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INTEGRATIVE REVIEW

O cuidado à criança com doença crônica ou incapacitante no contexto hospitalar

The care of the child with chronic or disabling disease in the hospital context

El cuidado a los niños con enfermedades crónicas o incapacitante en ámbito hospitalario

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ABSTRACT

Objective: to describe and analyze the implications of the hospitalization in the care of the child with chronic or disabling disease in the hospital context. **Method:** this is a type of bibliographical research of integrative review. The search was conducted in the databases LILACS and MEDLINE in English, Spanish and Portuguese languages, without specified temporal cutting. The data were organized in an analytical chart that was submitted to the thematic content analyses. **Results:** the papers were grouped into two categories: “Factors influencing in the daily care of the child with chronic and disabling disease and its family in the hospital context” and “Strategies for the accomplishment of comprehensive care of the child with chronic and disabling disease and its family in the hospital context”. **Conclusion:** the care provided to the child with chronic or disabling disease is mainly being performed by the family and that this institution finds difficulties to deal with this reality, both in the hospital context and in their daily life within the household. **Descriptors:** pediatric nursing, child care, chronic disease, nursing team, family.

RESUMO

Objetivo: descrever e analisar as implicações da hospitalização no cuidado à criança com doença crônica ou incapacitante no contexto hospitalar. **Método:** trata-se de uma pesquisa bibliográfica do tipo revisão integrativa. A busca foi desenvolvida nas bases de dados LILACS e MEDLINE nos idiomas inglês, português e espanhol, sem recorte temporal especificado. Os dados foram organizados em um quadro analítico que foi submetido à análise de conteúdo temática. **Resultados:** os artigos foram agrupados em duas categorias: “Fatores que influenciam no cotidiano de cuidado à criança com doença crônica e incapacitante e sua família no contexto hospitalar” e “As estratégias para a realização do cuidado integral à criança com doença crônica e incapacitante e sua família no contexto hospitalar”. **Conclusão:** o cuidado prestado à criança com doença crônica ou incapacitante está sendo desenvolvido principalmente pela família e que esta instituição encontra dificuldades em seu cotidiano para lidar com essa realidade, tanto no ambiente hospitalar quanto no domicílio. **Descritores:** enfermagem pediátrica, cuidados da criança, doença crônica, equipe de enfermagem, família.

RESUMEN

Objetivo: describir y analizar las implicaciones de la hospitalización en el cuidado de los niños con enfermedades crónicas o incapacitante en el ámbito hospitalario. **Método:** se trata de una revisión de la literatura de tipo integral. La búsqueda fue desarrollada con base en los datos LILACS y MEDLINE en los idiomas inglés, portugués y español, sin recorte de tiempo específico. Los datos fueron organizados en un marco analítico que fue sometido a análisis de contenido temático. **Resultados:** los artículos fueron agrupados en dos categorías: “Factores que influyen en el cuidado diario de los niños con enfermedad crónica e incapacitante y su familia en el ámbito hospitalario” y “Las Estrategias para lograr una atención integral a los niños con enfermedad crónica e incapacitante y su familia en el ámbito hospitalario”. **Conclusión:** La atención prestada a los niños con enfermedad crónica o incapacitante se desarrolla principalmente por la familia y que esta encuentra dificultades en su vida diaria para lidiar con esta realidad, tanto en el ámbito hospitalario como en el hogar. **Descriptorios:** enfermería pediátrica, cuidados de niños, enfermedad crónica, equipo de enfermería, familia.

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INTRODUCTION

Children with chronic or disabling disease are inserted into the group of *Crianças com Necessidades Especiais de Saúde* (CRIANES), which is the name used in Brazil to define a group of clinically fragile children and dependent on continuous health care^{1,2} In United States, this group is studied since the 1980s and was named as Children with Special Health Care Needs (CSHCN)³, focusing not only on only specific chronic health conditions, but also defining as its basis how special are the health needs of the child, how they affect their lives and their needs or use of services related to health.⁴

Because of their clinical fragility, as well as their demands for continuous or temporary care, the CSHCN are faced with prolonged hospitalizations, numerous rehospitalizations and increased diagnostic complexity², which requires that the family is adapted to this reality. In order to meet the demands of care that these children present, the family caregivers have the help of health professionals, who can provide information and teach them about the best way to conduct the necessary care.

