



**FAMILY HOME CARE TO THE CHILD WITH CHRONIC DISEASES: AN
INTEGRATIVE REVIEW**
**CUIDADO FAMILIAR EM ÂMBITO DOMICILIAR À CRIANÇA COM DOENÇAS CRÔNICAS:
REVISÃO INTEGRATIVA**
**CUIDADO FAMILIAR EN EL HOGAR AL NIÑO CON ENFERMEDADES CRÓNICAS: UNA REVISIÓN
INTEGRADORA**

Denise Maia Leão¹, Andressa da Silveira², Elisa de Oliveira Rosa³, Rodrigo de Souza Balk⁴, Neila Santini de Souza⁵, Odete Messa Torres⁶

ABSTRACT

Objective: analyzing, in the national and international literature, family care to children with chronic diseases. **Method:** an integrative review, with a view to answering the guiding question << *What are the scientific evidences on the care practices developed by the family / caregiver in the home environment to children with chronic illness?* >> The research was conducted in LILACS and BDENF databases, employing the descriptors: home care, family and child. To analyze the articles we sought to the nuclei of meaning that make up the corpus of 15 selected articles. **Results:** excelled in caring the maternal figure. The predominance of studies at home and productions those aimed to understand how it is managed, experienced and perceived by the family care for children with chronic illness framework. **Conclusion:** evidently, the presence of family in the implementation of home care, while providing continuous care, this may feel unprepared to care for a sick child, due to poor knowledge about the disease, jeopardizing the achievement of general care and complex procedures. **Descriptors:** Home Care; Family; Child.

RESUMO

Objetivo: analisar, na literatura nacional e internacional, o cuidado familiar de crianças com doenças crônicas. **Método:** revisão integrativa, com vistas a responder a questão norteadora << *Quais as evidências científicas sobre as práticas de cuidado desenvolvido pelo familiar/cuidador no âmbito domiciliar à criança com doença crônica?* >> Foi realizada a busca nas bases de dados LILACS e BDENF, empregando os descritores: assistência domiciliar, família e criança. Para a análise dos artigos buscou-se os núcleos de sentido que compõem o *corpus* de 15 artigos selecionados. **Resultados:** destacou-se no cuidado a figura materna. Predomínio de estudos no âmbito domiciliar e produções que objetivaram compreender como é gerenciado, vivenciado e percebido o cuidado pela família à criança portadora de doença crônica. **Conclusão:** evidenciou-se a presença da família na execução dos cuidados domiciliares, embora prestem cuidados contínuos, esta pode sentir-se despreparada para cuidar de uma criança doente devido ao precário conhecimento sobre a doença, comprometendo a realização de cuidados gerais e procedimentos complexos. **Descritores:** Assistência Domiciliar; Família; Criança.

RESUMEN

Objetivo: analizar, en la literatura nacional e internacional, el cuidado familiar de niños con enfermedades crónicas. **Método:** una revisión integradora, con el fin de responder a la pregunta guía << *¿Cuáles son las evidencias científicas sobre las prácticas de atención desarrolladas por la familia / cuidador en el entorno del hogar para niños con enfermedades crónicas?* >> La búsqueda se realizó en las bases de datos LILACS y BDENF, empleando los descriptores: cuidados en el hogar, la familia y el niño. Para el análisis de los artículos buscó se los núcleos de significados que componen el corpus de 15 artículos seleccionados. **Resultados:** se destacó en el cuidado la figura materna. El predominio de los estudios en el país y producciones que tuvieron como objetivo comprender cómo se gestiona, experimenta y percibe se el cuidado de la familia para los niños con enfermedades crónicas. **Conclusión:** se evidenció la presencia de la familia en la aplicación de cuidados en el hogar, mientras la prestación de atención continua, esta puede sentirse despreparada para cuidar a un niño enfermo, debido al escaso conocimiento de la enfermedad, poniendo en peligro la consecución de los cuidados generales y los procedimientos complejos. **Descriptor:** Cuidados en el hogar; Familia; Niño.

