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REFLECTIVE ANALYSIS ARTICLE

REFLECTING ON THE CONSTRUCTION OF CARING IN PEDIATRICS

REFLETINDO ACERCA DA CONSTRUÇÃO DO CUIDADO EM PEDIATRIA

RELEXIONANDO ACERCA DE LA CONSTRUCCIÓN DEL CUIDADO EN PEDIATRÍA

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ABSTRACT

Objective: to provide critical reflection about the care of the hospitalized child to subsidize the practice of the professionals and to assist them in proposing actions consistent with the reality of the pediatric unit, reviewing their daily practices, emphasizing the creation of fewer workspaces alienators, valuing the dignity of the hospitalized child and family. **Method:** this is a reflexive study, based on a review of the literature in which scientific articles were consulted in the LILACS databases and the SciElo virtual library. **Results:** the child-family was initially presented as the subject of nursing care, and then the child-family-nursing professionals co-participation: building care in pediatrics. **Conclusion:** nursing has empirical and theoretical knowledge that allows it to negotiate with its families a plan of human and integral care. **Descriptors:** Health Institutions Environment; Humanization of Assistance; Pediatrics; Hospitalized Child; Nursing.

RESUMO

Objetivo: oportunizar a reflexão crítica acerca do cuidado à criança hospitalizada, de forma a subsidiar a prática dos profissionais e lhes auxiliar na proposição de ações condizentes com a realidade da unidade de pediatria, revisando suas práticas cotidianas, enfatizando a criação de espaços de trabalho menos alienantes que valorizem a dignidade da criança hospitalizada e família. **Método:** estudo reflexivo, a partir de revisão da literatura na qual foram consultados artigos científicos nas bases de dados LILACS e na biblioteca virtual SciElo. **Resultados:** apresentam-se, inicialmente, a criança-família como sujeito do cuidado de enfermagem e, a seguir, a coparticipação criança-família-profissionais de enfermagem: construindo o cuidado em pediatria. **Conclusão:** a enfermagem possui um acervo de conhecimentos empíricos e teóricos que lhe permitem negociar com os familiares um plano de cuidado humano e integral. **Descritores:** Ambiente de Instituições de Saúde; Humanização da Assistência; Pediatria; Criança Hospitalizada; Enfermagem.

RESUMEN

Objetivo: dar la oportunidad la reflexión crítica acerca del cuidado al niño hospitalizado, de forma a subsidiar la práctica de los profesionales y auxiliarlos en la proposición de acciones condizentes con la realidad de la unidad de pediatria, revisando sus prácticas cotidianas, enfatizando la creación de espacios de trabajo menos alienantes que valoren la dignidad del niño hospitalizado y la familia. **Método:** estudio reflexivo, a partir de revisión de la literatura en la cual fueron consultados artículos científicos en las bases de datos LILACS y en la biblioteca virtual SciElo. **Resultados:** se presentan, inicialmente, el niño-familia como sujeto de cuidado de enfermería y, a seguir, la coparticipación niño-familia-profesionales de enfermería: construyendo el cuidado en pediatria. **Conclusión:** la enfermería posee conocimientos empíricos y teóricos que le permiten negociar con los familiares un plano de cuidado humano e integral. **Descriptor:** Ambiente de Instituciones de Salud; Humanización de la Atención; Pediatria; Niño Hospitalizado; Enfermería.

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INTRODUCTION

The hospital is an environment causing tension and uncertainty, mainly because the connection with it occurs through a critical and delicate situation of illness. When an event evolving a childhood, it has special contours since it implies changes not only in the routine of the child but in the whole family.¹⁻²

Besides leaving school, friends and playing, the child has contact with invasive procedures, medications, equipment, new terms and words, feelings of pain and suffering.³ Such changes contribute to the hospital being configured in a stressful environment, where support for coping with the disease is usually restricted in such a way that one of the only sources of security is parents, who are also emotionally vulnerable in witnessing the limitations and suffering imposed on the child.² This is a delicate moment for the family, as it implies an increase in expenses, displacements, absences from work and absences in the home, consequently, provoking a reconfiguration of family dynamics and routine.⁴ Thus, it significantly affecting the family relationship, physical health, health maintenance of the social network of its members.⁵

Faced with this context, some questions arise: Is the family prepared to take care of the hospital environment? Should the family take care or be cared in the hospital environment? Is the child only the subject of care? Are the nursing professionals prepared to take care of the child-family binomial? What is the implication of the nursing professional to transform care, considering the specificities of this binomial?

