ABSTRACT

Objective: to know the preparation for hospital discharge carried out by the multi-professional health team for children with chronic conditions and their families. Method: qualitative, exploratory-descriptive research carried out between November 2018 and March 2019 through semi-structured interviews with ten professionals from the multidisciplinary health team at the Pediatric Clinic of a hospital in Paraíba. The interviews were submitted to Minayo’s Thematic Analysis. Results: the preparation for hospital discharge is complex and suffers several influences from the dynamics of the service. We observed that it is difficult to include integrated actions in the preparation for discharge during the daily care of the multi-professional team. During this process, the importance of including the child in care is highlighted, emphasizing the need for self-perception about their current health situation, as well as the possibility of carrying out self-care, depending on their age, understanding, and risks when performing the procedure. Final considerations: there are several weaknesses in the implementation of the preparation for hospital discharge in the pediatric clinic, such as the lack of a protocol or standard that guides this process, carrying out disjointed and individualized interventions inherent to each professional training, hindering the family’s effective learning process, compromising the safe return home.

Keywords: Patient discharge. Chronic disease. Child health. Patient care team.

INTRODUCTION

During hospitalization, the preparation for hospital discharge is done by the multi-professional health team to enable the binomial child and family to continue the care necessary to maintain life and health at home safely through knowledge of the patient health condition, updating and training to carry out the preparation, effective communication with the patient and family and beginning of the discharge plan since admission (1).

In this context, the execution of hospital discharge planning shared by the multi-professional health team provides the binomial learning through practices that reinforce the individual’s autonomy in a dialogical and emancipatory approach (2).

However, against this perspective, a study states that many families of children with chronic conditions need to continuously develop complex care at home without the support of prior knowledge and/or technologies available in the hospital, due to inadequate discharge planning, increasing the complexity diagnosis, having repercussions for recurrent and prolonged hospitalizations (3).

During the interviews, parents of children with chronic diseases reported waiting for access and support from health professionals with appropriate knowledge and experience. However, they stated that even having these skills, the professionals did not know how to pass them on, generating information overload (4).

Another study carried out in a hospital in the southeastern United States showed that children with chronic conditions were readmitted less than 30 days after discharge and concluded that
this reality was due to the lack of necessary information and guidance according to the children’s singularities in chronic health conditions\(^5\).

In this sense, it is urgent to prepare the family for the transition from hospital to home care, using appropriate strategies to meet the demands in a comprehensive, continuous and humanized way\(^6\), with the challenge of collaborating the family to cope learning unusual knowledge and practices in everyday life.

When recognizing the relevant role of parents/caregivers in the care of children with chronic conditions, the health professional also recognizes the need to include the family in the care and to promote coherent actions directed to everyday reality to facilitate the involvement and management of care at home\(^7\).

This process requires qualified and proactive health professionals aware of the care demands, offering assistance based on critical reflections on the actions developed for the reality of the target audience aiming at better care practices\(^8\).

Facing this problem, this study is important because of the scarcity of research on the activity of the multi-professional team in preparation for hospital discharge in Brazil and the need to expand the theme for better care management aiming at home care after discharge, as well as success in instrumentalization and decrease in the rates of readmissions or post-discharge complications\(^9\). Therefore, this article aims to know the preparation for hospital discharge performed by the multi-professional health team for children with chronic conditions and their families.

**METHOD**

This is an exploratory-descriptive study with a qualitative approach carried out between November 2018 and March 2019, at the Pediatric Clinic (PC) of a general university hospital in Paraíba. The hospital has 24 pediatric beds and is a reference for the diagnosis and treatment of chronic diseases and rare in the state. Ten professionals from the multidisciplinary health team who work in the sector participated in the study. We carried out semi-structured individual interviews for data collection, recorded in audio, in an electronic device, and with an average duration of 12 minutes each.

