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Escola de Enfermagem Alfredo Pinto – UNIRIO

INTEGRATIVE REVIEW OF THE LITERATURE

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## EDUCATIONAL PRACTICES IN HEALTH WITH FAMILIARS OF CHILDREN WITH SPECIAL HEALTH NEEDS: INTEGRATIVE REVIEW

*Práticas educativas em saúde junto aos familiares de crianças com necessidades especiais de saúde: revisão integrativa*

*Prácticas educativas en salud con familiares de niños con necesidades especiales de salud: revisión integrativa*

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### ABSTRACT

**Objective:** to identify the scientific production on educational practices in health with familiars of children with special health needs. **Methods:** integrative literature review developed in five informational resources in January and February 2021. **Results:** nine articles were included in the qualitative synthesis, among which the majority were national, with descriptive methodological design and level VI of evidence. The health educational practices found were: group activities such as conversation circles and dialogue groups, educational technologies in booklet format, in addition to integrative practices such as massage and musical activities. **Conclusion:** the scientific literature on the adoption of educational practices in health that help home care for children with special needs and their familiars are still limited, indicating the need for productions that enhance this type of care. Thus, the development of new research and development of educational technologies aimed at this theme is suggested.

**DESCRIPTORS:** Health education; Family; Child health.

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## RESUMO

**Objetivo:** identificar a produção científica sobre práticas educativas em saúde junto aos familiares de crianças com necessidades especiais de saúde. **Métodos:** revisão integrativa da literatura desenvolvida em cinco recursos informacionais nos meses de janeiro e fevereiro de 2021. **Resultados:** incluíram-se nove artigos na síntese qualitativa, dentre os quais a maioria foi nacional, com delineamento metodológico descritivo e com nível VI de evidência. As práticas educativas em saúde encontradas foram: atividades grupais como rodas de conversa e grupos de diálogo, tecnologias educacionais em formato de cartilha, além de práticas integrativas como massagem e atividades musicais. **Conclusão:** a literatura científica sobre a adoção de práticas educativas em saúde que auxiliem o cuidado domiciliar às crianças com necessidades especiais e suas famílias ainda é limitada, indicando-se a necessidade de produções que potencializem esta modalidade de assistência. Assim, sugere-se o desenvolvimento de novas pesquisas e desenvolvimento de tecnologias educacionais voltadas para essa temática.

**DESCRITORES:** Educação em saúde; Família; Saúde da criança.

## RESUMEN

**Objetivo:** identificar la producción científica sobre prácticas educativas en salud con las familias de niños con necesidades especiales de salud. **Métodos:** revisión integradora de la literatura desarrollada en cinco recursos informativos en enero y febrero de 2021. **Resultados:** se incluyeron nueve artículos en la síntesis cualitativa, entre los cuales la mayoría fueron nacionales, con diseño metodológico descriptivo y nivel de evidencia VI. Las prácticas educativas en salud encontradas fueron: actividades grupales como círculos de conversación y grupos de diálogo, tecnologías educativas en formato folleto, además de prácticas integradoras como masajes y actividades musicales. **Conclusión:** la literatura científica sobre la adopción de prácticas educativas en salud que ayuden a la atención domiciliar de los niños con necesidades especiales y sus familias es aún limitada, lo que indica la necesidad de producciones que potencien este tipo de atención. Así, se sugiere el desarrollo de nuevas investigaciones y desarrollo de tecnologías educativas orientadas a esta temática.

