# Hospitalized children with complex special healthcare needs: multiple case studies

## Crianças hospitalizadas com necessidades de saúde especiais complexas: estudo de casos múltiplos

## Infantes hospitalizados con necesidades de salud especiales complejas: estudio de casos múltiples

Jéssica Renata Bastos Depianti[1] https://orcid.org/0000-0002-9157-3159
Ivone Evangelista Cabral[1,2] https://orcid.org/0000-0002-1522-9516

**How to cite:**
Depianti JR, Cabral IE. Hospitalized children with complex special healthcare needs: multiple case studies. Acta Paul Enferm. 2023;36:eAPE012732.

**DOI**
http://dx.doi.org/10.37689/acta-ape/2023AO0127332



**Keywords**
Child, hospitalized; Multiple chronic conditions; Child care; Comprehensive health care

**Descritores**
Criança hospitalizada; Múltiplas afecções crônicas; Cuidado da criança; Assistência integral à saúde

**Descriptores**
Niño hospitalizado; Afecciones crónicas múltiples; Cuidado del niño; Atención integral de salud

**Submitted**
June 30, 2022

**Accepted**
April 24, 2023

**Corresponding author**
Jéssica Renata Bastos Depianti
E-mail: jrbdepianti@gmail.com

**Associate Editor (Peer review process):**
Myriam Aparecida Mandetta
(https://orcid.org/0000-0003-4399-2479)
Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, SP, Brasil.

## Abstract

**Objective:** To describe the medically complex cases of children with special healthcare needs in continuous hospitalization and to analyze the nature of medically complex care demands during hospitalization.

**Methods:** This is a multiple case study of three hospitalized medically complex children. Data collection occurred between January and March 2020 in the medical records in the observation of care and spontaneous interaction documented in a fieldwork note and interview. Seven people participated, two family members, three nursing technicians, and two nurses. Thematic analysis was applied, guided by the typologies of Collière's care and the demands of children with special healthcare needs.

**Results:** The cases included girls and a boy aged three, ten, and 11 years, and hospitalization time from 4 months to 6 years. They all generated lines of convergence with the care demands of children with special healthcare needs, providing survival, well-being, and comfort. These cases extracted continuous and complex care demands of stimulation, pacification, and comfort; and seemed convergent with developmental and modified daily life activities (bath, grooming, feed, and mobility) care. Compensating care in managing bodily technologies and administering continuous-use medication converged with demands for technological and medication care.

**Conclusion:** The need for survival, determined by children's medically complex nature, directs the priority of care to the continuous use of multiple medications, the management of technologies, and the safety of hospital environments. Although essential, it is necessary to consider the other developmental and social care demands, integrating them with the medically complex ones.

## Resumo

**Objetivo:** Descrever os casos clinicamente complexos de crianças com necessidades de saúde especiais em hospitalização contínua e analisar a natureza das demandas de cuidados clinicamente complexos durante a hospitalização.

**Métodos:** Estudo de casos múltiplos de três crianças clinicamente complexas hospitalizadas. A coleta de dados ocorreu, entre janeiro e março de 2020, em prontuário, na observação de cuidados e interação espontânea registrada em diário de campo e entrevista. Participaram sete pessoas, sendo dois familiares, três técnicos de enfermagem e duas enfermeiras. Aplicou-se a análise temática, orientando-se pela tipologia de demandas de cuidados de crianças com necessidades de saúde especiais e classificação de Collière.

**Resultados:** Os casos de meninas  e menino, com três, dez e 11 anos de idade, e tempo de internação de 4 meses a 6 anos, geraram linhas de convergências com as demandas de cuidados de crianças com necessidades de saúde especiais, proporcionando sobrevivência, bem-estar e conforto. Desses casos

[1]Escola de Enfermagem Anna Nery, Universidade Federal do Rio de Janeiro, Rio de Janeiro, RJ, Brazil.
[2]Faculdade de Enfermagem, Universidade do Estado do Rio de Janeiro, Rio de Janeiro, RJ, Brazil.
**Conflicts of interest:** nothing to declare.