The study included individuals who met the following inclusion criteria: being a health professional who assists children with chronic conditions; working at the PC of that hospital for at least one year. The exclusion criteria were not being in psychological conditions; be on leave or vacation during the data collection phase. Participants were selected for convenience. However, we preferred to interview at least one health professional in each category working in the service. The nursing category was interviewed in a greater number because it operates continuously in the care of hospitalized patients. Also, some categories only have a professional in the researched sector, such as psychology and occupational therapy.

The interview script was the same for all respondents and contained the following questions: Describe what you understand by preparing for hospital discharge; How do you perform this care during your work at the PC? We used a sufficiency criterion to close the data collection when the collected material allowed to answer the study objective and the information started to recur\(^10\).

The analysis of the data took place through Thematic Analysis in three stages: pre-analysis, which is the researcher's immersive reading in the research data; and recognition of the material. In this phase, the research objectives were resumed to allow the organization of data and the establishment of central thematic units for categorization; and finally, data interpretation, in which the representative statements were highlighted and suffered the researcher's inferences and interpretations based on the current literature on the topic\(^11\). Thus, two thematic categories emerged: Preparing the family and the child with a chronic condition for hospital discharge and Agreements and disagreements of the multidisciplinary team in preparation for hospital discharge.

The study complied with the ethical aspects that involve research with human beings in the country and the Research Ethics Committee of the University Hospital Lauro Wanderley approved it under opinion No. 046382. It is linked to the research project “Care Management in Chronic Conditions in Children and
Adolescents”. All respondents signed Informed Consent Form (ICF) and were identified by the letter E, followed by the ordinal sequence number of the interviews to ensure their anonymity.

RESULTS

The participants were all female, from different professional categories: two nurses, two nursing technicians, a doctor, a psychologist, a nutritionist, an occupational therapist, a physiotherapist, and a social worker. They were between 32 and 55 years old and between one and ten years of professional experience in that PC, in which five (50%) had been working for less than five years in the sector, two (20%) for more than five years, two (20%) more than ten years ago and one (10%) a year ago.

I – Preparing the family and the child with a chronic condition for hospital discharge

The health professional's understanding of the preparation for discharge influences the team's work process in carrying out the guidelines and the means that will be used to provide home care.

The professionals saw the preparation for discharge as an intervention process initiated since the child's arrival at the hospital, in which the main caregiver technically adapts to the care that should be performed at home:

[...] you teach what she {mother} can do to improve that child’s quality of life [...] you adapt the mother to that reality [...] you try to show her what she can do at home ... do the care we do here to minimize hospital visits (E01).

The preparation for discharge needs to start as soon as the child arrives at the service because these are guidelines that the family will have to ... adapt to care (E04).

The process that involves some educational awareness and intervention care, which the {multiprofessional health} team needs to give to caregivers of patients who are hospitalized and who often already have a long period of handling with it (E07).

Technical training for the development of procedures at home was the focus of intervention by the nursing team and physiotherapist:

They will have guidelines beyond just medical guidance, because care, especially nursing, for me, is different. It is that care that the mother will be able to do the best, with more technical capacity (E02).

So, the {multiprofessional health} team has the obligation or duty to teach during their assistance, explaining to the family member all the procedures that will be necessary to do when the child is discharged (E03).

The whole team tries to mobilize to arrive, talk to the mother, tell her how this care needs to be performed [...] we often follow this care to get a sense of what she knows, how skilled she is for this movement or this specific care (E04).

It is often necessary for the team to train, explain, clarify some behaviors more objectively, some things to the family member (E07).

During the family training for home care, the teaching-learning process emphasized observing the family's care performed by the team and simulating these technical procedures, in addition to creating educational and illustrative material:

When thinking about discharge guidelines, the project {university extension} has contributed a lot ... The girls when they come to the activity ask who the mother is, how they are [...] drawing strategies, others more practical and less abstract strategies to guide this mother (E04).

The mother, who was the caregiver, had a lot of difficulties because she did not know how to read and we made a simple booklet, illustrating her hand about how the aspiration was done correctly so she could use it when need it (E07).

