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Complex care for children with chronic diseases from the perspective of care management

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Atención terciaria a niños con enfermedades crónicas en la perspectiva de la gestión de la atención

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ABSTRACT

Objective: To analyze the actions developed in hospitals for children with chronic diseases from the perspective of care management.
Method: Qualitative research, conducted with 14 health professionals from pediatric units in two northeastern hospitals, between November 2018 and March 2019, through semi-structured interviews. The empirical material was interpreted by thematic inductive analysis considering the care management construct.
Results: The actions of the multi-professional team are fragmented, making it challenging to prepare and involve the family in care and not always responding to the child's unique and complex demands. The insufficient number of professionals, lack of material resources and inadequate infrastructure of hospital services reflect in the care practice, generating work overload and inadequate actions.
Final Considerations: Care management is an indispensable tool in coping with chronic childhood illnesses. The actions carried out by the multi-professional teams in hospitals must develop support to expand the care.
Keywords: Child. Hospitalization. Chronic disease. Health management.

RESUMO

Objetivo: Analisar as ações desenvolvidas na atenção terciária à criança com doença crônica na perspetiva da gestão do cuidado.
Método: Pesquisa qualitativa realizada com 14 profissionais da saúde de unidades pediátricas de dois hospitais nordestinos, entre novembro de 2018 e março de 2019, por meio de entrevista semiestruturada. O material empírico foi interpretado por análise temática indutiva à luz da gestão do cuidado.
Resultados: As ações das equipes multiprofissionais apresentam-se fragmentadas, dificultando o preparo e o envolvimento da família no cuidado e nem sempre respondendo às demandas singulares e complexas da criança. O número insuficiente de profissionais, falta de insumos e infraestruturas inadequadas dos serviços hospitalares refletem na prática assistencial gerando sobrecarga de trabalho e ações desarticuladas.
Considerações finais: A gestão do cuidado contribui para a reestruturação dos processos de trabalho no hospital para que as ações da equipe atendam às demandas singulares e complexas dessa população.
Palavras-Chave: Criança. Hospitalização. Doença crônica. Gestão em saúde.

RESUMEN

Objetivo: Analizar las acciones desarrolladas en la atención terciaria a niños con enfermedades crónicas en la perspectiva de la gestión del cuidado.
Método: Investigación cualitativa realizada con catorce profesionales de la salud de unidades pediátricas de dos hospitales del noreste, entre noviembre de 2018 y marzo de 2019, a través de entrevistas semiestructuradas. El material empírico fue interpretado mediante análisis temático inductivo a la luz de la gestión del cuidado.
Resultados: La actuación del equipo multiprofesional está fragmentada, lo que dificulta la preparación y participación de la familia en los cuidados y no siempre responde a las demandas únicas y complejas del niño. El insuficiente número de profesionales, la falta de insumos y la inadecuada infraestructura de los servicios hospitalarios se reflejan en la práctica asistencial generando sobrecarga de trabajo y acciones desarticuladas.
Consideraciones finales: La gestión del cuidado es una herramienta indispensable para el enfrentamiento de las enfermedades crónicas en los niños, y las acciones realizadas por el equipo multiprofesional en la atención terciaria deben apoyar un cuidado ampliado y resolutivo.
Palabras clave: Niño. Hospitalización. Enfermedad crónica. Gestión en la salud.

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INTRODUCTION

Hospitalization has a strong impact on the life of the child and their family due to the need to leave their homes and interrupt their daily activities and routines to be in an unfamiliar environment. This can lead to a many feelings, such as sadness and fear(1).

The illness and hospitalization of children affect their interaction with family, friends, and school. This repercussion extends to the routine of their family and, especially, their main caregiver, who now needs guidance, support and monitoring from health professionals(2).

Children's chronic diseases, in addition to being one of the main causes of hospitalizations, make children and their families start seeking treatment in the services that make up the Health Care Network (HCN). The management of the disease requires special attention, as this population will need constant monitoring by specialists and the guarantee of continuity of care over time(3), triggering an overload for those responsible for home care in personal, family and sociocultural factors(4).

Even in developed countries, like England, which achieved significant improvements in the care for children who require longitudinal follow-up, a study showed weaknesses in the coordination of care and access to services to meet the needs of this population(5). The family is in a vulnerable situation and starts to wander through different services in search of resolutive care(3).

