Nursing care management for children hospitalized with chronic conditions

Gerenciamento do cuidado de enfermagem à criança em condição crônica hospitalizada

Gestión de atención de enfermería a niños hospitalizados con condición crónica

Thiago Privado da Silva, Marcelle Miranda da Silva, Glaucia Valente Valadares, Italo Rodolfo Silva, Josete Luzia Leite

1 Universidade Federal do Rio de Janeiro, Anna Nery School of Nursing, Postgraduate Program in Nursing. Rio de Janeiro, Rio de Janeiro, Brazil.

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ABSTRACT
Objective: to understand the interactions of nurses managing nursing care for the hospitalized child with a chronic condition.
Method: Theoretical and methodological references were used, Complex Thought and grounded theory, respectively. In the study 18 subjects have participated arranged in three groups: nurses, nursing technicians and family members. A semi-structured interview was used as technique for data collection. The data analysis followed three stages of coding: open, axial and selective.
Results: the category “Needing to manage nursing care to the hospitalized child with chronic condition in Pediatric Inpatient Unit” and their subcategories show the complex inter subjective bindings established by nurses that support the practice of nursing care management.
Conclusion: There are difficulties for nursing professionals to interact with the child’s family and the dialogical order/disorder/interaction/organization in the implementation of the management process of care is.
Key words: Pediatric Nursing; Management; Child Care; Interpersonal Relations.

RESUMO
Descritores: Enfermagem Pediátrica; Gerência; Cuidado da Criança; Relações Interpessoais.

RESUMEN
Objetivo: comprender las interacciones del enfermero en la práctica del gerenciamiento del cuidado de enfermería al niño con condición crónica hospitalizada. Método: se utilizó como referenciales, teórico y metodológico, respectivamente, el Pensamiento Complejo y la Grounded Theory. Participaron del estudio 18 sujetos organizados en tres grupos: enfermeros, técnicos de enfermería y familiares. La entrevista semiestructurada fue utilizada como técnica para recoger datos. El análisis siguió las tres etapas de codificación: abierta, axial y selectiva. Resultados: la categoría “Necesitando administrar el cuidado de enfermería al niño con condición crónica en la Unidad de Internación Pediátrica” y sus respectivas subcategorías revelan las complejas vinculaciones intersubjetivas establecido por el enfermero que apoyan la práctica del gerenciamiento del cuidado de
INTRODUCTION

The management of nursing care for children hospitalized with a chronic condition is characterized as a complex phenomenon which requires the nurse to establish multiple interactions and thinking that values the singularity, the multidimensionality and the social context of the child and his family. The care of their multiple needs demand from nurses and their teams the development of strategies of action and interaction anchored in the perspective of complementarity, reciprocity, recursiveness, and nonlinearity. Only from a dynamic, interdisciplinary and multi-directional approach will the care for the child and his family, in their complexity, be possible.

In addition, in the management of nursing care for the child hospitalized with a chronic condition, the nurse faces multiple situations of uncertainty, unpredictability, with the death/child's life dialogue and particularities of the pediatric context, requesting the development of thinking that appreciates the context and the complexity of the experienced facts. These circumstances reinforce the work of nurses as a complex phenomenon, as at this juncture, there is an issue of inseparable heterogeneous constituents, events, actions, interactions, retroactions, determinations, and chances that constitute the real world. Within the complex interpersonal relationships that permeate the management of nursing care, interaction appears as the first activity of the professional, acting as a facilitator to the encounter between individuals and the establishment of a connection between the professional, the patient and his family. The interaction prevents the emotional detachment and attenuates the patient's isolation and, moreover, expands self-knowledge, self-acceptance and critical reflection. It can be understood as a heterogeneous process that occurs in coexistent contexts, in which the movements that cooperate both for approaching, as well as to the distancing of those involved in the phenomenon are produced and reproduced.

Interaction is mentioned in the National Humanization Policy as a challenge for health production, improvement of poor interaction in the teams, and overcoming of fragmentation of the relationships between the different professionals and between them and the users. Also mentions the need for shared management in which workers, managers and users of the Unified Health System are and feel co-responsible and protagonists of the health production process.

