

CONTEXTUAL SPECIFICITIES OF NURSING CARE TO HOSPITALIZED CHILDREN WITH CHRONIC CONDITION¹

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ABSTRACT

This study aimed to understand the contextual specificities of nursing care given to the hospitalized children with chronic conditions. The qualitative approach was used based on the theoretical and methodological frameworks, respectively, the Complex Thought and the Grounded Theory. Data were collected from July to November 2012 through semi-structured interviews. The study included 18 subjects arranged in three sample groups: nurses, nursing technicians and family. The category *Revealing contextual specificities that influence nursing care given to hospitalized children with chronic conditions* and its subcategories present the meanings of nursing care, aspects about the hospitalization of children with chronic conditions and perceptions of participants about the care context. We concluded that the care relationships and the hospitalization of children with chronic condition are characterized as complex phenomena, requiring from the nurse and the nursing team the appreciation of the context and articulation of multiple knowledge and practices.

Keywords: Pediatric Nursing; Chronic Disease; Nursing Care; Hospitalization.

INTRODUCTION

Health conditions can be understood as short or long term circumstances in people's lives that require reactive or proactive, episodic or continuous social responses and fragmented or articulated with the health care systems. At this juncture there are chronic health conditions that transcend the concept of chronic diseases including persistent infectious diseases, health conditions related to motherhood and perinatal period, health conditions linked to the maintenance of health through life cycles, long-term mental disorders, continuous physical and structural deficiencies, metabolic diseases, as well as the vast majority of oral diseases⁽¹⁾.

Currently, chronic health conditions are responsible for 60% of all the burden of disease in the world. This growth is so vertiginous that

estimates show that by 2020, 80% of the burden of disease in developing countries will come from chronic problems. In these countries, the rate of adherence to treatment is 20%, leading to negative statistics in health field and causing high costs to society, government and family⁽²⁾.

In childhood, chronic condition leads the child to experience frequent readmissions, impacting their social life as well as the dynamics and the functionality of their family^(3,4). The child demands attention and permanent care of the nursing staff and their families in order to avoid health problems and promote quality of life⁽³⁾. This situation highlights the disturbance experienced by the family during the hospitalization of the child and expresses the complexity of the nursing care to hospitalized children with chronic condition.

In this regard, the nursing care to hospitalized children with chronic condition requires from

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the nurse and their team a thought of the context and the complex, because it is understood that in addition to biological, the child is a social being and, as such, they cannot be decontextualized of their environment in care practices, since they are part of a family with certain lifestyle habits, values, knowledge and needs, and both the family and the child are inserted in a society⁽⁵⁾. The thought of the context is the one that values the relation of inseparability and inter-
feedbacks between the phenomenon and its context, while the thought of the complex is what captures the relationships and interrelationships of multiple aspects of multidimensional phenomena, addressing the diversity and the unity of the parts and of the whole of these phenomena⁽⁶⁾.

There are times when the relationships of nursing care to hospitalized children with chronic condition are permeated by feelings of selflessness and prejudice by the professional to the child and their family. Such an event has favored the social isolation of the latter⁽³⁾ encouraging the development of research in Pediatric Nursing on social network and support to families of children with chronic conditions, and also on the subjective aspects that permeate the care relationships.

On this latter perspective, it has been questioned: What meaning does the nursing team attribute to the care of hospitalized children with chronic condition? How do the nursing staff and family members perceive the care context to hospitalized children with chronic condition? How do they characterize the hospitalization of children with chronic condition? Such questions allowed defining the research question to be investigated: What are the contextual specificities of nursing care to hospitalized children with chronic condition? The objective is therefore to understand the contextual specificities of nursing care to hospitalized children with chronic condition in light of the complexity.

We hope with the results of the study to understand the multiple aspects related to nursing care context to hospitalized children with chronic condition in order to contribute to a contextualized and humanized management

to children and their families. The relevance of this study is to reveal the meanings that permeate nursing care, aspects regarding hospitalization of children with of chronic condition and perceptions of the nursing staff and family members about the care context. These are points that can be configured as subsidies for nurses in environmental and nursing care management.

METHODOLOGY

This is a qualitative study, anchored in the theoretical and methodological frameworks, respectively, the Complex Thinking and the Grounded Theory (GT).

The Grounded Theory is a research method that has long been used in the nursing area because of its contribution to the understanding of unexplored phenomena and production of explanatory models and theories⁽⁷⁾. As for the Complex Thinking, it is a way of thinking the reality that opposes the one-dimensional view considering it poor and insufficient for understanding the multidimensionality of complex phenomena⁽⁶⁾.