¹Graduate student, Nursing College, Federal University of Pampa / UNIPAMPA. Uruguaiiana (RS), Brazil. Email: niseleao@gmail.com;

²Nurse; Master Teacher of Nursing, Nursing College, Federal University of Pampa / UNIPAMPA; Doctoral student, Postgraduate Program in Nursing, Federal University of Santa Maria / UFSM. Santa Maria (RS), Brazil. Email: andressadasilveira@gmail.com ³Graduate student, Nursing College, Federal University of Pampa / UNIPAMPA. Uruguaiiana (RS), Brazil. Email: elisarosa94@hotmail.com; ⁴Physiotherapist; Professor of Toxicological Biochemistry, Federal University of Pampa / UNIPAMPA. Uruguaiiana (RS), Brazil. Email: rodrigo.balk@gmail.com; ⁵Nurse; Professor, Nursing College, Federal University of Pampa / UNIPAMPA, Doctorate in Nursing - Dinter Unifesp / UFRJ / UFSM. São Paulo (SP), Brazil. Email: neilasantini@hotmail.com; ⁶Nurse; Professor, Nursing College, Federal University of Pampa / UNIPAMPA; Doctoral Student of Nursing - Dinter Unifesp / UFRJ / UFSM. São Paulo (SP), Brazil. Email: odetetorres@gmail.com

INTRODUCTION

In 2011 was approved the Ordinance 2.488 of the National Primary Care Policy (BANP), setting the review and redefinition of guidelines and standards for the organization of primary care and home care.¹ Home care aims to providing technical and structural support to the family of the patient to return home by providing conditions to occur the rehabilitation of child health.² In this context, health professionals, especially nurses, should support the family in coping with chronic illness.²

A chronic health condition is one whose condition lasts for more than three months,³ affects the daily activities of the child, and requires care at home, persisting for an extended period of slow progress. Chronic diseases can be still called Chronic Non-Communicable Diseases (NCDS),³ seen as a global health problem that threatens the health and human development. In Brazil it is estimated that NCDS account for 72% of total deaths.³⁻⁴

It is noted that there was an increase in mortality from chronic disease among children aged one to nine years old, mainly in Brazil and in Latin America and in the Caribbean.⁵ Chronic diseases do not generate immediate mortality in children, however, lead the various types of gravity, may be asymptomatic way indefinitely and / or manifesting only in acute events.³⁻⁵ Depending on the level of exacerbation of symptoms, the presence of chronic diseases in childhood promotes organic, emotional, social structural changes and requiring intensive care and adaptation of housing context by the familiar caregiver.⁶

It is considered a caregiver the person that most directly develops care⁵continuously and may or may not be a family member. Whereas the caregiver is directly involved in daily child with chronic diseases, it is necessary to agree upon knowledge, valuing prior knowledge of these caregivers.

Exercising daily family care is a key element for the care of its members; in particular for the most dependent individuals as those with chronic diseases.⁷ The family has a direct influence on the health of the patient, contributing⁵⁻⁷ as a partner in improving practices and effectiveness of care. It can be understood as a group of individuals who are united by emotional ties and the feeling of belonging to this group and who identify as members of that family.^{5,7}

OBJECTIVE

- Analyzing in the national and international literature, family care of children with chronic diseases.

METHOD

It was selected as a method of the features of evidence-based practice⁹⁻¹⁰, integrative review, specific method, which summarize the past of empirical or theoretical literature, to providing a more comprehensive understanding of a particular phenomenon.⁸ The integrative review enables synthesis of published studies, allowing the generation of new knowledge grounded⁹⁻¹⁰ in results presented by previous researches.