extraíram-se demandas contínuas e complexas de cuidados de estimulação, apaziguamento, confortação e parecer convergentes com o de desenvolvimento e habituais modificados (banho, arrumar-se, alimentação e mobilidade); os cuidados de compensação, no manejo de tecnologias corporais e a administração de medicamentos de uso contínuo, convergiram para demandas de cuidados tecnológicos e medicamentosos

**Conclusão:** A necessidade de sobrevivência, determinada pela natureza clinicamente complexa da criança, direciona a prioridade dos cuidados no uso contínuo de múltiplos medicamentos e manejo de tecnologias, na segurança do ambiente hospitalar. Embora essenciais, precisa-se contemplar as outras demandas de cuidados de desenvolvimento e social integrando-as às clinicamente complexas.

## Resumen

**Objetivo:** Describir los casos clínicamente complejos de infantes con necesidades de salud especiales en hospitalización continua y analizar la naturaleza de las demandas de cuidados clínicamente complejos durante la hospitalización.

**Métodos:** Estudio de casos múltiples de tres infantes hospitalizados clínicamente complejos. La recopilación de datos se realizó de enero a marzo de 2020, en la historia clínica, en la observación de cuidados e interacción espontánea registrada en un diario de campo y en entrevista. Participaron siete personas, de las cuales dos eran familiares, tres técnicos de enfermería y dos enfermeras. Se aplicó el análisis temático, orientándose por la tipología de demandas de cuidados de infantes con necesidades de salud especiales y clasificación de Collière.

**Resultados:** Los casos de las niñas y el niño, de 3, 10 y 11 años, entre 4 meses y 6 años de tiempo de internación, generaron líneas convergentes con las demandas de cuidados de infantes con necesidades de salud especiales, donde se proporciona supervivencia, bienestar y consuelo. De estos casos se observaron demandas continuas y complejas de cuidados de estimulación, apaciguamiento, consuelo y opinión convergentes con los del desarrollo y los habituales modificados (baño, arreglarse, alimentación y movilidad); los cuidados de compensación, con el manejo de tecnologías corporales y la administración de medicamentos de uso continuo, convergieron en las demandas de cuidados tecnológicos y medicamentosos.

**Conclusión:** La necesidad de supervivencia, determinada por la naturaleza clínicamente compleja del infante, direcciona la prioridad de los cuidados en el uso continuo de múltiples medicamentos y en el manejo de tecnologías para la seguridad del ambiente hospitalario. Aunque sean esenciales, es necesario contemplar otras demandas de cuidados de desarrollo y sociales e integrarlas a las clínicamente complejas.

## Introduction

Medically complex children (MCC) are defined as a subgroup of children with special healthcare needs (CSHCN) that lead families to seek more health services or who present a diagnosis of medically fragile, severe functional limitation, and or associated with the use of continuous use of technology and makes use of health services and specialized care.[1]

The expression CSHCN was introduced by the Maternal and Child Health Bureau of the United States of America in 1998 to designate an emerging population of children with special health needs due to chronic physical, emotional, developmental, and behavioral impairment, perceived or with defined diagnoses and continuous dependence on health services, in more significant numbers than children in general.[2] In Brazil, CSHCN was free translated as *crianças com necessidades de saúde especiais* (CRIANES), having its definition adapted to the local context as those who have or are at greater risk of developing a physical, developmental, behavioral, emotional, or chronic condition that generally requires a type and amount of health services beyond those required by other children.[3]

The nature of medically complex care focuses on the transition of the epidemiological profile of children who, due to technological advances, have better access to health services and living conditions and survived complex conditions. In recent decades, on the one hand, there has been a lower infant mortality rate, but, on the other hand, an increase in the number of children with chronic and or disabling diseases.[4] Although many of these children may improve when receiving optimal care, sequels are potentially long-lasting, leading to prolonged hospitalization and total dependence on different demands for specific, complex, and specialized care.[4,5] Added to this, those children who spend part of their childhood living for long periods in hospitals impact their quality of life, damaging social and family coexistence. Often, family members cannot continuously monitor their hospitalized child, whether due to financial issues or difficulties in carrying out medically complex care.[6]

