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Continuity of care for children with chronic conditions after discharge: a constructivist grounded theory

Continuidade do cuidado à criança com condições crônicas após a alta: uma teoria fundamentada construtivista

Continuidad del cuidado de niños con condiciones crónicas después del alta: una teoría fundamentada constructivista

Caroline Cechinel-Peiter[I]
ORCID: 0000-0003-0032-6791

Gabriela Marcellino de Melo Lanzoni[I]
ORCID: 0000-0001-5935-8849

Eliane Tatsch Neves[II]
ORCID: 0000-0002-1559-9533

Maria Aparecida Baggio[III]
ORCID: 0000-0001-6901-461X

Nelly Donszelmann Oelke[IV]
ORCID: 0000-0002-1666-5360

José Luís Guedes dos Santos[I]
ORCID: 0000-0003-3186-8286

[I]*Universidade Federal de Santa Catarina. Florianópolis, Santa Catarina, Brazil.*
[II]*Universidade Federal de Santa Maria. Santa Maria, Rio Grande do Sul, Brazil.*
[III]*Universidade Estadual do Oeste do Paraná. Foz do Iguaçu, Paraná, Brazil.*
[IV]*The University of British Columbia. Kelowna, British Columbia, Canadá.*

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Corresponding author:
Caroline Cechinel-Peiter
E-mail: carolcechinel@gmail.com

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ABSTRACT

Objectives: to understand the meaning of continuity of care for children with chronic conditions through transitional care from hospital to home. **Methods:** this is a qualitative study, conducted from a Constructivist Grounded Theory perspective. Purposive and theoretical sampling were used to recruit 35 participants, including nurses, professionals from the interprofessional hospital team, and actors responsible for healthcare in the home context. The research was conducted at two large hospitals, between March and September 2019. Semi-structured interviews were conducted. Data analysis was carried out using initial and focused coding, according to constructivist grounded theory. **Results:** the substantive theory that emerged from this study was named "Postponing the next hospitalization". Eight categories-concepts and 18 elements were derived from the data to support the substantive theory. **Final Considerations:** transitional care from hospital to home acts as a reminder for the resumption of continuity of care after discharge.

Descriptors: Child; Chronic Disease; Continuity of Patient Care; Nursing Care; Grounded Theory.

RESUMO

Objetivos: compreender o significado da continuidade do cuidado para crianças com condições crônicas por meio do cuidado de transição do hospital para o domicílio. **Métodos:** estudo qualitativo, realizado na perspectiva da Teoria Fundamentada Construtivista. A amostragem intencional e teórica foi utilizada para recrutar 35 participantes, entre enfermeiros, profissionais da equipe interprofissional do hospital e atores responsáveis pela atenção à saúde no contexto domiciliar. A pesquisa foi realizada em dois hospitais de grande porte, entre março e setembro de 2019. Foram realizadas entrevistas semiestruturadas. A análise dos dados foi realizada por meio de codificação inicial e focalizada, segundo a teoria fundamentada construtivista. **Resultados:** a teoria substantiva que emergiu deste estudo foi denominada "Adiando a próxima internação". Oito categorias-conceitos e 18 elementos foram derivados dos dados para apoiar a teoria substantiva. **Considerações Finais:** a transição do hospital para o domicílio funciona como lembrete para retomada da continuidade do cuidado após a alta.

Descritores: Criança; Doença Crônica; Continuidade da Assistência ao Paciente; Cuidados de Enfermagem; Teoria Fundamentada.

RESUMEN

Objetivos: comprender el significado de la continuidad del cuidado de niños con condiciones crónicas a través de la transición del hospital al hogar. **Métodos:** estudio cualitativo, realizado desde la perspectiva de la Teoría Fundamentada en Datos Constructivista. Fueron utilizados muestreos intencionales y teóricos para reclutar 35 participantes, entre enfermeros, profesionales del equipo interprofesional hospitalario y actores responsables por el cuidado en el contexto domiciliario. La investigación se realizó en dos grandes hospitales, entre marzo y septiembre de 2019. Se realizaron entrevistas semiestructuradas. El análisis se realizó mediante codificación inicial y focalizada. **Resultados:** la teoría sustantiva que surgió de este estudio se denominó "Aplazamiento de la próxima hospitalización". De los datos se derivaron ocho categorías-conceptos y 18 elementos para sustentar la teoría sustantiva. **Consideraciones Finales:** la atención de transición del hospital al hogar actúa como un recordatorio para la reanudación de la continuidad de la atención después del alta.

Descriptores: Niño; Enfermedad Crónica; Continuidad de la Atención al Paciente; Atención de Enfermería; Teoría Fundamentada.