To review the development of six steps, there were performed: the first step was to define the guiding research question, in the second stage there were delimited the criteria for inclusion and exclusion, and in the third stage there were elected the databases and made the search of scientific productions, in the fourth stage data analysis was performed at the fifth stage was developed the data discussion, and at the sixth stage was presented the synthesis of the review.¹⁰

The guiding question of the study was: what scientific evidence on the care practices developed by the family / caregiver in the home environment to children with chronic illness?

Thus, there were employed the inclusion criteria: articles to make available the full text, articles with the online version freeway, national and international productions, published in Portuguese, Spanish or English. The delimited timeline were the years 2006-2013 in order to portray the scientific production today. There were excluded theses, dissertations, monographs and articles that after reading the summary did not converge with the object of the proposed study, apart from publications that were repeated in the databases.

The search was performed by two reviewers, ensuring rigor in the selection process on the basis of Articles of Latin American Literature data and Caribbean Health Sciences (LILACS) and Database of Nursing (BDENF) in the second half of 2013, with standardized and available Descriptors in Health Sciences Headings (MeSH): "home care" [and] "Family" [and] "child".

After reading the titles and abstracts, the selected studies were analyzed using an already validated instrument, evaluating data relating to the identity of the original article,

methodological characteristics of the study, assessment of the methodological rigor of interventions measured, and the results found in articles to the journal, author, study and level of evidence⁹: 1 - systematic reviews or meta-analysis of relevant trials; 2 - evidence from at least one randomized controlled trial well-designed; 3 - well-designed clinical trials without randomization; 4 - cohort studies and well-designed case-control; 5 - systematic reviews of descriptive and qualitative studies; 6 - evidence derived from a single descriptive or qualitative study; 7 - opinion of authorities or expert committees including interpretations of information not based on research.¹⁰

Through thematic analysis or categorical technique type of content analysis⁸, operated from dismemberment of text units (categories) according to analog systematic regrouping.⁸

The analysis is constituted by reading the 15 articles selected, subsequently sought to discover the meaning clusters that make up the corpus of the study, concerned with the

frequency of these cores, in the form of targetable data and the like where they underwent further analysis and it fell into two categories respectively: Adaptation of the nuclear family for the care of children with chronic illness and Home care and Family autonomy.

RESULTS

The results showed that 12 (76,92%) of the titles of scientific publications had focused on family and child care experience and three (23,07%) with an emphasis on networks of attention to child health.

In relation to the timeline of the studies, the highlights were the years 2007, 2008 and 2009 respectively with three (23,07%) of the findings each. Followed by the year of 2012 with two findings and the years of 2006, 2010, 2011 and 2013 with an article (7,69%), there are 12 publications (76,92%) presented evidence level VI, according to figure 1.

Code	Title	Authors	Method	Evidence level	Year of publication
A1	Care of children with congenital anomaly: the family experience	Bolla,BA Fulconi, SN Baltor, MRR Dupas, G.	Narrative interviews, which, after systematic transcription, were then to assume the family experience.	VI	2013
A2	Facilities and difficulties of the family in caring for the child with cerebral palsy	Dantas, MAS Pontes, JF Assis, WD Collet, N.	Qualitative, exploratory, descriptive, aimed to seize the advantages and difficulties of the family in caring for children with cerebral palsy.	V	2012
A3	Impositions and conflicts in every day life of the families of children with chronic diseases	Nóbrega,VM Reichert,APS Silva,KL Coutinho,SED Collet, N.	Exploratory and descriptive study, qualitative, based on the testimony of families that do experience the experience of having a child with chronic disease.	VI	2012
A4	Proposal of home care to children with chronic renal failure	Freitas, TAR Silva, KL Nóbrega,MML Collet, N.	Descriptive qualitative research with escorts of children and/or adolescents hospitalized with chronic kidney disease.	VI	2011
A5	Experiences of nurse in transpersonal caring to newborns families discharged from the intensive care unit	Luciane Favero, L, Mazza, VA Lacerda, MR.	Qualitative research descriptive case study type. We used the theory of Transpersonal Care operationalized by the process of caring for L.	VI	2012
A6	The family looking after the dependent child of mechanical ventilation at home	Lima, EC Ribeiro, NRR.	Case studies with family caregivers.	VI	2009
A7	Between dose and volume: the principle of mathematics in medical care for HIV positive children	Gomes, AMT Cabral, IE.	Creative and qualitative because reflective criticism and has opted for the strategy of group dynamics.	VI	2009
A8	Support network for	Viera, CS	Descriptive study,	VI	2010

