AND "sueño" AND "prevención"). After identification, the results were exported to the Rayyan application of the Qatar Computing Research Institute (QCRI), where the selection process was performed.

After excluding duplicates, the articles were independently selected by two reviewers for further reading of the title and abstract. Those that met the eligibility criteria and had consensus among the reviewers were read in full for inclusion or exclusion from the review.

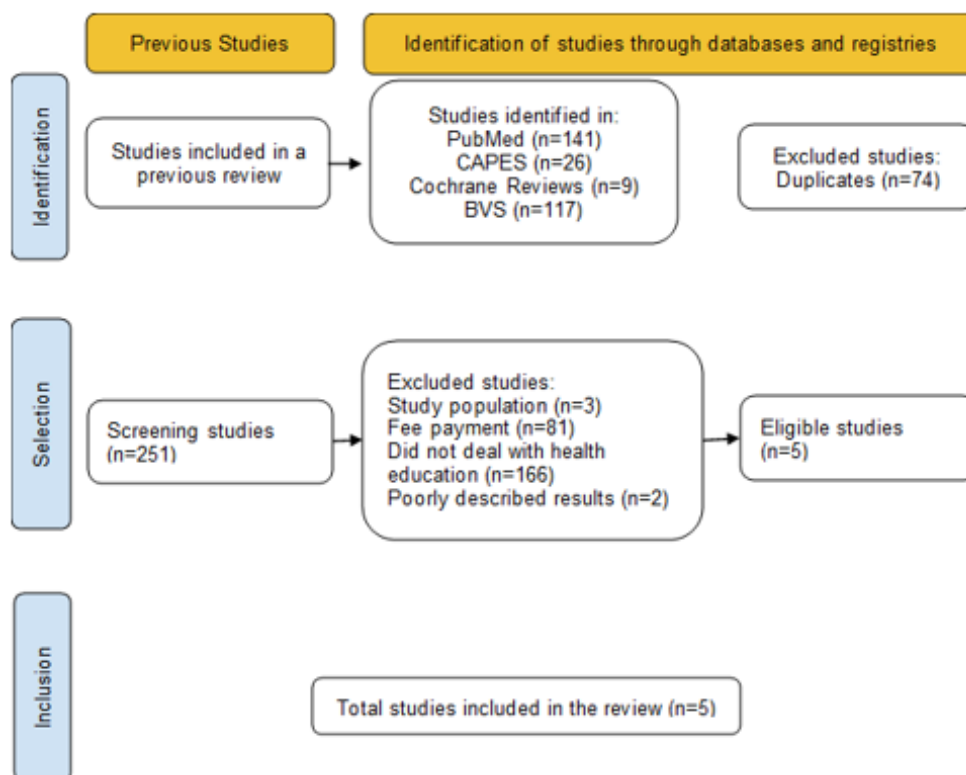
The included studies had their data summarized (Chart 1), identifying: the title, author, year and country of publication, type

of study, and methodological quality -according to the pyramid of evidence proposed by CAPES- and main results.

RESULTS

Five studies were selected for this review, as described in the following flowchart (Figure 1):

Figure 1 – Preferred Reported Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA- ScR) Flowchart, 2020 adapted to studies selection. Niterói, RJ, Brazil, 2022



Source: The Authors, 2022.

Chart 1 – Studies selected for review. Niterói, RJ, Brazil, 2022

Id.*	Title	Author and Year	Country	Main Results
A1	Sudden Infant Death Syndrome: do parents follow the recommendations?	Botia IR; Peñarroya PC; Left AD; Sanchez JMM; Santamaria AB, 2020	Spain	Campaigns to raise awareness and prevention of SIDS are needed, as well as to disseminate current evidence of risk and protective factors among health professionals and communicate this information to families so that they can integrate it into decision-making
A2	A hospital-based initiative to reduce postdischarge sudden unexpected infant deaths	Krugman SD; Cumpsty F; Carolyn J, 2018	United States	Education by all nursery staff has the potential to play a role in reducing sleep-related deaths in babies born in the hospital
A3	Preventing sudden infant death syndrome and other sleep-related infant death	Maged M; Rizzolo D, 2018	United States	Education efforts should specifically target high-risk populations that do not adhere to safe sleep recommendations
A4	Safe infant sleep interventions: what is the evidence for successful behavior change?	Moon RY; Hauck FR; Colson ER, 2016	United States	It is important and useful to carry out formal evaluations that include both quantitative and qualitative components so that interventions are more easily translated to other communities
A5	Impact of an educational intervention to improve adherence to the recommendations on safe infant sleep	Rivarola et al, 2016	Argentina	There was a 35% increase in the position of sleeping in dorsal decubitus ($p < 0.0001$); exclusive breastfeeding increased by 11% ($p = 0.01$); and sleeping together decreased from 31% to 18% ($p < 0.0005$)

*Identification

Source: The Authors, 2022

After reading the articles, two categories of analysis were identified: Health education topics ($n=3$) and barriers and facilitators to adherence to prevention recommendations ($n=2$). The categories that emerged from the review were constructed from the analysis of the themes listed in the selected studies.