Seeking to broaden the knowledge and support the practice of pediatric nursing, this study had the opportunity of critical reflection on the care of hospitalized children to subsidize the practice of professionals and assist them in proposing actions consistent with the reality of the unit of Pediatrics, reviewing their daily practices, emphasizing the creation of less alienating workspaces that value the dignity of the hospitalized child and family.

METHOD

Reflective-theoretical study from a literature review. Scientific articles researched in the LILACS (Latin American and Caribbean Health Sciences Literature) databases and in the Scientific Electronic Library Online (SciElo) virtual library were consulted, with authors that address the topic of pediatric care as a subsidy. For its

effectiveness, the selection of theoretical elements related to the theme was sought. Then, there was an analysis of these elements and, subsequently, their interrelationship with the proposed reflection, from two categories: a) The child-family relationship as the subject of nursing care; B) Co-participation child-family-nursing professionals: building care in pediatrics.

RESULTS

♦ The binomial child-family as subject of nursing care

When the child enters in the hospital environment, besides having to deal with the sickness caused by the illness, he is removed from his family environment, his friends, his school, and his personal belongings, losing much of his references. It is an environment that imposes many changes to be assimilated by him, such as interacting with unknown people - doctors, nurses, nutritionists, psychologists and students; perform tests and interventions that may be painful or unpleasant; mandatory rest; use of medicines and appliances; different schedules from his routine for daily food and hygiene activities; noise and other nuisances that contribute to many children perceiving the hospitalization experience as stressful and traumatic.⁶⁻⁷

Being a stressful and traumatic environment, the hospital triggers a series of reactions, ranging from aggressive behaviors such as anger and violence, or constant crying, followed by distress and depression, to learning difficulties and developmental delay.⁸ These reactions may vary in each child, according to their age and previous experiences of hospitalization. At a very young age, children do not understand what it means to be sick, nor why they feel pain and should stay in an environment that is strange to them, showing their fear, most of the time, through crying. Older children are more apprehensive about procedures, often opposing them.

The experiences of previous hospitalizations influence the reactions of the child according to their nature, intensity, and duration, with a high probability of increasing the sensitivity to vulnerability if they were negative. On the other hand, if they were positive, they contribute to the adjustment of the child to the new situation and act as a protective factor for successful coping with adverse situations that may occur in the future.⁷ Thus, children with negative memories regarding previous hospitalizations and those who have never been hospitalized before, tend to present greater anxiety, fear

and insecurity at admission to the hospital than children with positive hospitalization experiences.⁹

Considering that not all children have the same reactions to hospitalization, the nursing and health team perform procedures that, although routine and necessary, can be stressful and traumatizing, such as blood collection, urine, cerebrospinal fluid testing, tomography, and even simpler procedures like X-rays and inhalation would need to be smoothed by the sensitivity of the professional. Because some exams, by requiring complex equipment, or because they emit sounds and noises, they contribute to the child perceiving them as more painful and aggressive.¹⁰

Through a close and continuous contact, nursing performs care related to the basic needs of children, such as bathing and feeding, others for therapeutics, such as checking for vital signs, administration of medications and procedures considered invasive. When the emergent contact of this practice is carried out in an impersonal way, without treating the child as an individual with needs related to their developmental phase, it can lead to stress and trauma.¹¹

In this sense, an evaluation study on the quality of nursing care performed with hospitalized children and adolescents pointed to behaviors adopted by nurses that positively or negatively influenced the perception of quality of care offered. Positive behaviors were those making the patient feeling good, comfortable, happy and safe, because the nurse met their needs when they needed it, as well as evaluating them frequently, administering medications, being friendly and listening to them. Negative behaviors were those that made them feel sad, evil, scared and angry, including waking them up and performing procedures that hurt or uncomfortable.