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INTRODUCTION

The epidemiological transition of the last decades has increased the prevalence of chronic health conditions, due to changing dietary habits, development of diagnostic and therapeutic technologies, and increased survival in the face of chronic health conditions. The successive increase in this prevalence requires patient-centered coordination of care by health services and active participation of the family. Comprehensive care for the health of patients with chronic conditions requires, in most situations, assistance by different professionals, in various services distributed in the Healthcare Network, to facilitate continuity of care over time[1].

Increased chronic conditions has also impacted children. In developing countries, the decrease in the infant mortality rate in the last three decades was due to policies and programs that were aimed at children's and women's health, such as immunization campaigns, improvement in sanitary conditions and income distribution programs. However, morbidity and mortality due to perinatal illnesses is a concern and responsible for most deaths of children under one year of age. Those who survive these illnesses constitute a group of children who live with chronic health conditions[2].

Although the mother-child care network is one of the priorities in many health systems, integration of services is fragile in healthcare for children. Communication structures are absent, therefore, there is a lack of communication between healthcare services, hindering continuity of care for children with chronic conditions. Moreover, there are no specific strategies directed to the healthcare for children with chronic conditions[3]. Children with special healthcare needs require longitudinal and continuous care from family, professionals, and health services, due to different symptoms they have, which vary in complexity and care demands[4].

For this group of children, continuity of care after discharge from hospital is fundamental, since it is related to a lower rate of readmissions to hospital, greater patient satisfaction and quality of life[5], promotion of comprehensive care and higher quality assistance[6]. Failures in continuity of care can generate new and prolonged hospitalizations for these children as well as the need for urgent care services to the detriment of Primary Healthcare follow-up[7].

Continuity of care is formed by three hierarchically related dimensions: relational, informational, and management continuity. Relational continuity refers to the link established between patients and professionals who assist them in their therapeutic trajectory, which generates communication and information transfer between services, leading to informational continuity. Relational and informational continuity require coordination of services, to facilitate patient care in a timely manner and place representing management continuity[8].

Patients who need care in different services become more vulnerable to fragmentation of healthcare. Transitional care from hospital to home involves a set of interrelated components for promoting continuity of care, including management of clinical condition, well-being and education of patient and caregiver, optimization of resources and availability of health services for continuity of care[9]. Patients with chronic conditions need healthcare from services integrated and coordinated by Primary Healthcare, aiming for comprehensive care. These patients require special attention from professionals and managers to address the need for continuity of care[1].

To meet the needs of children with chronic conditions, healthcare rearrangement is needed to ensure comprehensive care. It is essential that care in the Healthcare Network takes place in a continuous and coordinated manner, focused on individuals' and family's specific health needs. However, a gap in knowledge has been revealed from studies that explore continuity of care for children with chronic conditions in the Healthcare Network[9]. A comprehensive understanding of professionals and family experiences in continuity of care is needed to support future guidelines and health policies, specially concerning children with chronic conditions. Thus, the question is: what are the meaning and experiences of professionals and family about continuity of care for children with chronic conditions through transitional care from hospital to home?

OBJECTIVES

To understand the meaning of continuity of care for children with chronic conditions through transitional care from hospital to home.

METHODS

Ethical considerations

Approval to conduct the study was provided by the Research Ethics Committee. All participants were informed of the objectives of the research and signed informed consent forms. To ensure anonymity, participants' statements were identified by the letter G, followed by the number corresponding to the sample group of participants, the letter I and a number indicating the order in which the interview was conducted (e.g., G1I08, eighth interview from the first sample group).

Study design

This is qualitative research based on theory, and methodology on the Grounded Theory (GT) (constructivist perspective)[10].

Study site

Data were collected from March to September 2019 at two large hospitals, specifically in the pediatric unit of a university hospital and a children hospital in Southern Brazil. Both institutions are important reference to the pediatric care in high complexity for the State.

Sample/participants

The approach of research participants was in person, at the hospital units. It was invited professionals who worked at the institution for at least six months, with direct involvement in the care for children with chronic conditions, as well family members responsible for children living with chronic condition. To define

chronic conditions included in this study, it was considered the most prevalent conditions in hospitalized children in Brazil[11]. It was excluded professionals who were on vacation or leave of any kind, and family members under 18 years old. The study included 35 participants (e.g., nurses, physicians, family members, nutritionists, psychologists, physiotherapists, social workers, speech therapists, hospital managers) that were divided into three sample groups, according to GT theoretical sampling, in which data are collected and analyzed simultaneously, and the material analysis and interpretation leads to new research stages, seeking to refine the categories of emerging theory[10].

Considering nurses' participation and contribution in the transitional care process, the first sample group was formed by ten nurses. From the analytical inferences based on the data of the first sample group, the hypothesis of the need of participation and integration of the interprofessional hospital team to increase continuity of care after discharge, conducted in the second group, was formed by 14 professionals. The second group reinforced the need for a coordinated work by professionals and family members in the home context. Therefore, the third group included 11 actors responsible for healthcare in the home context, when it was reached the theoretical saturation.