Reflecting on this challenge for the care managerial practice this study object was the nursing interactions in nursing care management for hospitalized children in chronic condition with the question: how the nursing interactions occur in child nursing care management with hospitalized chronic condition? The objective was to understand the nurse interactions in the nursing care management to hospitalized children with chronic conditions in the light of the complexity of Edgar Morin.

METHOD

This is a descriptive study of qualitative approach using grounded theory (GT), or the theory based on the gathered data, in Portuguese, as a methodological framework and, the complex thought of Edgar Morin as a theoretical reference (GT).

Grounded theory is a research method used in the nursing area because of its contribution to the understanding of less explored phenomena and the production of explanatory models and theories, providing to the researcher a useful benchmark in the study of interpersonal relationships in the environment care. Complex thought it is a way of thinking about reality that opposes the unidimensional perspective, partially because it is considered reductionistic and insufficient for understanding the multidimensionality of complex phenomena.

The study was conducted at the pediatric inpatient unit (PIU) of a university hospital in Rio de Janeiro, Brazil. It is a hospital that specializes in pediatrics, where more than half of the hospitalized children are affected by chronic or rare diseases, or are admitted without a clinical diagnosis.

The study included 18 subjects who were organized into three groups, based on the GT theoretical reference, which instructs the investigator to look for places, people or events that maximize opportunities to discover variations among concepts and density of the categories in relationship to their properties and dimensions.

The technique used for data collection was a semi-structured interview, from July to November of 2012. Initially, interviews were conducted with nurses, as this professional is responsible for activities involving care and management of nursing services. Participants met the following inclusion criteria: being a nurse, with a minimum of three years of experience in the care of children with chronic conditions; be assigned to the PIU; working in the institution for one year. Nurses who were on vacation, on medical leave, or away from work were excluded. This first group was composed of eight nurses, seven female and one male, with experience in care of pediatric patients with chronic conditions ranging from four to 32 years.

Nurses stated in the interviews that the nursing technician is involved in the practice of nursing care management through the provision of direct care to the child hospitalized with a chronic condition. Based on this fact, interviews with nursing technicians were necessary in order to understand their involvement in this practice. So, the same inclusion and exclusion criteria for the interviews with the nurses were considered. Six nursing technicians were part of this second
group, all female, with experience in caring for children with chronic conditions ranging from five to 27 years.

Nursing technicians presented in interviews their involvement in the practice of nursing care management, emphasizing the importance of and the family’s involvement in the nursing care management of the child. To understand this phenomenon, interviews were conducted with family members who met the following inclusion criteria: being a family member of a child hospitalized in the PIU with a chronic condition. This third group was composed of four family members, mothers of children with chronic conditions. The mothers revealed in interviews their participation in nursing care management, enabling the understanding of their involvement.

The completion of data collection in each group of subjects was determined by the use of theoretical saturation, in which the new data collected were no longer changing the consistency and theoretical density of concepts that were built.

In GT, data are collected and then comparatively analyzed using open coding, axial coding and selective coding. In open coding, data were coded line by line, generating preliminary codes that, when grouped by similarities, originated conceptual categories and subcategories. In axial coding, categories were related to each other and to their subcategories to determine their properties and dimensions. For integration of the categories and determining the structure and process of the investigated phenomenon, the paradigm was used, an analytical mechanism suggested by the authors of the method. The determination of the central category of the study occurred in the selective coding. Combined with this encoding process, memos and diagrams were used, which are important analytical tools and assist the investigator in the theoretical analysis of the data.

The category “Needing to manage the nursing care for the child hospitalized with chronic conditions in the pediatric inpatient unit” emerged from the data analysis as an important category to reveal the multiple interactions of nurses, and their ways of managing nursing care for the hospitalized child with chronic conditions.