Among the leading causes of prolonged hospitalization of MCC, respiratory, neoplasms, and neurological causes stand out. In Brazil, in 2013, it was estimated that for every 331 children per 100 thousand inhabitants who were hospitalized, 240 thousand (13.5%) required highly complex care.[6] The low epidemiological representativeness can compromise the definition of strategies and actions to be promoted by professionals and little visibility

in formulating public policies aimed at this subgroup of the child population. Mainly due to the specialized, prolonged, and uninterrupted nature of continuous care of these CSHCN, there is a high cost for the health system with pharmacological and oxygen therapies, special food, and a health team both in Brazil and in other countries, even those who are in-home care.[7,8] Cost analysis of 146 children with complex chronic conditions in continuous use of technological devices (drains, gastrostomies, and catheters) was associated with a higher number of readmissions and high cost of hospital care.[7]

Dependency as the impossibility of satisfying one or several survival needs has been described in its quantitative and qualitative dimensions, especially those that analyze the impact on the family. In the quantitative dimension, the magnitude of the problem and its relevance for developing policies aimed at hospitalization/home care are highlighted in the face of economically more vulnerable families.[8,9] In the qualitative dimension, the complexity of continuous care for the nursing team, family, and hospital-home-community transition is determined.[10,11] However, the specificity of the continuous nature of this complex care has yet to be systematized to understand the specific demands of this population subgroup of CSHCN.

Considering the above, the aim is to describe the medically complex cases of CSHCN in continuous hospitalization and to analyze the nature of medically complex care demands during hospitalization.

## Methods

This qualitative, descriptive-analytical study was developed using the multiple case study method, considering individuals with specific characteristics to be researched as part of reality. [12] The method uses multiple sources of scientific information and is widely used in nursing research due to its applicability in different epistemic orientations. It allows investigating in a natural context of nursing care, leading to reflection on problem-solving with the advancement of knowledge.[13]

Cases were intentionally selected according to eligibility criteria, such as CSHCN aged between three and 12 years old, with demands for medically complex care and total dependence, and uninterrupted hospitalization longer than three months. As for nursing professionals, nurses and technicians who worked in direct care at CSHCN and had worked in the sector for at least one year, present in the research setting on the day of field observation, were included. Regarding family members, those accompanying and providing direct care to CSHCN during the event observed on the day of data collection were included.

Notably, among the family members present on the day authorized by the research setting institution to conduct observation, only one family member did not allow their child to be observed. All nursing professionals involved in the observation agreed to participate in the study. Thus, observations of care and interaction events took place from January to the first week of March 2020 (on average eight weeks), one to three times a week for one to three hours per observation shift, totaling 35 hours of field journaling.

During the same period, information was collected from medical records, and a semi-structured interview was conducted with nursing professionals and family members, totaling three hours of recording. Such techniques were used to deepen the data related to CSHCN-MCC's history and elucidate the meaning of observed events.

Before starting the research fieldwork, the first author stayed with the ward's nursing team and family members for a week, facilitating her presence and receptivity in the observation environment. The setting was the clinical ward of a pediatric hospital, sustained by the Ministry of Health and Education, which admits children aged 30 days to 14 years, which is a reference for CSHCN-MCC care in the medium and high complexity health care network of the Brazilian Health System (*Sistema Único de Saúde*) in Rio de Janeiro. A study conducted with 21 CSHCNs admitted to this institution revealed that 23.8% had neurological problems, had technological devices (tracheostomy and gastrostomy), and depended on medically complex care. [14] Thus,

the data justify the existence of the unit of analysis of multiple cases, indicating the construct validity and reliability necessary for the implementation of this type of case study as a qualitative research methodology,[12] despite the low epidemiological representativeness in the general population. The report of primary data sources (medical records, observation, and interview) was subjected to thematic analysis,[15] starting with the successive reading of information to familiarize yourself with each case's common and singular elements. Then, codes (keywords and expressions) were assigned with the support of WebQDA®,[16] a qualitative data analysis software. Codes were grouped and regrouped in successive reading and rereading movements to constitute the themes interpreted according to the nature of continuous care associated with the typology of CSHCN's care demands[17] and Collière's typology of care.[18]

