ABSTRACT

Objective: to investigate the scientific production about the direct and/or indirect nursing care for children with chronic conditions. Method: it is an integrative review conducted in February 2012 in the databases LILACS (Latin America and Caribbean Health Sciences Literature), IBECs (Spanish Bibliographic Index of Health Sciences), BDENF (Brazilian Nursing Database), MEDLINE (Medical Literature Analysis and Retrieval System Online), using the followings descriptors “Pediatric Nursing”, “Chronic Disease” and “Nursing Care”, in a accordance with the inclusion criteria. Results: the final sample consisted of eleven papers. The studies selected have revealed an appreciation of the family, as a unit of assistance and recognition in relation to the care for children with chronic conditions, as something complex. Conclusion: the data analysis allows us to infer that there is the need for bigger studies about this theme with the purpose of deeply exploring the complexity of the nursing care towards this clientele. Descriptors: Pediatric Nursing; Chronic Disease; Nursing Care.

RESUMO


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INTRODUCTION

The nursing care for children with chronic condition is revealed as a single and intense experience that requires sensitivity, competence and scientific knowledge from professionals with sights to provide children a quality care. From this perspective, it should be emphasized that care cannot be fragmented, technician and incomplete, thus needing to be managed in order to contemplate the dimensions of the child with a chronic condition. To do so, it should be highlighted the importance of multidimensional and complex knowledge, with a view to subsidizing a comprehensive and humanized care.

Complex knowledge requires a thought that is able to know and appreciate the many dimensions that comprise the complex reality and that might effectively capture mutual relationships, interrelationships and implications of multidimensional phenomena, starting from a non-linear viewpoint, but integrator, i.e., articulator in the pursuit for multidimensional knowledge. 1 In this sense, and with regard to health care, it becomes necessary that the nursing professional is aware of the multidimensional aspects of children with chronic conditions, assuming a closer gaze towards the biological, social, psychological, emotional, cultural and spiritual aspects of these children and their family members.

Thus, the nursing care for children with chronic conditions is presented as a challenge, since it requires from professionals the adoption of attitudes that address the multidimensionality and the needs of these patients. This is a caution pervaded by doubts and uncertainties, particularly those related to the children patients’ future and their new limitations, which is a fact that suggests to nurses to develop strategies to better cope with adversities and unpredictabilities that emerge from their relationship of care with the children and the children's families.

Allied to this perspective, there is sometimes a difficulty from nurses in dealing with families and the situation of imminent risk of death of these family's children, which is generally common when it comes to a chronic condition. 2 In this respect, nurses might unveil feelings of helplessness, sense of inadequacy and a disbelief in the available therapeutic measures, which might impact on the quality of care to be offered. 3 Therefore, it becomes crucial having an investment in relational, interactive and retroactive processes during the nursing training, as well as institutions’ efforts to promote psychological support to nursing professionals in dealing with these situations.

On the other hand, nursing care for children should be extended to the family scope. Thus, literature, especially in relation to Nursing, reveals a failure to provide quality care to children with chronic conditions without including the family in the plan of care. For this purpose, it becomes necessary to know the family and its daily life in order to identify contextual elements relevant to nursing care. 4 Accordingly, it might be understood as a system composed of affective, social and economic bonds, which integrate a specific dynamics. 5 Hence, it should be emphasized that each family is unique and holds its own characteristics, which differentiate them from each other.

In general, chronic conditions are considered as long-term and require that people affected by it reorganize their daily lives in such way to find new manners of living. 6 Thus, the onset of a chronic condition in childhood causes changes in the child’s life, as well as in the daily life of all members of the family, which requires adaptation strategies to the new routine imposed by the disease. Under this perspective, it should be inferred that the chronic condition in childhood causes a change in family structure and dynamics, which reaches the routine of family members, as well as its relationships, given that it might be presented in the form of overload and provoke a considerable emotional impairment in those involved subjects, requiring sensitivity and a careful listening from professionals for these situations. 5

Accordingly, the family feels responsible to minimize suffering and ease the effects of the chronic condition of the child, striving to subsidize a growth and development as satisfactory as possible to this creature. It is often a painful experience for parents and, frequently, they need the support from various strands, whether they are material, emotional, informational and emotional, or even, a social exchange. 7 Under this viewpoint, the care, when directed to the family, should provide spaces for dialogue, knowledge, reflection, acceptance, support and strengthening of bonds. To know the family in its particularity and needs, in fact, means, to give value to the otherness as a fundamental dimension in relationships of care.