Data were collected in the Pediatric Inpatient Unit (PIU) of a Federal University Hospital, located in Rio de Janeiro, Brazil, from July to November 2012, through semi-structured interviews. This is a hospital specialized in pediatrics, where more than 50% of hospitalized children have chronic or rare diseases, or are hospitalized without a clinical diagnosis⁽⁸⁾.

It is understood that the nurse is the professional responsible for nursing care services. Thus, initially there were interviews with these professionals who met the following inclusion criteria: being a nurse with a minimum experience of three years in the care of children with chronic condition; being working in the PIU; having a year of binding to the institution. Nurses were excluded if they were on vacation, on leave or away from work. Eight nurses composed this first sample group, seven females and one male, with length of experience in the care of children with chronic conditions ranging from four to 32 years.

Analytical treatment of the interviews with the nurses revealed that the nursing care to hospitalized children with chronic condition is developed with the participation of nursing technicians who perform direct care to the child. This situation directed the research to nursing technicians in order to understand their involvement in the development of this practice. Therefore, these professionals should meet the same inclusion and exclusion criteria established for the composition of the first sample group, according to their professional category. Six nursing technicians participated in this second sample group, all females with length of experience in caring for children with chronic conditions ranging from five to 27 years.

By revealing their involvement in nursing care to hospitalized children with chronic condition, the nursing technicians reported that the children's family members are involved in this practice influencing and developing some care. This fact directed the research to the families of hospitalized children with chronic condition, seeking to meet their involvement in nursing care. For this, it was established as inclusion criteria: being family member of a hospitalized child with chronic condition in PIU. Four family members composed this third sample group, all of them being mothers.

The organization of participants in sample groups derived from an analytical GT tool called theoretical sampling, whose objective is to seek places, people or events that increase the possibility to discover variations among concepts constructed with respect to their properties and dimensions.

The completion of data collection in each sample group was determined by the use of theoretical saturation, in which new data collected were not changing anymore in consistency and theoretical density those concepts that had been built ⁽⁹⁾.

Data were collected and analyzed comparatively following the coding steps: open, axial and selective. Coupled with the coding process we carried out memos and diagrams that helped the theoretical analysis of the data ⁽⁹⁾.

The category *Revealing contextual specificities that influence nursing care given to hospitalized children with chronic conditions* emerged from the analysis of data as contextual condition of the phenomenon *Establishing relationships and interactions for the management of nursing care to hospitalized children with chronic condition in the Pediatric Inpatient Unit*. Given its relevance to highlight the contextual aspects of nursing care to hospitalized children with chronic condition, we decided to present it separately in this article.

In view of the recommendations of Resolution 466/12 of the National Council of the Ministry of Health, data collection was initiated only after approval of the study by the Research Ethics Committee of Anna Nery Nursing School - EEAN/HESFA/UFRJ, under opinion number 8921, and by the Research Ethics Committee of the University Hospital Federal, where the study was conducted, under the opinion number 07/12. The study subjects were asked to sign the Informed Consent Form (ICF). To ensure anonymity of thereof, the speeches of the nurses were identified by the letter N, the letter T for the nursing technicians and the speeches of family members by the letter F. All are followed by a number regarding the order of interviews in each sample group (N1, T1, F1).

RESULTS AND DISCUSSION

The category *Revealing contextual specificities that influence nursing care given to hospitalized children with chronic conditions* invites us to appreciate the context as component condition of nursing care, emphasizing the need for a thought of the context and the complex in care relations. It is composed of the subcategories: *Understanding the nursing care to hospitalized children with chronic condition*; *Introducing aspects of the hospitalization of children with chronic condition*; and *Exposing perceptions about care context of children with chronic condition*.

The subcategory *Understanding the nursing care to hospitalized children with chronic*

condition reveals that the development of this practice is considered a challenge for nurses and their team since it comprises the development of relational, subjective, cognitive and technical skills, having ethics as the axis of care relationships. This is a practice that require from the professional permanent care to children and dedication to the achievement of care because, in general, these are children with a variety of needs that transcend the biological dimension. The speech of the nurse shows how this practice is challenging for nursing staff:

The care for these children is double because they are very dependent children [...] it involves more work and the observation has to be greater. The care for these children is too much work, we have to be in a constant observation because there is a dependency. They are very dependent children. (N8)

The dependence of hospitalized children with chronic condition to nursing care highlights the importance of these professionals in the care of this population, which should enhance the multidimensional aspect of the child and develop a systematic management. It should be added that in the context of hospitalization, in addition to professional care, this group of children needs the care of their family members/caregivers, while the literature shows that these are involved in care related to body hygiene and administration of oral medications ⁽⁸⁾.