The lack of coordination of care and communication between the primary/basic and tertiary/complex levels of health care contribute to the inadequate provision of health care, and to the dissatisfaction and stress of patients and their families, reducing their safety in these health services(6).

Families face difficulties in accessing the HCN and are often not considered in primary care, thus being accompanied by services and professionals from specialties and/or rehabilitation, leading to a process of transferring responsibility for care(6). To support comprehensive care in situations of chronic childhood illness, health systems must be more responsive to chronic demands, especially with families in vulnerable situations(7).

Health care management is defined as "the provision or availability of health technologies, according to the unique needs of each person, at different times of their life, aiming at their well-being, safety and autonomy"(8). It comprises multiple dimensions: individual, family, professional, organizational, systemic and social(8).

Weaknesses in the management of care in the different points of the HCN generate difficulties in the continuity of care, such as an increase in the maternal burden, disarticulation and poor resoluteness of services, in addition to a lack of information provided by professionals(9). This hinders comprehensive and continuous care for children with chronic illnesses.

The lack of articulation in the HCN hinders the continuity of care and can increase complications and/or unnecessary hospitalizations for children with chronic diseases(10). Network care will only be carried out based on the articulations between the services that comprise it and the organization of the offer according to the users' demands(6).

This study seeks to increase the visibility of the care offered to children with chronic illnesses, both for professionals and for government officials and researchers in the area, in order to trigger reflections on the health actions carried out in tertiary/complex care. A new approach to the child population aims to sensitize professionals and managers to develop care and management practices that provide resolutive and comprehensive care.

Given the above, the following research question was created: How has care management been implemented during the hospitalization of children with chronic diseases? The aim of this study was to analyze the actions developed in tertiary care for children with chronic illnesses from the perspective of care management.

METHODS

Qualitative, exploratory-descriptive research, carried out according to the recommendations of the Consolidated Criteria for Reporting Qualitative Research *(COREQ)*. Study developed between November 2018 and March 2019, in pediatric hospitals caring for children with chronic diseases in a Brazilian northeastern state.

These institutions are public and provide care at secondary and tertiary levels, besides being federal teaching hospitals and a reference for children with chronic and rare diseases. They can be clinical and surgical inpatient units, intensive care units, and outpatient clinics, in addition to a state pediatric hospital, a reference for the care of acute and chronic cases in children.

The main researcher addressed 16 members of the multidisciplinary teams of the pediatric units of both institutions in person and by convenience, including nurses, nursing technicians and assistants, physicians, speech therapists and physiotherapists. The researcher introduced herself, explained the research and obtained consent. The inclusion criteria used were: providing care to hospitalized children with a chronic disease and working in the inpatient unit for at least six months. The following exclusion criteria were adopted: professionals who were on leave, vacations, or absent for any other reason during data collection. It is noteworthy that two professionals, one from each hospital, refused to participate in the study claiming to lack time, thus totaling 14 participants, 8 from one institution and 6 from another.

Depending on the availability of the participants, the semi-structured individual interview could take place on the same day or be scheduled. The interviews were conducted in a room available at the institution, in an environment with guaranteed privacy, recorded in audio, lasting for an average of 35 minutes. They were conducted by an undergraduate student belonging to a study group with experience in the qualitative method of data collection. A script was used with the following guiding question: what actions do you develop in your work that contribute to expand the care for children with chronic illness and their families? The end of the collection followed the saturation criteria, that is, the collection was stopped when we made sure that it reached an internal logic of the data and made it possible to draw a comprehensive picture about the object of study(11).

Data were interpreted by the inductive thematic analysis (ATI)(12) and the conceptual framework that guided this analysis was the management of health care, which is expressed in multiple dimensions: individual, self-care focused; family, including family members, friends and neighbors who share care management; professional, comprising professional competence, ethical posture, and ability to build bonds with the patient; organizational, encompassing the ability of each professional to favor interaction between the team to achieve common goals; systemic, encompassing the formalization of regulated connections between health services; and, finally, State-related, involving the State's public policies in the formulation and implementation of strategies to achieve goals(8).

In the operationalization of the ATI, the topics were extracted from the data, without prior coding, and comprised six stages, which did not follow a rigid form: familiarization with the theme, from the active reading of the empirical material before searching for codes and meanings; generation of initial codes, with the identification of similar sets and production of initial codes manually; search by topic, with the selection of different codes in potential topics; review of topics, in which topics were refined by reading all data extracts that were part of each topic and visualizing the relationship between topics; definition and naming of topics, with clear identification of topics; and production of the final text(12).