	families of low birth weight babies after discharge from hospital: a qualitative study	Mello, DF Oliveira, BRG Furtado,MCC.	qualitative, with reports of six families with children graduating from NICU, accompanied by way of home visits.		
A9	Experience of mothers of children with leukemia: feelings about home care	Klassmann J Kochia KRA Furukawa TS Higarashi IH Marcon SS.	Descriptive study, monitors in interpretative schema.	VI	2008
A10	Model Calgary family assessment of newborns: teaching strategy for nursing students	Christoffel MM Pacheco STA Reis CSC.	Case studies, whose goal is to describe the experience of using the Calgary Model of evaluation and Intervention in Family Nursing consultation to child.	VI	2008
A11	Percepção materna quanto ao apoio social recebido no cuidado às crianças prematuras no domicílio	Simioni, AS Geib, LTC.	Qualitative descriptive study.	VI	2008
A12	Difficulties and conflicts faced by families in the daily care of a child with chronic illness	Marcon SS Sassá AH Tsumura N Soares I Molina RCM.	Case study, developed with an assisted family for extension project.	VI	2007
A13	Type 1 diabetes in the family context and social	Góes APP Vieira MRR Júnior RDRL	This is a descriptive and transversal study.	V	2007
A14	Network Technology support to household technology dependent child discharged from a hospital public health	Drucker LP.	Cross-sectional study using semi-structured questionnaire administered to parents and children with diabetes mellitus type 1.	VI	2007
A15	Mother / family knowledge about the care provided to sick children	Prado LSRA Fujimori E.	Exploratory, descriptive, cross-sectional nature.	V	2006

Figure 1. Article code, title, author, and method, level of evidence and year of publication.

The periodic analysis showed the presence of 15 (100%) national journals, as evidenced, Figure 2.

Periodicals	Total
Revista Escola de Enfermagem Anna Nery	3 (20%)
Revista Online Brazilian Journal of Nursing	2 (13,33%)
Revista Ciência, Cuidado e Saúde	2 (13,33%)
Revista de Enfermagem REBEN	2 (13,33%)
Revista de Enfermagem da UERJ	1 (6,66%)
Revista Ciência e Saúde Coletiva	1 (6,66%)
Revista da Escola de Enfermagem da USP	1 (6,66%)
Revista Brasileira de Pediatria	1 (6,66%)
Revista Gaúcha de Enfermagem	1 (6,66%)
Revista da Rede de Enfermagem do Nordeste	1 (6,66%)

Figure 2. Journals where the articles were published.

As to the objectives of the studies predominated productions that aimed to understand how it is managed, experienced and perceived the care by the family for children with chronic disease in nine (60%) of the articles. Followed by four (26,66%) that aimed to know how is the technical assistance

and support to families after hospitalization. An article (6,66%) aimed to understand how children experience their daily self-care and one (6,66%) was aimed at developing a program of care for families of children with chronic diseases, such data are shown in Figure 3.

Code	Objective	Total
A1- A2- A3- A7- A9- A10- A11- A12- A15	Understand how it is managed, experienced and perceived by the family the chronic child care.	9 (60%)
A5- A6- A8- A14	Knowing how technical support and assistance to families after hospitalization.	4 (26,66%)
A13	Understand how the child experiences its daily self-care.	1 (6,66%)
A4	Develop a care proposal for families of children with chronic diseases.	1 (6,66%)

Figure 3. Article code and object of the publications.