From this perspective, it is emphasized that inclusion of the family in the care process of hospitalized children is a skill that deserves to be developed by nurses and health professionals, based in dialogue and negotiation in order to encourage the joint participation of family members in the decision-making involving the child's health-disease process ⁽¹⁰⁾. In this regard, we emphasize the need for nursing professionals to have a thorough preparation to work with the family in order to value them as facilitators and caregivers of their own members ⁽¹¹⁾.

Given their dependence on professional care and the need for multiple natures support, hospitalized children with chronic condition

are perceived as different beings as shown in the speech of the professional below.

These children are differentiated [...] they need attention, affection, care. (N5)

About nursing care to this group of children, it is emphasized that their management should be performed by the nurse in accordance with the actual needs of thereof, given that each of them experiences their chronic condition in a unique way. This perspective reiterates the challenge of recognizing the unity in the diversity of beings and to value the child as a complex, singular, autonomous and multidimensional being ⁽¹²⁾.

Therefore, knowing the singularities, the clinical condition and the child's pathology are fundamental aspects to obtain advances in nursing care.

Depending on the child's diagnosis, care will be different [...] each child demands a special care. There are children who are chronic and cannot get out of bed, others can go out and feed themselves. (N6)

In addition to technological devices and theoretical and practical knowledge, the statements of nursing technicians show that hospitalized children with chronic condition have emotional needs that deserve to be considered by professionals managing care, as it is understood in the view of complexity that whatever is human contains affection ⁽⁶⁾. In this context, it is reiterated that hospitalized children with chronic condition requests support of various kinds.

You have to take a little time to pay attention [...] these children lack of it, they ask for our attention and we learn from them. (T1)

In the case of chronic patient it is important the care, attention [...] the affection is not something technical, but it is everything and it is very good. There is a great exchange [...] we have to have a lot of good will to donate in care. In fact, you dedicate yourself too much. (T2)

From the above statements, it is understood that the care to hospitalized children with chronic condition is developed through interactions in which it is possible to see the reciprocity and mutuality as intrinsic components of this practice. From this

perspective, it is understood that the care to children with chronic condition turns out to be an enriching experience for the nurse while this professional experiences overcoming, discoveries and constant learning situations ⁽³⁾.

The subcategory *Introducing aspects of hospitalization of children with chronic condition* states that this phenomenon is extensive, complex and marked by changes in the child's and their family's lives. The child starts to dwell in the hospital for a long period as shown in the statements that follow.

Most chronic children live here, practically. (N8)

In my ward (hematology) children keep hospitalized for a long time. (T1)

In the case of my daughter, who has leukemia, it is two years of treatment, so it is two years in hospital. (F2)

Hospitalization of children with chronic condition is usually long and is marked by frequent readmissions that limit their social and family relationships ⁽³⁾. It is an unpleasant experience for the child and their family because in this period performed several tests and various invasive procedures are performed to protect children from harm and injuries. Indeed, the child suffers from routine care on the unit and may develop a sense of fear of health professionals, as the following family member reports:

At the beginning my daughter took a lot of injections, she had to do many tests and she could not see anyone of white coat that she thought she would receive an injection [...] they (children) can't see anyone with white coat they start to cry. (F2)

In the course of hospitalization of children with chronic condition, changes arising from the treatment and disease occur. In most situations, devices are installed on the child's body, signaling their limitations and their new demands for care.

There are those chronic diseases that are not degenerative and the child will not change, but in degenerative disease at a given time of hospitalization the child will need a gastrostomy because they can't eat through the mouth anymore, they don't talk normally anymore because of the tracheostomy, she came in ambient

air with basic support at home and goes to an advanced mechanical ventilation. (N1)

There are often neurologically impaired children and they come into the hospital in a way and return to their house with some device, a tracheostomy. (N8)

With respect to physical limitations, it is revealed that hospitalized children with chronic condition may present mixed feelings, from acceptance to resentment. At this juncture, study ⁽¹³⁾ recorded that they feel excluded before others and seek mechanisms of adaptation in order to improve their quality of life. Aside from the emotional, physical and biological issues, hospitalization imposes social and financial changes in the child's and their family's lives, as seen in the speech below.

