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HEALTH EDUCATION WITH FAMILIES OF CHILDREN WITH SPECIAL HEALTH NEEDS: LITERATURE REVIEW

EDUCAÇÃO EM SAÚDE COM FAMILIARES DE CRIANÇAS COM NECESSIDADES ESPECIAIS DE SAÚDE: REVISÃO DA LITERATURA

EDUCACIÓN EN SALUD CON FAMILIARES DE NIÑOS CON NECESIDADES ESPECIALES DE SALUD: REVISIÓN DE LA LITERATURA

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ABSTRACT

Objective: to analyze the scientific production about health education with family caregivers of children with special health care needs. **Method:** study of systematic review of literature, with a search in the LILACS and MEDLINE databases with the strategy: “children with disabilities” [Subject descriptor] and “health education” [Subject descriptor] and “Spanish” or “English” or “Portuguese” [Language] in June 2012. The analysis of production was based on thematic analysis. **Results:** two analytical categories emerged: Strategies of health education with family caregivers of children with special health care needs; and Contributions and educational actions for family caregivers of children with special health care needs. **Conclusion:** health education is considered an excellent strategy to perform the exchange of knowledge between the nursing staff and the family so that it can develop child care at home. **Descriptors:** Health Education; Family; Pediatric Nursing; Caregivers; Child Health.

RESUMO

Objetivo: analisar as produções científicas sobre educação em saúde com familiares cuidadores de crianças com necessidades especiais de saúde. **Método:** estudo de revisão de literatura, com busca realizada nas bases de dados LILACS e MEDLINE com a estratégia: “crianças com incapacidade” [Descritor de assunto] and “educação em saúde” [Descritor de assunto] and “Espanhol” or “Inglês” or “Português” [Idioma], em junho de 2012. A análise das produções pautou-se na análise temática. **Resultados:** emergiram duas categorias analíticas: Estratégias de educação em saúde com familiares cuidadores de crianças com necessidades especiais de saúde; e Contribuições das ações educativas para os familiares cuidadores de crianças com necessidades especiais de saúde. **Conclusão:** a educação em saúde é considerada uma excelente estratégia para realizar a troca de saberes entre a equipe de enfermagem e a família para que esta consiga desenvolver os cuidados com a criança no domicílio. **Descritores:** Educação em Saúde; Família; Enfermagem Pediátrica; Cuidadores; Saúde da Criança.

RESUMEN

Objetivo: analizar las producciones científicas sobre educación en salud con familiares cuidadores de niños con necesidades especiales de salud. **Método:** estudio de revisión de literatura, con busca realizada en las bases de datos de LILACS y MEDLINE con la estrategia: “niños con discapacidad” [Descriptor de asunto] y “educación en la salud” [Descriptor de asunto] y “Español” o “Inglés” o “Portugués” [Idioma] en junio de 2012. El análisis de las producciones se basó en el análisis temático. **Resultados:** surgieron dos categorías de análisis: Estrategias de educación en la salud con familiares cuidadores de niños con necesidades especiales de salud; y Contribuciones de las acciones educativas para los familiares cuidadores de niños con necesidades especiales de salud. **Conclusión:** la educación en salud se considera una excelente estrategia para realizar el intercambio de conocimiento entre el personal de enfermería y la familia para que se puedan desarrollar los cuidados con los niños en el hogar. **Descriptores:** Educación en la Salud; Familia; Enfermería Pediátrica; Cuidadores; Salud del Niño.

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INTRODUCTION

In Brazil, in recent years, occurred significant changes in the profile of child survival, a considerable increase in medically fragile children is verified, in chronic conditions and/or health disabling, called in Brazil as children with special health care needs. In the United States, this group is studied since the 1980s and was named by the *Maternal Children Bureau* as *children with special health care needs* (CSHCN) to designate children with delicate state of health, and the dependence of continued health care to survive.¹

CSHCN are characterized by the need for health care, and beyond the care of children in general, may present temporary or permanent disabilities and still be porters of a chronic disease: heart disease, kidney disease, lung disease, blood disorders, sequelae caused by long-term intensive therapy, such as disuse syndrome of some organs, blindness from retinal damage, deafness by environment noise excess and may present neuromuscular dystrophies.²

In this context, nurses, and other health professionals, should be aware of the needs of children and their families and work with all the care looking to ensure that these be attended. The nursing staff has an important role in the development of educational actions, assisting families to adapt to this new situation, making them aware of the provided care, as well as the promotion process and recuperation of health and quality of life.

