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Nurse's performance in the hospital discharge process of children with chronic disease

Atuação da enfermeira no processo de alta hospitalar de criança com doença crônica

Desempeño de la enfermera en el proceso de alta hospitalaria de niños con enfermedad crónica

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ABSTRACT

Objective: To analyze the nurse's performance in the hospital discharge process of children with chronic disease.
Method: Qualitative research conducted from May to August/2019 with ten nurses working in a pediatric unit of a public hospital. The data, collected through semi-structured interviews, were submitted to inductive thematic analysis.
Results: In the preparation for hospital discharge, nurses recognize health education as their attribution, valuing family knowledge in the training regarding home care. Nevertheless, their practice is weakened by the little articulation among the multiprofessional team, reduced nursing sizing and disarticulation in the health care network.
Conclusion: There is a paradox between the report and the practice of the hospital discharge process accomplished by nurses. Although they have theoretical knowledge, their work process is influenced by the disarticulated way in which the multiprofessional team interacts, and the conditions provided by the institution to work in the preparation for hospital discharge of these children.
Keywords: Patient discharge. Chronic disease. Pediatric nursing.

RESUMO

Objetivo: Analisar a atuação da enfermeira no processo de alta hospitalar de crianças com doença crônica.
Método: Pesquisa qualitativa realizada de maio a agosto/2019 com dez enfermeiras de unidade pediátrica de hospital público. Os dados, coletados por meio de entrevistas semiestruturadas, foram submetidos à análise temática indutiva.
Resultados: No preparo para alta hospitalar, as enfermeiras reconhecem como sua atribuição a educação em saúde, valorizando o saber familiar na capacitação quanto aos cuidados domiciliares. Entretanto, sua prática é fragilizada pela pouca articulação entre a equipe multiprofissional, dimensionamento de enfermagem reduzido e desarticulação na rede de atenção à saúde.
Conclusão: Evidencia-se paradoxo entre o relato e a prática do processo de alta hospitalar efetivado pelas enfermeiras. Embora possuam conhecimento teórico, seu processo de trabalho sofre influência do modo desarticulado como a equipe multiprofissional interage e das condições disponibilizadas pela instituição para atuarem no preparo para alta hospitalar dessas crianças.
Palavras-chave: Alta do paciente. Doença crônica. Enfermagem pediátrica.

RESUMEN

Objetivo: Analizar le desempeño de enfermeras en el proceso de alta hospitalaria de niños con enfermedad crónica.
Método: Investigación cualitativa desarrollada de mayo a agosto/2019 con diez enfermeras de una unidad pediátrica de un hospital público. Los datos, recogidos mediante entrevistas semiestructuradas, se sometieron a un análisis temático inductivo.
Resultados: En la preparación para el alta hospitalaria, las enfermeras reconocen la educación en salud como su atribución, valorando el conocimiento familiar en la capacitación en cuanto a la atención domiciliaria. Sin embargo, su práctica es socavada debido a la escasa articulación entre el equipo multidisciplinario, el dimensionamiento de la enfermería reducido y la desarticulación en la red de atención sanitaria.
Conclusión: Se evidencia la paradoja entre el relato y la práctica del proceso de alta hospitalaria efectuado por las enfermeras. Aunque tengan conocimientos teóricos, su proceso de trabajo se ve influenciado por la forma desarticulada en la que interactúa el equipo multidisciplinario y las condiciones que brinda la institución para trabajar en la preparación de estos niños para el alta hospitalaria.
Palabras clave: Alta del paciente. Enfermedad crónica. Enfermería pediátrica.

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INTRODUCTION

Chronic diseases in childhood can be defined as those of a biological, psychological or cognitive nature that last or have the potential to persist for at least one year[1]. In the national scenario, a study points out to a change in the epidemiological profile with the growth of chronic diseases in childhood, emphasizing the increase in hospitalizations of these children and the complexity of care[2]. In a pediatric hospital in Ceará, 48.1% of hospitalizations were due to chronic conditions[3].