She (the child) is stuck in the hospital only because we cannot afford to have a home care, the mother fight in court to get it because she has no financial condition to keep at home and the government says there is a law that does not allow the patient to stay home when they need mechanical ventilation [...] she (the child) could have a social life at home but she is stuck in the hospital because of that. (N1)

The Ordinance of the Ministry of Health no. 963/2013 ⁽¹⁴⁾ that redefines Home Care under the scope of Unified Health System (SUS) specifies that the user is not included in the Home Care Service (SAD) if they have need for invasive mechanical ventilation. This situation has motivated the parents of children undergoing mechanical ventilation free of continuous monitoring to seek judicial support for a home care to their children in order to reduce their long stay in the hospital and reinsert them in the family environment. It is considered that the separation of the child from the family environment is a condition that interferes in family interactions and, as such, the nurse must take a stand in support the family who experiences this and other circumstances that influence the intra-family relationships ⁽¹⁵⁾.

It should be added that during hospitalization the permanence of a guardian or one of the parents is ensured by law, as stated in art. 12 of Chapter I of the Statute of

Children and Adolescents ⁽¹⁶⁾. This event has triggered changes in care planning, as well as changes in family dynamics, because the long and repeated hospitalizations cause separation of the child and the guardian from other members of the home environment who stayed at home ⁽¹⁷⁾. The speech of nurses below confirm this event.

The mother is often in despair because she needs to be at home, she has a husband, has a life outside the hospital. A child stuck three in a hospital during three years means three years of the mother's life stuck at a hospital. (N1)

It should be noted that the separation of family members can change family relationships, especially married life of the couple, disfavoring coping the situation ⁽¹⁷⁾.

Palliative care in hospitalization proved to be necessary in circumstances of severe discomfort and suffering of the child affected by cancer and other chronic health conditions, and also in situations in which there is no more possibility of disease-modifying treatment. In this perspective, the approach should be guided in a total active care, including the body, the mind and the spirit of the child and also family support ⁽¹⁸⁾.

I work at hematology ward and in it, children are hospitalized frequently and sometimes the child is terminally ill and what we do is palliative. (T5)

It is understood that hospitalization of children with chronic condition is pervaded by uncertainty and events, making the care relationships complex. The dialogic life/death interpellates nursing professionals challenging them to provide quality care through actions involving comfort and support to the family at the end of life.

Exposing perceptions about care context of children with chronic condition is the subcategory that addresses the relational environment of the Pediatric Inpatient Unit of the researched hospital. In this unit there is a high number of hospitalized children with chronic condition, as shown in statements that follow:

This is a chronic patient hospital. (N1)

Since it is a teaching hospital, a public institution [...] we have a very large demand of chronic patients in the hospital due to that. (N7)

We work with children with diseases easy to be treated, chronic diseases, serious illnesses [...] there are a lot of these children in the institute. (N8)

The Pediatric Inpatient Unit presents a different physical structure and care dynamics when compared to other hospital units.

Here I have the wards where I see everything that is going on, we have the boxes with glass, so I have an overview of everything. (N3)

In the Intensive Care Unit there is a whole physical structure for us to have all the material on our hands, at our side. Here in the ward it does not work like that, but we try to do this with the chronic patients. (N7)

You notice that even the distribution of wards is different from other places where the nursing station is located far away. (N8)

In the context of investigation, there was a predominance of neuropathic hospitalized children. These, in general, inspire greater care from team and their family because of their limitations and dependence on professional and family care. This situation is presented as reality of a study ⁽¹⁹⁾, in which it was observed that among the chronic health conditions of hospitalized children, 61.3% corresponded to neuropathies, followed by rare syndromes/inborn errors of metabolism 21%, kidney diseases 9.7% and heart diseases 8%.

Here in the inpatient Pediatric Inpatient Unit we have many neuropathic children that are chronic. (N3)

It is noteworthy that the studied hospital develops professional training courses aiming to qualify health workers. This is an activity that can provide the development of cognitive skills of professionals, making them more secure and able to perform care to hospitalized children. In this sense, we emphasize the need to integrate education and work to stimulate critical thinking to update the knowledge in the professional routine ⁽²⁰⁾.

Since it is a university hospital, we are always doing courses. I just did a course of 180 hours, so we remain up to date in what the patient needs, within what the institution needs. (T2)

Family members realized the hospital as specialist in treating children with chronic

condition and are satisfied with the child care offered.

Here, though it is a public hospital, we have the best nurses, technicians and nursing assistants [...] he (child) feels in the family environment because professionals provide it in here. (F1)

Here, despite of being a public reference hospital, I have nothing to complain about. (F2)

Given the above, we realized the Pediatric Inpatient Unit as the context of interaction between professionals, child and family members, permeated by aspects of order/disorder that influence the care relationships. This is a context with unique structure and dynamics situated in a hospital perceived as a reference in caring for children with chronic condition in the city of Rio de Janeiro.