Increasingly, the family is present in child care within the hospital environment, thereby becoming an active subject of this care. The family should be considered a subject that has rights and needs support from health professionals, in order to enhance its skills for the practice of care actions towards the CSHCN.⁵

Given this reality, the health professionals, specifically from the nursing team, need to direct their gaze to the family as an object of care, with a view to developing a production process of relationships and interventions beyond the clinical knowledge. Thus, the nursing team must develop a type of care based on comprehensiveness and that includes the family in this process, thereby establishing bonds of trust and accountability and ascribing respect to the uniqueness of the child-family binomial.⁶

Despite the current health legislation in the country advocates the comprehensive care of users, and actions are guided by the humanization of care, it is necessary to change the existing paradigm in the health context of the child in our country. To that end, when working with CSHCN and their families, one needs to integrate the biopsychosocial dimensions, with basis on new ways to act and interact with the practice, which incurs the need for changes in work organization, training and performance of health professionals.⁸

Under this perspective, the nursing team act in promoting and recovering the CSHCN and their families, which allows the establishment of an affective therapeutic bond in which the uniqueness and historicity of the family is appreciated.⁵ Due to the complexity and difficulties that permeate the care of CSHCN, both for health professionals and for their family members, it was felt necessary to research on the care of CSHCN in the hospital context in the light of the scientific literature, since there is a modification in everyday of children and families in this context.

Accordingly, the question is: how the hospitalization implies in the care of the child with chronic or disabling disease? This study aims at describing and analyzing the implications of the hospitalization in the care of the child with chronic or disabling disease in the hospital context.

We opted to use the descriptor "child with chronic or disabling disease", because the name CSHCN is not yet a descriptor and the number of productions found with this word is reduced. Nevertheless, it is made clear that the meaning of CSHCN is broader than chronic disease, since not all CSHCN have a chronified health condition, because their demands for care might be temporary.

METHOD

This is a bibliographical research of integrative review, with a descriptive approach. The search for papers was conducted in the month of April of the year 2013, through the Virtual Health Library (VHL), in the databases Latin American and Caribbean Health Sciences Literature (LILACS) and International Literature on Health Sciences (MEDLINE).

In order to quest for papers, the following strategy was carried out: In LILACS, we used (HOSPITALIZED CHILD) and "chronic disease" [Subject descriptor] and ("CARE") or "ASSISTANCE" [Words] and "SPANISH" or "ENGLISH" or "PORTUGUESE" [Language]. As for MEDLINE, we used ("hospitalized child") and "chronic disease" [Subject descriptor] and ("CARE") or "ASSISTANCE" [Words] and "SPANISH" or "ENGLISH" or "PORTUGUESE" [Language].

From this strategy, we have found seven productions in LILACS and 74 productions in MEDLINE, totaling 81 productions. Subsequently, a careful reading of the abstracts was held, in which the inclusion and exclusion criteria were applied. Regarding the inclusion criteria, we listed productions in paper format, online available, in full text, free and that presented the abstracts available in the base. As for exclusion criteria, we ruled out those that did not comply with the proposed thematic or those with incomplete abstract. There was no temporal cutting for the selection of productions.

In order to analyze the results, the data were organized in a synoptic chart with information that helped in organizing the data. Next, the data analysis was performed, based on the thematic content analysis.⁹The thematic analysis seeks the encrypted interpretation of material of qualitative nature. The thematic content analysis entails a collection of relationships and might be graphically displayed by a word, a phrase or an abstract. Hence, one can find the units of meaning that compose a communication, which mean something for the analytical object under observation. The following steps were respected for analysis: pre-analysis (which is decomposed into floating reading, constitution of corpus, formulation and reformulation of hypotheses and objectives): material exploration and, lastly, treatment of obtained results and interpretation.⁹

RESULTS AND DISCUSSION

After reading the abstracts and application of previously established inclusion and exclusion criteria, from the seven productions found in LILACS, one was excluded for being a thesis and two for having nothing to do with the proposed thematic. Accordingly, four papers were selected. As for MEDLINE, from the 74 productions found, 18 were excluded for not presenting their abstracts available or are incomplete, nine were not found in their full versions, two were repeated in the other base researched and 30 were out of the proposed thematic, thereby leaving 15 to be analyzed. Thus, we totaled 19 selected papers. Next, there was a thorough reading of the papers in their full versions, leaving 13 papers to be analyzed.

Sequentially, we organized the papers into a synoptic chart with the following topics: code, author, title, journal and year. This chart served as the basis for the formulation of categories according to the topics found.

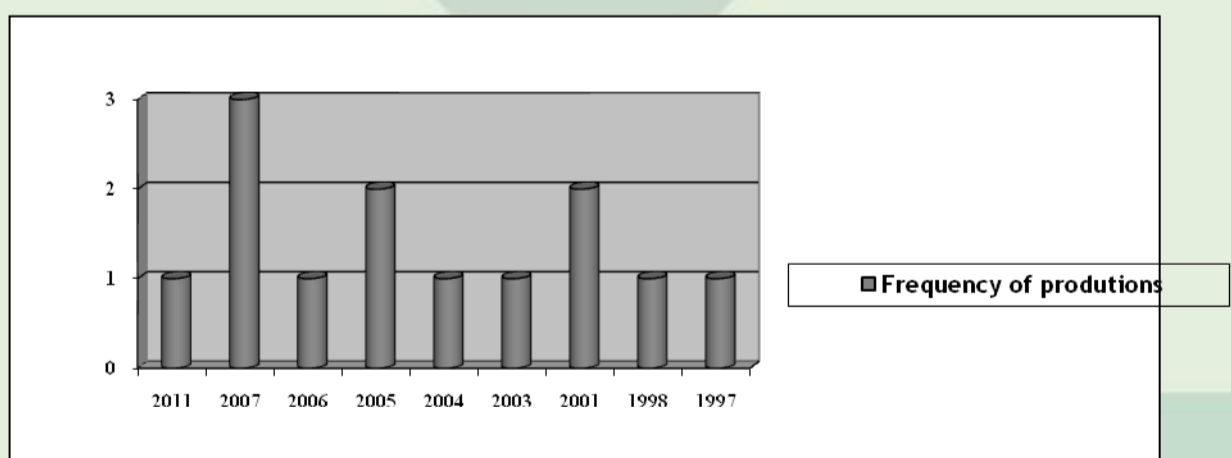
Figure 1- Synoptic chart for the presentation of productions with identification of code, author, title, journal and year, selected in the study, Santa Maria, RS. 2013.