After hospital discharge, children with chronic disease and their relatives experience important rearrangements in the routine of the home space. Family members begin to develop care, sometimes complex, without being equipped with the necessary knowledge, without having the available technologies and the support of professionals in care management[4].

The unpreparedness of these families is associated to the way they are included in care during hospitalization. A study showed that family involvement in the care plan is still incipient and demonstrates that conflicts are generated by insufficient information, lack of dialogue, lack of empathy, in addition, difficult interpersonal interactions can influence understanding and learning, impairing bonding and the quality of care[5].

These gaps in discharge preparation during the family's hospital stay can lead to recurrent hospitalizations of children with chronic disease. Furthermore, the lack or precarious articulation between the services of the health care network to ensure the continuity of care after hospital discharge tends to worsen the situation[6].

In this context, it is identified the need for professionals to understand the peculiarities of coordinating the process of transition to home environment and the importance of the interprofessional team in developing joint actions in planned care beyond hospitalization. By rethinking care from this perspective of care management, with home, outpatient and primary health care follow-up, it is guaranteed the follow-up of children with chronic disease after discharge[7] .

In this integrated work, support should also be offered to families for shared construction of a plan that contributes to their autonomy in the performance of home care with safety and quality[2], improving the quality of life of the child and the family as a whole.

When turning to work integrated in the network, it is necessary link between the points of care to ensure continuity and coordination of care for children with chronic disease after discharge. Care cannot be restricted to the hospital environment, requiring organization to allow the follow-up of care in the different levels of care of the Unified Health System (*Sistema Único de Saúde* – SUS)[8].

The Health Care Network (HCN) with Chronic Diseases redefined by Ordinance No. 483/14 of the Ministry of Health (MH) seeks to meet the needs of this public, advocating comprehensive care at all points of the network with coordination of care[9]. Among these, there is the hospital subcomponent, whose nurse stands out as a member of the multiprofessional team of this specialized care service, positioning itself as a link between the health team and the family in the care transition process before the HCN, regarding hospital discharge planning, as stated in article 15 of this ordinance.

Based on this context, the following research question is presented: What is the nurse's performance in the hospital discharge process for children with chronic disease and their families? The objective was to analyze the performance of nurses in the hospital discharge process of children with chronic diseases.

METHOD

Qualitative, descriptive-exploratory study, anchored in Ordinance No. 483/2014 of the Ministry of Health on the Health Care Network for People with Chronic Diseases, more specifically in the competencies of the hospital subcomponent, together with the National Policy for Comprehensive Child Health Care (*Política Nacional de Atenção Integral à Saúde da Criança* – PNAISC) which refers to the axis responsible for watch over chronic diseases in childhood.

The study was conducted in a pediatric unit of a medium-sized federal public hospital, located in Natal, Rio Grande do Norte. The unit has 31 beds and is considered a specialized reference for the care of children and adolescents with chronic diseases in the age group from zero to 16 years old. At the time of data collection, the size of nursing staff at the pediatric unit was reduced due to the high rate of absenteeism due to maternity leave and the granting of vacations to two day worker nurses.

Nurses who worked in the morning and/or afternoon shifts in the pediatric inpatient unit of the respective hospital participated, selected for convenience. The inclusion criteria were providing care to children with chronic disease and their families, and working in this unit for more than six months. Nurses who were away from the service due to leave or medical certificate during the data collection period were excluded. Those who met these criteria were approached by the interviewer at the workplace, according to their availability. It is noteworthy that no professional refused to participate in this study.

Data collection took place from May to August 2019 through a semi-structured interview, guided by the questions: How is the preparation for hospital discharge of the family of children with chronic disease in this service? How does the nurse perform in the hospital discharge process of children with chronic disease and their families? The interviews were conducted by a researcher with a degree and experience in the data collection technique. These were previously scheduled and held in a reserved place, whose audios were recorded and had an average duration of 40 minutes, being transcribed in full after the participants' consent. The collection was closed using the criterion of sufficiency, that is, when the material produced allowed a deeper understanding of the object of study based on the researcher's judgment[10].

