

Intervening factors in the management of nursing care for children hospitalized with rheumatic heart disease

Fatores intervenientes na gerência do cuidado de enfermagem à criança hospitalizada com cardiopatia reumática

Factores que intervienen en la gestión del cuidado de enfermería al niño hospitalizado con cardiopatía reumática

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ABSTRACT

Objective: to analyze the factors involved in the management of nursing care for children hospitalized with rheumatic heart disease.

Method: this is a descriptive-exploratory study with a qualitative approach, which used Data-Based Theory and Symbolic Interactionism, respectively, as methodological, and theoretical references. Data was collected in an institution specializing in cardiac care in the city of Rio de Janeiro. Nineteen nursing professionals were interviewed using a semi-structured script. **Result:** the following intervening factors in the practice of care management emerged: the family's socioeconomic status, the child's behavior, working conditions, ineffective communication, continuing education, teamwork, and professional experience. **Conclusion:** the results point to the need to propose strategies for action and interaction that facilitate management practice in caring for children with rheumatic heart disease and their families, given the intervening factors identified.

Descriptors: Pediatric Nursing; Child, Hospitalized; Rheumatic Heart Disease; Patient Care Planning.

RESUMO

Objetivo: analisar os fatores intervenientes na gerência do cuidado de enfermagem à criança hospitalizada com cardiopatia reumática. **Método:** estudo descritivo-exploratório com abordagem qualitativa, que utilizou a Teoria Fundamentada em Dados e o Interacionismo Simbólico, respectivamente, como referencial metodológico e teórico. A coleta de dados foi realizada em uma instituição especializada em atendimento cardiológico, no município do Rio de Janeiro. Foram entrevistados 19 profissionais de enfermagem através de um roteiro semiestruturado. **Resultado:** emergiram os seguintes fatores intervenientes na prática da gerência do cuidado: condição socioeconômica da família, comportamento da criança, condições de trabalho, comunicação ineficaz, educação permanente, trabalho em equipe e experiência profissional. **Conclusão:** os resultados apontam para a necessidade de proposição de estratégias de ação e interação que facilitem a prática gerencial de cuidado à criança com cardiopatia reumática e sua família face aos fatores intervenientes identificados.

Descritores: Enfermagem Pediátrica; Criança Hospitalizada; Cardiopatia Reumática; Planejamento de Assistência ao Paciente.

RESUMEN

Objetivo: analizar los factores que intervienen en la gestión del cuidado de enfermería al niño hospitalizado con cardiopatía reumática. **Método:** estudio descriptivo-exploratorio con enfoque cualitativo, cuyos marcos metodológico y teórico fueron la Teoría Fundamentada y el Interaccionismo Simbólico, respectivamente. La recolección de datos se realizó en una institución especializada en atención cardiológica, en la ciudad de Río de Janeiro. Fueron entrevistados 19 profesionales de enfermería mediante un cuestionario semiestructurado. **Resultado:** surgieron los siguientes factores intervenientes en la práctica de la gestión del cuidado: condición socioeconómica de la familia, comportamiento del niño, condiciones de trabajo, comunicación ineficaz, educación continua, trabajo en equipo y experiencia profesional. **Conclusión:** los resultados indican que es necesario proponer estrategias de acción e interacción que faciliten la práctica de la gestión del cuidado al niño con cardiopatía reumática y a sus familiares, con respecto a los factores intervenientes identificados.

Descriptores: Enfermería Pediátrica; Niño Hospitalizado; Cardiopatía Reumática; Planificación de Atención al Paciente.

INTRODUCTION

Rheumatic heart disease is a systemic immunological condition resulting from complications of rheumatic fever following infection of the throat by group A beta-hemolytic streptococcus. It is a critical form of heart disease acquired in childhood or adulthood all over the world¹. It is therefore a preventable disease with a significant impact on morbidity and mortality rates, especially in low- and middle-income countries².

