

REVIEW ARTICLE

**Nursing approach to family in chronic condition in childhood in Brazil: a review**

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ABSTRACT

**Background:** Along history, acute problems like infectious diseases and trauma, are the main concern of health care systems. Advances in biomedical science and public health have reduced the impact of numerous infectious diseases; on the other hand, the number of chronic diseases has increased. Aim: The present study aimed to know the nursing approach to family in chronic condition in childhood in Brazil.

**Methods:** This is an integrative literature review with a view to characterizing the production of knowledge. The driving question was "How does Nursing assist the family experiencing chronic condition in childhood?". The following keywords Nursing, Family, Children and Chronic Condition were used in the research in electronic databases.

**Results:** The literature reviewed shows the growing concern of Brazilian nurses to know how families live with children with chronic conditions, changes in routine, concepts and stories of families. In the meantime, few studies have described methods to assist the family in chronic condition during hospitalization.

**Conclusion:** We observed that authors stress the importance of the bond with the family, realize the difficulty faced by the family in the new condition and the need for a support group. It was possible to identify the importance of nurses to families for health promotion.

**Keywords:** *Pediatric nursing, Child, Family, Chronic Diseases*

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## Introduction

Along history, acute problems like infectious diseases and trauma, are the main concern of health care systems. Advances in biomedical science and public health have reduced the impact of numerous infectious diseases; on the other hand, the number of chronic diseases has increased (Mendes, 2011).

Epidemiologic Transition has occurred in Brazil and several other developed countries, such as the United States and countries of the UK, mainly due to the increased number of chronic diseases or Diseases of Modernity (Elsen et al. 2002; Anderson & Horvath, 2004). In 2008, the Brazilian Institute of Geography and Statistics (IBGE), through the National Household Sample Survey (PNAD), evidenced that 9.1% children aged zero to five years and 9.7% aged six to 13 years have a chronic illness (IBGE, 2010). These results are very important, because chronic disease affects not only organic functioning, but social and family aspects.

The chronic condition is characterized by alterations in the normal functioning of the body in the long term and is defined as an incurable disease that affects body functioning for more than three months per year and requires the use of permanent devices for adaptation. Acute conditions are manifestations of short term illnesses, such as dengue and influenza. In turn, long-term infectious diseases has been considered chronic conditions. Therewith, it has been considered a new category of acute or chronic health conditions and not acute or chronic diseases (Mendes, 2011).

Chronic conditions affect the child and change intensely and irrevocably the routine of family and social relationships, rapid mobilization and family ability to manage the crisis (Silva & Correa, 2006). The difficulties faced by the family to get adapted are related to duration and risk of complications, which require permanent care and control, due to potential sequelae that may occur, thus highlighting the role of the family (Elsen et al. 2002).

Therefore, nursing care should meet the child's family, offering support, guidance, training and health care toward the adoption of new habits of life, in order to promote family health and capacity for self-caring. Nowadays, working with families is a way to achieve better medium and long-term results with professionals from different areas. In this way, it is imperative a multidisciplinary approach involving clinical aspects, psychological and social consequences for children with chronic illness and their families. Moreover, a good relationship between child, family and health profes-

sionals facilitates acceptance and adjustment of the family to the new condition (PEDROSO & MOTTA, 2013).

Given the above, this study aimed to verify the knowledge produced between 2006 and 2013 on the nursing approach to families with children in chronic condition through analysis of national literature

## Methods

To develop this study, we used the integrative literature review, since it enables one to examine the bibliographic production as a whole and helps to identify common themes and gaps that remain and need to be filled in order to guide future research and improvement clinical actions. This method allows to analyze data from both theoretical or empirical literature, as different types of searches: ethnographic, observational, experimental and / or quasi-experimental. It provides a synthesis of different types of published studies and general conclusions about a topic or area of study.

This integrative review conducted involved the following steps: 1st) Identification and selection of the theme of the research question; 2nd) Establishment of criteria for inclusion and exclusion; 3rd) Identification of pre-screened and selected studies; 4th) Categorization of selected studies; 5th) Analysis and interpretation of results; 6th) Presentation of results (MENDES; SILVEIRA; GALVÃO, 2008). The criteria for selection of articles considered the objectives of this study, i.e., national articles that address the nursing care to families in chronic conditions in childhood indexed in the databases LILACS (Latin American Literature in Health Sciences) and/or MEDLINE (Medical Literature Analysis and Retrieval System Online), between 2006 and 2013. The following keywords were used: Child, Chronic Diseases, Family, Nursing. Studies whose research subjects were adults were discarded. For the selection, exhaustive reading of titles and abstracts were made in order to check for the response to the driving question of this study and the selection criteria.