According to the recommendations of Resolution 466/12 of the National Council of the Ministry of Health Health, data collection only began after the study was submitted for ethical consideration based on the CAAE protocol: 01535812.3.0000.5238 and was approved by the Ethics and Research Committee of the Anna Nery School of Nursing - EEAN / HESFA / UFRJ, on protocol number 8921, and by the Ethics and Research Committee of the Federal University Hospital, where the study was conducted, protocol number 07/12. The study subjects were asked to sign the Terms of Free and Informed Consent (TFIC). To ensure anonymity, the statements of nurses were identified by the letter E, the technical nurses by the letter T, and the family members by letter F. All of the letters of identification were followed by a number showing the order of each group of interviews (E1, T1, F1).

RESULTS

“Needing to manage the nursing care for the child hospitalized with chronic conditions in the pediatric inpatient unit” is constructed of the following subcategories: unveiling the multiple interactions for nursing care management; managing the nursing care for the child hospitalized with a chronic condition on day shift; managing the nursing care for the child hospitalized with a chronic condition on night shift; and valuing interactions to meet the family’s needs.

The subcategory “Unveiling the multiple interactions for nursing care management”, presents the material of nursing interactions for the management and care of the child hospitalized with a chronic condition. In this network, the nurse acts and interacts with professionals of the multidisciplinary health team, with the family, and with the child hospitalized with a chronic condition.

Regarding the nurses’ interactions with the nursing staff, the following lines reveal the existence of a relationship based on friendship, teamwork and trust, even with some relational disorders.

I have a lot of confidence on my team [...] we have a good relationship with the team [...] but sometimes there is conflict in the very team. (E3)

A relationship of friendship with the team, both with technicians, assistants and also with the medical staff; I always try to have such interaction, friendly relationship, nothing of being superior, of course, respecting the hierarchy, but on the level of friendship as well. (E5)

In accordance with the statements above, the nursing staff members who care for the children with chronic conditions reported having a good relationship with the nurses. In this regard, they recognized that the parameters of the nurse’s role is different from theirs.

I have good relationship with the nurses [...] usually, we have a good relationship, I have no difficulty. (T2)

It is good, I have no problem with the nurse, as I told you, there is the hierarchy, each one does his part, but always has union with each other. (T4)

Nurses reported having an interaction with professionals in the multidisciplinary health team similar to that experienced with the nursing staff, although isolated conflicts with the medical team were reported, caused mainly by power relationships and consequently the sense of devaluation of their professional autonomy.

It is a good relationship [...] I see that here, a very nice opening exists, because we participated in the round and our opinion is valued, because they listen to us. (E6)

I (a nurse) never had a problem with my multidisciplinary team, nor with the mother, nor with the client. I manage it very well. (E4)

There are conflict situations between the nursing knowledge with the knowledge. (E1)

Sometimes, a group appears (doctors) who act without giving a damn about what the nurse observes, complicating this relationship. (E3)
In interaction of nursing professionals with the child hospitalized with a chronic condition, there are reports that express feelings of devotion and concern from the first to the second. However, E7, a professional, reported having some difficulty in establishing limits on affective relationships with the child.

We try to have a loving, caring relationship with the child. (E5)

I try to provide the maximum possible care, and I think this is the most important. (T5)

It is difficult, we create a great emotional bond, and then try to protect that. (E7)

The statements of family members confirm that nurses are related to the child with a chronic condition with care and affection, making the hospital environment into a familiar environment for the binomial child / family.

They are very attentive [...] they always try to be close to the child and their interaction with the mother is also very good, it’s like a family, very close to each other. (F3)

They deal with them as if they were their children, all of them. (F1)

However, some nurses reported difficulties in interacting with the family in the management of nursing care, as noted:

What I find more difficult is the relationship between companion and the professional [...] because the companion is always intervening. (E1)

I have plenty of difficulty with the companion. (T1)

The subcategory “Managing the nursing care for the child hospitalized with a chronic condition on day shift” describes the implementation of this practice during the day shift, and the involvement of the nursing technician and family in its development.

The management of nursing care begins on admission of the child with a chronic condition, and this is a moment of interaction that enables the identification of needs that will guide the planning of care. The implementation of this activity seems to be based predominantly in the biological perspective that, although initially important, is insufficient to care for the child/family binomial in its complexity.