Data collection

Semi-structured interviews were used, digitally recorded and transcribed verbatim. The interviews were conducted by the main researcher, PhD student at the time of data collection, with previous experience in qualitative research, including GT. They took place a confidential space in the hospital and lasted about 24 minutes (SD=14.7).

Data analysis

Data analysis followed a constant comparative analysis model, as recommended by GT, in which each interview only happened after the analysis of the previous interview. Based on constructivist GT, the data were coded in two phases: initial and focused coding[10].

The initial coding was done word by word, line by line or segment by segment. In the focused coding, the codes were contrasted and compared with each other, to form subcategories and categories. For material processing and organization, NVIVO®, version 10 was used. Data collection was closed when theoretical saturation was reached, a moment in which the collection of new data does not add new theoretical insights or indicate new properties of existing categories. The theoretical model representative of the substantive theory was submitted for validation by experts in the method and subject of the study, totaling six participants, remotely through an online survey[10]. The analysis process was conducted by the same researcher responsible for data collection.

A variety of strategies were used to ensure credibility and validity of the emerging findings according to GT, including the use of memos and diagrams during the constant data collection and analyzing process until theoretical saturation was reached, as well as validation of substantive theory by experts[10]. The research complied with the COREQ checklist for qualitative studies.

RESULTS

The substantive theory that emerged from this study was named "Postponing the next hospitalization"". Eight categories-concepts and 18 elements were derived from the data to support the substantive theory. Each of these categories, along with their elements, are presented in Chart 1.

Chart 1 - Presentation of the study categories and subcategories, Florianópolis, Santa Catarina, Brazil, 2021

STUDY CATEGORIES AND SUBCATEGORIES
1. Caring for the child with chronic conditions in the pediatric ward
Valuing the comprehensive care for the child with chronic conditions
Perceiving change in the family dynamics of the child with chronic conditions
2. Acting in an integrated manner in the interprofessional hospital team
Working as a team in transitional care
Recognizing the importance of the nurse for the transitional care
Experiencing the impact of nurse overload on transitional care
3. Building the tripod of hospital discharge to transitional care
Stabilizing signs and symptoms that led to hospitalization
Educating patient and family to self-manage the chronic condition
Expecting equipment and materials necessary for the continuity of care at home
4. Starting the transitional care from hospital to home
Reconnecting the child with chronic conditions to the Healthcare Network
Preparing the transitional care throughout hospitalization
5. Seeking to promote continuity of care in the Healthcare Network
Taking responsibility for restarting the continuity of care in Healthcare Network
Positioning itself as a reference for guidance on the care of children with chronic conditions
6. Facing difficulties to promote continuity of care
Feeling the lack of communication mechanisms between the healthcare services
Needing Primary Healthcare and other healthcare services to be prepared to facilitate continuity of care
7. Not knowing the patient's trajectory after hospital discharge
Feeling anguish for not knowing the child's trajectory after hospital discharge
Overburdening oneself with the fragility of continuity of care in Healthcare Network
8. Waiting for the next hospitalization
Knowing that the next hospitalization is not completely avoidable
Developing a bond with children with chronic condition and their families

The continuity of care process is initiated by (re)hospitalization, when care transition for children to other points of care in the Healthcare Network begins for reintegration into community-based health services, especially Primary Healthcare. The following sections outline each of the categories and their respective subcategories.

Caring for the child with chronic conditions in the pediatric ward

Children's chronic condition directs the care for the interprofessional hospital team. They link the understanding of their life history, family and home situation, and other specificities that may impact continuity of care after discharge, as exemplified in the speech below:

> *She is hospitalized with a life story, internal with this family context as well. So the child is part of this family, and many times the family that already comes from fragile situations, already comes with symptoms that have a whole history.* (G2I01)

According to research participants, the family experiences important changes in the standard of living due to children's chronic condition, especially impacting daily life and the life of the maternal figure:

> *It is just me* [mother]. *It is just me. About her care, it is just her and myself*. (G3I08)

> *Everything changed* [...]. *But this is our life. During twenty-four hours per day, she is the priority. In first, second, and third place is her. Everything is her.* (G3I09)

Acting in an integrated manner in the interprofessional hospital team

Professionals recognize the importance of having different actors in the team and believe in the contribution of an interdisciplinary approach to quality of care. Research participants indicate that periodic meetings to discuss cases are an important strategy to meet the care requirements for children's' health:

> *The interdisciplinary relationship is productive because everybody can learn with each other.* […] *The interdisciplinary relationship is fundamental for any health professional.* (G3I02)

> *Here we have team meetings every Thursday, at 11 a.m. This is the moment when we can discuss some cases that demand more energy from the team, some difficult cases* […]. *We have these meetings where we can dedicate our attention to this.* (G2I03)