Health education topics

SIDS has a heterogeneous pattern of occurrence, i.e., the epidemiologic profile of the disease cannot be precisely defined, which should be considered in health education.⁸ There are socioeconomic characteristics that can be seen in more than one locality, but it is not a rule and therefore the number of studies to describe them in different scenarios.

A3 highlights Filiano and Kinney's triple risk model, which suggests that SIDS can occur in infants with (1) intrinsic vulnerability (e.g., brainstem anomaly), (2) who experience an external stressor (e.g., airway obstruction) during a (3) critical developmental period. Thus, the overlap of these risk factors would increase the risk of SIDS.⁸ Of all these factors, the authors point out that the most critical are the external stressors, which are amenable to change and where parental and caregiver health education efforts should be more focused.⁸

For example, A2 describes a risk reduction quality improvement project that analyzed the reduction of SIDS deaths in a unit. The authors hypothesized that focusing on the actual number of SIDS deaths would provide significant motivation for the nursing team to invest in a culture change within the unit.⁹ The project consisted primarily of increasing education about safe sleep practices for newborns for all parents. The title of the intervention was "Baltimore County Health Department's Safe Sleep Alert for Injury Prevention: Healthy Babies Are Dying. Recognizing that the distribution of educational materials, while important and necessary, was not sufficient to influence behavior change, they committed to increasing exposure to health

education for the nursery.⁹ In a second moment, after realizing that nurses were inconsistent in promoting safe sleep, HHEARS assessed nursery, neonatal intensive care unit, and pediatric emergency room staff. Only 44% of the staff responded to the questionnaire.⁹ Doctors and nurses reported less willingness to influence parents on recommendations.⁹

Frontline staff, including auxiliary staff, believed that their behavior and knowledge could influence parents about child safety.⁹ Finally, a mandatory infant sleep education module was created for all nursery and ward staff.⁹ In addition, a video and pledge were formulated for parents to commit to always placing their children in a safe position during sleep (alone, in the crib, and on the bench).⁹ In 2011, this pledge became part of the users' electronic medical records.⁹ During the intervention, SIDS deaths went from 1 to 584 deliveries. After the intervention ended, it went from 1 to 1420 deliveries.⁹

Although scientifically based education and intervention strategies are available, some babies continue to sleep in environments with potential risk for SIDS.⁸ In A3, the authors emphasize that the health professional can identify risk factors through a good social/family history and physical examination, in addition to playing the role of health educator, encouraging adherence to recommendations. In this approach, the positioning of the baby during sleep, promotion of breastfeeding, room sharing and non-sharing of the bed, arrangement of soft objects and bedding in the sleeping area, exposure to cigarette smoke during and after pregnancy, and overheating of the baby should be highlighted.⁸

In A5, to determine the impact of an educational intervention at 60 days of life, health professionals were trained to provide information to families on safe sleep practices.¹⁰ Counseling sessions were developed, written materials and informational stickers were provided. positioning of the baby in the crib. Five hundred and fifty (550) newborns were included in the analysis,

from February 2014 to September 30, 2014.¹⁰ Three phases were conducted: 1- observation of baseline status, 2- educational intervention, and 3- observation of post-intervention status.¹⁰ Parents received instruction from trained professionals as a requirement for hospital discharge, in addition to the support of the "checklist" in the cribs in the form of an adhesive that included the AAP's key recommendations, according to the Safe to Sleep campaign. The classes were taught by pediatricians, authors of articles, and collaborators by the SIDS risk reduction guidelines of the AAP and the Argentine Society of Pediatrics.¹⁰ At the end of the intervention, there was a 35% increase in the number of babies sleeping in the supine position ($p < 0.001$), an 11% increase in exclusive breastfeeding ($p < 0.01$), and a decrease in bed-sharing from 31% to 18% ($p < 0.0005$).¹⁰ No changes were found in this study regarding room-sharing, living with tobacco users, and consequent exposure to smoke, or pacifier use.¹⁰