Empirical data were submitted to Inductive Thematic Analysis (ITA), following six steps for the analytical process: familiarization with the data, transcription of verbal data, initial coding, classification of codes into pre-themes, reviewing pre-themes, definition of themes and the construction of the final report[11].

All empirical material transcribed constituted the corpus of analysis, which was read repeatedly for familiarization with the data set, allowing, later, the beginning of the coding process. The codes were grouped into pre-themes and sub-themes, according to affinities and established relationships, organized around central questions to answer the questions and objectives of the study[11].

Then, these pre-themes and sub-themes were refined through the review of the coded extracts, as well as the review of the data set of each one of them regarding the precision of the meanings and representativeness of the studied reality. At this point, the essence was identified by naming the themes for the elaboration of the analysis structures and the construction of the final report[12]. This was guided by the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ).

In the analysis, it was used as support version 8.0 of the ATLAS.ti software. This tool allowed the organization of qualitative data and the development of a manual word coding scheme for the elaboration of the research results[13] in the construction of the themes.

In compliance with Resolution No. 466/12 of the Ministry of Health, which regulates the conduct of research involving human beings, the project obtained a favorable opinion from the Research Ethics Committee (No.3,232,709, approval year 03/29/2019, CAAE: 40792120.7.0000.5183). All participants signed the Free and Informed Consent Form (FICF) and, to ensure anonymity, they were identified by "NUR" followed by a numeral referring to the order in which the interviews were conducted.

RESULTS

Ten nurses participated in the study, aged between 30 to 47 years old, with training time ranging from seven to 25 years and one to 24 years of performance in the service. All had a *lato sensu* postgraduate degree in child health, six had a *stricto sensu* postgraduate degree and one had a multiprofessional residency.

The participants explained that in this unit there is a higher frequency of hospitalizations of children with the following chronic diseases: type 1 diabetes mellitus, nephrotic syndrome, cystic fibrosis, West syndrome, Crohn's disease, and systemic lupus erythematosus.

From the data analysis, two themes were constructed, described below:

Health education: performance idealized by nurses in the preparation for hospital discharge

Figure 1 shows the main competencies of nurses in the preparation for hospital discharge of children with chronic diseases.

Health education was highlighted as one of the main competencies of nurses in the preparation for hospital discharge. With this it enables the family to provide care at home environment.

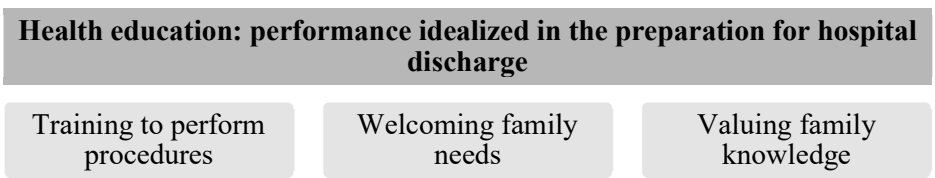

Figure 1 – Health education theme and identified codes.
Source: Research data, 2019.

The nurse's role is to provide guidance [...] *from the period of hospitalization to hospital discharge,* [...] *clarify the care, for being closer to the child with chronic disease and their family* (NUR2)

[...] *we do a previous continuous education with the family member, when we know that the child with chronic disease and his/her family will be discharged or when some care the family member will have to perform at his/her home and how we have this bond, this direct contact with the patient, we managed to promote this guidance* (NUR5).

Among these cares, there are the specific technical procedures for the treatment of each disease and that the family will have to develop at home.

[...] *the guidance covers specific hygiene care, care regarding medication administration, in addition to general care of aspiration, the passage of a probe, the urinary catheter for relief with a clean technique, care with nebulization, medication, dosage, all this nursing performs* (NUR4).