From the analyses, 65 codes were identified, which generated two main themes: Actions of the multidisciplinary teams to the child/family during hospitalization; and Organizational structure of hospital services that impact on the care of children with chronic illnesses and their families.

The research followed the current ethical guidelines in the country, being approved by the Research Ethics Committee under CAAE: 66663617.9.0000.5188 and Opinion nº 2046382, and by the two institutions involved. All participants signed the Informed Consent Form (TCLE). To ensure anonymity, the professionals were identified with the initial letters referring to their profession in Portuguese and the interview number, such as: nurse (E1, E2, E3), nursing technician (TEC1... TEC4), nursing assistant (AX1, AX2), physician (M1), speech therapist (FO1, FO2), and physiotherapist (FI1, FI2).

RESULTS AND DISCUSSION

Of the 14 health professionals interviewed, three were nurses, four nursing technicians, two nursing assistants, one pediatrician, two speech therapists and two physical therapists, aged between 31 and 68 years, all female. The time working in a pediatric inpatient unit ranged from 6 months to 38 years and the work regime from 24 to 36 hours a week.

Actions of multidisciplinary teams for the child/family during hospitalization

This category refers to the actions developed by the professionals of the multidisciplinary team for the care of the child and/or family during hospitalization. The following themes were identified: role of family members; bond with the child/family; carrying out procedures; and preparing the child/family to return home. In some situations, professionals develop strategic actions for the family members to assume a main role in the care, which will continue at home.

> *We work with her [the hospitalized child's mother] for a while and even watch to see if she's doing it correctly* [...] *so that when she's at home she doesn't have so many doubts* (FI1).
>
> *Here [at the hospital] we do [care for children with chronic illnesses] and, even so, there are times that we have to let them [mothers] do it, so that when they get home, they can continue the treatment* (TEC2).
>
> *When you're going to do a procedure, call the family member and explain what you're doing, to help us, if it's something he [caregiver] will do outside [at home]* [...] *like a diet that uses the catheter, we try to guide them to do it correctly* (TEC3).

Actions that follow this direction can promote the family's involvement in care, triggering the process for a possible autonomy, contemplating, even if partially, the individual dimension of care management. During hospitalization, since admission, it is essential that the multidisciplinary team prepare the family to manage all the care that the child with a chronic disease requires in order to prepare them for home care.

In the individual dimension, it is essential to offer support for self-care management through the instrumentalization of the child and their family, reflective listening, open questions, motivation, and support during the hospitalization period, especially for the care that will be part of daily life. Thus, the relative is effectively involved as a partner, which increases the likelihood of improvements in health and education(13)

The family's involvement in care during hospitalization contributes for a better disease management at home and encourages their self-confidence. Furthermore, it reduces the occurrence of readmissions. A study pointed out that the communication established between the professional and the family is essential in meeting the child's needs, in addition to preparing them to face possible demands after a hospital discharge(14).

The development of strategies to provide humanized care through a closer relationship between the child/family and the health professional was important for bonding. This was reflected on the maintenance of care actions and monitoring of the disease.

> *I think that a child who has a bond with a professional and the family that has also a bond to that professional generate a comfortable situation of trust* [...] *they will trust the procedure, they will seek support for that child's needs, and this will facilitate the whole process* (FI2).
>
> *Maintaining this bond greatly improves child care, because when the mother manages to realize that despite the child having a chronic condition that need complex care, she will be responsible for this care and that she can, in certain situations, depending on her posture, improve her child's health,* [...] *she ends up feeling more empowered* (E1).

The bond is a fundamental tool for work and enhances relationships of trust in the care provided by the professional. The work focused on a close relationship and dialogue to strengthen the professional dimension of care management can minimize the suffering resulting from child hospitalization. By being attentive and able to listen to the caregiver, the professional can contribute to the expansion and strengthening of social support networks by reducing the isolation of families, creating new bonds and effective assistance in the care of children with chronic illnesses, thus improving their quality of life both at the beginning and during the course of the disease(10).

Since these are institutions that work in the care of children with chronic illnesses, the professionals of the two hospitals demonstrated that they understand the importance of the bond both to clarify doubts and enhance security in carrying out care at home.

A study(15) showed positive impacts on the care of children with complex health problems, such as chronic diseases, based on an effective coordination of care and partnerships with families to better understand their needs. The health professional should promote expanded, family-centered care actions based on clarifying information, teaching self-care skills and techniques, feedback strategies, and reinforcing effective and quality communication(16).