Regarding discharge, every time I intervene in the ward or the rehabilitation room, I always take the caregiver. Because they will continue {the care} at home, both in terms of ADL {Activities of daily living}, as well as in the quality of life (E08).

In the view of the health team, the people to be targets of this intervention were the main caregiver and the child with a chronic condition:

So that we can guide who is going to be closest to providing this care, who is more with this child [...] You need to make sure of that and bring {the primary caregiver} to the service and guide him so, on their return to home, the person with the
The greatest bond is guided towards this care (E04).

When the child is older, he also actively participates in this process [of preparation for discharge]. All this guidance care to keep this treatment at home (E05).

The nursing team and the psychologist were more sensitive to recognize the relevance of an intervention aimed at helping the family and the child to face the fears arising from the chronic condition and its implications:

[...] this new view of the body, a new view of knowledge, of seeing their child now not only as a child with a chronic illness, but a child who will continue to demand care, but more specific [...]. Creating a mother-child relationship, not the mother of the sick boy, but the mother who has more knowledge and who applies it to the child because of the condition he is now, but not only because of that (E02).

These difficulties we found from those who will receive guidance are the greatest because they will require greater communication skills from the professional [...]. What is the best time for a person to receive that information? [...] Is she available to understand what you are giving? (E04).

It is the whole professional process of guiding the family and the patient [...] they are very insecure because here the team does all the handling and when they go home the responsibility at home becomes theirs [...] We do this support mainly from the beginning here, this issue of emotional security, this patient and this family [...] (however) we do this preparation when there is time. This support for them to be strengthened at home, some guidance, that if anything happens, they can return, also guidance about the health center (E05).

In addition to preparing the caregiver to continue care at home, there is a concern of having the necessary resources to assist the child, as well as ensuring access to the services of the health care network:

There are many families, mothers, who have a somewhat difficult ability to understand, [besides] the problem of them living in places that have difficulties in accessing materials, even health care [...] The problem of reference and counter-referral to avoid these readmissions. The biggest difficulties are understanding, teaching, and trying harder, repeating things, and accessing materials (E03).

Organizing all the demands that the child will need after discharge, like medication [...] What would be the access for her to continue [with the monitoring of] diagnosed pathology, if it would be here at the university hospital [or] in the city if the mother can buy the medication she will use. Often, the mother is not able, if it is a [medication] that we have here in the hospital, we provide it and when it is not, we ask the social service to contact them (E06).

The difficulties we found are those of the network, obtaining material for some techniques, obtaining the equipment, being able to enter the service flow of SUS [Unified Health System]. There are several difficulties, which I think that the family faces much more than the professional (E07).

Many patients need a report to enter the city hall and get a diet. This report needs to be delivered at the hospital so that she can enter the city hall so that when she goes home, she is already with her or is close to receiving it. As there are some syndromes that the government makes available, I need to make this quick report so that the whole process is communicated and occurs (E09).

Another concern is a nurse on the team was the need to assess at the end whether the preparation for discharge reached the objectives after the guidelines performed:

We need to make sure that the mother is sure of this care so that the multi-professional team together with the medical team also provides security for them to release for discharge [...] There are those [professionals] who provide guidance and believe that it was enough, [but] they are not sure about learning. When you come back to the issue, people did not understand what was said (E04).

II - Agreements and disagreements of the multidisciplinary team in preparation for hospital discharge

During the hospitalization period, the multi-professional team experienced many agreements and disagreements in planning hospital discharge since admission. Some of the gaps evidenced in this process were the absence of an institutional protocol that systematizes joint actions, the lack of articulation, and the failure to share information between health professionals:

Unfortunately, these guidelines occur more for the
An unexpected discharge, at least for me, when I think the child is going to spend a few days here, he is discharged today or tomorrow. So, the process ends up being more accelerated and I can't do the quality process as it should be, it ends up being a lack of communication between the team (E05).

The difficulty is that sometimes discharge is not advised to nutrition. So, some children leave without guidance, because they are not warned (E09).