| CODE | AUTHOR | TITLE | JOURNAL | YEAR |
|------|--|---|---|------|
| A1 | Holanda ER, Collet N. | The difficulties of schooling of children with chronic disease in the hospital context. | <i>Revista da Escola de Enfermagem da USP</i> | 2011 |
| A2 | Silva JB, Kirschbaum IRD, Oliveira I. | Meaning ascribed by the nursing professional in the care provided to the hospitalized child with chronic disease and accompanied by family member. | <i>Revista Gaúcha de Enfermagem</i> | 2007 |
| A3 | Pinho SR, Souza BSF, Cunha CCC, Costa DM, Nunes LN, Fonseca LCG et al. | Behavioral changes in children with chronic illnesses and their impact on family: Children's Hospital - Social Works of Sister Dulce, Salvador, BA. | <i>Revista de Ciências Médicas e Biológicas</i> | 2007 |
| A4 | Silva FM, Correa I. | Chronic disease in childhood: experience of the family member during the hospitalization of the child. | <i>Revista Mineira de Enfermagem</i> | 2006 |
| A5 | Mack JW, Co JP, Goldmann DA, Weeks JC, Cleary PD. | Quality of Health Care for Children: Role of Health and Chronic Illness in Inpatient Care Experiences. | <i>Archives of Pediatrics & Adolescent Medicine</i> | 2007 |
| A6 | Garro A, Thurman SK, Kerwin MLE, Ducette JP. | Parent/Caregiver Stress During Pediatric Hospitalization for Chronic Feeding Problems. | <i>Journal of Pediatric Nursing</i> | 2005 |
| A7 | Hopia H, | Child in hospital: family | <i>Journal of</i> | 2005 |

| | | | | |
|-----|--|--|----------------------------------|------|
| | Tomlinson PS, Pohjanmaa EP, Astedt-Kurki P. | experiences and expectations of how nurses can promote family health. | Clinical Nursing | |
| A8 | Garro A. | Coping Patterns in Mothers/Caregivers of Children with chronic Feeding problems. | Journal of Pediatric Health Care | 2004 |
| A9 | Feudtner C, Haney J, Dimmers MA. | Spiritual care needs of hospitalized children and their families: a national survey of pastoral care providers' perceptions. | Pediatrics | 2003 |
| A10 | Lima RAG, Rocha SMM, Scochi CGS, Callery P. | Involvement and fragmentation: A study of parental care of hospitalized children in Brazil. | Pediatric Nursing | 2001 |
| A11 | Balling K; McCubbin M. | Hospitalized children with chronic illness: parental caregiving needs and valuing parental expertise. | Journal of Pediatric Nursing | 2001 |
| A12 | Boyd JR, Hunsberger M. | Chronically ill children coping with repeated hospitalizations: their perceptions and suggested interventions. | Journal of Pediatric Nursing | 1998 |
| A13 | Burke SO, Handley-Derry MH, Costello EA, Kauffmann E, Dillon MC. | Stress-point intervention for parents of hospitalized children with chronic conditions. | Research in Nursing & Health | 1997 |

Below, we will present the characterization of papers according to the year, origin, type of study, design, occupation of authors, scenario and subjects.

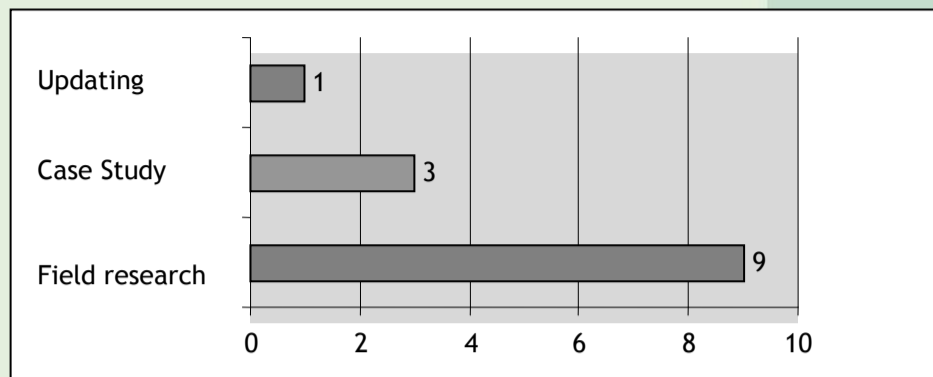
Figure 2: Frequency of productions distributed by the year of publication. Santa Maria, RS. 2013.