The access to the multidisciplinary team to establish a bond with the child/family contributes to the safety of the family in care actions(17). Multi-professional work must be able to support expanded care by identifying the unique demands of children with chronic illnesses and their families(18).

The actions developed in the hospital can become mechanical and centered on daily procedures, impoverishing care.

> *I provide all the necessary assistance, medication, help with the bath, because since this is pediatrics [service], the child is not bathed here, it's the family, but* [...] *there are some patients that we get to participate in more direct care, bathing, changing positions, medications, changing underwear* (AUX2).

At other times, when specific guidance is needed for children with chronic illness and their families, individual responsibility of each professional category occurred, exposing the fragmentation of actions in the hospital.

> *Depending on the type of disease, it is good for the psychology to come in to talk to the mother, give psychological support, even social services, giving guidance* [...] *the doctor too, advising, saying how it is, what the child has, passing it on to her [mother]. Because it causes a lot of insecurity, fear* (TEC2).
>
> *The technicians not so much [give guidance], it's more the nurses who have this contact, to give information* [...] *because, as they do the visit every day, it's in that moment that the mothers tell their complaints, what they are feeling, then it is that direct contact* (TEC4).

Although they report a certain proximity to the family, weaknesses are highlighted in the professional dimension with regard to technical competences related to the ability, due to their experience and training, to respond to health problems, and to the articulation of the team in the development of health guidelines. Professionals do not meet the biopsychosocial demands of this population, especially in relation to the construction of self-care.

Corroborating these findings, a study(9) highlights vulnerability in the way the work process of multidisciplinary teams is organized, hindering the preparation and involvement of families in child care. The obstacles make health education unfeasible to prepare the family for the care of these people, reiterating the fragmentation in the professional dimension.

Hospital care cannot be limited to routine procedures, exams and surgeries, but must meet the various hospitalization interfaces, maintaining the multidisciplinary team-child-family interaction to provide comfort, maintaining hope and patience through self-care guidance. It is important to use clear, optimistic language and encouraging words that help family engagement(2).

Some professional categories stated that they did not recognize as part of their professional function the act to prepare the child and their family to return home. They believe this is a responsibility of the physician.

> *No, we discharged from speech therapy and what we can help during hospital discharge is that, often, the patient is still weaning [from oxygen therapy], he is only waiting for this to actually be discharged from the hospital, but who really refers to hospital discharge is the medical staff* (FO1).
>
> *When the patient is clearly ready to leave, then you will notice over time and it is a simple, very simple procedure, the discharge is authorized, he signs [the physician] and leaves, there is not much to do, there is not much of a protocol* (TEC1).
>
> *The doctor that gives the discharged, but generally they [physicians] look at the examination part, if there is any kind of participation for us [nurse], it is something they want to know. There are cases where the mother says that the patient is having this and that and they come to know if the patient is really having what she reported* (E2).

Fragmented actions in preparation for discharge show shortcomings of the organizational and professional dimensions of care management, as they do not provide sufficient elements for the continuity of care at home. The repercussions of chronic diseases on family life are exacerbated by the lack of knowledge for the continuity of child care due to the lack of information provided at the hospital.

A pilot study(19) carried out in a pediatric hospital in the United States incorporated a successful strategy called the Post-Hospitalization Action Grid (PHAG) in order to facilitate the development, documentation and implementation of post-discharge goals centered on children who need care of high complexity and their families, as well as communicating this information in a standardized format in the care transitions. In addition to the goals aimed at safe transport home, there was educational monitoring of families before discharge to ensure they were comfortable taking care of their children at home and evaluation of communication with external professionals (primary care, nurses working on the schools) to update the new complex care needs of these children.

In both institutions that participated in the research, the discharge, as a procedure centered on the physician, was evidenced. It is noteworthy that the preparation of chronically ill children and their families to return home is conducted by fragmented actions of the multidisciplinary team. The discharge becomes a merely bureaucratic moment, eschewing comprehensive and humanized care.

The little practice of actions of this nature does not favors the professional dimension(8). In addition to the competence to carry out technical activities and an ethical posture, professionals are responsible for developing an empathetic relationship with the child and their family during hospitalization.

In order to generate effective and comprehensive actions for the care and monitoring of this population, the importance of the multiple dimensions of care management during the hospitalization period should be emphasized. This is a stage in which the child undergoes changes in his/her routine and begins a phase permeated by uncertainties alongside the family, therefore, it requires greater involvement from the multidisciplinary team.