The difficulty of implementing joint activities between the different segments is another factor that hinders activities in the multidisciplinary field, which can result in dubious information to patients and their families, situations that could be minimized in the relationship between the different types of knowledge:

I miss a bigger conversation between doctors and nursing [...] They often discharge the child without warning. So, there is no time ... for example, the child will be discharged tomorrow. There is no way for the mother to learn [...] in two days what she needs to take care of her child at home (E01).

Even the issue of diagnostic disclosure is often made without asking for support [from psychology], so we find out at the last minute. The diagnosis of chronic disease is difficult, so it should be routine for the hospital to call the psychology team to make the diagnosis (E05).

Here in pediatrics, I think it is very easy, everyone does their own. The nutritionist usually guides her part, nursing guides the part of care, the medical team already leaves the return marked for the specialty that she [child] will need to follow or to the graduate laboratory (E06).

We do the orientations according to the pathology, it is individual. Then, we do the calculation, print an initial guideline, and send it to the nutrition clinic to continue the follow-up. Usually, I maintain the clinic's conduct, I guide the mother to evolve and the ideal is that she returns to the clinic so that the wrong diet at home does not evolve if it is a serious case (E09).

Even with the agreements and disagreements of the multidisciplinary team in the preparation for the hospital discharge, it is possible to achieve positive results, according to the professional's perception, when the mother is empowered:

We managed it, within all limitations, to make these guidelines have a different impact on the lives of these children, because many of them when mothers can empower with this information, many of these children reduce their visit to the service (E04).

DISCUSSION

When observing at the work process of the multidisciplinary team of the pediatric unit under study, the issue most praised by professionals in preparing for discharge was the concern with training the family and, when relevant, the child with a chronic condition for technical care.

To meet the care demands, the caregivers need to be guided so that they understand how to proceed at home, being accompanied in the performance of this care, even in a hospital environment after the child's clinical stability, more conducive to the emotional availability of the caregiver to learn and perform care under supervision (12).

The preparation for a safe, concrete, and effective discharge is due to health education actions permeated by the dialogue, listening, and bonding, empowering the family and favoring their autonomy with care at home (6).

The creation of educational material by the professionals of the team collaborates in the process of family training and constitutes a promising strategy in the preparation of hospital discharge. This printed material reinforces the guidelines and it is a consultation tool in case of doubts when the family develops care at home (6).

However, through the terms “teach the technique” and “adapt the mother to care” used by the interviewees, a teaching-learning process is permeated by the narration of content aimed at teaching standardized techniques, seeking the acquisition of skills, and dexterity to perform a certain activity.

Therefore, this discharge planning rather than
being a collaborative family-centered care action is limited to the prescription of treatments and verticalized care planning, deficient in supporting parents in the role of managing the management of their child's condition. This is because there is an overload of information that makes parents unable to process the information or effectively contribute to the care discussions⁴.

This transfer of knowledge as an absolute truth can hinder the development of the family's autonomy when facing the care when it follows a script of observation, execution, and evaluation without critical reflection on the importance of the actions taken and adaptation to the family reality.

In the process of emancipation to achieve autonomy in care, the family needs to actively engage in the learning process. In this engagement, they need to transpose the passive transfer of information so that the caregiver feels safe and able to continually improve knowledge and shape it according to the most diverse situations that can be experienced in the home context¹³.

With the confidence and security acquired by the family to take care of at home, the risks to the child's health are reduced. However, despite being relevant, family preparation for hospital discharge is still incipient in many health services in the country¹²,¹⁴.

An important aspect with an unfavorable impact on the preparation of hospital discharge is the use of inappropriate communication by the team professionals when talking to families. This is either due to a language inaccessible to the target audience that hinders the caregiver to understand during care, either due to the scarcity of an institutional protocol that systematizes the conduct of the multidisciplinary team to carry out the guidelines. The absence of standardization and adequate communication between the professionals results in divergent or inconsistent information with the family's reality, which makes the guidelines ineffective¹².