[...] *when the child is hospitalized and needs to know some intrinsic nursing activity, we take advantage of the hospital stay to train the relative. In the specific case of diabetes, we teach how to handle insulin and we also refer them to the pediatric outpatient clinic* [...] *and in the case of self-care, regarding gastrostomies, tracheostomies and some wounds that are yet to be bandaged at home* (NUR5).

In addition to technical procedures, nurses are concerned with emotional aspects that may influence at home care.

[...] *the nurse is a professional who is able to guide the family in an comprehensive way. Not only regarding the procedure itself, but we try to guide the family regarding potential care.* [...] *seeks to prepare the psychological of the relative* (NUR1).

[...] *Nursing is closer in the day-to-day of hospitalization, we are seeing, constantly experiencing the anguish of family members and children with chronic disease* (NUR4).

As they follow the family's daily journey through the hospital, they believe they have the ability to understand their needs and seek to value the family's previous knowledge so that it develops skills for care in the home context.

Thus, it becomes easier to understand the patient's needs (...), *valuing the knowledge of the child's family and we adapt* (the guidance) *to the patient's condition* (...) (NUR2).

(...) *at that moment we observe and realize what the family already knows, what they already know about the child's condition and based on what they already know, we guide and teach care for discharge* (...) (NUR6).

Nurses recognize in health practices the importance of interpersonal relationships to better understand the problems of children with chronic diseases and promote family training. With that, aspects such as welcoming, humanization, resolution, bonding, and trust were considered essential for this interaction.

[...] *I believe that in daily life, as we are closer to the family and the child with a chronic disease, we create a bond, through direct contact, this generates trust, so we can guide and establish a more humanized care* [...] (NUR3).

[...] *we are closer to the family, we spend a lot of time with them, so they feel welcomed* [...] (NUR6).

Nursing participates more actively, solving all the doubts of this family and this child. With this, care must be more humanized, so that the possibility of a return, readmission, due to a complication, is lower, because the greater the knowledge about their problem, the greater the resolution, in the case of this child and this family (NUR9).

This relationship integrates the basic foundations for humanized care and the achievement of comprehensiveness in hospital discharge planning. Humanization must be present throughout the hospitalization period, as it promotes a better understanding of the unique demands of each family, contributing to the minimization of complications and morbidities after discharge.

Between saying and doing: aspects that influence nurses' performance in the preparation for discharge

In view of the findings, it was possible to understand that the way nurses perform is influenced by different aspects. These may favor or not their performance in the preparation for hospital discharge, as detailed in Figure 2.

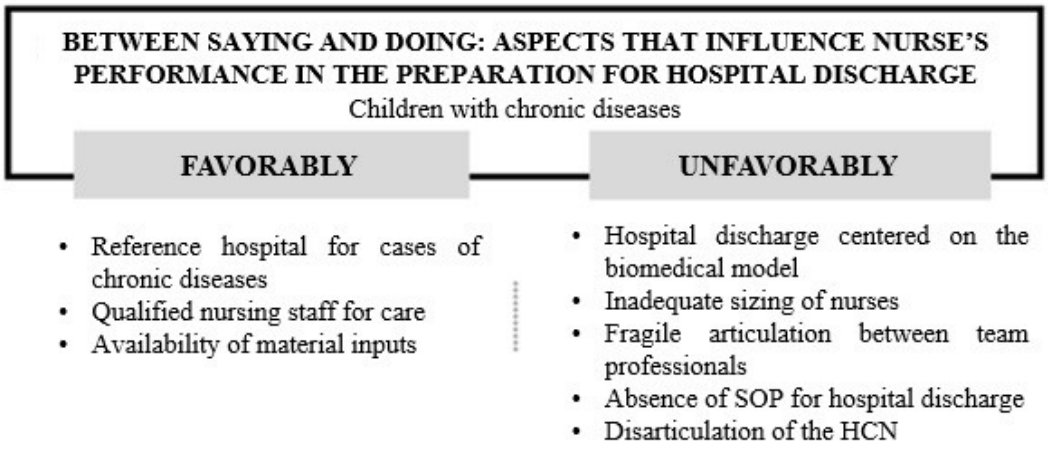

Figure 2 – Theme between saying and doing and the identified codes.
Source: Research data, 2019.