Health education is an effective tool in the assimilation of the lived transformations. Therefore, it is necessary to perform educational practices through participatory methodology and dialogue between subjects, which allows reflection and awareness.³ From the dialogue and exchange of scientific and popular knowledge, professionals and users can build, in a shared way, a knowledge about the health-disease process. It is believed that health education is a process that happens, based on dialogue, covering the whole, completeness and continuity.⁴

The actions of health education are constituted in articulated strategies between the context of health and the possibility of generating attitudes of changes, from each health professionals, teamwork and many services seeking a transformation in the context of health population.⁵ In this context, care for CSHCN requires knowledge and skills of health professionals to meet the child with their demands and provide adequate support to family caregivers. The nurse is a

professional able to perform the care of CSHCN, using health education as a means of caring in nursing, as well as stimulating the knowledge, the skill and self-confidence among family members.

Starting from these considerations, the question is: What has been produced in the scientific literature about health education with CSHCN family caregivers? Thus, this study aims to analyze the scientific production about health education with family caregivers of CSHCN.

METHOD

Study of integrative review with descriptive approach. To systematize, the study was organized according to the following steps: delimitation of the subject and research problem; search for articles; definitions of information that would be analyzed; description of the results and discussion of findings.

The search was conducted through *online*, by the Virtual Health Library (VHL), in the bases LILACS (Latin American and Caribbean Literature on Health Sciences) and MEDLINE (International Literature on Health Sciences), in the month of June, 2012.

The following strategy was used: “children with disabilities” [Subject descriptor] and “health education” [Subject descriptor] and “SPANISH” or “ENGLISH” or “PORTUGUESE” [Language], without time frame. The choice of these descriptors is justified because children with special health care needs is not a descriptor and the fact that children with disabilities and or chronic disease are inserted in the group of CSHCN.

Five articles in LILACS and 25 articles in the MEDLINE database were found, totaling 30 productions. As inclusion criteria, the productions in article format were considered, available in full, *online* and free, with complete abstracts. As exclusion criteria, items not related to the proposed theme. After applying the inclusion and exclusion criteria, four articles in LILACS and 16 articles in MEDLINE were selected. Subsequently, the exhaustive reading of the articles in their entirety was performed, which remained three articles in LILACS and 12 articles in MEDLINE, for a total of 15 articles analyzed. A synoptic table was organized to facilitate the analysis containing the following information of the selected articles: code of production, journal, year, authors, and article title.

The productions were analyzed by Minayo thematic.⁶ This consists in discovering the meanings that compose the communication, whose presence or frequency means

something to the analyzed object. Thematic analysis consists in: pre-analysis, material exploration, processing of the obtained results and interpretation. The pre-analysis is the initial stage of the analysis of documents from the resumption of the initial hypotheses and research objectives. The exploration of the material corresponds to the time at which the data will be worked to better understand the text and the processing of results and

interpretation, interrelating with the theoretical framework designed, initially, or opening new leads around new theoretical dimensions, suggested by material reading.⁶

RESULTS

Hereafter, the productions analyzed in this study are presented, listed according to the code production, article title, author, method, level of evidence⁷, journal and year.