In view of this and aiming at providing a nursing care supported by concepts and critical and/or scientific reflections that promote the theoretical and practical
progress of the profession at stake, it becomes imperative to investigate the scientific production of the nursing care for children with chronic conditions with sights to allow improvements in the production of care towards this clientele. Thus, the following study object was delimited: the scientific production of nursing care for children with chronic conditions, having as the guiding question: What has the literature on nursing care for children with chronic conditions? We have outlined as study object the fact of investigating the scientific production about direct and/or indirect nursing care for children with chronic conditions.

The relevance of this study lies in the appreciation of the issue in question, which might mediate the relationships of care among nurses, children and families. We hope that the results can identify gaps in scientific production, in addition to deepen the knowledge of nursing care for children with chronic conditions.

It is an integrative literature review, which allows the synthesis of the state of knowledge of a given topic, enabling the identification of knowledge gaps that need to be filled with the accomplishment of new researches. This research method allows the synthesis of several published studies and enables to draw general conclusions with regard to a particular area under study. Accordingly, the integrative review allow us to build a knowledge in Nursing, thereby producing a based and uniform knowledge for nurses performing a quality practice.

For its preparation, we have observed the following steps: identification of the theme and development of the study question; establishment of criteria for inclusion and exclusion of studies; categorization of studies; assessment of the studies included in the integrative review; interpretation of results and synthesis of knowledge.

After identification of the theme and preparation of the guiding question of the study, we proceeded to the search for information in the literature in the following databases from the site of the Virtual Health Library (VHL): LILACS (Latin America and Caribbean Health Sciences Literature), IBECS (Spanish Bibliographic Index of Health Sciences), BDENF (Brazilian Nursing Database) and MEDLINE (Medical Literature Analysis and Retrieval System Online). The data survey was conducted in February 2012 by using the following indexing descriptors contained in MeSH (Medical Subject Headings): “Pediatric Nursing”, “Chronic Disease” and “Nursing Care”. As to the inclusion criteria for studies, we have considered complete studies with abstracts available in databases in English, Portuguese and Spanish, addressing direct and/or indirect nursing care for children with chronic conditions as the study object and that were indexed in the last ten years.

After this stage, in order to ensure a proper collection and organization of data, we have produced a tool containing the following variables: journal, publication year, contexts and situations of care, methodology and main contributions to the Nursing field. Next, we organized them into themes by observing their similarities and differences, going through the following steps: pre-analysis, material exploration and data handling. This organization gave rise to three categories: recognizing the complexity of care for children with chronic conditions; strategies for caring of children with chronic conditions and valuing the family as the unit of care.