Favorably

Figure 2 shows the nurses' perception of the potentialities for their performance in preparing the hospital discharge of children with chronic disease.

Nurses consider the fact that the institution is a reference in the care of this public a strong point to ensure the quality of care, as it has a qualified and specialized team.

> *The hospital where we work is a reference in the care for chronic children, generally from all over Rio Grande do Norte and some states in the northeast* (NUR8).
>
> [...] *the structuring of our service today is very favorable for these multidisciplinary issues* (at hospital discharge), *in addition to being very favorable for the advancement of nursing, even with some limitations* (NUR9).
>
> [...] *I believe that a great potential is the qualified nursing team, which is very favorable for the advancement of nursing* (NUR10).

The availability of material resources during hospitalization facilitates family care and training, with the necessary support to meet the needs of the binomial.

> [...] *in the hospital we have the inputs, so this facilitates care, in this case, when we are introducing this mother to a practice that she will develop outside the hospital, we not only talk and guide, but we show the mother the actual practice, with the inputs offered, different from other realities* (NUR9).

Unfavorably

In the nurses' work process, weaknesses were identified in the preparation for hospital discharge of families of children with chronic diseases. Although they have pointed out important aspects of nursing performance in preparing these families for discharge, the nurses showed little involvement specifically in these actions.

> *For the time I worked here* [...], *I never participated very actively in this discharge process, I cannot say much about it, because I have never actually witnessed this discharge process, the guidance in relation to discharge* (NUR9).
>
> *I believe that nurses fall a little short of this process* (hospital discharge) (NUR10).

Among the reasons for this little involvement is the inadequate staff sizing. This has generated work overload and interfered in the actions developed by nurses.

> [...] *currently we do not have an adequate sizing, this impair care* (NUR5).
>
> [...] *it ends up being such a fast-paced routine, with so much demand, several situations occur at the same time during discharges and also during admissions that, often, the team is overloaded, in addition to presenting a lower-than-expected quantity, the staff sizing of nurse* (NUR7).

The absence of an instrument defining the competencies of each professional of the multiprofessional team in the

sector was pointed out as an unfavorable aspect for their performance and teamwork. This hinders the systematization of nursing care in the discharge planning.

> *Really regarding this issue, we identified that there is no protocol in the sector* [...] *regarding the nurse's performance in the hospital discharge process* (NUR5).
>
> [...] *something more concrete is needed,* [...] *like creating a Standard Operating Procedure (SOP) to guide discharge, in our pediatric unit,* [...] *having a checklist in this SOP* (NUR6).

A poorly articulated work process and the fragile integration between the professionals of the multiprofessional team makes it difficult to plan hospital discharge and the nurse's performance, compromising family preparation.

> *The articulation does not exist so deeply, the joint discussion, in the multiprofessional scope,* [...] *independent guidelines predominate, for example: physical therapy comes to evaluate the patient and prescribes it, nursing prescribes the inputs, physicians prescribe them, nutrition prescribes them, the reality here is still very individualized* (NUR2).

Furthermore, the hospital discharge process focused on the biomedical model, centered on the figure of the physician and on the care for the disease, interferes with the recognition of nursing competencies in teamwork and, consequently, in the comprehensive look at the demands of preparing the family for the home care.

> [...] *who actively participates in this discharge process is the medical professional, the resident physicians, so occasionally when they need to ask for an input or some guidance, they look for nursing* (NUR9).
>
> *Although the nursing team has a multiprofessional perspective, discharge is still centered on the figure of the medical professional, it is one of the limitations that we need to overcome* (NUR10).