Regarding the subject of publications, there was a preponderance of 14 (93,33%) where the study subjects were familiar

caregivers, especially the mother figure. Followed by (6,66%) of children presented in

Code	Research subjects	Total
A1- A2- A3- A4- A5- A6- A7- A8- A9- A10- A11- A12- A14- A15	Family caregivers, highlighting the maternal figure.	14 (93,33%)
A13	Children.	1 (6,66%)

Figure 4. Article code and subject of the research.

The scenario that was highlighted was the home environment in 10 (66,66%) of the research, followed by Units Ambulatory Health 3 (20%) and the hospital scenario in 2 (13,33%) of the productions.

Regarding the Brazilian State of origin of productions, was the State of Rio de Janeiro with 5 (33,33%) articles, followed by Paraná with 4 (26,66%) and Rio Grande do Sul with 3 (20%) of the findings. Sao Paulo and Paraíba with two (13,33%) and 1 (6,66%) articles, respectively.

For the results presented in the analyzed production, we have five (38,46%) that revealed on care about the child, and this transcends the biological dimension and

hegemonic biomedical model, demonstrating the importance of understanding the family as a biopsychosocial and cultural whole. In 6 (46,15%) publications unveiled the need to combine home care of the multidisciplinary team where it was established a dialogical interaction with the family to optimizing the health care and social interaction and shared care between family, easing the anxiety. In 2 (15,38%) samples it was revealed that the care provided in the home generates tranquility for the child to be near her family. A summary of results is found in Figure 5.

Code	Summary of Results
A1	Highlighted the need for health professionals acting as a support for these families, more than guiding the completion of care, as the bug also qualified by investing in interpersonal relationships, to effectively qualify the assistance and assist the family of the child with anomaly.
A2	It is essential that the follow-up of children with Cerebral Palsy has revised its guidelines in each unique situation and your family background.
A3	Chronic illness in childhood causes profound transformations in the dynamics and family life due to intrinsic needs triggered by illness in the family, leading to a process of dismantling and modification of the roles played by each Member, resulting in conflicting times and on interference in daily life.
A4	Moments of anguish experienced by families are linked to non-acceptance of the disease; required the establishment of dialogical interaction.
A5	The objective of the actions take care needed to be combined with the human reality of care being careful in its own domain environment.
A6	Remain in hospital indefinitely hindered the maintenance of linkages and family structure; home care patient's tranquility to be generating close to their families.
A7	Combining multiprofessional care to home care, proposition of dialogical education in health for problem resolution.
A8	The family must be understood as a biopsychosocial unit. Shared care between families eases the anguish.
A9	Mothers devote themselves with nurturing care, but feel the need to interact with the health team; become visible gaps within the educational function for health care.
A10	Reflections on teaching learning process between University-Health and community service and training the competence of nurses.
A11	The grandparents as builders and maintainers of the nest; discouragement of abandonment and secure base; and social inclusion promoted by his friends. The social support not supplied focused on child care and household activities.
A12	Milder disease coping with family support and multidisciplinary team; Watch the family goes beyond the biomedical care.
A13	There have been difficulties for parents: the cost of special food; the fear of the unknown; have to learn about the disease quickly and for the child: be ashamed of having diabetes. Her mother was the next of kin who helped the child in treatment.
A14	The family assimilates the technology becoming Manager of care at home; the family must be understood as the unit of care.
A15	The importance of educational action as a component of impact being directed to construction of citizenship as an emancipatory element in replacement to the hegemonic model.

Figure 5. Article code and synthesis of results.

DISCUSSION

The discussion will be presented by means of analytical categories that emerged after reading attentively the articles and descriptive analysis of the results.

• Adaptation of the family for the care of children with chronic illness

Faced with changes in the Brazilian scenario, is paramount discussing the importance of family in the development of home to children with chronic illness care, since the disease has a direct interference in the lives of children and their families.