With respect to the year of production, we highlight that, from the year 2001, there was a significant increase in the number of productions, and, in 2007, there was a greater number of productions (25%). Regarding the country of origin of papers, Brazil and United States were prevalent, with 42% of productions; followed by Canada (17%) and Finland (8%).

The frequency of the type of research found in the papers is described below.

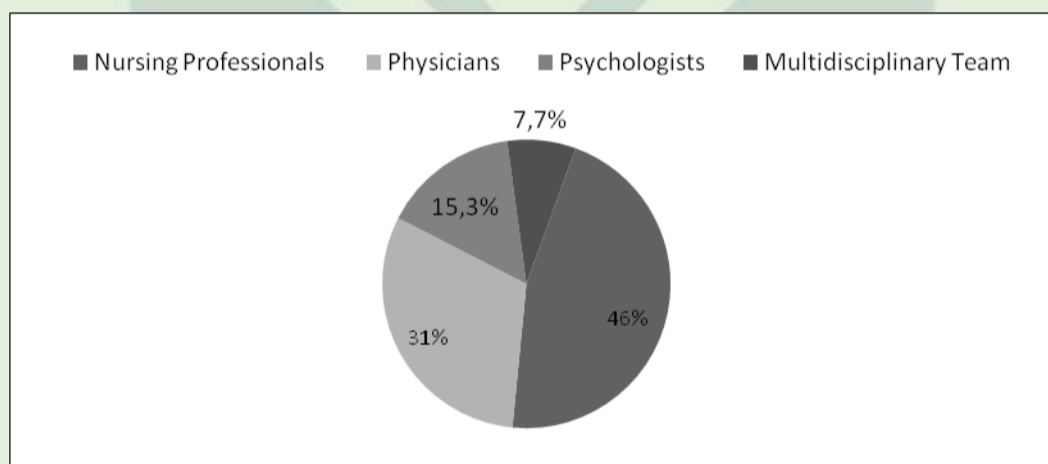
Figure 3: Frequency of production by type of research. Santa Maria, RS. 2013.



With regard to the type of research, the field research showed higher frequency (69,2%), followed by case study (23,1%). As for the approach of the studies, the qualitative approach was the most used, with 75% of productions, while the quantitative studies represented 25%.

Concerning the sub-area of studies, we highlight that the studies were elaborated by several health areas, which are mentioned hereinafter.

Figure 4: Frequency of productions distributed by occupation of authors. Santa Maria, RS. 2013.



The occupations that stood out in the authorship of papers articles were nurses, with 46%, and physicians, with 31% of productions. As for the subjects of the research, family caregivers of children with chronic diseases appeared in nine studies (69,2%), followed by nurses, religious caregivers and children with chronic diseases, with frequency of one production for each (7,7%). In relation to the scenario of studies, it was the hospital environment, since we have selected the studies dealing with the hospitalization of children with chronic diseases or about issues related to this audience.

After analysis, the papers were classified and grouped into categories according to similarities in the themes, through the use of thematic content analysis, as previously described. The categories used for discussion were: **“Factors influencing in the daily care of the child with chronic and disabling disease and its family in the hospital context”** and **“Strategies for the accomplishment of comprehensive care of the child with chronic and disabling disease and its family in the hospital context”**.

Factors influencing in the daily care of the child with chronic and disabling disease and its family in the hospital context

In this category, we grouped papers relating to factors that influence, both positively and negatively, the daily care of the child with chronic or disabling disease due to hospital admissions.

From the studies, we have identified that the hospital readmissions are frequent during the life of the child with chronic disease, which provokes its removal from school activities, often resulting in the loss of the school year, thereby causing a deficit in learning. This occurs due to the school institution and the hospital environment itself are not prepared to meet the educational needs of the child, as well as to offer educational activities that provide continuity of teaching for the child during hospitalization.^{A1, A3}

A study conducted in USA reported that 21% of school-age children who have some special health need already repeated some year in school, and this percentage is only 8% for the general child population.⁴The lack of knowledge from the school institution in relation to the child's impairment by a chronic pathology, the carelessness on the part of hospitals about the pedagogical process of patients, the difficulty of negotiating between the school and the hospital and, moreover, the lack of follow-up by teachers within the hospital environment are some of the factors that hamper the pedagogical teaching of the child.¹⁰

The pedagogical work in the hospital environment must include actions for the acquisition of knowledge, quality of life and health, not being restricted to the completion and approval of the school year that was jeopardized by the hospitalization.¹¹