This obstacle comes from a non-procedural discharge preparation, with only punctual actions, not systematized and, often, centered on the reproduction of procedures. Thus, the professional who performs the preparation is unable to establish an approximation with the concrete reality and the vocabulary cultural universe of the caregiver. In an effective communication preparing for hospital discharge, professionals must bring care guidelines closer to the family's reality, paying attention to the needs of monitoring in the care network, to minimize readmissions³.

A study shows that this communication deficit generates incomplete or incorrect information, increasing the chance of adverse events, preventable treatments, unplanned rehospitalizations, and extra costs¹⁵. Frequent rehospitalizations reflect the difficulties faced by the family in the management of children with chronic diseases after hospital discharge. These difficulties are due to gaps in health education during hospitalization, the devaluation of the social needs of families, and the lack of concern to ensure continuity of care in the care network after discharge¹⁶.

As a solution, weekly or daily meetings of the health team to jointly decide the likely date of discharge could contribute to the team's planning with better worked and understood guidelines¹⁷.

However, the lack of human resources, time to prepare a hospital discharge plan, and communication difficulties for the transition of care among health professionals make this process difficult¹⁸-¹⁹.

However, there were different ways of acting for the training of families among the team's professionals. This finding corroborates a study⁸ that found in the same team professionals who understand the need to undertake new actions in practice and develop innovative initiatives and other professionals who, on the other hand, do not follow the changes and are limited to following only the routine of individual performance.

In this context, we can observe the importance of the multi-professional team to be the distance from a mechanical activity and develop education and care strategies that invite the family to be active in preparing for hospital discharge. During this process, educational actions and simulation of procedures, with an illustrative and scientific basis developed by health professionals guided by dialogue and interaction, strengthen the teaching-learning process of those involved with direct child care in the home environment.

Health education in a dialogical and
emancipatory perspective is a tool that provides autonomy to family members and/or children through actions that promote disease prevention and clinical recovery, seeking quality of life, reducing risks and costs related to health conditions\(^{(2,14)}\).

Therefore, a study analyzing 72 articles highlighted that most intervention research that addressed hospital discharge for pediatric patients focused on the education of caregivers without establishing an intervention process composed of readjusting the physical and social context of families; modeling strategies for imitating behaviors aspired by people and training to reduce barriers to accessing means of change\(^{(19)}\). These aspects can generate more uncertainties regarding the disease and treatment, which can result in family vulnerabilities\(^{(21)}\).

When monitoring this binomial, the professional needs to be aware of the relatives' understanding and reality and their interest, realizing the proper moment to include them in the care, allowing them to approach, assist and participate in the procedures until that the caregiver can perform care under supervision.

These educational actions can also include the child in the practice of care, expanding the possibilities for his diagnosis, and providing the protagonism of his health\(^{(22)}\). This event depends on the patient's perception of his current health situation, as well as whether he can perform self-care depends on his age, understanding, and risks when performing the procedure.

The difficulty in articulating the hospital with the Family Health Unit (FHU) is another point to highlight. This is a reflection of weakened communication between the services of the care network, which compromises the continuity and quality of care at home, as the obstacles in the referral process interfere with the support to the caregiver outside the hospital context\(^{(21)}\).

However, a hospital with an integrated, articulated team that performs systematic interventions and participation in academic programs, such as professional residencies and undergraduate students, has great possibilities to prepare hospital discharge planning capable of enhancing family care in the home\(^{(19)}\). In the hospital under study, the university extension project is configured as an empowering strategy in the preparation for hospital discharge of children and adolescents living with chronic conditions.

Given this context, we observed that the professionals participating in this study recognize the importance of guidelines for hospital discharge and its results. However, they have difficulties in implementing the actions, especially the integrated ones. These adversities are related both to the understanding of the duties assigned to them in preparation for discharge and to the importance of finding joint strategies with professionals from other services in the care network to ensure continuity of care in the post-discharge in-home environment.