The first thematic unit classified CSHCNs into six care demands: developmental, modified usual, technological, continuous medication use, mixed, medically complex, and social. Among the developmental care demands are activities that involve continuous rehabilitation and social interaction. Technological care demands require safely handling technological devices such as gastrostomy, tracheostomy, and implantable catheters. Medication care implies safe handling, using it continuously to ensure the survival of CSHCN. The demands of modified usual care consist of dressing, grooming, feeding, and cleaning children using adaptive resources that ensure physical integrity, well-being, and comfort. In mixed care demands, there is a combination of one or more care demands, excluding those related to managing technologies implanted in the body. Those medically complex care consists of a combination of all of the above plus total dependence on technology to sustain life.[18] In the social care demands, interventions (social, educational, financial) address social vulnerabilities that can determine an intensive, medically fragile child.[19,20]

In Collière's typology of care, seven types of care were presented: restorative maintenance, stimulation, compensation, emancipation, pacification, and comfort. Restorative care is performed to limit the disease by focusing on its causes. Maintenance care relates to daily life and psychological, affective, and social needs, contributing to personal development. Stimulation care awakens the senses, develop motor skills, and creates expectations, desires, and affective reactions. Compensation care replaces what was not purchased or compensated when one cannot do it themselves. Emancipation care is implemented to awaken and strengthen the sense of self. Pacification care promotes rest and the release of tensions, calming turbulence, and restlessness. Comfort care favors the acquisition of confidence, identifying what needs to be comforted.[18]

The study was approved by the Research Ethics Committee under Opinion 3,790,972, meeting the recommendations contained in Resolution 466 of 2012 of the Brazilian National Health Council. All participants signed the Informed Consent Form. To preserve anonymity, alphanumeric coding was used, being C (1, 2,3) for child, F (1, 2,3) for family member, NT (1, 2...) for nursing technician and N (1,2) for nurse.

## Results

The cases involved two girls and a boy, aged three, ten, and 11 years, with a hospital stay of 4 months to 6 years, belonging to low-income families living in poverty, residing in the greater Rio area (city of Rio de Janeiro). One child was old enough to attend kindergarten; another left school when they fell ill; and the third child is not included in the formal education system. Two children are part of the Income Transfer Program, and another is not. The child is bonded with the mother's daily follow-up (F3, Case C3); one receives a visit from the paternal grandmother on weekends (F2, Case C2), and the other rarely has family follow-up (F1, Case 1). Observation of care events and moments of spontaneous interaction involved two nursing technicians (NT3 and NT5) with a child here called C1; a nursing technician (NT2) with C2; a relative (F3, mother) of C3; a family member (F2, grandmother) from C2; and interview with a nurse (N2). The nursing professionals and the family members

were women with whom the children maintained a professional and affective bond in providing continuous and prolonged care due to a long coexistence in the hospitalization of more than one year. The cases created lines of convergence and singularities by identifying the nature of medically complex care demands, presented in special health needs and medically complex demands common to the three cases and singular to each.

## Special healthcare needs and medically complex demands common to the three cases

Children of preschool and school-age were diagnosed with chronic encephalopathy, chronic motor, sensory, cognitive, and physical limitations, and tracheostomy (TCT) breathing; one was on mechanical ventilation, and the others were on room air. Feeding to meet the nutritional needs of two children is done by gavage in gastrostomy (GTT) and one by nasoenteric tube (NET) but with surgery scheduled for button insertion (Chart 1).