In this integration, nurses are indicated as a link in the team and a bridge between patient and other professionals, due to greatest contact with children and the family. This dynamic shows the dependence of other professionals on nurses, who coordinate the relationship of the teams relationship with children and family:

> *The assistant nurse is our right and left arm sometimes. Everything ends up passing to him. From the behaviors we will take now, to what we are doing with the patient to get him out of here.* (G2I04)

This dynamic, the recurrent lack of professionals and the high workload reflect an overload of this professional. The resulting stress and emotional instability, diminishes nurses' willingness to participate in the discussion of cases in the interprofessional team:

> *A better sizing of personnel should be done here* [...]. *Because, in fact, we work with few people, many demands, and, to do a very perfect service, very nice, it is difficult.* (G1I03)

> *The nurse pulls his own weight. I believe they are very overloaded in the sectors. So sometimes there is no time* [to participate in case discussions]. (G2I07)

Building the tripod of hospital discharge to transitional care

Hospital discharge is guided by three factors: stabilization of disease signs and symptoms, process of health education with children and family caregiver, and access to materials, equipment and devices needed for home care, especially special food, medication, and dressings, as revealed by participants:

> *When we have all this tripod structured, the medical part, the mother trained in this new function, all the inputs in the municipality,* [...] *when we have all this structured, then it happens the discharge.* (G1I08)

Clinical stabilization is considered the first and most evident element of the tripod for discharge. For health education, the second element of the tripod, professionals hold meetings with the family, prepare printed information, and encourage parents to supervise care during hospitalization, paying attention in factors that may influence readmissions. These findings are exemplified in the following statements:

> *You must to empower the mother of that care, because otherwise she will return to the hospital again, she returns to the hospital again.* (G1I05)

> *They* [professionals] *taught me* [mother] *how to aspirate, how to use the infusion pump,* […] *how to use the mechanical ventilator and how to auscultate*. (G3I09)

The frequent delay in the acquisition of materials, equipment, and devices, most of the times supplied by the Municipal and State Health Departments, requires prolonging hospital stay. Foreseeing this, the team anticipates the referrals for the respective requests that guarantee continuity of care after discharge, as reported below:

> *The chronic patients go home with tracheostomies, mechanical ventilation, oxygen therapy, etc. We try to do this de-hospitalization, it's a little slower. We have to wait for the patient's ventilator to arrive,* [...] *the oxygen therapy equipment, we have to check if the parent has the aspirator.* (G2I08)

Starting the transitional care from hospital to home

Hospital professionals use e-mail, phone calls, letters and meetings with Primary Healthcare teams as transitional care actions developed during hospitalization to connect patients to the next

service in the Healthcare Network and ensure continuity of care after discharge, as shown by research participants:

> *It is one of our roles to identify these demands, to identify which service in the Healthcare Network can support this continuity of care.* (G2I01)

> *We send letters and we call the Primary Healthcare unit to try to communicate with someone.* (G3I04)

> *We make this contact, always by telephone or letters.* (G1I06)

Nurses use Systematization of Nursing Care (SNC) as a tool to guide nurses' work in transitional care to home beyond hospital stay:

> *The discharge must be worked on since the beginning of the hospitalization, we have to identify these problems and go to work. What we can work on throughout the internment, and then what we can continue working on* [after discharge] *and the team there* [Primary Healthcare] *will also identify some things.* (G1I05)

> *We predict what we will do to care for that patient who may even have some questions for the discharge.* (G1I01)

Seeking to promote continuity of care in the Healthcare Network

For patients to experience continuity of care, it is necessary to establish the integration between health services, to follow their therapeutic trajectory and the link established with these services. Thereby, the hospital interprofessional team feels responsible for facilitating patient connection with the health services necessary for continuity of care at home, as exposed by participants:

> *Sometimes we get in touch, sometimes the Primary Healthcare team comes here, trains with us, it also depends on the will of the team.* (G2I08)

> *When the patient leaves the hospital, I have to guarantee that he will continue his therapy.* (G1I04)

Even after discharge, these professionals make themselves available as a support both for family caregivers and for professionals from the other less technologically dense areas of Healthcare Network, making their telephone contacts and e-mails available, preparing and disseminating printed informative materials, holding meetings and case discussion meetings and training for Primary Healthcare teams.