The household is composed by parents, grandparents, siblings, aunts who beyond caring for the child, can provide safety and tranquility.^{5,8,10,11} The father, when performing care, presents more difficulties in supporting feelings mobilized by the disease.^{5,12} When dispensing physical and emotional presence, the father reiterates the importance of his role, and supports the mother.^{5,10} Older siblings end up helping in the care of the sick child, since the mother often cannot get all time next to the child³ their collaboration makes coping with milder disease. That's because chronic disease imposes changes in the life of the child and his family^{5,10,13} requiring retrofits forward to the new situation, such as a reorganization of roles on the care needs, which thus has significant implications for life people who live with chronic illness in children.^{10,14}

It becomes essential as home care support to family caregivers of children with chronic¹⁷ diseases seen that treatment should cover physical, social and psychological needs.¹⁶ Home care aims to provide social and economic¹⁷ benefits, such as: Tranquil the patient to be close to their family, humanizing care and quickly during recovery; reduction in the risk of nosocomial infection. At home the risk of infection is lower, the home environment offer the child the warmth of family.^{2,16,18} Thus, home care is understood by the family as access to specialized monitoring, deployed in the territory where the child lives, the integrated primary care service.¹⁶

To provide full care, it is important that the caregiver is responsive and able to sympathize with the problems and situations of others, whether or not resolvable. Caring is an action directed to the needs of the other, this relationship often provides resignation and giving.⁵ The home and family provide a means for the child to develop and participate in everyday activities.^{8,16,17} In this context, the

presence of family in the rehabilitation process of the sick child is fundamental.^{2,10,16}

When a chronic disease affects social relationships in the family system, ie, when the impact on family life influences the construction of social ties, this can influence the performance of daily activities often considered as a stressor element that affects the normal development of child, and yet, could interfere with the educational process and the interpersonal relationship of the child.¹⁵ Thus, we stress the importance of social support in the daily lives of these families and children with chronic diseases, since this support presents as an important factor in minimizing the effects of stressful situations in family life.³⁰

In the case of a chronic disease⁴ the option to conduct treatment in the home environment, with family, appears often as the most appropriate strategy to the specific needs of the child. Study with family caregivers of technology-dependent children revealed that family members play a careful abnegation of personal and social life.¹⁹ The family lives along with the sick child the process of coping with the disease and^{2,5} the daily challenges of caring for an otherwise healthy child, who finds himself subjected to physical, physiological and psychological changes.²

Although the family performs continuous care in the home environment, they may feel unprepared, unqualified to care for a sick child due to poor knowledge of the disease, jeopardizing the achievement of general care and complex procedures.^{3,16,18,20,21}

Chronic disease can awaken the child's family latent feelings such as fear, denial and despair facing the diagnosis, families are later to accept the child's situation and begin to use own coping strategies before the diagnosis.^{8,21} Therefore, it is crucial that health professionals assist the family responsible¹⁷ for the care of children with chronic diseases, especially during the diagnosis, considering that childhood asthma can cause suffering on members of the family core.

Given these assumptions, the family should also receive support from the health team, establishing an effective communication through the exercise of dialogue^{3,5,22} so that family members to feel valued and can be exploited⁷ to take care of children with disease chronic autonomously.

• Domiciliary care and family autonomy

During hospitalization procedures are performed by qualified health professionals, however, post-discharge care required by

children with chronic disease are being developed by the family at home. These practices enable the family to take responsibility in the home environment by technical procedures.^{2,7,18,21-2}

A research conducted with caregivers found that at discharge the family received superficial information about the disease and the degree of need for home care, making it difficult to perform activities for family caregivers.¹⁸ In these circumstances, we perceive the inability of family members deal with this new situation, and it is essential that the health team initiate new knowledge so that parents can continue to procedures.²⁰

Proper home care can prevent or delay complications, decreasing rehospitalizations.¹⁶ For this reason caregivers should be trained by the health team.^{7,23} These skills must be developed, but especially improved, respecting the social reality of individuals.²⁴ Become unavoidable investments in health care that prepares individuals for continuity of care beyond the hospital setting.^{18,25}

We emphasize the need for nurses to assume the role of educator to health, providing clarification on the treatment necessitated by chronic child at home. The nursing guidelines should have a single language, considering the circumstances of each family, so that the caregiver can clearly understand the information passed by the health professional.^{26,27} Research has revealed that, as they engaged with professionals who have provided support and enlightenment, family members of children with chronic illness they felt safe to take full care, since the host and empathy of the health professionals strengthened.²⁸ Thus, there is a need for health professionals to act properly and empathetically with this family.