So the first thing I see when I know that a child with a chronic diagnosis will be admitted, I try to learn why the child is coming to the hospital [...] I try to see what this child needs, if she needs oxygen, to be suctioned, if she has a tracheostomy, if she has gastrostomy. I try to see about everything a chronic patient can usually need within an institution, and then I prepare everything. (E6)

Shift change was cited as the starting point for nursing care management, as shown in the following statement:

So, everything starts in the shift changes, when all information on the chronic children is shared in more detail. (E2)

From the nursing care management, the nurse initiates the shift by prioritizing. The statements below describe the practice.

I always give priority to the most severe child; when the child comes to the chemotherapy unit, we always prioritize the venous access puncture and then, the intravenous hydration and then, sending the prescription to the pharmacy to begin as soon as possible. (E4)

I give priority to what may require more attention at the time. (E6)

Care management involves the arrangements of human resources in which nurses reallocate more nursing technicians to the wards where there are children with chronic conditions, as, in general, they have high care demands. At this juncture, the interaction between the professional and the child is a valued aspect in adequate staffing.

We try to place more workers in that ward with more chronic patients. (E8)

We always prioritize the ward that has chronic patients to bring more staff, we put a worker who has a better relationship with the child, with that family. (E7)

The material resources management as well as the organization of the care environment are also included as nurses’ activities in nursing care management.

There is the material issue too, excessive spending for the patient, we try to create a single environment for him. We separate a side table, where we put the procedure tray, procedure gloves just for that patient, gauze, small distilled water, saline solution, tube for aspiration, everything is separated for him. (E7)

Attempting to involve the nursing staff, what occurs in performing some nursing activities is observed. The following statements focus on performing procedures.

We administer medications, body hygiene, and sometimes venous access puncture. (T4)

We give medication, check vital signs, monitor some medications, chemotherapy, transfusion. (T1)

Family members are also involved in implementing that activity. They contribute by providing important information for nurses, which are configured as subsidies for care management, and cooperate in performing some direct care for the child. In this regard, nurses and nursing technicians perform training with the family members of patients in the PIU, so that they develop skills for the home care of the child.

I try to get into all the rooms, ask the mothers and companions how that child is today, if her condition is improving, I think this is important. (E2)

The mother also does care, suction secretions, baths and sometimes we just help her. (T6)
I observe the medication, when it ends I go there and I say that the medication is finished; closing what has to be closed; all I can do is to facilitate the work I do [...] Not only that, hygiene and feeding is with me, oral medication, in case I am not present, they do this for me. (F3)

The subcategory “Managing the nursing care for the child hospitalized with a chronic condition on night shift” refers to the dynamics of this practice on the night shift, and presents some aspects of nursing and nursing technician activities in that working period. The statements below elucidate that reality.

Night service routine is quite different from the day shift, which has several treatments and medical visits; we assess the child, see if she has any change, if there is any procedure to be done, guide the team; it is a continuity of what is happening during the day. (E3)

The nurse on the night shift is usually called for doing more complex procedures. (E3)

At night, care is the administration of medication, observing the child's reactions, pain, irritation, medicine and also giving some attention. (T1)

Only in the case that you have something more serious would you request the nurse’s help, because at night the number of nurses is reduced. (T2)

The intentionality of nursing professionals to meet the family’s needs appears in the subcategory “Valuing relationships and interactions to meet the family’s needs”. Nursing professionals expressed interest in offering comfort, care, emotional and spiritual support to promote the permanence of the family and minimize their suffering.

With the companion, a caring relationship, helping in whatever is needed, giving them emotional support, sometimes spiritual, I try to be as close as possible to them. (E5)

I usually say that I became a social worker because at least with me, they are relieved, they tell me their problems, they talk, they want to ask questions, sometimes complain about what the doctor did not explain right. (T5)

This circumstance is prized by family members who recognize the relationship of concern from the nursing staff for them during their stay in hospital.

I cry a lot, it is a very personal problem, we cry with them and give affection to them, they hug us, hold us on their lap, give us some comfort. (F1)

I see that they care about us and not only about the patient. (F2)

The statements above express the support given by the nursing staff to the child’s family, reinforcing the existence of a caring approach directed toward the child with a chronic condition, as well as to his family.