**DESCRIPTORES:** Educación para la salud; Familia; Salud de los niños.

## INTRODUCTION

The United Nations (UN) estimates that, worldwide, there are at least 150 million children with some type of disability, represented by any structural, functional or psychic, physical or anatomical loss or abnormality.<sup>1</sup> Children with special health care needs (CSHCN) refers to a group of children who present clinical fragilities due to chronic, physical, developmental, behavioral, or emotional conditions. This group requires long-term rehabilitation follow-up and differentiated care from the multi-professional team at all levels of health care, due to the need for multiple, continuous, and complex care.<sup>2</sup>

According to care demands, CSHCN are classified into six types. The first, developmental, includes those with neuromotor muscle dysfunction, functional limitations, and disabilities. Technological care includes children using life-sustaining devices, such as gastrostomy, tracheostomy, colostomy, etc. In relation to medication care, there are those who make continuous use of drugs. In modified usual care, the child needs adaptations in daily care and activities of daily living. In mixed care, there is a combination of one or more demands, excluding technological ones. In clinically complex care demands, there is a combination of all the above including the management of life support technologies.<sup>3</sup>

A study published in 2014 estimated that 15% to 20% of US children between the ages of 0 and 17 had some special health need.<sup>4</sup> Although there are no epidemiological data on the number of CSHCN in Brazil, a study conducted in three cities (Santa

Maria/RS, Ribeirão Preto/SP and Rio de Janeiro/RJ) found a prevalence of 25.3% among children under 12 years.<sup>5</sup>

At home, these children require continuous care of complex nature, constituting challenges for their family caregivers. Therefore, it is necessary to incorporate new knowledge and practices into the families' daily routine so that they can continue the care and treatment safely and with quality.<sup>6</sup>

Under this view, the role of the health professional goes beyond the ability to develop and guide the technical procedures specialized to CSHCN. A consistent hospital discharge process is essential, involving an interdisciplinary work, coordinated by a discharge manager, to guarantee the integrated and articulated participation between professionals and familiars and the integrity of care, which includes health education with the families. In this process, the nurse's participation as an educator of these children's familiars stands out, especially as a mediator of the technological care learning.<sup>3</sup>

For this, it is required investment in the development of innovative educational strategies with the family, listening to them about their fears, doubts, needs and supporting them in overcoming their limitations and difficulties. In view of the above, it becomes necessary to gather and synthesize the available scientific production on the subject, in order to add knowledge for the development of quality and effective health educational practices by health professionals, especially nurses, based on the best scientific evidence. Thus, the objective of this study was to identify the scientific production on health educational practices with familiars of children with special health needs.

## METHOD

Integrative literature review, with the purpose of gathering and synthesizing the scientific knowledge already produced about the investigated theme. Data collection and analysis were carried out from the steps concerning the method.<sup>7</sup>

After identifying the theme, the PICO strategy was considered for formulating the research question, in which the P for population, in this study, corresponds to familiars/caregivers; the I, to the phenomenon of interest, considering children with special health needs, and the Co, to the context, considering the health educational practices. Thus, the research question was: What is the scientific production on health educational practices with familiars of children with special health needs?"

The inclusion criteria for the studies were: original research articles and studies that addressed educational practices for the population of families of children with special health care needs. The exclusion criteria were: duplicate publications, that is, for the same articles in more than one database only one was kept; studies related to educational practices directed to professionals; letters to the reader; dissertations; and publications in proceedings.

The literature review was conducted between January and February 2021 in the US National Library of Medicine from the National Institutes of Health (PUBMED), Cumulative Index of Nursing and Allied Health (CINAHL), Latin American and Caribbean Health Sciences Literature (LILACS), Brazilian

Nursing Database (BDENF), and Scientific Electronic Library Online (SciELO). The terms used in the search strategy are shown in chart 1. The Boolean operators AND and OR were used to adequately correlate the terms. We chose to filter the languages in Portuguese, English and Spanish to optimize the selection process and the full text reading of the studies. There was no time frame.

The search terms used, combined with the Boolean operators are exemplified in the search strategy below; Chart 1.