Ways of organizing hospital services that impact the care of children with chronic illnesses and their families

This category addresses how the organization of the hospital influences the care of children with chronic illnesses. The themes identified were: interaction between professionals; insufficient number of professionals; guarantee of hospital resources; flow of assistance.

The way the multidisciplinary team organizes itself in its work environment is a result of the importance of each care demand of children with chronic diseases and their families[16]. To carry out resolving actions of care, professionals understood that it is necessary to have an open dialogue between the multidisciplinary team.

> *We have a multidisciplinary team that works in an interdisciplinary way* [...] *the patient treated by a health team cannot be cared by one professional, because my actions can affect the behavior of the other* (FI1).
>
> *We can really be part of a multidisciplinary team, the doctor usually tries to listen to us, is very solicitous of what we ask, they also ask us a lot, that we participate, that our conduct is important to reach a consensus, the doctor and the nurse, the nutritionist, social worker, psychologist, because we, together, make a team. Neither do I work alone, nor does anyone else work* (FO2).

The diversity of professionals working in a hospital institution is vast. The exchange of information must be based on the individual look of these subjects during their activities with the child with a chronic disease, which expands the care provided and can strengthen the organizational dimension. This dimension is characterized by the technical division of work with the development of strategies for carrying out team activities[8].

The interaction between professionals from different areas becomes one of the strategies to ensure the continuity of care in partnership with the family. When supported in this process, the family will be able to feel more secure and confident in the therapeutic project, contributing to the reduction of the physical and emotional burden that falls on them.

In view of the changes that hospitalization causes in the life of a child with a chronic disease, the health team must minimize stress and anxiety through playful skills appropriate for each age group to face these feelings[1].

Some members of the multidisciplinary teams reported difficulties in carrying out resolutive health actions in the hospital routine. This is justified by the insufficient number of professionals in the staff of these institutions, which generates work overload, that can trigger obstacles in care.

> *We work with the lowest number of professionals allowed and when [someone] is absent, it gets worse.* [...] *If there is no one to come to the sector, you have to do as much as you can, so it ends up being something to be desired* (E3).
>
> *We do as much as we can within our limitations, because we have an entire hospital to attend* [...] *we try to prioritize according to severity, the more sick the child, the more attention we pay, because unfortunately there is nothing we can do, there are no professionals* (FO2).
>
> *Sometimes we are here with four, five neuropathic patients, all tracheostomized. How does the nurse handle it? It's not possible, she will go crazy* (AUX2).

The insufficient number of professionals generates an overload in the execution of many different hospital activities, which can lead to disarticulate care actions. A fact that will reflect both on the organizational dimension of the work process, due to its technical division and (dis)organization, and on the professional dimension, since the work overload generates distress in professionals who are unable to exercise care as they want and need to.

Unlike federal hospitals, that are guided by a regulation system, in the state pediatric hospital, which is open to the public service, the lack of professionals was more evident due to the large daily demand of patients. The lack of institutional support makes it difficult for professionals to carry out their work and leads to poor health practices during hospitalization, which do not allow families to recognize the team as a source of support[17].

On the other hand, the provision of satisfactory support to the child/family during hospitalization can be enhanced when the institution promotes the necessary support to the health team. This will be possible when an adequate physical structure, supplies quality and specific exams are present.

> *With the structure that the hospital [university] has... today we can. The child is hospitalized, undergoes tomography, an image exam, we have X-rays, ultrasound, tomography that we did not have before* (E3).
>
> *So far, the supplies are guaranteed to children here [state hospital]. I don't think there's a lack of supplies, at least not in my area* (FO1).
>
> *The physical infrastructure, I don't think, leaves much to be desired* [...] *and everyone says that pediatrics is different because it has air conditioning, which not all clinics have. So, this is already a positive point* (TEC1).

When the social dimension in care management is considered, it contributes to improving the quality of care in the hospital environment and facilitates the work of health professionals. Thus, it can reduce the impact caused by the social distancing of hospitalized children with chronic illnesses and their families.

It is essential to seek strategies for the development of self-care that enable comprehensive, humanized and quality care, and lead to the active involvement of this population. These strategies may eventually reduce costs for health services[18].