Because the hospital environment is the living space for days, weeks, or months, stressful experiences can lead the child to believe that all nurses or people dressed in white will cause them pain, suffering, or bodily injury.¹⁰ This evidences the children with a unique way of giving meaning to their hospitalization, combining reality and imagination. Thus, it is necessary that the hospital environment and the professionals who work in it are organized in the best possible way to meet their needs, guiding them to reality and combating frightening fantasies.¹³ However, most of the time, the hospital environment is organized to attend to the disease, without any planning for the

individuality of each child and the global needs of childhood.¹¹ The monotonous and repetitive rhythm due to its rules and routines, make the hospital environment different from the active daily life of children, with school activities, games, and sports.⁹ In this context, the presence of the family member is a reference in the life of the child outside the hospital, to whom he entrusts the task of a spokesperson of his desires and rights.^{3,14} The child finds in his caregiver the strength and security necessary to face the fear, the pain and the other feelings generated by the illness and hospitalization.

The family is a source of strength and security for the child at that moment, and it is often difficult to meet these needs since the child does not know how to act in the hospital environment, facing the child's illness and still dealing with their demand.¹⁶ It is a delicate moment for the family, as it implies an increase in expenses, displacements, absences from work and absences in the home, consequently, provoking a reconfiguration of family dynamics and routine.⁴

Therefore, hospitalization is stressful for both the child and his or her family. Given this, researchers point out that pediatric services and child care should be planned around the needs of children and their families to minimize the negative effects of hospitalization. Thus, the focus of care ceases to be exclusively the child and begins to encompass the family, making them active partners in the process of health production.⁴

However, not infrequently, the family feels vulnerable in the hospital environment, because they have their power and right denied to choose, having to submit to situations of conflict in the relationship with the health team. There is no authentic relationship of partnership, but of inequality and distance, in which the absence of dialogue gives space for the family to perceive disrespected and distanced from its role.¹⁷ There are also feelings of frustration related to the lack of information about procedures and treatments, lack of knowledge of hospital rules and regulations.¹⁴ Similarly, a study carried out with the objective of knowing the perception of the hospitalized children's attendants about the medical diagnosis and the possible aggravating factors of the hospitalization showed that the majority were unaware of the real diagnosis. This led to the conclusion that they constructed assumptions about the cause of the child's hospitalization, demonstrating that there may be a lack of

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communication between them and the members of the health team.¹⁸

In this sense, the authors point out that the provision of information, guidance, and clarification about the child's health conditions could avoid a series of conflicting situations between the family and the health team, since the family would be aware of what to expect and which is expected of it.¹⁴⁻

¹⁵ Thus, the family feels empowered to care for the hospitalized child and must also be considered by health professionals in the development of their care actions.¹⁶

To minimize the stress of hospitalization for children and their families, several efforts have been undertaken, ranging from investigations into the participation of the family in the care of the hospitalized child to the creation of health policies. It is noteworthy that it was through Platt's 1959 report in the United Kingdom that the importance of family permanence and participation in the hospital environment was recognized.⁴ In Brazil, the Child and Adolescent Statute of 1990, in its Chapter I - Right to Life and Health, recommends that health services should provide conditions for full-time relatives to stay in cases of child hospitalization.¹⁹

Nursing has undergone a continuous process of organization and reorganization in the work dynamics to follow the evolution of the concept of care and to integrate the family in the care of the child, seeking to integrate the subsidies conferred by the research in its practice. However, this process of inclusion imposes some obstacles that have greatly hampered its application in daily practice.⁴ In this sense, research carried out with pediatric nurses, with the purpose of describing the meaning of child care and the perception of family to team indicated that, even acknowledging the right and importance of the presence of the family for the recovery of the child, the professionals expressed doubts regarding the presence of the parents. It shows that there are still many difficulties that permeate this process, such as the presence of parents during the performance of the procedures.¹⁴

Although a relationship of cooperation and partnership between nurses and the family of the hospitalized child is expected, it is still common the existence of a relationship of domination-subordination, in which professionals tend to transform the right of the family to stay with the child in a duty, delegating the performance of care that competes to the professionals of the service. When their behavior does not obey this model

of work agent, adopting a more critical and questioning posture, it generates conflict and distancing with the team.¹⁶