Barriers and facilitators in the adherence to prevention recommendations

In A4 they describe them in five groups. Firstly, innovation, i.e. the idea that the message must be feasible, credible, and accessible.¹¹ It is not interesting for the message to be coercive or prohibitive, since this can damage communication between the parties and make it difficult to comply with the recommendations.¹¹

Secondly, we have the professional who, as a holder of knowledge, must promote motivation for behavioral change.¹¹ However, it is observed that many do not believe that babies should sleep on their backs, for example, because of the same concerns of parents (suffocation, choking). In addition, there is no standard of care and evaluation for infant sleep practices in hospitals or daycare centers.¹¹

In addition, we have the caregiver, who in some situations does not have the financial means to buy a crib, has not been trained, or for some reason has the knowledge but does not act on it in attitudes and behaviors.¹¹

Fourth, we have cultural and family factors that may directly interfere with the choice of this parent/caregiver (an older relative who discourages a certain attitude, for example).¹¹ Attitudes and intentions may not be predictors of actual behavior, i.e., knowing what is right, but due to unforeseen barriers or external interference/disapproval, do not do so.¹¹ Finally, we have no regulations for safe sleep practices in child care, and often health education on the subject is not provided in maternity hospitals.¹¹

Botia et al. showed in their study ($n=640$ families) that only 41.3% of infants younger than 6 months and 59.7% of infants between 6 and 11 months of age slept in the recommended position, and only 6.4% of families followed the five recommendations analyzed (supine position, correct sleeping position, breastfeeding, use of non-nutritive sucking, and non-exposure to cigarette smoke).¹² In addition to the fact that a randomized clinical trial is the standard for testing interventions, it is diffi-

cult to conduct a randomized clinical trial in the SIDS setting for several reasons.

Another important point to address is that conducting a randomized clinical trial, the gold standard for testing an intervention, is difficult in the SIDS scenario for several reasons.¹¹ In addition to being expensive and time-consuming, there is no way to conduct them for ethical reasons (separating a prone control group and a supine control group and evaluating the results would be inappropriate) and the generalizability of the results is limited (would require a very large selection of people).¹¹

For these reasons, interventions are usually tested in observational studies, which do not allow causality to be defined and are more prone to bias.¹¹ The most common are pre- and post-intervention analysis studies, which make it difficult to know whether the results are sustainable over time if they are not followed up qualitatively and quantitatively over a reasonable period.¹¹

In A4, the authors emphasize that people are more likely to follow the recommendations if they understand the reason and the benefits of the actions.¹¹ The professional should be sensitive in approaching those who are more resistant, bringing to the fore the idea that every baby has a potential risk of SIDS.¹¹ This is necessary because the assessment of the personal risk of disease directly affects the likelihood of adherence to a behavioral change.¹¹

The approach is ideal if it is carried out at different levels and in different places and can be more effective than focusing on a specific scenario. Finally, it is useful for those implementing the intervention to carry out quantitative and qualitative analyses over an appropriate period, so that the processes are transparent and more easily transferable to other communities.¹¹

DISCUSSION

In the field of health, there is often a desire to improve technical and scientific knowledge so that care for patients, families, and the community can be qualified. SIDS continues to challenge our knowledge and practice. In terms of scientific production, much progress has been made in the knowledge of the mechanisms and risk factors that should be avoided.¹³ In the context of SIDS, a child is considered vulnerable if he or she has had little intrauterine growth and development, has immature neurological connections concerning the response to asphyxia, or is in the first year of life growth and neurodevelopment and exposure to risk factors. In this sense, the professional has a primary role in acting on these risk factors, removing the individual from a vulnerable place susceptible to the occurrence of this preventable disease, mainly through health education.

The Ministry of Health identifies health education as "a set of practices in the sector that contribute to ensuring the autonomy of people in their care and in the debate with professionals and managers to achieve health care according to their needs".¹⁴ It is a powerful tool for nurses to the extent that, by incorporating

educational activities in patient care, it improves nursing care and facilitates the creation of bonds between the parties.^{14, 15} This approach, if done in an accessible and collaborative way, facilitates the change in daily practices to promote health.¹⁵

Given this, it is important that nursing seek strategies to enable knowledge and remain persistent in the search for protection, promotion, and support for the health of infants and their families. The concern for the support of the individual must go through techniques aimed at a better understanding and communication between these parties to guarantee safe and quality care.¹⁵ Any effort in favor of the growth and development during the first year of life of the child is beneficial and promotes a more productive opportunity for a healthy life.¹³ Therefore, there is a need for training and updating of professionals involved in all areas related to neonatal/pediatric care.