Nursing must develop ways to approach the family at home, create strategies that enable meet the individual needs and plan actions for the involvement of family.¹⁰ Given the chronic conditions of the child, it is often necessary to adopt changes in lifestyle and daily behavior.⁴ This way, the central focus of the educational activities of the nurse must be patient and family centered.^{25,27,28}

The multidisciplinary team is an important ally of the caregiver orientation to learning of care activities at home, where technical information in a simplified manner and offering support to the caregiver and the patient must be provided. The process of knowledge construction within the household must be grounded in an interactive, horizontal, dialogical and reflexive

relationship between professionals and carers.²³⁻⁴

Teaching is not just transferring knowledge,²² but to create opportunities for its construction, as it requires the exercise of criticism and reflection and respect for the autonomy of those who are building the knowledge.^{23,26}

In this study also highlighted the lack of preparation of professionals to work in the home space,^{6,15} it is vital that health professionals seek to empower in order to qualify their work and enhance patient care.²⁹ Therefore, the training and qualification must be guided by the needs of the population that will be served.

It is believed that health professionals should take a revolutionary position,²⁷⁻⁸ empowering the family in care processes, as in everyday life.^{13,24} Therefore, the physician must establish a close and continuous relationship with the family, rescuing the essence of the integral to see each other's needs, taking into account social, cultural and emotional aspects of care. Moreover, it is necessary that health professionals bet a qualified hearing, so from that family feel safe and confident.^{29,30} Based on these, should be coherence between vocational training and the involvement of family caregivers in the care process, so that they can have autonomy and combine specific knowledge with knowledge constructed in everyday life.

CONCLUSION

The study revealed the presence of family in the implementation of home care to children with chronic illnesses; however, not always the family is prepared to assume this responsibility.

Children with chronic diseases require daily care and differentiated, whereas the presence of the disease is constant in their lives. Living with a sick child can generate feelings of sadness and frustration in the family. Often family members do not accept the diagnosis and may even move away from the child.

In the diagnostic disclosure process and in preparation for home care nursing should offer support to families, debunking myths about the disease and guiding the family in performing procedures. From the moment that the nurse works the educational demands presented by the family is possible to improve the popular and naive knowledge to know how to cut for scientific knowledge.

In this study it becomes evident need for teaching-service integration and points to the importance of universities, especially public

ones, to maximize their efforts to train competent health professionals and critics to work in primary health care, which will meet the learning demands of patients and families.

Regarding the categorization of studies, such as gaps in knowledge, the study found that the lack of intervention studies showed strong evidence, since it was observed that the majority of the studies were descriptive, classified as level of evidence⁶, considered weak.

Through this study, it was possible to gaps in knowledge, the study revealed that although the family and chronic illness of the child to be searched, yet, regarding the inclusion of children as subjects of research, the studies are still incomplete. You can still be observed, the predominance of the female figure represented by the mothers and grandmothers. Thus, the father becomes figurative, or does not participate in the care process, leading to maternal burden.

Recommend up research studies on the topic here, to disseminate official rates on these clients, because studies linked to home care for children with chronic illnesses are facing the major centers of reference and research. By being closer to the nuclear family, the nurse should empower family caregivers to ensure that care is built on a consolidated basis.

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Corresponding Address

Andressa da Silveira
Rua Prado Lima, 2280/402
Bairro Nova Esperança
CEP 97510420 – Uruguaiana (RS), Brazil