## Results and discussion

The bibliography researched allowed to identify the answer to the guiding question "How does Nursing assist the family experiencing chronic condition in childhood?". These studies evidenced the importance of knowing the family reality and suggest

ways to develop the care for the chronic condition (Table 1).

The literature reviewed shows the growing concern of Brazilian nurses to know how families live with children with chronic conditions, changes in routine, concepts and stories of families. In the meantime, few studies have described methods to assist the family in chronic condition during hospitalization. As for the objectives of this study “to know how the nurse assists the family in chronic condition in childhood”, we observed that authors stress the importance of the bond with the family, realize the difficulty faced by the family in the new condition and the need for a support group (Alves et al. 2006, Marcon et al., 2007, Motta et al., 2009).

The study that sought to identify the meaning

assigned by the nurse to the care for a child with chronic conditions reported that the nurse performs the child care in a fragmented way, focused on changes in the biological body, and provides families with education in single protocol, without an individualized learning plan (SILVA et al., 2007). These professionals justify this attitude, and state that the institution establishes rigid standards and routines, which makes impossible a high quality care that meets the needs of children and families, in addition to having difficulties in assisting the family (Silva et al., 2007).

According to Alves et al. (2006), nurses feel unable to take care of children with chronic disease, indicating emotional distress and difficulty in dealing with the different demands that chronic situations imposes. These professionals recognize that the family depends on the assistance provided to improve the quali-

**Table 1.**Characterization of Brazilian studies regarding the methodology, the way the nurse performs the care to the family with chronic conditions in childhood and recommendations of the authors for the work with the family, published between 2006 and 2013.

Title	Author	State where the study was conducted	Type of study	Nursing care to families in chronic conditions	Recommendations and conclusions of the study
Meaning assigned by nurse to care provided to child in chronic condition hospitalized and accompanied by family.	Silva et al.(2006).	São Paulo	Exploratory qualitative study	Child care is fragmented and focused on changes in the biological body; provide families with education, to perform technical care.	Suggests a reflection on the role of the nurse to intervene with the family in this situation.
Difficulties and conflicts faced by families in the daily care of a child with chronic illness.	Marcon et al (2007).	Paraná	Case Study		Families have difficulties to perform complex procedures, because they were not trained for such tasks.
Effectiveness of supportive care in events accompanying the disease chronification of hospitalized child.	Alves et al. (2006).	Paraná	Qualitative, descriptive exploratory study, with participation of 9 nurses from the inpatient unit.	Nurses feel emotional difficulties in working with the child; accompany family breakdown, change of routine; perform the supportive care.	Recognizes that family needs support for care; recommend hospitalization at home whenever possible.
Groups as a strategy for teaching and care of family, child and adolescent with chronic disease.	Motta et al..(2009).	Rio Grande do Sul	Reflection addressing group activities, like teaching strategies and health care for families, children and adolescents with chronic illness.		Group activities that use the Creative-Sensitive method in teaching learning process.

ty of life of the child, and that his/her function is to train, advise, support (by listening), and encourage to achieve the expected goals. Furthermore, nurses believe they are viewed by families as a friend and caring person, besides a technical and scientifically enabled professional to care for their child, because he/she provides an honest and realistic dialogue of the experienced situation.

Besides the difficulty in accepting and living with chronic illness, families have difficulties in performing complex procedures at home (Marcon et al., 2007). This may occur because, according to these authors, they were not as well trained as to the procedures required or even by fear, by the specificity of the technique, or for fear of causing pain and distress to the child, besides being an additional inconvenience in daily routine, since all they have to reconcile their everyday commitments to care for the sick child.

The studies consulted suggest a reflection on the role of nurses to intervene with the family in chronic condition, since care is centered on disease and does not meet the needs of the family (Silva et al., 2007). The care cannot be superficial, without dialogue, must go beyond the fragmentation, technicism, aimed only at pathology, must be concerned with the whole, and performed with availability, empathy, commitment, reciprocity and interaction (Alves et al., 2006).