> *I give a brief information about the disease with my professional contact to get in touch, if needed.* (G3I03)

> *Many professionals from Primary Healthcare call us to clarify doubts about some things they are not so used to, for instance, about children who use specifics devices.* (G1I06)

Facing difficulties to promote continuity of care

According to participants, despite the lack of logistic and support systems that integrate the different health services, professionals recognize the importance of information management in continuity of care and understand that information and communication systems, by enhancing dialogue between services, impact quality of care and reduction of health costs:

> *I think the first thing would be to have a unique patient's chart. Because I realize that there is a pilgrimage of children in the health services that parents can't always remember everything.* (G1I07)

Professionals in the hospital team understand care in Primary Healthcare as incomplete and insufficient after hospital discharge. They suppose that, in many cases, Primary Healthcare does not include comprehensive care to children with chronic conditions because it understands that they are responsibility of specialized secondary care, as exemplified below:

> *We need this link with the Primary Healthcare. But they are still disconnected from the hospital.* (G3I11)

> *The professionals of the Primary Healthcare are very afraid of dealing with these chronic patients, both for technical reasons, even inexperience, and I do not know if they are psychologically prepared.* (G3I05)

Not knowing the patient's trajectory after hospital discharge

Professionals promote actions for transitional care, but are unaware about what happens following discharge, which prevents them from assessing whether their approaches were effective or not for quality continuity of care. Professionals wish to minimize this situation, with some sort of feedback mechanism, so they know what to change for the future. However, currently, this is only possible when the next hospitalization takes place, as shown in the reports:

> [...] *From the moment the patient left the hospital and goes back home, I can only know what happened if this patient returns* [intern]. (G1I02)

> *This is an anguish that remains for everyone* [...] *who works with patients with chronic conditions.* (G3I03)

The insufficient preparation of Primary Healthcare professionals for managing chronic conditions reflects in fragile bond of trust between the family and the Primary Healthcare service. According to participants, Primary Healthcare is recognized by users as low complexity care, which overload hospital services:

> *I also don't have much contact there* [Primary Healthcare], *I go there only when I really need it. Besides, since the child appointment is here* [hospital outpatient], *they are all here* [...]. (G3I07)

> *Due lack of information, communication,* [...] *because they* [patient/family] *think it will not be solved, they go straight to the hospital.* (G1I01)

> *Today, at the Emergence Department, most patients are classified as mild risk.* [...] *the lowest possible risk rating, in the vast majority* [...] *of people who are not needing the assistance of a hospital emergency.* (G3E11)

Waiting for the next hospitalization

Participants recognize that children are continuously surrounded by aspects of health and disease, whose oscillating symptoms lead to episodes of worse health in the evolution of the chronic condition. Although new hospitalizations cannot be avoided, actions can extend the time between one hospitalization and another, which impact quality of life for children and family:

> *The chronic condition has a trajectory that can be very difficult for children, which is: at a certain moment in their lives, they will have to be hospitalized. Because exacerbations will become more and more frequent.* (G3I02)

> *I like to talk about it as if it were a carousel. Now the child is here, she will take a walk, I don't know what will happen to her, but then I know she will be here again. I know she will come back.* (G2I05)

The frequent and repeated hospitalizations favor establishing links between children and families and professionals in hospital care. While children and families feel they can trust the professionals, professionals engage in the child-family diary, proportionally to the frequency with which they are readmitted, as indicated:

> *Here* [hospital]*, we know she* [child] *is in good hands, that they* [professionals] *will do everything that is possible and impossible for her. (G3I09)*

> *Whether we like it or not, we get involved, because they are children that we already know, they create a bond with us as well, as we create with them, with the child, with the family.* (G2I03)

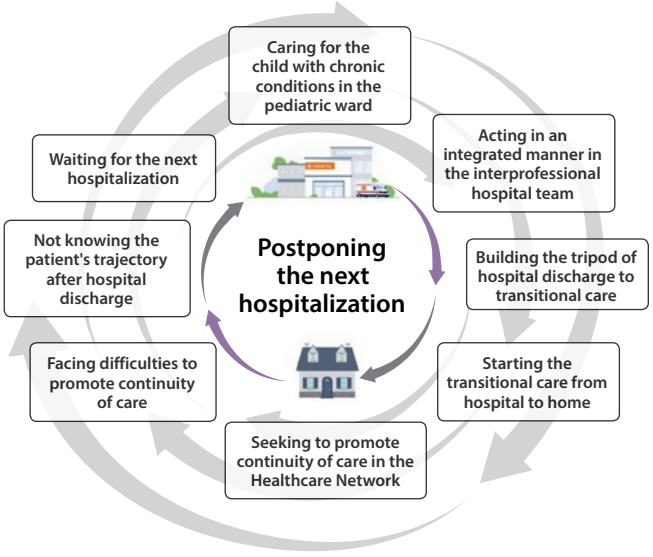

Figure 1 – Representation of substantive theory, Florianópolis, Santa Catarina, Brazil, 2021

The integration between categories and subcategories revealed the central category named "Postponing the next hospitalization". While professionals take care of children with chronic conditions in the pediatric ward, they plan for an effective care transition from hospital to home. Despite the lack of official strategies, professionals understand the importance of interprofessional care, health education, the early identification of patients' needs to effective care transition and facilitate continuity of care after discharge. Nonetheless, professionals recognize the difficulties for continuity of care and are unaware of patients' therapeutic trajectory in the home context. They understand that over time, increased and worse symptoms are inherent to chronic conditions. Therefore, children with chronic conditions hospitalizations take place as part of a circular and constant process, where the final objective of professionals is not to avoid the next hospitalization, but to postpone it, with quality of life and health, through care transition. The articulation of categories is presented in Figure 1.