In Brazil, mortality rates from rheumatic fever and rheumatic heart disease increased by 215% and 42.5%, respectively, considering the period from 1998 to 2016. In addition, the estimated cost of procedures related to the diagnosis of rheumatic fever and rheumatic heart disease, surgical interventions and hospitalizations was almost 27 million dollars in 2019³.

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Among the manifestations of rheumatic heart disease are myocarditis, decompensated congestive heart failure, arrhythmias, and valvular heart disease¹. In addition to these clinical conditions, the literature highlights that a chronic disease in childhood can cause long periods of hospitalization, changes in family dynamics and structure, monitoring of the child by a multi-professional team, recurrent consultations, surgeries, emergency care and death^{4,5}.

Based on the above, within the scope of the work of the multi-professional health team, the nursing team is the one that spends the longest time with children with rheumatic heart disease, a fact that makes it easier to identify their care needs. As this is a chronic health condition, it is imperative that the management of care, aimed at improving attention and direct care for the citizen⁶, is carried out based on symbolic interactions aimed at promoting the quality of life of the child and their family through actions involving bedside care and care planning⁷.

To this end, the management of nursing care for children with rheumatic heart disease must consider the intervening factors that condition the effectiveness of care, i.e. it must take into account the limiting and facilitating factors that permeate the symbolic interactions of management practice. The literature on the subject has focused especially on the epidemiological aspects, diagnosis and treatment of the disease⁸⁻¹¹, and there is a lack of studies on the managerial practice of nursing care for the child in question, which justified the development of this study.

This raises the question: what factors are considered to be involved in the management of nursing care for children hospitalized with rheumatic heart disease?

The aim was to analyze the factors involved in the management of nursing care for children hospitalized with rheumatic heart disease.

THEORETICAL FRAMEWORK

Symbolic Interactionism (SI) is the theoretical framework used in this study, based on which it is understood that the care management of hospitalized children with rheumatic heart disease is a social phenomenon, made possible by symbolic interactions, from which emerge the meanings that will guide nursing professionals in their decisions and actions.

It is a theoretical framework that focuses on individuals and their behavior in society. The first theorist to approach SI was Herbet Blumer, who wrote a book called *Mind and Society* in 1937. However, the interactionist conception emerged with George Herbet Mead, who is considered to have inspired SI¹².

SI privileges the symbolic nature of social life, proposing that meanings are produced from interactive activities between individuals. SI has three basic premises that underpin it: human beings act in relation to things based on the meanings that things have for them; the meanings of things derive from social interaction between individuals; meanings are modified by the interpretative process used by individuals when dealing with the things and situations they encounter¹².

Based on the above, it is understood that SI is pertinent to the interpretation and discussion of the results of this study.

METHOD

This is a descriptive-exploratory study with a qualitative approach. The Grounded Theory (GT) was the research and data analysis method, with a qualitative approach that enables the elaboration of theoretical categories/concepts, which through their properties and dimensions, make it possible to understand phenomena of a social nature¹³.

The data was collected through semi-structured interviews, recorded in digital format, carried out between March and July 2023, in a federal health institution, a reference in the care of people with heart problems, in the city of Rio de Janeiro, Brazil. The interviews were conducted in the pediatric inpatient unit in a room reserved for this purpose. The children's inpatient unit has 19 beds occupied by children with different cardiac pathologies, in pre- and post-surgical conditions with prolonged treatment. The unit has ten nurses and 20 nursing technicians, organized on a 12x60-hour or daily basis.

The study participants were organized into two sample groups: the first consisting of nine nurses and the second of ten nursing technicians. This was made possible by the use of theoretical non-probabilistic GT sampling¹³, the aim of which is to seek out people who maximize the possibility of understanding the phenomenon. Nursing care management is the responsibility of nurses, but the initial interviews showed that nursing technicians are professionals who are also at the bedside providing direct care to children and their families, a fact that affects

management practice. In order to understand how this phenomenon occurs, nursing technicians were considered in the study to make up the second sample group.