**Chart 1.** Summary of cases that demonstrate the clinical complexity of children dependent on continuous and prolonged care during hospitalization.

| |
|---|
| **The girl from Case C1**, hospitalized for one year, belongs to a family whose social history is marked by socioeconomic vulnerabilities and dependence on the child's benefit from the Income Transfer Program. Several readmissions due to pneumonia complications culminated in the need for technological devices such as TCT for oxygenation in room air, continuous monitoring of vital functions, and GTT button for special diet by gavage. |
| **The boy from Case C2**, hospitalized for six years, is followed by his paternal grandmother on weekends and is rarely visited by his parents. The family lives in a context of socioeconomic vulnerability and also receives the benefit of a national minimum wage from the Income Transfer Program. The child needs oxygenation by mechanical ventilation via TCT and is fed by gavage by GTT with a special diet. |
| **The girl from Case C3** has been hospitalized for four months and is accompanied by her mother full-time. Her mother has difficulty understanding the complex nature of child care dependent on the nursing team in the simplest tasks. She receives visits from family members and people from the evangelical church they attend. TCT meets her need for oxygenation in room air, and feeding is by NET, indicating elective surgery for implantation of a GTT button. At the time of observation, she was not included in the Government Income Transfer Program. |

Medically fragile was also marked by the continuous use of more than one class of medication due to chronic encephalopathy and social vulnerability due to not having the family member under continuous monitoring (Case C1 and C2) or not receiving the benefit (Case C3). They depend on the Brazilian Unified Health System to maintain survival with support resources in the hospital, which is a high cost, as illustrated in the estimated value for hospitalization in a clinical ward and covered by the public health sector (Chart 2).

**Chart 2.** Cost of hospitalization in a clinical ward and types of continuous use medication for hospitalized children with special health care needs-medically complex children

**Case C1 and C3** - daily cost of BRL 465.46 and estimated monthly cost of BRL 13,963.80 for admission to a hospital ward.
**Case C2** - the daily cost of BRL 656.71 and estimated monthly cost of BRL 19,701.03 for admission to a hospital ward and use of mechanical ventilation.

| Medications | Cases |
|---|---|
| **Anticonvulsants**<br>Phenobarbital<br>Clobazam<br>Sodium valproate | C1, C2, C3 |
| **Bronchodilator**<br>Salbutamol spray<br>**Analgesic/antipyretic (SOS)**<br>Dipyrone (SOS)<br>**Stomach protector**<br>Ranitidine/omeprazole<br>**Antiemetic (SOS)**<br>Ondansetron | C1, C2, C3 |
| **Ophthalmic solutions**<br>Dextran + hypromellose | C2, C3 |
| **Oxygen therapy**<br>Oxygen<br>**Antimicrobial agent**<br>Azithromycin<br>**Anticonvulsants**<br>Diazepam<br>Lamotrigine<br>Atropine sulfate<br>**Corticosteroid**<br>Beclomethasone dipropionate<br>**Ophthalmic solution**<br>Polyacrylic acid | C2 |

## Special healthcare needs and medically complex demands singular to each case

The path of special health needs is unique for each case. In Case C1, it was confirmed from the diagnosis of Zika virus and chronic encephalopathy. Over time, there were several attempts to keep the child in-home care; however, due to the family (mother) living in precarious housing conditions, the child had a worsening of his health condition and several readmissions. Case 2 started with the diagnosis of Leigh syndrome, becoming complex with pneumonia diagnosed at the age of two, which evolved into a chronic encephalopathy. There were no homecare attempts due to housing conditions and the child's full-time caregivers. In the latter case, it resulted from complications of the appendectomy, which led to cardiorespiratory arrest, with several unsuccessful resuscitation attempts and chronic encephalopathy. There was no attempt at-home care because the child is awaiting surgery to place a GTT button.

The typology of CSHCN care demands associated with those described by Collière was considered, indicating the complexity of actions involving each case's needs (Chart 3).

Based on the above, the dependence of these children on continuous and complex care leads to the need for dedication and an intense daily schedule of care provided by family members, nursing professionals and other members of the health team.