Besides this change in the everyday of the child, other obstacles were cited by the authors as factors that interfere in the child care and that must be relevant in the period of hospitalization, such as anxiety, difficulty of dealing with pain and other physical symptoms. Furthermore, emotional and physical limitations and impaired self-image are factors directly linked and affected by the long period of hospital admission and readmissions.^{A1,A3,A8}

The relationships of these children in their sociocultural environment, mainly those that happen in the school setting, might be hindered by the existence of the disease, by frequent hospitalizations and by the impaired body image, being that the prejudice is an important factor for social isolation.¹²

When the child is imposed to get out of its context and insert itself into another, there is a loss of its privacy and of its daily life, often making it impossible that the child exerts its autonomy due to the rules and routines imposed by the hospital environment. Associated with this, the possibility of feeling pain is an important aspect in the experience of hospitalization of the child.¹³

By considering the family as an essential part in the care of the child with chronic or disabling disease, when receiving the diagnosis of illness, as well as the demand for care actions that the child needs, this institution faces several changes in its structure, such as greater family unity; concern with physical sequels; acceptance of the disease; fear and sense of compassion.^{A3}

During hospitalization, the family ends up getting involved in low complexity activities, such as, for example, bathing, feeding, recreation and conversation with the child. Nonetheless, the family members end up feeling unprepared due to lack of knowledge, lack of guidance and information about the diagnosis and accomplishment of

procedures towards the child. They usually realize that their opinions and experiences are not appreciated by health professionals.^{A2, A4, A5, A9, A11}

The hospitalization process also brings feelings of fragility, constant worry and even guilt to the family. These feelings are added to the overburden of care actions that the clinical condition of the child requires and to the need for adaptation of the family to this new situation.¹⁴

Children dependent on some kind of technology make the professionals aware of the concerns to ease the care on the part of the family, by teaching in accessible language about the best way to accomplish it. Accordingly, the introduction of the family in the care seeks the continuity of the treatment in the household, like a form of psychological support, in order to contribute to the quality of life of the child.¹⁵

Thus, during hospitalization, a relationship of power on the part of professionals is established, as well as the deficiency of multiprofessional work that includes trained professionals to meet such demand. In light of the foregoing, the care of children with chronic diseases ends up being targeted to the disease; hence, the work of health professionals is fragmented and focused on biological changes, medication administration and technical procedures. Often, the care was reported by individuals as specific of technical activities targeted to the disease, which influences in a failure in the comprehensive and humanized care.^{A1, A2, A3, A6}

The nursing team and the physicians were the professionals remembered by family members with regard to the child care during hospitalization. The nursing professional helps the family to develop coping strategies in critical situations during the hospitalization process. However, the actions are still focused on the biologicist model, focusing on the treatment of the physical symptoms and execution of technical procedures.^{A3, A7, A10, A13}

The care provided by nursing team often end up revealing actions that meet the biomedical and hospital-centered model, focusing on technical actions and procedures. The practice of care from the perspective of professionals is fragmented and technicist, with focus on healing.¹⁶

In the light of the above mentioned presuppose, the aim is to meet the needs of families, thereby making essential the reorganization of the health care model, which is often based on the biomedical, biologicist and technicist model and do not address the several aspects related to health. Thus, the health professionals, mainly the nurses, must develop and put into practice actions that encompass a systemic and multidimensional vision, thereby meeting the urgent demands of the family.¹⁷

One factor found by the nursing team is that the introduction of parents in the participation in the care actions implies a reorganization of work. From this, there was the inclusion of the family in the care shares that were previously only assigned to the nursing staff; however, there is a failure in relation to its effect over the daily work and how professionals would act in the face of this reality and how it would interfere in their professional routine.^{A2, A9}

Less complex care actions have been conducted by family members of children without even the knowledge of the team towards this situation, and there is a flaw in the system of work organization of the team. Some care actions are already cited by the team

as assignments of the family, because they resemble home care shares and not the tasks of nursing.¹⁶

The professionals involved in the care of children and their families need to develop peculiar actions with the purpose of enabling caregivers to insert more complex care shares for children in the household into their daily lives. The inclusion of the family member is a concern of health professionals in child care, who consider that one should start slowly and gradually, evolving in line with its own learning pace and to the extent that the doubts are solved. Accordingly, they will make the family member able to perform these tasks within the home environment in a practical and technically efficient manner, in the pursuit of a better quality of life for the child.¹⁸

Strategies for the accomplishment of comprehensive care of the child with chronic and disabling disease and its family in the hospital context

In this category, we highlight the main strategies found for the care of the hospitalized child with chronic disease and its family.