DISCUSSION

Results of the study promote the understanding of nurses’ relationships and interactions in nursing care management for children hospitalized with a chronic condition. In this regard, understanding the relationships in the light of the complexity, subsidizes the understanding of living in society and how interactions are processed, enabling the dual understanding between being different and being unique in the multiplicity of human life.

The understanding of the object, the multiplicity of human life, is reflected in the way that nurses manage the nursing care. Therefore, inter-subjective connections are developed in a context in which complexity is expressed by the relationship of interdependence and the complementary work in health. According to the results, nursing care management is implemented through a shared modality, according to the statement of National Policy of Humanization.

At this juncture, nurses establish with the technical nurses a relationship in which feelings of friendship and trust prevail, which does not nullify the occurrence of any relational conflicts between them. These feelings promote effective teamwork and reflect on the quality of nursing care. On the other hand, relational conflicts in the team, understood in this study as disorders, contribute to new relational arrangements, consensus, and agreements favoring order in a disordered scenario.

The relationship at work in the multidisciplinary health team was characterized as satisfactory by some nurses interviewed. Others, however, referred to isolated conflicts with the medical team. This circumstance is repeated in other care settings and is presented as a frequent event derived from hierarchical authority and disputes of power and knowledge.

The interaction with the child was expressed in the statements, permeated by feelings of affection and care. This reflects the sensitivity and affection of nurses in caring relationships with the child hospitalized for a chronic condition. Through the lens of complexity, it is understood that everything that is human involves affectivity, and it emerges in the encounter of subjectivities. Affection is what allows warm communication in interpersonal relationships, sympathy, identification with others, and makes space for the understanding of the inter-subjectivity. Affection is nourished by sensitivity, and this attitude in health care conducts improvements in the interactive processes.

Emotional involvement may be present in caring relationships between the professional and the child hospitalized with a chronic condition, since professionals are human beings that include emotional, subjective and existential dimensions. However, there is a need for limits on the emotional involvement, in order to prevent future mental, emotional, psychological depletion, conditioning professional practice. In this regard, the literature shows that in a pediatric oncology context, the child’s length of stay in hospital, and the emotional involvement with the caring relationship between the professional and the child are among the reasons for professional limitations to overlap with caring relationships.

Nursing professionals revealed difficulties in interacting with the family, which can be related to the lack of preparation to cope with the pain and the suffering of children and
their family[11]. Allied to this perspective, the team’s lack of preparation to deal with the constant family interventions in nursing care can also generate a conflict situation between them. At this juncture, one study[12] showed that in the pediatric oncology context, health professionals had difficulties in working with complex families, with demanding, rude or angry parents, who have different views on treatment and palliative care, and the need to transmit bad news.

Nursing care management begins upon admission and upon the shift change. Admission is the occasion during which the nurse gets to know the child and his family, and collects social data and important information about the general state of the child[13]. The statement of E6 showed a focus on first identifying the pathology, however, nursing care should be focused on the multidimensional needs of the patient, regardless of his pathology[10]. However, the nurse demonstrated the importance of environmental preparation to receive the child based on his diagnosis, aiming to meet his physical needs in order to provide comfort.

At shift changes, children with chronic conditions are described in detail, according to the severity of their health. Knowing well the general condition of the child, the nurse organizes herself, having children with chronic conditions who are in grave condition as a priority, whether in nursing care and in order of attendance, as well as with regard to the provision of human resources. Thus, priority setting is configured as a management strategy of nurses in the care of the hospitalized child with a chronic condition.

Human resource management appears in the reports as an important activity of nurses in care management. In that regard, in his statement the nurse, E7, exposes his position in valuing the relationship between the professional and the binomial child/family in appropriate staffing of nursing technicians. This practice, when performed properly, can avoid work overload, stress and conflicts among the professional nursing staff. However, the literature[14-15] points out that this practice is still not empirically based, and there is very little scientific knowledge.