Of the 26 pre-selected studies, eleven met the inclusion criteria, being that five were from LILACS, three from BDENF, one from IBCES and two MEDLINE. In view of a better description of the results, the data are organized and presented in Figure 1, considering the variables: journal, publication year, contexts and situations of care, methodology and main contributions to the Nursing field.
<table>
<thead>
<tr>
<th>Journal/publication year</th>
<th>Contexts and study objects</th>
<th>Methodology</th>
<th>Main contributions to the Nursing field</th>
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<tbody>
<tr>
<td>Rev. Eletr. Enf./2006</td>
<td>Admission Unit of a hospital in Cuiabá-PR; the chronicity of illness of admitted children and its intersection to the effectiveness of supportive care</td>
<td>Content qualitative analysis; field research</td>
<td>The supportive care in the professional practice of nurses enables a humanized nursing care in its different dimensions, free from automatism, as well as from impersonal and uninvolved care</td>
</tr>
<tr>
<td>Rev. Enferm. UFPE on line/2010</td>
<td>Pediatric Oncology Unit of a hospital in João Pessoa-PB; relationship between the practice and the pursuit for knowledge production in Pediatric Oncology</td>
<td>Thematic analysis; qualitative approach; field research</td>
<td>The pursuit for knowledge in the professional practice of nurses is presented as a crucial issue to provide a sensitive care, open to listening and dialogue, with wisdom, dignity and competence. For the construction of the knowledge in pediatric oncology, it is important to build knowledge and also develop skills to elaborate surveys</td>
</tr>
<tr>
<td>Rev. Gaúcha Enf./2007</td>
<td>Pediatric Oncology Unit of a university hospital in Porto Alegre-RS; Perceptions of undergraduate students experienced during internship in the Pediatric Oncology Unit</td>
<td>Experience report</td>
<td>The Pediatric Oncology Unit is unveiled as a place full of life, filled with hopes and pursuits. One needs to look at this environment under new lenses; to realize the needs for comfort of patients and family members; to understand the changes taking place in their lives and how all these factors determine the care to be developed</td>
</tr>
<tr>
<td>Rev. Eletr. Enf./2006</td>
<td>Pediatric Oncology Unit of a Hospital in João Pessoa-PB; dialogue between nurses and mothers of children with cancer in the light of the Theory of Humanistic Nursing of Paterson and Zderad</td>
<td>Phenomenological Nursing; qualitative approach; field research</td>
<td>The dialogue, when intuitively and scientifically conducted, allows mothers to receive care that promote their well-being and being-best in the situation with the children. Moreover, it allows reflection, conceptualization in being and doing of nurses in a humanistic relationship with mothers of children with cancer</td>
</tr>
<tr>
<td>Esc. Anna Nery Rev./2008</td>
<td>Pediatric Admission Unit of a hospital in Santa Maria-RS; aspects of existentiality of world-life of children with HIV</td>
<td>Phenomenological approach from the Theory of Humanistic Nursing; field research</td>
<td>Nurses in the caring circumstances should understand the existentiality of children and families as the unit of care</td>
</tr>
<tr>
<td>Arq. Ciênc. Saúde/2005</td>
<td>Pediatric Unit of a hospital in São Paulo do Rio Preto-SP; perceptions and feelings of nurses in caring for children with cancer</td>
<td>Empirical categorization; qualitative approach; field research</td>
<td>The nursing staff should give account of the importance of its role within the institution and, based upon this, to articulate itself by mobilizing the potential of its professionals in a creative and dynamic way; need for support and security to caregivers when dealing with stressful situations; need for greater scientific knowledge of nurses in Pediatric Oncology</td>
</tr>
<tr>
<td>Rev. Gaúcha Enf./2007</td>
<td>Pediatric Admission Unit of a hospital in Campinas-SP; meaning for nurses of caring for chronically ill children who were admitted and accompanied by family members</td>
<td>Content analysis; qualitative approach; field research</td>
<td>The nursing professional should seek to know better the work process, to know what its role within it in order to be able to actively act and intervene on it</td>
</tr>
</tbody>
</table>
| Rev. Enferm. UFPE on line/2010 | Pediatric Chemotherapeutic Outpatient Unit of a hospital in Rio de Janeiro-RJ; experience report of nurses about the management of nursing care | Experience report | The management of the care for children with cancer is benefited when is dynamic and accomplished in accordance to the experienced situation, making use of capacity for judgment, decision,
It should be observed in Figure 1, regarding the indexed journals, that (02) two studies were published, respectively, in the Revista Eletrônica de Enfermagem\(^{13,14}\), Journal of Nursing UFPE on line\(^{8,15}\), (03) three studies in the Revista Gaúcha de Enfermagem\(^{11,16,17}\), (01) one study in the Journal of the Anna Nery Nursing School\(^{18}\), (01) one in the journal Arquivos de Ciências da Saúde\(^{1}\), (01) one in the Online Brazilian Journal of Nursing\(^{19}\) and (01) one in the journal Index de Enfermería\(^{20}\).

As to the contexts of the selected studies, it should be evidenced that six of them were held in pediatric admission units\(^{1,3,13,17,18,19}\), four in pediatric oncology\(^{11,14,16,20}\), units and one in pediatric hemotherapeutic outpatient unit.\(^{15}\)

It is worth to remember that the nursing care for children with chronic conditions might be developed in different environments, which include both hospital and outpatient context and the home and/or community context. In this study, it is observed an interest of researchers by the hospital context at the expense of the home and/or community context, however, it should be emphasized that these contexts concentrate the set of care for children with chronic conditions. Regarding the region, it should be observed that four studies were developed in the South Region\(^{16,13,17,18}\), four in the Southeast Region\(^{1,3,15,19}\), two in the Northeast Region\(^{14}\) and one in Seville - Spain.\(^{20}\)

Concerning the investigated situations, it is noted in Figure 1 an interest from nurses in the meanings of care for children with chronic conditions\(^{1}\); in perceptions and feelings of this professional in relationships of care for children with cancer\(^{3-5}\); in the relationship between the practice of care and the pursuit for scientific knowledge of nurses in Pediatric Oncology\(^{2}\); in the management of care for children with cancer\(^{12}\); in the dialogue between nurses and mothers of children with cancer\(^{14}\); in the care for children with HIV/AIDS\(^{17,18}\); in the relationship of chronicity of diseases of admitted children with the effectiveness of the supportive care\(^{17}\); in the role of the nursing staff together with children with chronic conditions\(^{19}\), as well as in the care quality to be offered to children and their families.\(^{20}\)