As a tool for data analysis, we built an analytical framework containing the title, journal, authors, year, place of publication, subject (object and objectives), methodology, and conclusions. The categories emerged from the themes addressed in the results and conclusions of the studies. The publications' level of evidence was also observed in order to determine the confidence in the use of the results of each study and to strengthen the conclusions that generate the current state of knowledge on the investigated theme, from the research design.<sup>7-8</sup>

The categorization of the evidence level was based on the Agency for Health care Research and Quality (AHRQ) categorization into seven classification levels: level 1, systematic review or meta-analysis of controlled clinical trials; level 2, well-designed randomized controlled trial; level 3, non-randomized controlled trial; level 4, well-designed cohort or case-control studies; level 5, systematic review of qualitative and descriptive studies; level 6, descriptive or qualitative studies; and level 7, opinion of authorities or experts.<sup>8</sup>

**Chart 1** – Search strategies in information resources. Niterói, RJ, Brazil, 2021

<b>P</b>	Familiars/ caregivers	(Family[mj] OR Family[tiab] OR Caregivers[mj] OR Caregiver*[tiab] OR Parents[tiab]) AND (Disabled Children[mj] OR Disabled Child*[tiab] OR Children with Disabilit*[tiab] OR "Children With Special Health Care Needs"[tiab]))	(Family OR Caregiver* OR Parents) AND ("Children With Special Health Care Needs" OR "Disabled Children" OR "Disabled Childrens" OR "Children with Disability" OR "Children with Disabilities")	(Family OR Familia* OR Caregiver* OR Cuidador* OR Parents)	(Family OR Caregivers OR Parents)
<b>I</b>	Child with special health needs	(Disabled Children[mj] OR Disabled Child*[tiab] OR Children with Disabilit*[tiab] OR "Children With Special Health Care Needs"[tiab]))	("Children With Special Health Care Needs" OR "Disabled Children" OR "Disabled Childrens" OR "Children with Disability" OR "Children with Disabilities")	("Children With Special Health Care Needs" OR "Disabled Children" OR "Disabled Childrens" OR "Criança com Deficiência" OR "Crianças com deficiências" OR "Niño con discapacidad" OR "Niño con discapacidades")	("Children With Special Health Care Needs" OR "Disabled Children" OR "Disabled Childrens" OR "Children with Disability" OR "Children with Disabilities")
<b>Co</b>	Educational Practices in Health	(Health Education[mj] OR Health Education[tiab] OR Health Promotion[mj] OR Health Promotion[tiab] OR Education[mj] OR Educational Practice*[tiab] OR Education[tiab] OR Teaching Materials[mj] OR Teaching Material*[tiab] OR Health Literacy[tiab])) AND (English[lang] OR Portuguese[lang] OR Spanish[lang])	("Health Education" OR "Health Promotion" OR Education OR "Teaching Materials" OR "Educational Practices" OR "Health Literacy")	("Health Education" OR "Health Promotion" OR Education OR "Teaching Materials" OR "Educação em saúde" OR "Promoção da saúde" OR "Materiais de Ensino" OR "Educación en salud" OR "Promoción de la salud" OR "Materiales didácticos" OR "Educational Practices" OR "Health Literacy" OR "Práticas Educacionais" OR "Alfabetização em Saúde" OR "Práticas educativas" OR "Alfabetización en salud")	("Health Education" OR "Health Promotion" OR TI(Education) OR "Teaching Materials" OR "Educational Practices" OR "Health Literacy") AND (LA English OR LA Portuguese OR LA Spanish)