Code Productions	Title	Authors	Method	Evidence level	Year	Journal
A1	Empowerment of families of children dependent of technology: conceptual challenges and critical-reflexive education of Freire	Leite NSL, Cunha SR, Tavares MFL.	Qualitative	Level 4	2011	Nursing Magazine UERJ
A2	Family impact of a school for parents of children with disabilities	Fontanilles AMM, Vernal YR.	Qualitative	Level 4	2010	Medisan
A3	Care of children with special health care needs: challenges for families and pediatric nursing	Neves ET, Cabral IE.	Qualitative	Level 4	2009	Electronic Journal of Nursing
A4	Internet Use and Literacy and health of parents and low-income whose children have special health care needs	Knapp C, Madden V, Wang H, Sloyer P, Shenkman E.	Qualitative	Level 4	2011	Journal of Medical Internet Research
A5	It's our job: a qualitative study of family responses to Ableism	Susan LNB, Carolyn JG, Ruth JR, Heather RH, Jane SH.	Qualitative	Level 4	2010	Journal of Intellectual & Developmental Disability
A6	A backward look: Lessons of activism in the family and recommendations for addressing today's challenges to Oral Health for children with special health care needs	Anderson B.	Quantitative Descriptive	Level 4	2007	Pediatric Dentistry
A7	An information kit for parents of children and youth with special needs	Stewart D, Law M, Burke-Gaffney J, Missiuna C, Rosenbaum P, King G et al.	Qualitative	Level 4	2006	Child: Care, Health & Development
A8	Self Evaluation of the Experience with Transport Security of Children with Special Health: A Therapist Perspective of Rehabilitation	Blake E, Sherman K, Morris L, Garry Lapidus G.	Quantitative Descriptive	Level 4	2006	American Journal of Physical Medicine & Rehabilitation
A9	Family-centered service: moving ideas into practice	Law M, Teplicky R, King S, King G, Kertoy M, Moning T et al.	Qualitative	Level 4	2005	Child: Care, Health & Development
A10	Influence of an educational program about asthma in parents with children suffering asthma	Trollvk A, Severinsson E.	Qualitative	Level 4	2005	Nursing and Health Sciences
A11	Connection: a community health information, evaluation needs of Texas families who have children with chronic illnesses and/or disabilities and their carers	Huber JT, Dietrich JD, Cugini E.	Qualitative	Level 4	2005	Journal of the Medical Library Association
A12	How do carers of disabled children cope? The prospect of Uganda	Hartley S, Ojwang P, Baguwemu A, Ddamulira M, Chavuta A.	Qualitative	Level 4	2004	Child: Care, Health & Development
A13	Parents' needs for knowledge about the medical diagnosis of their children	Starke M, Möller A.	Qualitative	Level 4	2002	Journal of Child Health Care
A14	The information that inform rather than alienate families with children with disabilities: developing a model of good practice	Mitchell W, Sloper P.	Qualitative	Level 4	2002	Health and Social Care in the Community
A15	The needs of parents with chronically ill children: a literature review	Fisher HR.	Literature Review	Level 5	2001	Journal of Advanced Nursing

Figure 1. Productions list with identification according to the production code, article title, author, method, level of evidence, year and journal of articles analyzed in the study. Santa Maria, RS, 2014.

Among the 15 selected productions, related to the year of productions, it is noteworthy that, from the year 2001, there was a significant growth of productions, related to the thematic. In 2005 and 2010, there was a greater number of productions, totaling 40% (Figure 2).

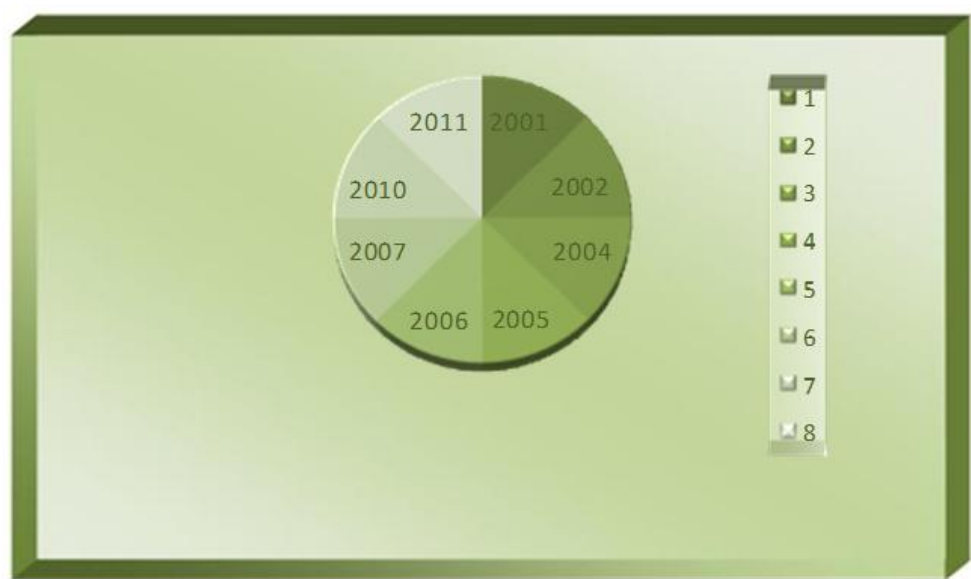


Figure 2. Frequency of productions, distributed by the year of publication. Santa Maria, RS. 2014.