The nursing care developed with the child with chronic disease aims at providing well-being by means of various distractions. From the time of receipt at the ward until the hospital discharge, activities such as watching TV, movies and jokes are some strategies used for distracting children. Another way reported by the children was the importance of the dialogue and interaction with professionals, which allowed exchanging ideas, relieving anguishes and anxiety, clarification on the procedures performed and conducts adopted during hospitalization.^{A7,A12}

A study involving nurses showed that these workers plan their care actions guided on the needs and individualities of the child, by guiding their actions by means of prior knowledge of the sociocultural characteristics and the context in which the child and its family are inserted. The ludic aspect and the dialogue are used to minimize the effects of the hospitalization and clarify the technical care accomplished, thereby easing the trauma that this situation can cause in the child. Thus, in order to recover the child, the assistance is based not only on physical care, but also in the emotional.¹⁵

Besides the emotional and well-being related questions, the inclusion of the child in its own care proved to be relevant as it promotes its autonomy. Based on this assumption, the child creates ways to conduct its own care, thereby assisting in the development of its plan of care both in the hospital environment and in the household.^{A11}

In this context, it is of paramount importance that the statements of children in relation to their health conditions are considered. In addition, the complaints of children must be guiding plans of care for them in the several environments in which they remain.¹²

Furthermore, it is essential that the professionals investigate the opinions, desires and values of each child, according to their expectations and in the way in which it is best suited to them, even giving the opportunity to the most reserved and quiet ones, leaving them free to express their ideas and opinions, besides participating in decision-making.¹³

The psychological support targeted to the child and the family proved to be compromised. The provision of spiritual and emotional care is effective; however, the hospital does not offer adequate spiritual care in a comprehensive way.^{A3, A8, A9}

In order to seek alternatives for the care and means to reduce anxiety and anguishes during hospitalization, the family reorganizes itself, often seeking refuge in the shelter of religiosity and spirituality, thereby using the belief in the child's recovery as a strategy to sooth anxiety.¹⁹

There is a strong relationship with God, which helps the family to keep the fight in the pursuit of the child's recovery. Hence, through spirituality and prayers, they believe they can protect children from clinical complications. In addition, the family believes that the lack of faith can generate despair and anguishes, and that has found the support that helped in accepting the disease inside the church.²⁰

The team can help the family by providing information about the disease, i.e., guidelines, so that assists in the preparation of parents for performing the technique within the home environment. However, the prior knowledge of the technique is not always enough to the health care process in the household. Guidelines in which the team contemplate the technique of certain procedures do not always meet the individual needs of the family, mainly the changes that this new condition brings and how the family might act in the face of this reality.^{A2, A5, A7}

A study conducted with nurses claims that, when thinking about families of hospitalized children with chronic diseases, one should advise, develop dialogue as a means to dispel doubts and offer support to families who experience the suffering of the childish hospitalization. Accordingly, the nursing team must observe that it is necessary to be together with the family to comprehend the care actions that this requires, given that the horizontality of the relationships between the family and the nursing team has been shown to be efficient.²¹

The care needs to be developed with the family, focused and appropriate, by enhancing its autonomy and self-confidence. The team needs to interact with the family, discover its actual needs and anxieties, in addition to knowing what parents want, should or could do to assist in the care of the child.^{A5, A7, A8}

The family feels the need to actively participate in the daily care of the child's life, both in technical care and in routine care of the hospital environment. In order to make it possible, the sharing of information between professionals and family members needs to be developed in the hospital routine, in an open and accessible parlance, since the family members becomes autonomous in the care, besides transmitting safety both for the child and for the other family members.^{A11, A13}

The planning of care has included recognizing the family as an active subject in child care. The family that has experience in the care of the child with chronic disease arrives to service with prior knowledge, i.e., able to make decisions in relation to the therapeutic project. Thus, it generates, through active listening and welcoming, a partnership with the family, thereby sharing the care of the child.²²

During the process of child's hospitalization, the act of interacting and cooperating with the family proves to be a good strategy, because it needs to reorganize itself for the completion of daily household tasks, thereby interfering as little as possible in the family dynamics. In addition, one should stimulate the family to preserve its social support, which, in a certain sense, avoids the psychological and emotional instability.²³

In addition to social support, the understanding of the clinical situation of the child through the guidance of the team in relation to changes related to treatment, disease and environment, as well as the exchange of information with other parent caregivers, assists in the daily coping and in the coexistence with the child disease.^{A6, A7, A8, A12}

In the hospital environment, the actions of nursing care are viewed and developed with caregiver of the CSHCN, mediated through a pedagogical relationship in which the strategies often address the training and explanation of how to perform the technical procedures, with support on the biologicist paradigm, on conduction of techniques to care for people and on the pathology and diagnosis of the child.²⁴

In light of the foregoing, we emphasize that the care actions must take place based on dialogue, and it must not be vertically conducted, but in such a way that there is a sharing of information, with basis on mutual respect, by seeking the quality of care.¹⁵

From the selected productions, we have identified some actions that the nursing team can play with the family caregiver during its stay within the hospital environment. It is important that the team respects the experiences and individualities relating to social, economic and cultural aspects in which the family is inserted, thereby providing a relationship of confidentiality between nursing/caregiver. By thinking about the well-being of the family caregiver, besides stimulating the sharing of emotional charge, the professional might suggest the removal of the caregiver to rest and a pleasant environment for its hospital stay.