**FINAL CONSIDERATIONS**

This study allowed the knowledge about the discharge preparation performed by the multi-professional hospital team of a PC and pointed out that they recognize the importance and know how this action should be performed. However, there are still several weaknesses in its implementation, and we observed that care is performed according to the practical and individual experience of the professional, with no protocol or rule that guides this process, hindering to systematize the actions and continuity of care at home.

The actions of health professionals who work in that service, although complementary, are not systematized, contributing to the preparation for hospital discharge to be focused on technique and procedures, leaving the expanded attention of health tangential to the process of caring for the binomial.

The lack of systematization between professional interventions makes the articulation between knowledge and multi-professional practices extremely difficult. Although this service has a complete multi-professional team, the family preparation process for hospital discharge is carried out in a fragmented way because there is no formal discussion about the conducts for each case, nor a consensus on how and when this information should be worked for the instrumentalization of the caregiver and even the child/adolescent with a chronic disease.

The limitation of this study was the discussion of a specific reality, which makes
EQUIPE MULTIPROFISSIONAL NO PREPARO PARA A ALTA HOSPITALAR DE CRIANÇAS COM CONDIÇÕES CRÔNICAS

RESUMO

Objetivo: Conhecer o preparo para alta hospitalar realizado pela equipe multiprofissional de saúde a crianças com condições crônicas e seus familiares. Método: Pesquisa qualitativa, exploratória-descritiva, realizada entre novembro de 2018 e março de 2019 por meio de entrevista semiestruturada com dez profissionais da equipe multiprofissional de saúde da Clínica Pediátrica de um hospital da Paraíba. As entrevistas foram submetidas à Análise Temática de Minayo. Resultados: O preparo para a alta hospitalar é complexo e sofre diversas influências da dinâmica do serviço. Evidenciou-se dificuldade de inclusão de ações integradas no preparo para alta durante a assistência cotidiana da equipe multiprofissional. Durante esse processo, destaca-se a importância da inclusão da criança nos cuidados, ressaltando a necessidade da autopercepção sobre sua situação atual de saúde, assim como a possibilidade de realizar o autocuidado, a depender da sua idade, compreensão e dos riscos ao realizar o procedimento. Considerações finais: Há diversas fragilidades na implementação do preparo para a alta hospitalar na clínica pediátrica, como a inexistência de protocolo ou norma que balize esse processo, realização de intervenções desarticuladas e individualizadas inerentes a cada formação profissional, dificultando o processo de aprendizagem efetivo da família, comprometendo o retorno ao domicílio com segurança.


EQUIPO MULTIPROFISSIONAL EN LA PREPARACIÓN PARA EL ALTA HOSPITALAR DE NIÑOS CON CONDICIONES CRÓNICAS

RESUMEN

Objetivo: conocer la preparación para el alta hospitalaria realizada por el equipo multiprofesional de salud a niños con condiciones crónicas y sus familias. Método: investigación cualitativa, exploratoria-descriptiva, realizada entre noviembre de 2018 y marzo de 2019 mediante entrevista semiestructurada con diez profesionales del equipo multiprofesional de salud de la Clínica Pediátrica de un hospital de Paraíba-Brasil. Las entrevistas fueron sometidas al Análisis Temático de Minayo. Resultados: la preparación para el alta hospitalaria es complexa y sufre diversas influencias de la dinámica del servicio. Se evidenció dificultad de inclusión de acciones integradas en la preparación para el alta durante la atención diaria del equipo multiprofesional. Durante este proceso, se destaca la importancia de la inclusión del niño en los cuidados, destacando la necesidad de autopercepción sobre su situación actual de salud, así como la posibilidad de realizar el autocuidado, dependiendo de su edad, de su comprensión y de los riesgos al realizar el procedimiento. Consideraciones finales: hay diversas fragilidades en la implementación de la preparación para el alta hospitalaria en la clínica pediátrica, como la ausencia de protocolo o norma que oriente este proceso, la realización de intervenciones desarticuladas e individualizadas inherentes a cada formación profesional, dificultando el proceso de aprendizaje efectivo de la familia, comprometiendo, así, el regreso al domicilio con seguridad.


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