The absence of a consistent and articulated health care network and the lack of ordering and well-defined care flows for children with chronic diseases were also recognized as obstacles to teamwork at hospital discharge. This weakens the counter-referral to other services in the network, making continuity of care unfeasible.

> *Regarding the child with chronic disease, the discharge exists, but there is no guarantee of the patient's return, it is not that planned discharge, from an organized network. With this, there is a weakness, since the network does not guarantee the follow-up of this patient at discharge, in the case of providing an outpatient follow-up and having a sequence* (NUR2).
>
> [...] *because we do not get this articulation effectively in the network, so I believe that this articulation or who will receive the patient in the municipality, presents a weakness in the continuity of this counter-referral* (NUR3).

DISCUSSION

The hospital integrates the HCN as a subcomponent of specialized care according to ordinance 483/2014 of the Ministry of Health, constituting a strategic point of care in cases of worsening of chronic diseases in people, whose competencies of this service are described in articles 15 and 21[9]. Thus, the nurse, as a member of the multiprofessional hospital team, has responsibilities in complying with these legal guidelines.

Regarding the PNAISC, specifically in the care for children with chronic diseases, it is observed that their attributes were considered by the nurses in the organization of the work process. In this study, the recognition of the performance of the family in the continuity of care for this child at home after hospital discharge was evidenced, by valuing family knowledge and welcoming their needs in the educational guidelines in the action plan. This recognition of nurses is important for the practical achievement of the competencies of this subcomponent of the HCN.

Health education is characterized as an orientation process that occurs throughout the hospitalization period and aims to train the family to care for this child population at home[14]. In this process, the nurse seeks to involve the child and their family in the construction and significance of self-care, encouraging responsibility and active participation in the implementation of care and health improvements[15].

In this sense, the nurse in the preparation for hospital discharge must work with the family on issues related to food, hygiene, the environment, child growth and development, the prevention of childhood accidents, facilitating the adherence of the child and his family to the treatment. Given these needs, in health education it is necessary to establish partnerships between these family members and professionals in the management of the condition so that adequate training strategies are developed to ensure continuity of care in the home context[14].

In this hospital discharge planning, it is essential to establish interpersonal relationships involving the family-child

binomial and the multiprofessional team to favor dialogue[14] and enable a real assessment of the vulnerability and self-care capacity of this population[9]. By not restricting the biological needs of the disease to the biomedical, hospital-centered model and valuing the relational and subjective aspects during the hospital stay, it is possible to understand the real demands of care and the context of family life to support assertive preparation actions to enhance management of chronic disease after discharge.

With this view, health practices are broadened and comprehensive care can be achieved, which is considered one of the central objectives of the PNAISC. However, there is still a predominance in the preparation for hospital discharge of actions centered on the disease and on the figure of the physician with fragile articulation of the health team. This condition impairs the recognition of the competence of each team member and, consequently, to have a comprehensive look at the demands of preparing the family for home care, fostering the performance of actions disconnected from the singularities of the child's life context. This type of preparation sometimes fails to achieve satisfactory results in minimizing complications and worsening of the chronic disease.

According to the aforementioned ordinance, the hospital must plan the discharge with the participation of everyone who is part of the multiprofessional team, providing guidance with an emphasis on self-care and empowerment of these people[9], stimulating the autonomy and ability of the child and family members so that they can actually take responsibility for their own care. However, multidisciplinary discussions on hospital discharge planning are limited to specific cases such as children with technological devices. In most cases, the lack of articulation between team members weakens the potential of discharge preparation actions, as they develop health practices in a timely and independent way. This triggers processes that disfavor comprehensive care and adequate discharge planning, based on the appreciation of the unique guidance needs of each family of children with chronic diseases for self-care at home.

Two other points highlighted may interfere in the nurse's performance in the preparation of these families for hospital discharge. These refer to the absence of standard operating protocols (SOP) for the multiprofessional team to plan hospital discharge, and the inadequate sizing of the nursing team.