### **Implications for Nursing Practice**

The literature indicates that nursing can contribute to strengthening family support network, which is important for decision-making and material, emotional and affective support, thus contributing to the welfare of the family (Nóbrega et al. 2010, Cruz et al. 2013). This support network can be formed initially by nursing with the development of support groups for the family, both in hospital and in other environments, using the creative-sensitive method that benefits the family as they discover they can learn to cope with situations causing worries, perceive themselves less vulnerable to share with other families, and through the support they realize that the challenges can be best addressed from the empathic understanding of the suffering of others (Motta et al., 2009).

### **Conclusions**

From the analysis of these studies, it is clear that chronic conditions change the family routine, communication, and affection to the child. This condition increases the intra-family conflicts, making it necessary to reorganize the everyday and seek guidelines for home care. Despite the lack of information about the care of

nursing to family with chronic conditions in childhood in Brazil, it is recognized the important role of this category in caring family to support, strengthen and direct it to face the crisis, building strategies of self-care and adapting to the new situation in an attempt to rebalance the family dynamics. It should be emphasized that all studies are from the South and Southeast regions, there are no studies in the other regions of the country. It is expected that nurses are encouraged to publish their studies and practices with families with chronic conditions in childhood.

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### **References**

- Alves, A.M; Gonçalves, C.S.F; Martins, M.A; Silva, S.T; Auwerter, T.C; Zagonel, I.P.S. (2006). A Efetividade do Cuidado Solidário Diante de Eventos que Acompanham a Cronificação da Doença da Criança Hospitalizada. *Revista Eletrônica de Enfermagem*. v.8, n. 2, p.192-204.
- Anderson, G.; Horvarth, J. (2004). The Growing Burden of Chronic Disease in America. *Public Health Reports*, v.119, p. 263- 270.
- Cruz, D.J.L.; Sousa, S.M.A.; Lima, S.F.; Paiva, S.S.; Gurgel, W.B. (2013). Cuidado Cultural e Doenças Crônicas: Análise da relação entre a teoria da diversidade e universalidade do cuidado transcultural e às necessidades da assistência de enfermagem no tratamento de doenças crônicas. *CADERNOS DE PESQUISA*, v.20, n.1, p.43-49.
- Elsen, I, Marcon, S.S & Silva, M.R.S (2002). O viver em família e sua interface com a saúde e a doença. Maringá (PR): Editora Universidade Estadual de Maringá.
- Instituto Brasileiro de Geografia e Estatística. (2010). Pesquisa Nacional por Amostra de Domicílios: um panorama da saúde no Brasil, acesso e utilização dos serviços, condições de saúde e fatores de risco e proteção à saúde, 2008. Rio de Janeiro: Fiocruz/MS/IBGE.
- Marcon, S.S, Sassá, A.H, Soares N.T.I & Molina, R.C.M. (2007) Dificuldades e conflitos enfrentados pela família no cuidado cotidiano a uma criança com doença crônica. *Revista Ciência Cuidado e Saúde*; 6 (Suplem. 2): 411-419.
- MENDES, E.V. (2011). As redes de atenção a saúde. Brasília, 2011. 549p.
- Mendes, K.D.S. ; Silveira, R.C.C.P.; Galvão, C.M. (2008). Revisão integrativa: método de pesquisa para a incorporação de evidências na saúde e na enfermagem integrative literature. *Texto & Contexto Enferm*, Florianópolis, v. 17, n. 4, p. 758 -764.
- Motta, M.G.C, Issi, H.B & Ribeiro, N.R.R. (2009). Grupos como estratégia de ensino e cuidado de família, criança e adolescentes com doença crônica. *Ciência, Cuidado & Saúde* (8): 155-161.

- Pedroso, M.L.R.; Motta, M.G.C. (2013). Criança e Família convivendo com a doença crônica: mesossistema em ligação com a vulnerabilidade programática. *Revista Texto e contexto em Enfermagem*, v.22, n.2, p. 493-499.
- Silva, F.M. & Correa, I. (2006). Doença crônica na infância: vivência do familiar na hospitalização da criança. *Revista Mineira de Enfermagem*, Belo Horizonte, v.10, n. 1.
- Silva, J.B., Kirschbaum, D.I.R. & Oliveira, I. (2007). Significado atribuído pelo enfermeiro ao cuidado prestado a criança doente crônica hospitalizada acompanhada de familiar. *Revista Gaúcha de Enfermagem*, 28 (2): 250-259.