Thus, one can establish a bond between family caregiver/nursing and, in order to keep it, the professional must remain calm and take some time to interact with the family member.^{A7, A13} In order to keep the family functioning, it is necessary that families learn to coexist with the disease, by facing the times of crisis, and try to adapt to this new reality.²³

In a study conducted with families of hospitalized children with chronic diseases²¹, it was found that the nursing care to these families is related to the support through listening, dialogue and advising during the long period of hospitalization. In the everyday care, it is essential that professional know, even without the explicit manifestation of the family member, the needs for care that the family has in its biopsychosocial aspects. These demands are important, since they might be neglected due to the care on behalf of the sick child.²¹

CONCLUSION

We have concluded that the implications of the hospitalization in the care of children with chronic or disabling diseases in the hospital context are related to the dimension of the family participation in the care shares and the strategies adopted by the team to deal with the situation of hospitalization of these children.

The care actions of these children considered less complex, such as bathing and feeding, are being performed by the family in the hospital context. Nevertheless, the family

finds difficulties to deal with this reality, both in the hospital context and in their daily life within the household.

The health professionals are reminded in the development of techniques, procedures, in a mechanistic and technician model of care focused on pathology and medicalization. Studies have shown that it is necessary to change this reality, in which the family becomes a subject of care, besides participating in this process in an active form.

The experiences of family members in the hospital environment shows that they feel unprepared to deal with a CSHCN at that moment, in which they are confronted by fears, anxieties, doubts and a high level of commitment, since are responsible for less complex care actions towards these children. This is even added to the lack of information and guidance for the provision of care, which makes cryptic and difficult this journey in the quest for the ideal care for the child.

The strategies highlighted refer to the care of the child and its fragilities at the time of admission, besides the way to meet the family's needs. There is a concern about the well-being of the child and its family during their stay in the hospital environment, as well as strategies that seek the best quality of assistance. The dialogue and the mutual exchange of information are considered as bases for developing a plan of care aimed at enabling the family members to be active and independent subjects in the caring of a CSHCN. The social and spiritual support was found as a source of help for the family at all stages of the disease and in the hospitalization process.

The health team must be aware of the needs of these children and their families, by strengthening bonds and sharing information with the family members, thereby respecting their opinions and experiences. Through these actions, one should seek to humanize the assistance by means of a holistic and comprehensive care, which might be centered on the family and its actual demands.

From the selected studies, we have shown that the productions are being developed with the family caregivers of CSHCN. There is a deficit of productions with regard to the vision of professionals of the health area on this care in the face of this emerging reality in health services and that requires a high degree of commitment on the part of the staff.

We recommend the accomplishment of interventionist researches that might help in the everyday of health professionals in relation to the performance in the face of this reality and might bring benefits in the care of CSHCN and their families within the hospital environment. In addition, we suggest the elaboration of strategies to ease the stay of the family member with the child and that allow greater autonomy of the relative of the CSHCN when performing home care actions.

REFERENCES

1. Hockenberry MJ, Wilson D, Winkelstein ML. Wong Fundamentos da enfermagem pediátrica. 8ª ed. Rio de Janeiro: Elsevier; 2011.