## RESULTS

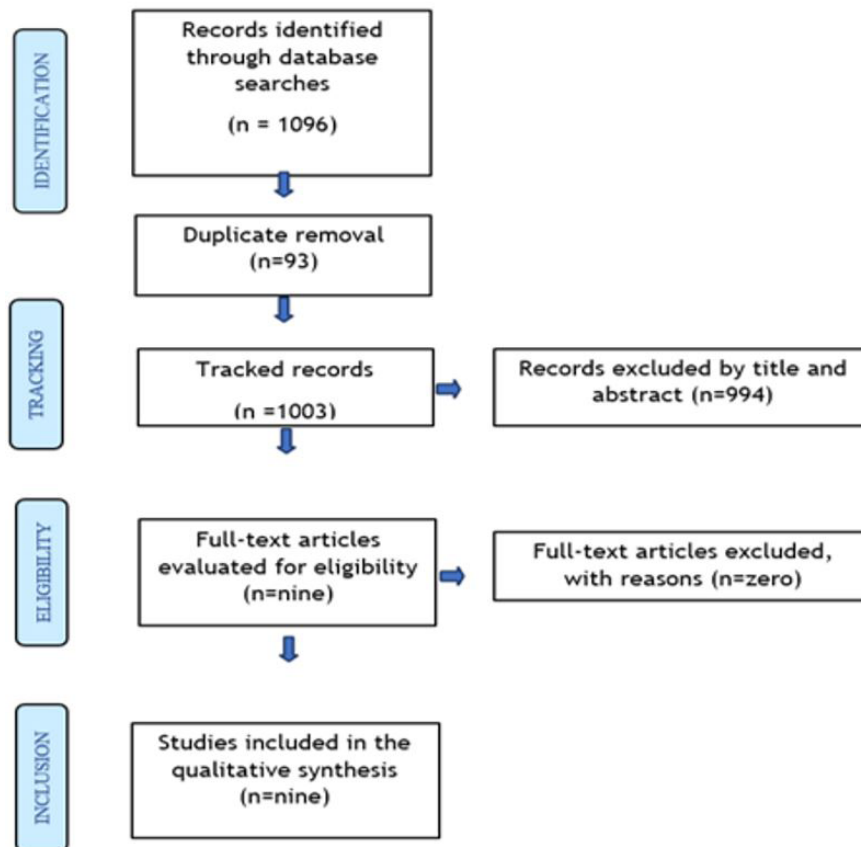
The search in the information resources initially captured 1,096 references, of which 723 were in PUBMED, 103 in LILACS, 27 in BDENF, 192 in CINAHL, and 51 in SCIELO. A total of 994 articles were excluded after the title and abstract were read. After this exclusion, 93 duplicate articles were excluded, nine studies were selected to be fully read, and all of them were included in the results of this review, as shown in Table 1.

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendation defined as a guideline that aims to help authors improve the quality of reporting of Systematic Review and Meta-Analysis data was used for study selection. PRISMA is composed of a 27-item checklist and a four-phase article selection flow diagram.<sup>9</sup> And it will be described in Figure 1.

The characterization of the selected studies, according to some variables of interest are represented in Chart 2.

**Table 1** – Number of articles obtained from informational resources. Niterói, RJ, Brazil, 2021

Databases	Articles Found	Excluded Articles	Selected Articles	Duplicate Articles	Total of analyzed articles
<b>PUBMED</b>	723	716	2	5	2
<b>LILACS</b>	103	72	3	28	3
<b>BDENF</b>	27	4	0	23	0
<b>CINAHL</b>	192	164	2	26	2
<b>SCIELO</b>	51	38	2	11	2
<b>Total</b>	1096	994	9	93	<b>9</b>



**Figure 1** – Prisma flowchart. Niterói, RJ, Brazil, 2021

**Chart 2** – Description of the studies included in the integrative review

Code	Results	Educational practice
A1 <sup>10</sup>	The familiars highlighted doubts about the child's transition from hospital to home. The conversation circle and the use of the doll favored the dialogue, the exchange of knowledge and experiences.	Conversation circle and use of a doll with attached devices
A2 <sup>11</sup>	Familiars highlighted several doubts related to the use of medications. The conversation circle favors the preparation of familiars to the discharge of CSHCN with demand for medication care.	Conversation circle
A3 <sup>12</sup>	The articulation of the Freirean method in group work was an important intervention in the facilitation process for adaptation in situations of chronic illness.	Space for exchange of experiences
A4 <sup>13</sup>	The pediatric units must promote spaces for dialogue, listening and learning that consider home care, and the training of nurses must transcend hospital practices and techniques.	Dialog, listening and learning spaces
A5 <sup>14</sup>	In the transition from hospital to home, it is up to the nurse to implement a dialogical educational process with the family caregivers of CSHCN.	Dialogical educational process, a listening and learning space
A6 <sup>15</sup>	The dialogical educational process is an appropriate strategy to prepare CSHCN familiars in hospital-home transition.	Dialogical educational process
A7 <sup>16</sup>	The educational technology (booklet) can contribute to the care of bedridden children and adolescents at home.	Educational material construction: Booklet
A8 <sup>17</sup>	Benefits highlighted included increased knowledge about 'disabilities' and greater understanding of the care for children with limiting conditions, more patience, greater confidence in their practice, adaptability and compassion.	Simple massage technique
A9 <sup>18</sup>	Co-creation involves music for health, which embodies the family's desire to do something meaningful together.	Musical co-creation