The following inclusion criteria were established for all participants: being assigned to the pediatric inpatient unit during the data collection period and having at least six months' experience in caring for children with rheumatic heart disease. The exclusion criteria applied to all participants were: being off work, on leave or on vacation during the data collection period.

The meetings with the participants took place individually, providing all the necessary privacy and confidentiality. The interviews lasted between 20 and 50 minutes. The interviews with the nurses were guided by the following question: what factors do you think influence the care management practice for children with rheumatic heart disease? The interviews with nursing technicians were guided by the following question: what do you think makes it easier and/or more difficult for you to care for children with rheumatic heart disease?

Data collection ended when theoretical saturation of the data¹³ was observed, at which point it was realized that the new data collected was no longer modifying the theoretical density of the object of study. The data was coded without the aid of software and followed the three stages of coding: open, axial and integration¹³.

In open coding, the raw data was subjected to microanalysis, generating initial codes, also known as preliminary codes. Later, through comparative analysis, these codes were compared with each other and grouped by similarities, generating conceptual codes. With each new interview, new preliminary and conceptual codes were produced, compared with each other and grouped with the conceptual codes from the previous interviews. After constructing the conceptual codes, a comparative analysis of the data by similarities and differences was once again carried out in order to understand the meanings revealed by these codes, giving rise to subcategories and categories. This led to axial coding, which allows categories to be related to related subcategories. In this analytical stage, the researcher used the paradigmatic model to capture the connections and relationships between the categories and subcategories. This model is made up of three elements: conditions, action-interaction strategies and consequences¹³.

The conditions correspond to the reasons given by the informants for the occurrence of a given phenomenon. Action-interaction strategies are the responses expressed by participants to events or problematic situations. The consequences refer to the expected or actual results of actions and interactions¹³.

In the integration stage, the categories were refined and integrated, culminating in the emergence of the central category/central phenomenon: Nursing care management for children hospitalized with rheumatic heart disease and their families. During all the analytical stages, memos and diagrams were drawn up to help the researcher make the categories denser in terms of their properties and dimensions¹³.

In compliance with Resolution 466/2012, data collection only began after the study had been approved by the Research Ethics Committee of the proposing and co-participating institutions. Participants were informed of the objective, method, and relevance of the research. Afterwards, if they were interested in taking part, they were asked to sign the Free and Informed Consent Form (FICF) in two copies. In order to maintain the confidentiality of the information and the secrecy of the participants, the nurses' statements were identified by the letter E and the nursing technicians by the letters TE, both followed by the number corresponding to the order in which the interview took place in the respective sample groups.

RESULTS

The participants had between six and 33 years of training. Their experience in caring for children hospitalized with rheumatic heart disease ranged from two to 30 years. All were female.

The category "Presenting the intervening conditions in the nursing care management" and its subcategories, "Revealing the aspects that hinder care management" and "Listing the aspects that facilitate care management", make up the intervening conditions of the GT paradigmatic model.

Revealing the aspects that hinder care management

The subcategory points to the child's acceptance of care, the family's socioeconomic status, low trust in health professionals and the family member's lack of adherence to treatment as limiting conditions for managing nursing care.

In relation to the child, it was identified that their behavior in not accepting nursing care is a hindering factor, as shown below:

The human difficulty is whether or not the child accepts being looked after, but we always find a way, we have a love and affection for them that ends up making it easier. But when there's no way, there's no way. We have to understand, that makes it difficult. (E1)

When the patient cooperates, it makes the nurse's job much easier. When the patient doesn't cooperate and doesn't appreciate it, it makes it very difficult. (E3)

In relation to the family's socio-economic status, the following reports are given:

The family's socio-economic situation makes work very difficult. No doubt about it. So when I see a child with a precarious condition, I can already see that the patient is going to be hospitalized again, it's going to be bad, it's notorious [...] Most of them have difficulties understanding, comprehending, communicating. That's a big difficulty. The majority of people admitted for rheumatic heart disease have low incomes. (E2)

Social class is also something that makes it difficult because the person isn't going to stop eating to come to the appointment. (E3)

The issue of the child having a difficult socio-economic situation makes care difficult. There are mothers who stay here for months, some who can't even afford a toothbrush, let alone medication. (E7)

In addition, it was mentioned that the lack of trust in health professionals and the family member's lack of adherence to treatment are factors that limit the care management.