Regarding to the country of origin of the articles, it is highlighted that 26.7% (n=4) were performed in the United States, 20% (n=3) in Canada, 13.3% (2) in Brazil and 13.3 % (2) in the UK; Cuba, Norway, Uganda and Sweden with 6.7% (1) each.

Regarding to the type of selected research studies, it is presented in Figure 3 below, the following frequencies by study type:

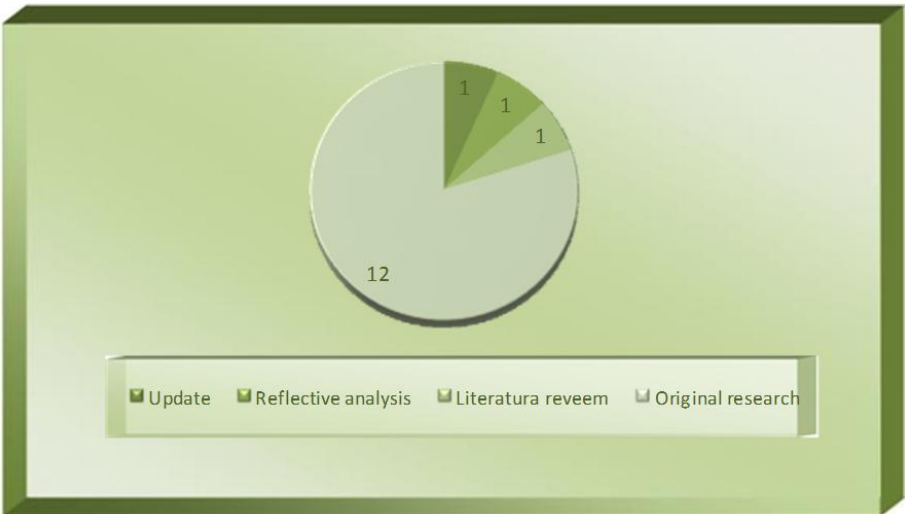


Figure 3. Distribution of productions according to the study type. Santa Maria, RS. 2014.

These results demonstrate that in the analyzed studies, 79% (n=12) are field research. In the research field, it is noteworthy that 92% (n=14) are qualitative researches and 8% (n=1) quantitative research.

Concerning the subarea of studies, these were produced by various professional areas, highlighting that publications in the field of nursing and medicine totalized 40%, plus productions in multidisciplinary team with 13.3%, and social work, psychology, special education and dentistry corresponded to 6.6% each.

Related to the productions scenario, a prevalence of surveys at home is verified, represented by 33.3% of the studies, and 13.3% were performed in the community and 13.3% in the hospital, and a total of 19.8 % corresponds to studies performed in the community/home, *online*, home/hospital, and 20% were not in the scene. The principal subjects of the research were family caregivers.

After reading the full articles, these were classified and grouped into categories according to thematic analysis. The categories that emerged were: Strategies of health education with family caregivers of children with special health care needs; and Contributions of educational actions for family caregivers of children with special health care needs.

- **Strategies for health education with family caregivers of children with special health care needs**

Some analyzed studies, showed several strategies that assist in the development of the actions of health education. Mediation of nursing care in different practice settings can contribute to the effectiveness of educational actions, since the family feel able to perform the care of children at home through horizontal relations between professionals and family.^{A1, A3}

The studies emphasize the importance of the performance of a multidisciplinary team developing programs, meetings, groups with families of children with special health care needs, enabling an exchange of knowledge among parents, family members and professional staff.^{A2, A6, A13} It is essential that health professionals perform updates related to the care of CSHCN, directed to family caregivers, especially emphasizing the emerging themes and needing a peculiar attention.^{A8}

The use of the Internet is referenced by the productions as a positive strategy for health education. The authors reported a large adhesion of this tool as a possible health education, as it allows to family caregivers, to access to various information and experiences providing to solve their questions in the daily care at home.^{A4, A11}

Besides the Internet, the use of information kits, brochures, booklets, manuals show to be valid for conducting health education. It highlights the importance of using these resources in planning educational actions, which can promote the family caregivers autonomy, capacity and ability to perform the care to CSHCN.^{A7, A9}

Although the strategies of health education, related to care CSHCN, focus the whole family, and mothers end up being the primary caregivers. With this, they receive the guidance and information, with an overload of responsibilities and activities related to the needs of the child.^{A1, A12, A13} Thus, the importance to develop a family-centered care is indicated as a strategy, and not just on a family caregiver.