Reinforcing the above, a study carried out by the nursing team of a school hospital, whose objective was to analyze the caring dimension of nursing and family care in hospitalized children, the team divides care with the family, but without understanding it as co-participant. This showed the lack of preparation of professionals to approach the child-family binomial in the daily hospital, lacking the knowledge to meet their needs and establish effective processes of dialogue.²⁰

The utilitarian view of the family, which turns it into a labor force, compromises care, once it becomes a tool and not a subject of care, which has needed to be met. According to researchers, this is due to insufficient human resources, overwork, overcrowding, dissatisfaction and professional demotivation.¹⁶ Faced with such a situation, it is necessary to rescue the ethical dimension of care, because even when the family cares for the child, nursing is the responsible for care.²⁰

Involving the family in the care of the hospitalized child implies a review of the ways in which nursing has delineated this process, seeking to humanize care, whose technological organization of work should be based on the approach, negotiation, sharing, listening and welcoming.²⁰ Although the nurses have specific scientific knowledge for care, it is the family member who can capture small changes in the child's health. For this reason, it can be a great collaborator in the treatment of the child offering important information that helps in the care and who must be valued by the nurse due to the potential to transform and enrich the care.^{15,21} Therefore, encouraging the family participation during hospitalization brings benefits not only for the child but also for the family members and the nursing team.⁴

As the care incorporates new elements such as toy and family, recognizing children's characteristics, it modifies the health production process and builds a new environment, less stressful and more humane for the agents involved - child, family and professional of nursing.

♦ Child-family-nursing professionals' co-participation: building care in pediatrics

The purpose of hospitalized child care is to minimize suffering and promote health, making it an active element in this process.¹⁰ To this end, it is the responsibility of health professionals to stimulate and provide spaces

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for the manifestation of the subjective dimension, with the participation of the child in the taking decision-making on issues related to the disease and its treatment. Initially, allowing to make decisions from less complex situations and, later, those of greater complexity, considering the maturity and true desires, so that empathically they can help to face their fears.²²

In this sense, a study carried out with pediatric nurses from a public hospital in São Paulo, Brazil, aimed at knowing their beliefs and actions regarding the autonomy of hospitalized children during therapeutic procedures, pointed to facilitating and limiting beliefs about child participation in decision-making. Facilitating beliefs are revealed when the nurse considers the child to be a being in growth and development, perceiving their fears, expectations, and desires in the context of hospitalization and illness. Believes that the child has the right to participate in decision-making concerning him/her, when he or she empathizes with the child's situation, accepting their limitations and understanding the reasons for their refusal, listening to the child and acting to help them cope the situation. On the other hand, limiting beliefs are evidenced when the nurse believes that the child is immature and unable to make any decision, acting in a coercive, non-interactive way, not listening to the child's motives and opinions.²²

The literature on humanized care in Pediatrics emphasizes that the opening of spaces for communication between nursing professionals and hospitalized children can favor the formation and consolidation of links and co-participation in health promotion. Through the body and speech, the child communicates and expresses their needs, providing valuable subsidies so health practices can be rethought for a comprehensive and welcoming care.^{3,23} However, it is observed in practice that, frequently, the health team isolates the child and talks only with the parents, disregarding their ability to understand the facts. Parents believe that by not sharing information about the disease and treatment with their child they are protecting the child. The information, besides being important to stimulate the bonding and co-participation of the child in the process of health production, constitute the right of the child to follow what is happening with him or her. It is up to the adults - family members or nursing and health staff - to adapt them to their level of maturity and their possibilities of understanding, avoiding that unknown aspects

of illness and the gaps left by the lack of explanations favor the construction of threatening fantasies and increase the suffering of the child.²⁴

Even children who are informed about their clinical situation may have difficulties in facing the events in the hospital since information alone does not solve all problems, but rather a resource that favors adaptation to the environment.²⁴ Researchers point out that hospitalized children experience moments of greater protagonism when it is given a chance to communicate through the playful, finding new ways to face the discomfort of the environment, procedures, and experiences arising from them. When playing, the child has control over the situation, since when practicing the same act to which it was submitted, he can feel the control of the situation and not as a passive individual.^{3,10,25}

In this sense, it is necessary to increase the forms of communication and children's approach, through reading, games, demonstration and explanation of the procedures to which children will be submitted.¹⁰ Thus, it is possible to establish health relationships that are not ruled by the assertion of the child to the normativity that is placed on the conception of health: rules and a lifestyle that prevent it from acting in a childish way, proper to his age. By betting on their capacity for expression and understanding, the child can manifest his/her subjectivity, as well as be a protagonist in coping with illness and hospitalization.