Seven studies were conducted in Brazil, one in England, and one in Norway. Regarding the year of publication, the oldest was published in 2008 and the most recent in 2020. As for the methodological design, 100% were descriptive, with level VI of evidence.

As for the participants in the studies, all were familiars of CSHCN and the educational practices are being carried out by nurses, except in studies A8 and A9, which involve the massage therapist and music therapist.

Of the nine studies, six use group activities as educational practice, one uses the booklet as educational technology, and two use integrative practices such as massage and musical co-creation.

The six studies found, A1, A2, A3, A4, A5 and A6, highlight the importance of dialogue, listening and learning spaces, as well as the conversation circle as an educational practice with familiars to assist in the caring of children with special health needs.

The study A1 proposes the conversation circle as an innovative educational practice capable of facilitating the development of contextualized and dialogic orientations in the preparation of CSHCN discharge, it also proposes the association with low fidelity simulation, when it uses the doll to demonstrate procedural techniques. The familiars participating in the research indicated the doll as a learning facilitator and the conversation circles favored the knowledge and experience exchange.

The A2 study used a conversation circle to problematize the doubts of familiars of CSHCN in relation to the use of continuous medications. During data collection, familiars were able to expose their doubts that were answered by the researchers, making possible the reflection of the families themselves about daily care and about the medications they prepare and administer in their

homes. This strategy of health education can help professionals in the preparation of familiars for the discharge of CSHCN with demand for medication care at home.

The article A3 discusses the importance of group work from an educational perspective as a space for experiences articulated with the Freirean method in the process of empowerment of families of children with special health care needs. The A5 study analyzed the educational demands of the familiars of CSHCN in the transition from hospital to home from group meetings and dynamics based on the Dynamics of Creativity and Sensitivity (DCS). Thus, it recommended the creation of listening spaces for familiars of children with special health needs to expose their fears, anxieties and feelings in the caring of these children in home environment.

Finally, article A6 shows that the dialogic educational process enables the sharing of knowledge and exchange of experiences, being accepted by family caregivers. Emphasizing, in this manner, the possibility of teaching and learning to feel more secure in relation to the caring of children with special health needs.

Study A7 proposed the construction and validation of a booklet for caregivers about the caring of children and adolescents dependent on home special care in order to improve the safety and quality of care provided to bedridden children and adolescents with irreversible diseases.

Article A8 proposes the instruction of the simple massage technique by the professional massage therapist to parents who care for children with life long and limiting conditions to contribute in the process of adaptation and confidence in this care.

Study A9 enabled the understanding of musical co-creation as a possibility of health educational practice in care instruction. Intervention proposed by a music therapist.

## DISCUSSION

The results of the studies showed that when CSHCN are discharged from the hospital, their families are faced with the need to perform care of different natures, which are necessary for the child's survival outside the hospital environment and this continuation of treatment requires some knowledge, in accordance.<sup>10-11</sup>

The transition from the hospital to the appropriate home, with the use of educational practices implemented in a procedural manner throughout the hospitalization period, enables the reduction of anxiety and increases the family member's confidence for care in home environment. Thus, it provides continuity of care at home, increases the rate of outpatient follow-up, and even reduces unnecessary hospitalizations.<sup>3</sup> In this way, the adequate preparation of caregivers for hospital discharge is essentially important, because allied to clinical fragility, the frequent hospitalizations of these children due to inadequately managed home complications can lead to the worsening of their health condition.<sup>6</sup>

In this directive, the findings pointed out that the conversation circles and the spaces for dialogue have been used by nurses as educational practices in the preparation of caregivers of technology-dependent children for hospital discharge. The results show these educational practices as strategies that promote dialogue, the raising of doubts and the exchange of knowledge and experiences among the participants. Its association with low fidelity simulation has the purpose of demonstrating procedural techniques.