In contrast, some healthcare professionals are unaware of safe sleep recommendations, while others are aware but do not implement them. The same could be said for families.¹³ A study conducted in South Dakota (USA) among pediatricians and family physicians showed that the proportion of safe sleep recommendations communicated by the healthcare team to parents and caregivers is low. In this study, physicians provided information on proper sleeping positions (81.2%) and breastfeeding (77.1%) as recommendations to reduce the risk of SIDS.¹⁶ The use of firm surfaces for the baby to sleep on (68.7%), the importance of not sharing a bed (54.2%), and room ventilation (35.4%) were less well-known.¹⁶ The authors also found that safe sleep instruction was associated with professionals with less than 15 years of experience, i.e., with more recent training.¹⁶ The study showed that despite knowledge of the risk factors for SIDS, there are gaps in the dissemination of information to new parents.¹⁶ This vulnerability highlights the need to strengthen parent and caregiver education strategies, in line with the recommendations of the AAP.¹⁶

Still, from the point of view of health education, a single and generic educational intervention is necessary, but not enough to influence a change in attitudes.¹³ In addition, most studies do not include a follow-up, making it impossible to analyze the retention of knowledge and practices in the long term.¹³ Moreover, according to DATASUS (BRAZIL, 2020), as in other countries, the highest number of births will take place in the hospital environment (2,684,834 births in 2020).¹⁷ These data show that the hospital environment is not only an excellent place to disseminate information on safe sleep and SIDS prevention but perhaps the most important one.

A study conducted in Colorado (United States) aimed to determine what factors influence infant sleep among adolescent mothers.⁵ A total of forty-three mothers were organized into seven focus groups, with 5-9 participants in each group.⁵ The organization allowed for discussion and exploration of opinions among the participants as they interacted more with each other.⁵ Participants in all groups shared that their sources of information included their mothers, teachers, and medical professionals, but that they tended to turn to professionals only

for medical concerns while seeking out parents and friends for more general questions about motherhood.⁵ Many mothers reported a natural "instinct" that allowed them to just "know" what to do, especially when faced with conflicting information.⁵ In this case, most participants said they were more likely to listen to their mothers, while others preferred medical advice.⁵ The vast majority explicitly stated that they were less likely to believe the pediatrician if the doctor did not have children, giving more weight to practical experience than to scientific knowledge.⁵ In terms of recommendations, almost all referred to the AAP's recommended sleep practices and understood that SIDS can happen to any baby, including the child.⁵ What draws the most attention in the study is the frustration and confusion about children's products, as many mothers believe there are no products in stores or they could not be offered for sale.⁵ Unsafe product options, primarily related to sleep, are not only available but are aggressively marketed.⁵ Among the beliefs about infant sleep, the study highlights: 1) maternal instinct for protection (the belief that they are safer and more protected); 2) bed-sharing is an opportunity to strengthen bonds with the infant; 3) ease of breastfeeding; 4) belief that the child will sleep better and, consequently, the mother will sleep better; and 5) feeling frequently judged by teachers, friends, doctors, and even family members.⁵

CONCLUSION

Most of the trials had to be excluded because of the payment of a fee. In addition, a few more robust studies were conducted. For ethical and cost reasons, the authors conducted more observational studies, which do not indicate a causal relationship and increase the risk of bias in the results. The present analysis is important to contribute to a possible beneficial impact on the quality of care provided to the patient.

It is concluded that the health professional has a fundamental role in promoting adherence to good health practices and in identifying the barriers and facilitators to adherence to recommendations. The entire healthcare team should be committed to knowing the most current best practices to reduce the incidence of SIDS, and to providing advice, especially to parents/caregivers who are resistant to these recommendations and to those at risk, regarding the positioning of the baby during sleep. The professional should use assertive, accessible language that encourages parental cooperation in seeking to promote and protect the infant. The team, as providers of assistance to the individual, should be encouraged by leaders and managers through initiatives and strategies to comply with infant sleep recommendations. Given the heterogeneous nature of SIDS, research that identifies the information that families have about SIDS can generate subsidies for nursing practice and the formulation of infant sleep protocols, especially in hospital care. In addition, the formulation of follow-ups of research results over an appropriate period can promote significant team motivation for cultural change within the industry. Related to this,

the distribution of educational materials based on scientific evidence is also of interest in the prevention of SIDS.

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