• The contributions of educational actions for family caregivers of children with special health needs

From the findings, studies report that health education with a critical and reflective approach, enables the empowerment of families providing autonomy, power and security to confront and take appropriate decisions in the face of daily needs. Thus, empowerment seeks to turn families into critical subject of their actions, thus acquiring

greater independence of health professionals and system.^{A1, A5, A10}

Nurses, like other health professionals, should value the knowledge and experiences of family members, since they live daily and know the peculiarities related to childcare. Corroborating this idea, professionals and family members need to share their experiences so that the orientations and strategies can meet the needs of the family, considering the reality in which they are inserted. Parents recover control of their situation and therefore, feel able to request a partnership with health professionals.^{A14, A15}

DISCUSSION

The educational group actions represent opportunities for families of children, to appropriate the knowledge, skills and competences co-constructed.⁸ The co-construct and co-responsibility are processes that are inserted in its development, as the stimulus and autonomy, the ability to solve problems creatively, encouraging the uptake of material and human resources and the recognition of community space as a constant source of mobilization and resonance of work.⁹

It should be emphasized that nursing, as art, enables to perform their functions creativity, and multiplicity of alternatives, not generalizing their actions to a common community, while maintaining the peculiarities inherent in every being.¹⁰ To provide information is not enough, but to use strategies to manage and communicate information. The information kit, as other resources, is used as a tool for parents to communicate, interact and care for their children with special needs.¹¹

Therefore, the use of groups and/or meetings with the use of accessible language, enables family interactions among participants, where there is the socialization of experiences, doubts and ideas. It is therefore, fundamental to disease prevention and health promotion, contributing to the quality of life for all involved.¹²

Thus, it is essential to try to understand the universe of the student, their beliefs, values and habits, so that educational activities will be relevant to each individual. Otherwise, education is not based on livings/experiences of the other, becoming vertical, imposing and not comprehensive.¹³

In this context, the scientific and technological development in the present society, is causing constant changes in the workplace and therefore, requiring a professional profile more open and able to

adapt to changes, instructed and motivated to keep learning throughout their life.¹⁴

The intra and inter-sectoral articulation, promotes the constitution of a network of communication, actions and analysis, on micro and macro level, aiming at the optimization of sectors, institutions, organizations and community, aimed at full health and well-being of the population.⁹

The internet is considered a good source of dissemination of health information, making it an instrument to facilitate the promotion and health education.¹⁵ Nowadays, the internet is the most complete and complex source of information, and is increasing its use for obtaining health information.¹⁶

The overload that falls on the shoulders of the mother, as the primary caregiver of a child with a chronic health problem, often causes the same pass to develop strategies for dealing with new contexts and new demands that life imposes. This, in turn, represents a stimulus for her to feel able and available for learning. In this support and caregiver support process, it is essential to develop a supportive home infrastructure, aiming to avoid the natural wear, caused by fatigue and stress associated with this charge.¹⁷ Therefore, it is essential to include the parents, as well as other family members in the orientations and their own involvement in care.

For this, the educator must understand that teaching is not to transfer knowledge, but to create possibilities for its production and construction, enabling the learner to awaken curiosity, making it increasingly more creative.⁴ The empowered caregiver can ensure a quality care for the child, take shared decisions with professionals and be effectively included in the care process.²

CONCLUSION

From this study, it was found that the tendency of production is focused on the family and the child's illness. It was noticed that most publications is international and only two are Brazilian. This is due to the fact that this clientele, although emerging in Brazil, does not have any visibility in epidemiological rates. Therefore, despite its clinical fragility and social vulnerability, does not have a structured and specific public policy for these children.

It was identified a gap in relation to the preparation of family caregivers in hospitals so that they can continue the treatment and care in the home environment. In this sense, it is necessary that the nurse is prepared to attend to this demand, involving the family in this context.

Studies have shown that health education is considered an excellent strategy to perform the exchange of knowledge between the nursing staff and family, so that this can develop child care at home. Educational actions enable a horizontal relationship between user and professional, in order to seek shared solutions to the presented challenges. Therefore, the pediatric nursing is facing a variety of demands on care and CRIANES in order to meet the needs of family caregivers.

It is recommended that constant training of health professionals, especially the nursing staff that need to pay attention to these clients and their families, who are the main carers of C SHCN. As the importance of developing support groups and programs of health education in different practice settings (hospital, clinic, community, home) so that relatives have a follow up and feel empowered.

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