<table>
<thead>
<tr>
<th>Journal / Year</th>
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<tbody>
<tr>
<td>Rev. Gaúcha Enferm./2005</td>
<td>Pediatric Admission Unit of a university hospital in Santa Maria-RS; meaning for the nursing staff for the act of caring for a child with AIDS</td>
</tr>
<tr>
<td>Online Braz. J.Nurs./2005</td>
<td>Surgical Clinic of a hospital in Rio de Janeiro-RJ; acting of Pediatric Nursing before the integrated and systematized care in the postoperative of correction of transposition of the great arteries (TGA)</td>
</tr>
<tr>
<td>Index. Enferm./2010</td>
<td>Unit of Preschoolers and Pediatric Hematology-Oncology; care quality perceived by parents in the aforementioned unit</td>
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</table>

**Figure 1.** Presentation of selected papers according to journal, publication year, contexts and situations of care, methodology and main contributions to the Nursing field, 2012.
Chronic conditions are long-term diseases that require some sort of management. From this perspective, it encompasses a broad category of health hazards that includes communicable diseases, such as HIV/AIDS, and non-communicable diseases, such as cancer, diabetes, cardiovascular diseases and structural disabilities, such as: amputations, blindness and disorders of the joints. All of them have in common the need for permanent care procedures. 

Thus, childish cancer was the most studied chronic condition according to the analysis of the studies. In this context, it is called childhood cancer a group of non-communicable diseases that strikes children and teenagers from 0 to 19 years, who have in common the onset of modified cells that quickly and disorderly multiply themselves, in some body organ, interfering with its operation. In childhood, the most common cancer types are leukemia, brain tumors, lymphomas, kidney tumors and sarcomas.

On the other hand, it should be highlighted that 70% of children diagnosed with cancer have a chance of healing when the diagnosis early takes place and the treatment is performed in specialized centers, which achieved progress are evident due to their scientific and technological development. Nonetheless, the difficult access to information and attendance in health care services, delay the diagnosis and hinders the treatment and the healing of the disease at stake.

Allied to this view, the beginning of treatment is usually accompanied by difficulties that require the involvement of families and children, as well as reorganization of family dynamics due to possible admissions, side effects arising from aggressive therapeutic methods, disruption of daily activities, limitations related to the large volume of new and complex information, possible financial misfit and feelings of anguish, pain, suffering and constant fear of the possibility of death. From this viewpoint, the nursing care for children with cancer is revealed as a challenge by requiring sensitivity, scientific knowledge, skills and competences, especially the relational abilities to deal with the difficulties that arise from the relationship with children and their family members.

Concerning the study design, eight field researches and three experience reports are performed in specialized centers, which achieved progress are evident due to their scientific and technological development. Nonetheless, the difficult access to information and attendance in health care services, delay the diagnosis and hinders the treatment and the healing of the disease at stake.

Scientific production of nursing care for...
relationship among complex beings with feelings, awareness, needs, limitations, difficulties and perceptions that are inseparably interrelated in a caring environment, determined by chance, uncertainties, doubts and unpredictabilities.

Given the above, the care for children with chronic conditions is referred to as complex due to the fact that it involves many aspects\(^1\), which are entwined in a relationship of interdependence that composes a integrator whole. These aspects are related to the phenomenon of being/doing of nurses in their daily work, the child with a chronic condition, in addition to the complex reality itself that is manifested to the eyes of everyone. This gaze towards the whole and the parts is focused on a complex thought of the multidimensional aspect, enabling critical reflections and understanding of phenomena.

From this perspective, the care for children with chronic conditions should not be fragmented as well as superficial, impersonal and uninvolved. It is needed to look at the whole, without losing sight of the uniqueness of the parties and integrate them, in order to get knowledge and re-knowledge of the multidimensional, which allows a comprehensive and humanized care.

- **Strategies for the care for children with chronic conditions**

  The nurse’s role in this caring environment requires from this professional the use of strategies of action/interaction and of tools enabling to act in a committed and empathetic way in relationships of care with children in situations of chronic conditions. In the quest to provide quality care permeated by a sensitive and ethical doing, the nursing professional should know beyond acts and technical procedures, i.e., to realize children and their families in their singularities. For this purpose, it becomes necessary to win the trust and confidence of children and their relatives in the intersubjective relationships of care, fostering the proximity and formation of narrow bonds.