I think what makes it very difficult is when the mother doesn't accept the care, you explain that this needs to be done and the mother sometimes doesn't understand, doesn't want you to do it, it's very complicated dealing with this patient and family member. The lack of trust in the professional also makes it very difficult. (E5)

There have been mothers here who don't want to let me touch the child, who choose who touches the child. We have to deal with mothers very well, sometimes they don't want to feed themselves, this makes it very difficult to manage care (TE18)

The work context, in terms of technological support, structure, logistics and the shortage of material resources, was another factor conditioning the practice of nursing care management, as shown below:

I think our limitations here are perhaps space, we work in an old building, with no access to the outdoors to take the children, which makes it difficult. (E2)

I think what makes our work difficult is the issue of monitoring. The cables don't connect to the monitors, the heart rate doesn't match the manual. This backward technology makes it very difficult. When the patient descends, we spend hours trying to monitor him, the patient arrives, and we think he's saturating a little and when he puts the manual on it's not that. The technological resources are poor. (E7)

It's difficult, it's the lack of materials, because when there's a lack of material it's difficult. (TE15)

Listing the aspects that facilitate care management

On the other hand, the subcategory "Listing the aspects that facilitate care management" presents the aspects considered by the study participants to be facilitators in the care management practice.

The participants highlighted professional experience in caring for children with rheumatic heart disease, effective teamwork, material support and continuing education as conditions that facilitate care management.

Experiences make everyday life easier. I think this is a facilitator, you have several cases, several conversations and then you acquire experience [...] professional experience facilitates the flow. (E1)

It makes it easier when there's good interaction, a good team partnership, the whole team speaks the same language, and with materials available, the patient is the winner. (TE15)

What makes work easier is when there are courses, training, this is very good, because sometimes we've been doing the same thing all our lives, but there are changes, science is there for that, from the moment there is investment in courses and training I think this improves a lot and makes the service easier. (TE17)

DISCUSSION

The facilities and limitations related to the practice of managing nursing care for children with rheumatic heart disease come from social, economic, and relational aspects with the child and the family member, as well as from structural, logistical, and educational conditions in the work context. These conditions influence nursing care practices, which are developed through the meanings that nursing professionals attribute to symbolic care interactions¹².

As for relational issues, the results of this study show that the child's behavior in accepting care, the lack of trust in health professionals and the family member's precarious adherence to treatment are factors that limit the

management of care. In the light of Symbolic Interactionism, it is understood that these relational aspects arise from communication and the subject's interpretation of the other person's behavior, which causes the mind to use symbols, assign meanings and guide action¹².

It is known that hospitalization is a complex phenomenon that alters children's daily lives and affects their behavior during this period. For this reason, in order to provide effective care, health professionals need to have welcoming attitudes towards the child who is going through this process, such as attention, respect, affection, patience, education and dedication, in other words, they need to establish relational and communication strategies that are relevant to the child's development¹⁴. It is accepted that communication is a fundamental condition for effective care management, taking into account the relational and social nature of nursing care.

It is therefore understood that communication is essential for fostering a relationship of trust and for gaining the attention and adherence of children and family members to issues involving care. When communication is not effective, it can lead to insecurity, making the care relationship more difficult¹⁵. It is from communication that symbols are constructed, which are elaborated from the perceptions that emerge from symbolic interactions, in which human beings interpret, attribute meanings, and develop realities¹².

The family's lack of trust in the work of the nursing team creates challenges in the performance of care, conditioning the symbolic interactions between the team and the child. This can lead to difficulties or facilities in the course of treatment, which makes the family an important intervening condition in the relationships established between health professionals and hospitalized children⁷.