DISCUSSION

Children with chronic conditions demand greater attention and support from the health team, requiring efforts of family members and professionals to continue their health trajectory without disruptions, ensuring continuity of care. Hospital care professionals understand the importance of an approach to children with chronic conditions care beyond physical health and demonstrate efforts to address children's multidimensional needs. However, an effective comprehensive approach to healthcare requires a multi-professional approach, with integration between the different services in the Healthcare Network[3,7].

The establishment of a collaborative work dynamic in the hospital environment, with interprofessional assistance and family-centered care, from hospital admission, are necessary factors for a high quality transitional care of children with chronic conditions[12]. Although the data indicates the search of professionals for integrated performance that goes beyond multi-disciplinarity and reaches inter-disciplinarity, power dynamics in interpersonal and inter-professional relations, characteristics of institutions strongly guided by the biomedical model, are evident. As far as nurses' work is concerned, care management represents the possibility of re-signifying the relational dynamics historically established in health institutions, since it allows visibility of their work, and confers a position of power in communication with other professionals. Thus, care management in the hospital environment should occupy a prominent place in nurses' work, in the search for recognition that results in quality of the relationship between professionals and reflects positively on the care provided[13].

Among the care management actions, transitional care includes strategies that facilitate the coordination and continuity of care during patients' transfer between health services[8]. This concept is not limited to the care provided at the time of hospital discharge[14] and confirms the team's efforts to promote continuity of care from transitional care.

About nurses' activities in transitional care, a study points out that the planning of care for discharge, aid in social rehabilitation, health education, as well as referrals with other services and post-discharge monitoring are essential indicators for effective transitions[15]. Nurses are responsible to identify and alert the other professionals to specific demands related to children's health status, including the identification of patients who need transitional care actions, planning for discharge and factors that influence these actions, and they are in the central role in transitional care.

Although the development of health education with families for the chronic condition management is essential for continuity of care after discharge, care should be taken to include the mother as early as possible in the care for children in the intra-hospital environment, prioritizing the relationship with children as their caregiver, not just to alleviate the effects of professionals' overload. Thus, family participation should be encouraged; however, we should pay attention to the emotional sensitivity caused by the period of hospitalization[16], and their needs for breaks from these tasks for their own mental health and wellbeing should be respected.

Participants recognize that planning actions must start within the first 24 hours of hospitalization to promote transitional care[17]. To do so, they identify children's needs at an early stage, begin the transition from the beginning of admission, and practice effective communication with children and family caregiver[14].

Effective transitional care allows the care trajectory to continue after discharge, ensuring continuity of care in the Healthcare Network. Continuity of care, from a management perspective, depends on the availability of integrated health services, providing continuous access for patient and family in the different health provider sites receiving care in each one, in an organized sequence, in an appropriate manner, to address their needs, scale and scope of services[8]. The availability of integrated services in the Healthcare Network, associated with the set of successful transitions between them, represents the driving force for continuity of care for children with chronic conditions.

To contribute to resumption of continuity of care, some professionals are available for guidance, even after discharge. This process was identified in a study that indicates post-discharge follow-up as one of the strategies for transitional care[15]. However, these initiatives start individually from professionals, due to the absence of formalized and planned flows for transitional care by the institution. In other words, it is not a guaranteed practice for all children. It depends on changing factors to be effective, such as the availability of hospital staff and the interest of professionals from other services. Moreover, after discharge, continuity of care for children with chronic conditions in the Healthcare Network depends on the availability of health services that meet patients' needs and the link established by them with these services.

The integration between services necessary for continuity of care is hampered by the absence of logistic and support systems that integrate the different health services that assist children with chronic conditions, resulting in loss of information, fragmentation of assistance and discontinuity of the therapeutic journey. The fragility of information and communication systems represents one of the main difficulties faced in continuity of care for children with chronic conditions. However, informational continuity of care, with strategies for storage, organization and access to health records, linking previous to current care and facilitating future care, can avoid loss to follow up that could result from the fragility of relational continuity[8,18].

Despite the benefits of continuity of care by Primary Healthcare, parents do not feel safe about how effective care is at this level and opt for access to secondary and tertiary services in acute situations indicating a fragile link for children with chronic conditions with the Primary Healthcare level[3]. A multi-centric study completed in Brazil with this clientele pointed out that its access to Healthcare Network is permeated by obstacles that end up causing the replacement of Primary Healthcare services by services in emergency units. This same study suggests the implementation of home visits and health education groups as promoters of continuity of care in Primary Healthcare[7].