Regarding the SOP, this is an instrument for systematizing care that provides team professionals, including nurses, to know their competencies in the preparation of hospital discharge for systematic planning with greater visibility of actions, according to multiple knowledge and experiences. In this way, practical knowledge, associated with theoretical support, promotes grounded, timely and quality nursing care[16]. This provides the development of effective strategies in the hospital discharge process, which meet the needs of children with chronic diseases and their families. However, despite the SOP being highlighted as a potential, this instrument does not exist in the studied scenario.

The possibility of aggregating different knowledge to meet the needs of the population can also stimulate reflection on the work process of these professionals, whether in the short or long term. The team's reflection process may provide improvements in work relationships with changes in praxis[5].

It is understood that, in addition to technical care, nurses need to be sensitized and open to the child and their family to mobilize discharge preparation actions that best suit the reality of those living with a chronic disease. This discharge planning to collaborate with the empowerment of families, as well as these children, must be performed by the multiprofessional team[8] and occur from the first contact with the binomial on admission. Thus, it enables the multiprofessional team to know and recognize the needs and limitations faced by the family and adequately prepare it for returning home.

Only from a dynamic, interdisciplinary, and multidirectional approach it will be possible to take care of children and their families in their complexity. Therefore, the multiprofessional approach based on interdisciplinarity is presented as a fundamental condition for meeting the multiple needs of this population[17].

In line with these findings, health professionals must develop their work based on proactive and caring actions in order to strengthen the bond at each meeting in the care process[17]. This way of assisting these families integrates the humanization of care, which is fundamental in the transition of care between the hospital and home environments.

In the humanization of care, the reception of demands is the core of the planning and the nurse, by staying most of the hospitalization time closer with the families, will be able to welcome them to better articulate the hospital discharge planning with the other members of the multiprofessional team. Thus, dubious and/or duplicated actions by professionals, delays in solving demands, deficit in the referral and counter-referral system and, consequently, the greatest burden on the health system are avoided[15].

A study asserts the importance of the multiprofessional team guiding their health actions together, through qualified listening and being attentive to the reflections, experiences and knowledge that those involved with chronic disease bring with them, in order to prioritize their needs and not be restrict only to therapeutic impositions[5], favoring the transition from hospital to home. Thus, teamwork based on

integrality will provide broadened care by integrating the various professional knowledge with that of the family, in the preparation of this public for hospital discharge.

In this sense, it is necessary for health professionals to build new practices and commitments around the social production of health to expand the autonomy of subjects and communities in the management of chronic disease[7]. On the other hand, without commitment from the professional in the hospital discharge process of these families, the improvement of care for the management of the disease to prevent readmissions is unfeasible.

In order to ensure integrality, the intersubjectivity created in the multiple meetings established during the hospitalization period and the humanization strategies in health, have been called to resolve the technicality that is still constitutive of the production of health care. Therefore, health professionals in their daily relationships must value the subjective dimension of the individual for comprehensive care[18].

In contrast, in the hospital, nurses are constantly faced with the necessary and difficult task of integrating health technologies with the closest interaction with the assisted public. The greater emphasis on hard technologies can hinder the construction of a space for humanized care and weaken interpersonal relationships, which are essential to improve the quality of care[19].

In this context, the sizing of the nursing team needs to adapt the working hours to patients/beds by a nursing professional, so as not to overload and compromise their work capacity. Overloaded by daily tasks, nursing can incur in the provision of mechanized and technical, non-reflective care, forgetting to humanize care. Faced with this problem, a paradox is evident in the reports of Nur9 and Nur10 between what they recognize as the nurse's attribution in this preparation, based on a perspective of comprehensive care, and what they do in daily practice, since little involvement and fragile co-responsibility in the face of this hospital discharge process, makes it impossible to perform the described care practice.

In this way, the adequate sizing constitutes an indispensable resource for nursing to organize the care process and comply with the singularities of the assisted public, respecting the degree of dependence[20]. With the appropriate dimensioning to the institutional reality, it contributes to guarantee the safety and quality of the care offered[19].