A study¹⁶ carried out in Australia found that a high prevalence of acute rheumatic fever and rheumatic heart disease among Aboriginal children is associated with a low understanding of the disease among families, a fact that reinforces the importance of nurses establishing action and interaction strategies that favor family adherence and understanding of the disease and its treatment.

When the family of a hospitalized child maintains a good relationship with the nursing team, they establish shared care, which adds good experiences to the development of care. In this respect, professionals must take an individualized approach to each child, maintaining respect for the family and meeting their demands during hospitalization¹⁷.

It was found that the financial and social conditions of the family of a child with rheumatic heart disease condition management practice, while generating challenges during the child's treatment. The literature¹⁸ shows that one of the parents' concerns when their child is hospitalized is the financial issue, due to the increase in expenses and the lack of financial resources. Some families live a long way from the hospital and don't have the money to buy medication or food. All these issues end up making the course of treatment challenging and worsening the prognosis for the child, who will live with the consequences of interrupted treatment.

Working conditions are factors that influence the nurses' work process when it comes to managing care for children with rheumatic heart disease. In this logic, it is understood that technological support within the hospital is something that conditions the work of the nursing team. The act of caring for a hospitalized child is complex due to the understanding and fear that children attribute to health professionals. With technological support, care becomes more precise, agile, and reliable, which makes the care provided more effective. Thus, it is accepted that the nursing team needs to seek technological support to improve professional practice, a fact that reverberates in the organization of the care provided¹⁹.

Within the scope of working conditions, material resources appear as an intervening condition in childcare relationships, while a lack of material resources makes it difficult to provide care, but when these resources are adequate, care is more effective, as the literature points out⁷.

In line with the results of this study, research^{15,20} shows that in addition to technological support, other factors contribute to optimizing nurses' professional practice, such as: nurses' management skills, leadership, adequacy of personnel and material resources, and the professional relationship between nurses and physicians.

Considering the complexity of the clinical condition of children hospitalized with rheumatic heart disease, as well as their multidimensional demands, the results of this study reveal professional experience as a facilitating condition for management practice. This perspective is in line with a study¹⁵ on the management of care for children with chronic cancer pain, in which the authors identified that professional experience provides greater security for the development of care, while it is related to the acquisition of subjective, technical, cognitive, and relational skills to deal with the challenges that emerge from care relationships.

Similarly, teamwork and continuing education emerged in the results as facilitating factors in the management of nursing care for hospitalized children with rheumatic heart disease. Teamwork, rooted in a collective perspective and collaborative leadership, with common goals and objectives among professionals, is fundamental for caring for children with rheumatic heart disease, taking into account the multidimensional nature of their care demands^{16,21}.

To this end, it is important that health professionals are up to date on the subject and trained to care for children with rheumatic heart disease safely and competently. Adequate resources and educational interventions are therefore necessary to improve health professionals' knowledge and confidence in the early diagnosis and treatment of rheumatic heart disease²².

This study has the implication for nurses' professional practice of pointing out the intervening factors that cross symbolic interactions in the care management of hospitalized children with rheumatic heart disease. By pointing out these factors, it is possible to establish action strategies that optimize care relationships with children and their families.

Study limitations

Among study limitations, it's pointed the contextual specificity of the results, which restricts their generalization, as well as the lack of data regarding the perspective of the multi-professional health team, family members and the child with rheumatic heart disease themselves on the care management developed, a fact that points to the direction of further studies.

CONCLUSION

The analysis of the factors involved in the nursing care management of hospitalized children with rheumatic heart disease made it possible to identify the existence of limiting and facilitating conditions that involve this practice. These are personal, family, social, relational, and work context factors. In this respect, Symbolic Interactionism helped us to understand symbolic interactions, in which participants perceive reality, attribute meanings and act on the basis of these meanings. In view of the intervening factors identified, the results of this study point to the need to propose action and interaction strategies that facilitate the management practice of caring for children with rheumatic heart disease and their families.

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Authors’ contributions

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