Despite the differences between each primary service, the bond between children with chronic conditions and Primary Healthcare benefits their care, because it is a patient-family-centered service, which provides longitudinal, comprehensive and coordinated care, besides being more economical for the health system, when compared to hospital emergency care[19-20]. According to an American study, parents of children admitted to a hospital from Primary Healthcare levels stated that their child is more likely to experience continuity of care compared to parents who arrived at the hospital through emergency service. They have difficulty in understanding Primary Healthcare's role and have no desire to have their child cared for by these professionals[21].

This study found that professionals do expect rehospitalizations for children with chronic conditions, no matter how great the transitional care is. A cross-sectional study conducted in Brazil found no association between the quality of transitional care and hospital readmissions, concluding that other factors influence these events[22]. On the other hand, although many factors influence the occurrence of hospitalizations and they cannot be completely avoided, international studies point out that the quality of transitional care can, in fact, influence the decrease of hospital readmissions, with better outcomes for the health situation of children with chronic conditions[12].

Children with chronic conditions were more frequent in hospital emergency visits and hospitalizations for sensitive outpatient conditions. However, those with a higher degree of continuity of care present a lower chance of re-hospitalization[23]. Thus, although it is not possible to prevent the next hospitalization, effective transitional care is associated with a lower frequency of hospitalizations, better health outcomes, quality of life, and continuity of care after discharge[12,24].

Limitations of the Study

Despite the inclusion of different actors as participants in this study, the restriction to the hospital setting may be a limitation in understanding continuity of care. However, it is important to look at this process from the perspective of the actors who contribute to continuity of care through transitional care from hospital to home.

Contributions to the Field

To facilitate transitional care from hospital to home, we identified strategies such as comprehensive care, including addressing child and family needs, by an interprofessional team, health education, and communication with other services through e-mails, phone calls, letters, and meetings, which can be applied in similar contexts, both with children and adult patients.

Professionals' efforts to promote transitional care for children with chronic conditions from hospital to home can help to build future institutional guidelines, focusing on facilitating continuity

of care. Nonetheless, it is important to highlight the need of management strategies, formalizing institutional actions such as information and communication systems, formal protocols to guide the practice of care transitions focused on children with chronic conditions that need continuity of care, and availability of professionals to carry out these functions.

FINAL CONSIDERATIONS

The interprofessional hospital team plays a key role in continuity of care for children with chronic conditions, paying attention to actions that postpone the next admission and promote better health outcomes and quality of life after discharge, since re-admissions are unavoidable. They highlight the need for comprehensive care, interdisciplinary action, and education for self-management of the disease, and referral and communication with other services in the Healthcare Network, which help solidify the bond of children and family with Primary Healthcare.

Among the main difficulties faced by children and families are the lack of communication mechanisms between services, the unpreparedness and lack of capacity of Primary Healthcare to care for this population, resulting in the overload of hospital services in the face of worsening symptoms. Despite the efforts in the transition to promote continuity of care, professionals cannot be sure of the effectiveness of their conduct. New studies are necessary to better understand this phenomenon, especially regarding continuity of care for children with chronic conditions within Primary Healthcare, ultimately responsible for coordination of care in the Healthcare Network.

SUPPLEMENTARY MATERIAL

Further details are available on https://doi.org/10.48331/scielodata.GL8NFF.