Furthermore, in general, the chronicity of the child's disease generates demands beyond the usual ones and, sometimes, there is a need for material inputs to perform daily care, as well as training the family to use them at home. Therefore, during the hospital stay, it is important for the service to provide the necessary inputs to assist in the training of families for the care that will be performed at home and to promote articulation with the HCN in a resolutive way, so that they continue to provide the inputs for the care after the discharge. These joint actions will facilitate adaptation to the condition experienced, in addition to ensuring quality, autonomy and safety when returning home.

It is up to the hospital team to foster the family to seek, after discharge, the Primary Care services and/or the specialized outpatient service of Specialized Care, performing the counter-referral of the child with chronic disease. However, during hospitalization, there must be periodic communication with the municipalities of origin, ensuring information continuity between the health teams responsible for care[9]. However, the nurse recognizes the fragility of the performance of the multiprofessional team to promote this articulation between the other points of the HCN to guarantee access to all levels of care, according to the child's needs.

It is understood that the health team must provide continuous care, permeated by accountability, welcoming and commitment in the planning of actions, in order to meet the inherent needs of chronicity[8]. In this sense, the network must offer emotional, material, service and informational support to people who have special health care needs. This articulation between the services is essential to support the family in coping with chronic disease, in order to guarantee access to medium and high technological density actions, minimizing their overload and suffering when seeking care alone in the HCN services[17].

Each point of care in the health care network that the family resorts should be a broad, concrete and permanent reference, in order to enable resolute follow-up. However, the difficulties facing HCN still generate many challenges that need to be overcome to avoid this pilgrimage of families in the network.

These points of attention must be articulated, since the care for children with chronic diseases will not be restricted to the hospital environment, requiring organization that allows the follow-up of care. Thus, hospital professionals must understand the peculiarities of the chronic disease, projecting care beyond the hospitalization process[17].

In view of the findings, it is apprehended the potential of nurses, as professionals in the hospital subcomponent, to coordinate discharge planning, since that institutional conditions favor their performance. This, by monitoring the cases more closely during hospitalization, can favor the mobilization of other team members to adequately meet the health needs and demands of the child with chronic disease and their family, by adding the multiple knowledge of professionals to the hospital discharge planning.

FINAL CONSIDERATIONS

The nurses' performance in the hospital discharge process of children with chronic disease is permeated by contradictions between what they report doing and what they do in care practice. Although the actions have a perspective of promoting self-care valuing the family's knowledge to develop care at home, they occur punctually. Therefore, they do not always include the preparation of the family to assume care with autonomy after discharge.

The inadequate sizing of the nursing team and the lack of articulation between health professionals for the shared planning of hospital discharge proved to be weaknesses in this process.

The planning for discharge preparation needs to start from admission, with the help of operational protocols that favor the systematic sharing of behaviors between the multiprofessional team and the partnership with families. Thus, the team will be able to meet the specific demands of the family in relation to care, supporting and strengthening it to face adversities when returning home.

Despite being a limitation of the study, the fact that it was performed in a single scenario in the Brazilian state, it brings relevant findings to contribute to the improvement of care for children with chronic diseases. Among them, the importance of hospital management being responsible for providing the institutional conditions for the team to perform in preparing families for discharge, as well as the need to employ more creative strategies in this preparation for health care, such as the elaboration of informative materials and creation of operational protocols focusing on hospital discharge.

In view of the challenges and problems evidenced in the singular reality investigated, it is highlighted the need to develop other studies focused on the creation and validation of protocols that contribute to the articulation of the interdisciplinary team, from the elaboration of hospital discharge planning, with the identification of the demands of the assisted people, to the implementation of preparation actions for home care. Thus, professionals will be able to understand their competencies in this process in order to prepare the family for the care of the child with chronic disease at home and contribute to improving the quality of life of those who live with the chronic condition in their daily lives.

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