FINAL CONSIDERATIONS

It was understood from the results presented that the care to hospitalized children with chronic condition appears as a complex and challenging experience for the nursing staff, which should make note of the objective and subjective dimensions that permeate its development and also for the multidimensionality of the child and their family. The child with chronic condition presents needs of various kinds that transcend the biological dimension and depends on professional care as well as care of their family members, who should be valued by the nursing staff in care relations. It is an activity that requires from professionals the knowledge of the uniqueness, the clinical condition and the child's pathological condition, and also the

development of technical skills to operate the technologies that permeate the care relationships.

Hospitalization of children with chronic conditions is complex, extensive and characterized by frequent hospitalizations and social, physical and financial changes in their lives and in their family's lives. The child is subjected to various procedures and tests that cause them pain, which may trigger the feeling of fear of health professionals. In addition, there are occasions when they need technological devices that are installed in their body exposing their new limitations and care demands.

The Pediatric Inpatient Unit was perceived by nurses as a singular context of the hospital, with particularities with regard to its structure and dynamics of care. Professionals reported receiving educational investments through training courses to develop skills and abilities to better care of hospitalized children. The hospital was characterized by the family members as a reference in caring for children with chronic health conditions in the city of Rio de Janeiro.

Given the above, this study indicates the need to value the otherness as strategy of action/interaction and the context as component factor of care management. In addition, it highlights the need for further research that attempts to understand the meanings attributed by children to their hospitalization, their perspective on nursing care, as well as the care context in order to better exploit the phenomenon in its complexity.

ESPECIFICIDADES CONTEXTUAIS DO CUIDADO DE ENFERMAGEM À CRIANÇA EM CONDIÇÃO CRÔNICA HOSPITALIZADA

RESUMO

Objetivou-se compreender as especificidades contextuais do cuidado de enfermagem à criança em condição crônica hospitalizada. Foi utilizada a abordagem qualitativa apoiando-se nos referenciais teórico e metodológico, respectivamente, o Pensamento Complexo e a *Grounded Theory*. Os dados foram coletados entre julho e novembro de 2012 por meio da entrevista semiestruturada. Participaram do estudo 18 sujeitos organizados em três grupos amostrais: enfermeiros, técnicos de enfermagem e familiares. A categoria *Revelando especificidades contextuais que influenciam o cuidado de enfermagem à criança em condição crônica hospitalizada* e suas respectivas subcategorias apresentam os significados do cuidado de enfermagem, aspectos relacionados à hospitalização da criança em condição crônica e as percepções dos participantes acerca do contexto de cuidado. Conclui-se que as relações de cuidado e a hospitalização da criança em condição crônica configuram-se como

fenômenos complexos, solicitando do enfermeiro e de sua equipe a valorização do contexto e a articulação de múltiplos saberes e práticas.

Palavras-chave: Enfermagem Pediátrica. Doença Crônica. Cuidados de Enfermagem. Hospitalização.

ESPECIFICIDADES CONTEXTUALES DE LA ATENCIÓN DE ENFERMERÍA A NIÑOS HOSPITALIZADOS CON CONDICIÓN CRÓNICA

RESUMEN

El objetivo fue comprender las especificidades contextuales del cuidado de enfermería al niño hospitalizado con enfermedad crónica. Se utilizó el enfoque cualitativo apoyándose en los marcos teóricos y metodológicos, respectivamente, el Pensamiento Complejo y la *Grounded Theory*. Los datos fueron recolectados entre julio y noviembre de 2012 por medio de entrevistas semiestructuradas. Participaron del estudio 18 sujetos organizados en tres grupos de muestras: enfermeros, técnicos de enfermería y familiares. La categoría *Revelando las especificidades contextuales que influyen en la atención de enfermería al niño hospitalizado con enfermedad crónica* y sus subcategorías presentan los significados de la atención de enfermería, aspectos relacionados a la hospitalización del niño con enfermedad crónica y las percepciones de los participantes acerca del contexto del cuidado. Se concluye que las relaciones de cuidado y la hospitalización del niño con enfermedad crónica se caracterizan como fenómenos complejos, solicitando del enfermero y su equipo la valoración del contexto y de la articulación de múltiples saberes y prácticas.

Palabras clave: Enfermería Pediátrica. Enfermedad Crónica. Cuidados de Enfermería. Hospitalización.

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