According to the literature, the conversation circle is an educational and integrative method that enables dialogical encounters, creating possibilities of production and re-signification of meaning and knowledge about the experiences of the participants. It is known that the choice of this methodology is based on the horizontalization of power relations. The subjects that compose it implicate themselves, dialectically, as historical and social actors who are critical and reflective in the face of reality.<sup>19</sup>

Moreover, the home care of a CSHCN implies great challenges for caregivers, requiring frequent learning and improvement, including the incorporation of complex skills. In this sense, simulation is shown as a great potentiality in the training of these caregivers, since it allows the improvement of technical skills, as well as the assessment of clinical manifestations and the conduct in face of home complications.<sup>20</sup>

In the United States of America, there was a tendency to decrease hospital readmissions of children on home mechanical ventilation, up to seven days after discharge, after the implementation of a family preparation program, which used high fidelity simulation as one of its strategies.<sup>21</sup> Moreover, a simulation-based educational program provides the caregiver with knowledge and the ability to apply it in stressful situations, such as dealing with a complication at home.<sup>20,22</sup>

Educational technologies, such as the booklet described in article A7, are considered indispensable tools to increase

knowledge, satisfaction, adherence to treatment, and self-care in various populations such as patients with chronic diseases, children with gastrostomy, and aged patients, which is consistent with the current findings.<sup>23-25</sup>

In this way, the use of printed educational technologies is considered a viable tool to inform and sensitize the population, because it opens new paths of health promotion, in a shared construction of knowledge between professionals and the population, besides allowing the use of new resources in the practice of care.<sup>26</sup>

They also allow access to other intelligences and skills, since they use not only written language, but also images, music, signs, symbols, and games, being produced according to the population group they are aimed to, resulting in greater identification between users and health professionals.<sup>27</sup>

Nurses have used printed educational technologies in the health education process, given the ease they provide to mediate teaching-learning. It is also a resource readily available for the child and his family to consult in case of doubts in the development of care.<sup>28</sup>

The study A8 despite teaching an integrative practice such as massage by the massage therapist rather than the nurse, does not exclude the importance of this intervention in caring for caregivers and children. A number of beneficial gains were noted by therapists, including greater knowledge about 'disabilities' in general and a greater understanding of how to care for children with lifelong and limiting conditions, more patience, greater confidence in their practice, adaptability and compassion.

Musical co-creation, identified in study A9, can be seen as a health educational practice for families with children with special needs. Musical activities such as listening, playing, and composing also contribute to creativity, autonomy, exploration of feelings and longings, and reduction of isolation. Patients can express their feelings with the creation of songs through their own compositions or parodies of well-known songs, promoting mental health and well-being for the family in the care of children with chronic conditions.

Finally, the development of educational practices must permeate child care and actively involve familiars. In this direction, the construction of a truly dialogical is sought, making these practices inherent and inseparable to hospital care, in a perspective of action-reflection-action that raises awareness.<sup>29</sup>

## CONCLUSION

The scientific literature on the adoption of health educational practices that help in home care for children with special needs and their families is still limited, indicating the need for productions that enhance this type of assistance. The identification of few studies related to the theme, even without using a time frame, made it difficult to obtain results. The results found encouraged the adoption of educational practices aimed at the care of children with special needs, as well as the development of new researches on this theme.

Given this reality, it is the nurse's responsibility and commitment to build skills for health education. The adoption of educational actions by the nurse becomes even more primordial to provide quality of life to them and their families, who need support not only during the hospitalization process, but mainly because they are learning to deal with new changes in their lives, which do not end at this moment. After discharge, the familiars who will take over the complex care their children need to live, so the apprehension is great.

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