2. Neves ET, Cabral IE. A fragilidade clínica e a vulnerabilidade social das crianças com necessidades especiais de saúde. *Rev gaúcha enferm.* [online]. 2008 jun; [citado 22 abr 2013]; 29(2):139-51. Disponível em: <http://seer.ufrgs.br/RevistaGauchadeEnfermagem/article/view/5533/3150>
3. McPherson MG, Arango P, Fox H, Lauver C, McManus M, Newachek PW, et al. A new definition of children with special health care needs. *Pediatrics.* 1998 jul; 102(1):137-41.
4. The Child and Adolescent Health Measurement Initiative- CAHMI. [online]. 2007. [citado 22 abr 2013]. National Survey of Children's Health (NSCH). Disponível em: <http://childhealthdata.org>
5. Motta MGC, Issi HB, Milbrath VM, Ribeiro NRR, Resta DG. Famílias de crianças e adolescentes no mundo do hospital: Ações de cuidado. IN: Elsen I, Souza AIJ, Marcon SS. *Enfermagem à família: dimensões e perspectivas.* Maringá: Eduem, 2011.
6. Quirino DD, Collet N, Neves AFG. Hospitalização infantil: concepções da enfermagem acerca da mãe acompanhante *Rev gaúcha enferm.* [online]. 2010 jun; 31(2):300-6. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-14472010000200014
7. Silva LRS, Christoffel MM, Souza KV. História, conquistas e perspectivas no cuidado à mulher e à criança. *Texto & contexto enferm, Florianópolis.* [online]. 2005 out/dez; [citado 22 mar 2013];14(4):585-93. Disponível em: <http://www.scielo.br/pdf/tce/v14n4/a16v14n4.pdf>
8. Ferreira RC, Vargas CRR, Silva RF Trabalho em equipe multiprofissional: a perspectiva dos residentes médicos em saúde da família. *Ciêns saúde coletiva.* [online]. 2009; [citado 20 mar 2013]; 14(Supl. 1):1421-8. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232009000800015
9. Minayo MCS. *O desafio do conhecimento: pesquisa qualitativa em saúde.* 12ªed. São Paulo: Hucitec; 2010.
10. Melo MMR, Cardoso TM Cardoso. Classe hospitalar e escola regular: estreitando laços. *Ponto de Vista, Florianópolis.* [online]. 2007; [citado 20 abr 2013];(9): 113-30. Disponível em: <http://www.periodicos.ufsc.br/index.php/pontodevista/article/view/20427/18661>
11. Holanda ER, Collet N. The difficulties of educating children with chronic illness in the hospital context. *Rev Esc Enferm USP.* [online]. 2011; [citado 20 abr 2013];45(2):381-9. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0080-62342011000200012&lng=en&nrm=iso&tlng=en
12. Nóbrega RD, Collet N, Gomes IP, Holanda ER, Araújo YB. Criança em idade escolar hospitalizada: significado da condição crônica. *Texto & contexto enferm, Florianópolis.* [online]. 2010 jul/set; [citado 20 abr 2013];19(3):425-33. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072010000300003
13. Vasques RCY, Bousso RS, Mendes-Castillo AMC. The experience of suffering: stories told by hospitalized children. *Rev Esc Enferm USP.* [online]. 2011; [citado 20 abr 2013];45(1):122-9. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0080-62342011000100017&lng=en&nrm=iso&tlng=en

14. Marcon SS, Sassá AH, Soares NTI, Molina RCM. Dificuldades e conflitos enfrentados pela família no cuidado cotidiano a uma criança com doença crônica. *Cienc Cuid Saúde*. 2007; 6(suplem.2): 411-9.
15. Rossi CS, Rodrigues BMRD. Típico da ação do profissional de enfermagem quanto ao cuidado familiar da criança hospitalizada. *Acta paul enferm*. [online]. 2010; [citado 20 abr 2013];23(5):640-5. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-21002010000500009&lng=en&nrm=iso&tlng=pt
16. Pimenta EAG, Collet N. Dimension of nursing and family care to hospitalized children: conceptions of nursing. *Rev Esc Enferm USP*. [online]. 2009; [citado 30 abr 2013];43(3):622-9. Disponível em: http://www.scielo.br/pdf/reeusp/v43n3/en_a18v43n3.pdf
17. Leite NSL, Cunha SR. A família da criança dependente de tecnologia: aspectos fundamentais para a prática de enfermagem no ambiente hospitalar. *Esc Anna Nery R Enferm*, 2007 mar; 11(1):92-7.
18. Góes FGB, La Cava AM. Práticas educativas em saúde do enfermeiro com a família da criança hospitalizada. *Rev eletrônica enferm* [online]. 2009 out/dez [citado 20 abr 2013];11(4):942-51. Disponível em: <http://www.fen.ufg.br/revista/v11/n4/v11n4a20.htm>
19. Silveira A, Neves ET. Crianças com necessidades especiais em saúde: cuidado familiar na preservação da vida. *Ciênc cuid saúde*. 2012 jan/mar; 11(1):074-80
20. Paula ES, Nascimento LC, Rocha SMM. Religião e espiritualidade: e Religião e espiritualidade: experiência de famílias de crianças com Insuficiência Renal Crônica. *Rev bras enferm*. Brasília 2009 jan/fev; 62(1): 100-6.
21. Azevedo ND, Collet N, Leite AIT, Oliveira MRP, Oliveira BRG. Cuidado de enfermagem a famílias de crianças hospitalizadas por doença crônica. *Ciênc cuid saúde*. 2012 jul/set; 11(3):522-8
22. Nóbrega VM, Collet N, Silva KL, Coutinho SED. Rede e apoio social das famílias de crianças em condição crônica *Rev eletrônica enferm*. [online]. 2010; [citado 22 abr 2013];12(3):431-40. Disponível em: <http://www.fen.ufg.br/revista/v12/n3/v12n3a03.htm>
23. Barbosa DC, Sousa FGM, Silva ACO, Silva IR, Silva DCM, Silva TP. Funcionalidade de famílias de mães cuidadoras de filhos com condição crônica. *Ciênc cuid saúde*. 2011; 10(4):731-8.
24. Moraes JRMM, Cabral IE. The social network of children with special healthcare needs in the (in)visibility of nursing care. *Rev Latinoam de enferm*, [online] Ribeirão Preto. 2012 mar/abr; [citado 21 abr 2013];20(2):282-8. Disponível em: <http://www.scielo.br/pdf/rlae/v20n2/10.pdf>

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