  This scenario of multiple relationships and human interactions highlight fragilities and weaknesses of each person, its limitations, as well as its potentialities to overcome the difficulties that permeate the treatment. Thus, the support and the emotional involvement are characterized as relevant interaction strategies, because they enable the nurse to know and recognize the difficulties, needs and fragilities of children and their families. When one starts from the premise that it is necessary to firstly know to perform interventions in a subsequent step, the support and the emotional involvement are revealed, therefore, as important strategies for action/interaction in caring for children and their families. Nevertheless, it becomes necessary to establish limits in such way not to hamper the care quality.

  It is worth to remember that the orientation is also an assignment of nurses, which suggests an attentive listening and a constructive dialogue that promote the exchange of experiences and the building of knowledge. The family member needs to know the pathology, clinical manifestations, therapeutic treatment, the chances of healing and even the care shares that are being offered to children with chronic conditions. Accordingly, the constructive dialogue is referred to as facilitating strategy of action and interaction in the relationships of care, enabling supportive and humanized attitudes.

  Therefore, the care, as an interactive and creative process\(^2\), requires affective and/or sustaining a professional bond relationship, fostering a relationship of involvement and emotional support, which is permeated by constructive dialogue and a sensitive doing. In this regard, it should be noted that the building of a bond between human beings is generated from relationships of care existing among thereof throughout their lives, being that we can find affection, respect and mutual delivery, as well as reflection in this process. In this construct, the establishment of a connection is presented as fundamental, given that it might express skills, ways of being, attitudes and cognitive structures of nurses to achieve a better human living.\(^25\)

- **Valuing family as a unit of care**

  The discovery of the chronic condition in childhood is accompanied by behavioral and emotional changes in children and in their family members. From this perspective, the family institution needs care as much as the children. On the other hand, the family needs to be qualified to provide every assistance and support needed to promote the children’s health. Hence, one can develop a daily care with quality and autonomy, preventing relapses and worsening to health of children with chronic conditions.\(^28\)

  The treatment of children with chronic condition is usually prolonged, complex and demands constant care shares in relation to the therapy itself and in relation to determinants that might worsen their health conditions. In this context, the family institution needs to be addressed as a unit of care. For this purpose, the family institution needs to know the disease, its manifestations and implications, in addition to having its...
ability to care encouraged and valued, seeking a better care for children.\textsuperscript{26}

The inability to cope with stressful situations, such as, for example, to experience the suffering of children and their new limitations, as well as fear and uncertainty in relation to the procedures, might trigger a set of conflicting feelings in families, which lead them to adopt ambiguous behaviors, sometimes contributing to the children’s care, sometimes hindering this practice. It is worth to remember that the family institution has a crucial role in caring for children with chronic conditions, given that it is the environment in which children find protection, support and safety to deal with the difficulties inherent in the treatment. Thus, care provided by a family member largely favors the survival of the human being in its several stages of the lifecycle.\textsuperscript{15} Hence, the act of training the families to cope with the disease and the clinical conditions, as well as for caring for children at home, is revealed as a demand required by nurses.\textsuperscript{15}

To ignore such feelings and their situations mean neglecting care to the family institution, leaving it in a vulnerable situation. Accordingly, it is a task of health care team to provide the resources needed to identify and meet the needs of this institution, including it in the perspective of care for children with chronic conditions. However, this practice requires a humanizing rebuilding in the health care practices and, in this sense, also screams for attitudes of sensitivity and responsibility from professionals, in order to assist the family in the quest for ways of conducting a better confrontation, adaptation and care for children.\textsuperscript{5}

\section*{CONCLUSION}

The integrative literature review makes evident a need for further studies on the direct and/ or indirect nursing care for children with chronic conditions. In the pursuit for information about the study object, we have observed that many studies have focused on the family institution and its care necessities, its organization and re-organization before the diagnosis of the chronic condition. This statement shows how important it is to contemplate the family as the unit of care and glimpse it as a facilitator in relationships of care.

Aside from this issue, it should be highlighted an interest in relation to childish cancer as a chronic condition for being studied. There was a predominance of studies conducted in hospital environments, which suggests intensifying efforts to redirect the studies for the several contexts in which the care for children with chronic conditions are developed.

On the other hand, studies were only identified in the Northeast, Southeast and South Regions of Brazil, which has revealed a gap in the Midwest and North Brazilian Regions. As a contribution, the studies indicate the need for management of care, a humanizing practice based on scientific knowledge and permeated by a sensitive and reflective practice of doing of nursing professionals. Accordingly, it should be emphasized the complexity that permeates the process of caring for a child with a chronic condition, which requires the use of strategies and tools for approximating and developing the care shares.

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