In the same way that the child, parents and family members need to be stimulated to exercise the protagonism through co-participation in the health-disease process. However, they are often left out in decision-making and are included as laborers for the execution of domestic care, that is, those already done at home and do not need elaborate knowledge to be developed. This establishes a division between intellectual and manual work, since the care provided by the nursing and health team is characterized by specialized technical-scientific knowledge.²⁶

This form of relationship established between the family and the nursing and health team solidifies the existing distance between both and delineates a technical and fragmented assistance model, marked by the division of the care and impersonality of the relations, that ignores the particularities that involve the hospitalization of children.¹⁶ It shows a point of resistance towards the construction of spaces that allow family participation and make humanized ambiances,

as well as tension in the ethical practice of the profession, since the nurse by delegating activities indiscriminately to the family can see situations that are contrary to the law of professional practice.

Research that investigated the negotiation of care among nursing staff and mothers of hospitalized children pointed out that nurses often use the rationale of training mothers for home care and delegate to them more complex care such as medication administration and diet by nasogastric tube, without any previous negotiation.²⁷ When taking care of the child in the hospital environment, the family has its function permeated by the meanings of the nursing universe, corroborating the construction of an area without clear limits on what is competence to nursing and family members.³

Consistent with this evidence, a study carried out with the objective of identifying the activities carried out by family members or caregivers and a nursing team in a pediatric hospitalization unit revealed that family members or caregivers who stay in the hospital for a longer period of time or who reintegrate with frequency, introduce the hospital culture to scientific terminology and develop strategies to protect the child from new punctures and hospital infection, such as: filling the microfix with serum or simulation of situations of contamination of this equipment.²⁶ In this sense, researchers warn that delegating and transmitting technical knowledge to the caregivers of children can cause problems to be managed by the nursing team, since they open the way for the occurrence of errors.

The presence of the relative produces a paradoxical situation of help, since, on one hand, the nursing professional is overworked and, on the other hand, the possibility of having someone else to perform them.³ Even the health services, adopting the model of humanized and integral care for the child, exhibit an ideologically effective discourse, but with effectiveness hampered by the scarcity of resources, work philosophy, lack of awareness and instrumentalization of professionals.¹⁶ Thus, emerging in the development of the work process: family participation in the care of hospitalized children in a responsible, respectable and ethical way.

The co-participation of the family member implies the development of a therapeutic project that integrates the family and nursing and health care team into the care of the child, which gives rise to the skills and capacities of communication, dialogue,

acceptance of diverse demands and opportunities to exercise as the protagonist in the care.³ However, literature has shown that the partnership relationship is being built and, it is not yet accepted and practiced by all professionals. Research that explored the perspective of nurses about child care partnership in pediatric services indicated that most participants (52.1%) used to negotiate nursing care with caregivers always, but noted that a high percentage of nurses (44.5%) said that only sometimes and still others (3.4%) never do.⁴

Although the family can gain space for participation as it develops and dominates a knowledge about hospital care, the attitudes of nursing and health professionals can create an environment in which they feel safe and strengthened to face hospitalization of the child. When the relationship between them is marked by impersonality, lack of information and attention, the results are confusing and unsafe about what they are expected or allowed to do during their stay in the hospital.

CONCLUSION

Nursing has a wealth of empirical and theoretical knowledge that allow it to negotiate with the family members a plan of human and integral care. In this sense, efforts must be made to overcome the resistance to change and make possible the child-family-professional partnership of nursing in a genuine way. To do so, it is necessary to open to the exercise of citizenship in which there is mutual respect between the child, family and nursing professionals, pondering information and experiences that best meet the needs of the hospitalized child and contribute to the quality of care.

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