As the social dimension of care management is responsible for the regulation and creation of public health policies[8], it is up to hospital services to guarantee a safe space with family engagement since admission, aiming to prepare them for discharge. However, if after hospital discharge there is no follow-up of the child with a chronic disease and support for their family, they will find it difficult to continue care in the HCN and at home.

> *When this mother arrives home, she does not have the same structure [as in the hospital] so, sometimes, this family lacks transport, there is no time to carry the child, to take the child to some service. There is that issue, not every municipality has the structure to provide home support. So, in my understanding, the chronic [disease] child, depending on the socioeconomic condition, is very isolated, he is without the network he needs, then the number of hospitalizations increases* (FI2).
>
> *If we could have what it is actually recommended [by the Ministry of Health], attention, embracement, a continuity of care between families and teams, maybe the clinical changes that the child has when she gets to the hospital in a more serious condition could be detected by the team of primary health care before. Our biggest problem with children with chronic diseases has been defining the diagnosis and maintaining follow-up due to complications* (E1).
>
> *We have the impression that when the mother has little knowledge, the child is only directed for care when the situation worsens... it has worsened, then she goes running to a UPA [Emergency Care Unit] or hospital and is admitted to the hospital. The mother does not have information, in her community there is no team to clarify, to keep an eye on it. It leads to a situation where only emergencies are treated* (M1).

Difficulties in accessing, lack of resolution and disconnection from the health network mean that tertiary care, despite its weaknesses, is the institution chosen to care for children with chronic illnesses. It is noteworthy that the hospital team often does not help families in the process of returning to their homes, as they do not interact to understand transport difficulties nor guide them in seeking the primary care service for the continuity of care.

A child with a chronic illness depends on different levels of health care. They need unique and individualized actions, with a sensitized and resolutive network for the execution of expanded and supported care, with articulation between the different services(6) , beyond the hospital walls.

The need for planning the actions of professionals and health services is highlighted, interconnecting care flows. This way of organizing the work process tends to minimize the family's search for necessary care, such as exams, procedures, specialized therapies, among others(20).

A study(3) showed the expanded view of managers and primary care professionals to guarantee the continuity of care offered to children and their families, in addition to mechanisms that guarantee the flow of the service. The organization of this process requires co-responsibility from health professionals and the planning of actions capable of guaranteeing that any issues will be dealt with.

It was found that after hospital discharge, children with chronic disease do not have a satisfactory longitudinal follow-up. This creates a family burden because the main caregiver is responsible for designing their own care itinerary in search for assistance, undermining the family dimension and contradicting what is recommended by the National Policy for Comprehensive Child Health Care (PNAISC)(20).

Structural changes in the organization of hospital services are necessary, including articulation with the primary and secondary levels, with the establishment of Guidelines of Care for the longitudinal and continuous follow-up of children with chronic diseases. These constitute powerful strategies in the construction of comprehensive care with the articulation of health actions and services under the coordination of primary care. Home care services represent an essential intervention for the provision of comprehensive and humanized care(20) and need to be integrated and articulated at different levels of care.

The recognition of vulnerabilities in the multiple dimensions of care management in the hospital environment highlights the pressing need for changes in work processes and in the organization and/or improvement of the HCN. This can facilitate the therapeutic of children with chronic illness and their families, guided by the principle of comprehensive care and humanization.

FINAL CONSIDERATIONS

From the perspective of care management, the actions developed by the hospitals' multidisciplinary teams for children with chronic illnesses during hospitalization were fragmented, hindering the adequate preparation and involvement of the family in care, and reducing the quality of the management of the disease at home. In care practice, the organization of hospital services need to be valued and restructured so that they can favor an empathetic and dialogical interrelationship between the actors involved that positively impact the care to meet the unique and complex demands of children with chronic illnesses and their families.

Health care management is an essential tool to reflect on the construction of expanded and resolutive care in hospitals and in coping with the hospitalization of children with chronic illnesses, and the actions carried out by multidisciplinary teams that should add support for such construction. Researches are needed to highlight the potential of care management in the monitoring process of these individuals, not only in hospital institutions, but also at different levels of health care.

The limits of this study included the fact that it included only the health professionals from two hospitals, not involving other care settings at the tertiary level. It presents contributions to the qualification of care during hospitalization by showing the necessary changes in the organization of the work process in tertiary services and in the articulation between the different levels of care. Further research involving different settings and actors in this process can broaden the understanding of the management of care for children with chronic illnesses and their families, from the perspective of building comprehensive, longitudinal, expanded and humanized care.

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