Material resources management also appeared in the reports as an action involved in the nurses’ managerial dimension. In statement of E7, a movement to organize the environment and provision of materials needed for use in nursing care is presented. From this perspective, the literature[16] demonstrates that material resources management is a critical activity to assure the quality, continuity and comprehensiveness of nursing care. Therefore, the investment of material resources with quality is a condition that positively influences the development of nursing care.

Nursing technicians are involved in nursing care management of children hospitalized with chronic conditions, especially in procedures, such as: medication administration, corporal hygiene, peripheral venipuncture, verification of vital signs, chemotherapy and initiation of blood transfusions. In this regard, the administration of intravenous medications represents 75% of the daily activities of the nursing team, and is seen as an important practice of these professionals[17].

In turn, family members contribute by providing information about the health of the child and its progression, as they can easily see improvement in his clinical condition, as they are often responsible for informing any alteration occurring with the child to the team[18]. In addition, in the PIU they perform body hygiene, suctioning of secretions, feeding, oral administration of medication and monitoring of intravenous medications. This event is in line with the results of a study[19] in which the family was involved in body hygiene and administration of medication for hospitalized children.

There are no regulations on family participation in care for hospitalized children, but it is emphasized that parents should be valued by the nursing staff in a caring relationship[20]. This is not a simple situation, as it implies a reorganization of care practices, requesting understanding of the dynamics of interpersonal relationships established in this process[17]. However, the care for the child in the family is historically focused. It presents itself as a space for human complexity, as it involves a very strong biological, psychological, cultural and social aspect capable of imprinting behavior, reactions and values in children[11].

On the night shift, nurses and nursing technicians are organized in order to continue provision of nursing care. The number of nurses is reduced, and they are requested by nursing technicians only in situations that require further technical and scientific knowledge. A study[18] showed that the reduction in the quantity of nurses on night shift favored the strengthening of a cooperative relationship in the nursing team. During this work shift, nurses mainly supervise the nursing care, acting as leaders. This is configured as complex practice, since it involves the coordination of multiple factors such as communication skills, trust, respect, proactivity, establishing bonds guided by the ethics and human values which impact the care and behavior of workers[19].

Aside from the issues related to nursing care for children hospitalized with a chronic condition, the results showed a targeted team approach also to meet family needs, with actions that involve promoting comfort, attention, emotional and spiritual support. This result is consistent with a study[20] showing that, sometimes, the family of the child with a chronic condition needs support of a different nature, whether it is material, emotional, informational, or social exchange. So, the care of the family of the hospitalized child should not only consider the physical aspect, but also the emotional, affective and social aspect of the family[11]. The statements of family members revealed that sometimes their needs were concentrated within the emotional and affective dimension, which should be valued by the nursing staff in its care management.

**FINAL CONSIDERATIONS**

The results of the study explore the relational and interactive processes of nurses in implementation of nursing care management for children hospitalized with a chronic condition. This practice happens in a shared way and does not uniquely occur in nursing care, although this is the professional in charge of it.

Nursing care management is facilitated by multiple interactions of inter-subjective connections, the child’s multidimensionality and family situations combined with the order and
disorder, responsible for characterizing the practice as complex. On both day and night shifts, nursing professionals deal with various circumstances that influence the management of nursing care, such as: relational conflicts, reduction in number of employees, unit dynamics, child and family emotional aspects. Results evidenced professionals’ difficulties in dealing with the subjectivity of the child and family, which can justify the relational disorders in the interaction between them.

In the nursing care management of the child hospitalized with a chronic condition, there are actions related to adequate staffing, material resources management, leadership, supervision of family care, as well as responding to their individual needs. The family needs seem to be focused on the emotional, affective and social dimension, which requires from nurses and their team the ability to think about their complexity. Thus, the multidisciplinary approach based on interdisciplinarity appears as a fundamental condition to meet the multiple needs of the child and his family.

The study suggests the need for further research that gives voice to hospitalized children with chronic conditions, and the multidisciplinary health professional team, as they are subjects who are involved in the web of nurses’ interactions in nursing care management. This will enable a more contextualized understanding of the object under study, considering its complexity.

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Nursing care management for children hospitalized with chronic conditions