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REFERENCES

1. Pena KS, Rollo RM, Reuter CLO, Santos VCF, Riquinho DL, Ramos AR. Care handover to chronic conditions to regionalized planning. Rev Gaúcha Enferm. 2020;41:e20190168. https://doi.org/10.1590/1983-1447.2020.20190168
2. Araújo PJ, Silva RMM, Collet N, Neves ET, Toso BRGO, Viera CS. History of the child's health: conquers, policies and perspectives. Rev Bras Enferm. 2014;67:1000. https://doi.org/10.1590/0034-7167.2014670620
3. Nóbrega VM, Silva MEA, Fernandes LTB, Viera CS, Reichert APS, Collet N. Chronic disease in childhood and adolescence: continuity of care in the Health Care Network. Rev Esc Enferm USP. 2017;51: e03226. https://doi.org/10.1590/s1980-220x2016042503226
4. Ferreira FY, Xavier MC, Baldini PR, Ferreira LTL, Lima RAG, Okido ACC. Influence of health care practices in the burden of caregivers mothers. Rev Bras Enferm. 2020;73:e20190154. https://doi.org/10.1590/0034-7167-2019-0154
5. Qiu C, Chen S, Yao Y, Zhao Y, Xin Y, Zang X. Adaption and validation of Nijmegen continuity questionnaire to recognize the influencing factors of continuity of care for hypertensive patients in China. BMC Health Serv Res. 2019;19(79):1–9. https://doi.org/10.1186/s12913-019-3915-6
6. Jackson J, MacKean G, Cooke T, Lahtinen T. Patient and provider experiences with relationship, information, and management continuity. Patient Experience Journal. 2017;4:38–47. https://doi.org/10.35680/2372-0247.1192
7. Neves ET, Okido ACC, Buboltz FL, Santos RP, Lima RAG. Accessibility of children with special health needs to the health care network. Rev Bras Enferm. 2019;72:65-71. https://doi.org/10.1590/0034-7167-2017-0899
8. Bahr SJ, Weiss ME. Clarifying model for continuity of care: a concept analysis. Int J Nurs Pract. 2018;25:e12704. https://doi.org/10.1111/ijn.12704
9. Silva MEA, Reichert APS, Souza SAF, Pimenta EAG, Collet N. Chronic disease in childhood and adolescence: family bonds in the healthcare network. Texto Contexto Enferm. 2018;27(2):1–11. https://doi.org/10.1590/0104-070720180004460016
10. Charmaz K. Constructing Grounded Theory. London: Sage Publications Ltd; 2014.
11. Moura EC, Moreira MCN, Menezes LA, Ferreira IA, Gomes R. Complex chronic conditions in children and adolescents: hospitalizations in Brazil, 2013. Ciênc Saúde Colet. 2017;22(8):2727–2734. https://doi.org/10.1590/1413-81232017228.01992016
12. Foster CC, Jacob-Files E, Arthur KC, Hillman SA, Edwards TC, Mangione-Smith R. Provider perspectives of high-quality pediatric hospital-to-home transitions for children and youth with chronic disease. Hosp Pediatr. 2017;7:649–659. https://doi.org/10.1542/hpeds.2017-0031
13. Mattar e Silva TW, Velloso ISC, Araújo MT, Fernandes ARK. Configuration of power relations in physicians and nurses' professional practices. Rev Bras Enferm. 2020;73:e20180629. https://doi.org/10.1590/0034-7167-2018-0629
14. Shahsavari H, Zarei M, Mamaghania JA. Transitional care: concept analysis using Rodgers' evolutionary approach. Int J Nurs Stud. 2019;99:e103387. https://doi.org/10.1016/j.ijnurstu.2019.103387
15. Weber LAF, Lima MADS, Acosta AM, Marques GQ. Care transition from hospital to home: integrative review. Cogitare Enferm. 2017;22:e47615. https://doi.org/10.5380/ce.v22i3.47615

16. Javalkar K, Rak N, Phillips A, Haberman C, Ferris M, Tilburg MV. Predictors of caregiver burden among mothers of children with chronic conditions. Children. 2017;4:39. https://doi.org/10.3390/children4050039

17. Aued GK, Bernardino E, Lapierre J, Dallaire C. Liaison nurse activities at hospital discharge: a strategy for continuity of care. Rev Latino-Am Enferm. 2019;27:e3162. https://doi.org/10.1590/1518-8345.3069.3162

18. Baird J, Rehm RS, Hinds PS, Baggott C, Davies B. Do You Know My Child? Continuity of Nursing Care in the Pediatric Intensive Care Unit. Nurs Res. 2016;65:142–150. https://doi.org/10.1097/NNR.0000000000000135

19. Conners GP, Kressly SJ, Perrin JM, Richerson JE, Sankrithi UM. Nonemergency Acute Care: When It's Not the Medical Home. Pediatrics. 2017;139:e20170629. https://doi.org/10.1542/peds.2017-0629

20. Veenstra M, Gautun H. Nurses' assessments of staffing adequacy in care services for older patients following hospital discharge. J Adv Nurs. 2021;77:805-18. https://doi.org/10.1111/jan.14636

21. Leyenaar JK, Rizzo PA, Khodyakov D, Leslie LK, Lindenauer PK, Mangione-Smith R. Importance and feasibility of transitional care for children with medical complexity: results of a multitask eholder delphi process. Acad Pediatr. 2018;18:94–101. https://doi.org/10.1016/j.acap.2017.07.005

22. Weber LAF, Lima MADS, Acosta AM. Quality of care transition and its association with hospital readmission. Aquichan. 2019;19:e1945. https://doi.org/10.5294/aqui.2019.19.4.5

23. Enlow E, Passarella M, Lorch SA. Continuity of care in infancy and early childhood health outcomes. Pediatrics. 2017;140:e20170339. https://doi.org/10.1542/peds.2017-0339

24. Costa MFBNA, Andrade SR, Soares CF, Pérez EIB, Tomás SC, Bernardino E. The continuity of hospital nursing care for Primary Health Care in Spain. Rev Esc Enferm USP. 2019;53:e03477. https://doi.org/10.1590/s1980-220x2018017803477