## Discussion

In the description of the three complex cases of CSHCN in continuous hospitalization, there is a demand for social care that is intrinsically associated with the family's vulnerabilities to receive them at home. Even concerning those included in the Income Transfer Program, resources received by children are insufficient to guarantee the monthly hospital cost

**Chart 3.** Specificity of complex care according to the typologies of care demands of children with special healthcare needs and Collière's.

| CSHCN's typology | Actions | Collière's typology |
|---|---|---|
| **Interaction and comfort** | | |
| F2 talks softly and melodiously with C2 (10 years old) while rubbing his head with his hand. Upon hearing the voice, he looks at her and smiles [...]. Then, the grandmother shaves the child's hair with a hair clipper, using slow movements interspersed with the affectionate touch of the hand on the head, and says, with the same voice, "You are a beautiful boy". When listening to it, C2 relaxes and keeps his eyes closed (Fieldwork Note. Observation, Case 2). | | |
| Developmental care | • Sing child's songs with a soft and melodious voice;<br>• Use recreational activities (storytelling, videos, TV, music, toys with different textures and colors) during interactions with the child;<br>• Massage during skin hydration after bathing;<br>• Encourage the visit and permanence of family members;<br>• Avoid unnecessary interruptions and allow for rest periods;<br>• Create an environment that resembles home, using personal objects of child and family;<br>• Maintain a reduced level of stimulation in the child's unit during rest periods and at night;<br>• Provide activities that encourage family interaction with the child such as haircuts. | Comfortation care<br>Stimulation care<br>Pacification care<br>Emancipation care |
| **Activities of daily living** | | |
| F3 (11 years old) separates the materials for bathing (cotton, gauze, towel, diaper, soap) on the bedside table next to the bed. Then, she removed the oximeter from the right index finger of C3, changed her position from supine to left lateral, took a cotton pad soaked in soap and water, and gently rubbed her back. In response, C3 has minor spasms as the water touches her body. F3 returns C3 to the supine position; repeats the same procedure for cleaning the thorax and abdomen; ends the bath by drying the front and back parts of the body, and dresses her. Performs oral hygiene with brushing, water, and mouthwash (Fieldwork Diary. Observation, Case 3). | | |
| Modified usual care | • Change the diaper whenever necessary;<br>• Avoid exposure, air currents, excess heat or unnecessary cooling during bathing;<br>• Keep the sheet well stretched to avoid folds;<br>• Use pillows or pads on parts of the body where there are bony prominences;<br>• Perform decubitus change every two hours;<br>• Transfer to the wheelchair if the child's tolerance. | Maintenance care<br>Restorative care<br>Emancipation care<br>Compensation care |
| **Medication administration** | | |
| NT3 repositions C1 (3 years old), placing her in the cradle; places the oximeter sensor on the right hallux and the sock on her feet. She separates the material for drug administration by GTT (tube, filtered water, and medications) and administers it. Then she washes the GTT route with water filtered by gavage (Fieldwork Note. Observation, Case C1). | | |
| Medication care | • Check (dose, route of administration, time) of medication before being administered;<br>• Ensure that the child is not allergic to the prescribed medication to be administered;<br>• Monitor the child for discomfort and nausea before and after medication administration;<br>• Check medications that have interactions and change the schedule/scheduling;<br>• Observe signs of drug intoxication related to the risk of dosage error (weight fluctuation, age change);<br>• Administer bronchodilators and other SOS medications and as prescribed. | Restorative care |
| **Technological device maintenance** | | |
| NT5 called N3 from the unit to assess the TCT subcannula of C1 (3 years old), who was sleepy. N3 approaches C1 softly, saying, "Hi, princess, let us wake up!". While she wakes up, N3 prepares the materials (SF 0.9% and flexible rod, fixation lace) for external cleaning of the sub cannula, performing the procedure calmly with the gaze directed to the sub cannula. During the procedure, the girl with a fever remains quiet and prostrate. A few minutes later, C1 opened her eyes slowly and stared at N3, who had finished cleaning. She replaces TCT fixation. In the end, N3, with a soft and childlike voice, calls her a princess. C1 smiles and looks at her! (Fieldwork Note. Observation, Case 1). | | |
| Technological care | • Protect TCT from water dispersion;<br>• Sanitize the hands before and after handling the mechanical ventilator system;<br>• Use aseptic technique to assemble the mechanical ventilator;<br>• Protect the Y connection when opening the mechanical ventilator system;<br>• Change the mechanical ventilator circuit when visibly dirty;<br>• Pay attention to mechanical ventilator alarms;<br>• Assess skin integrity around GTT stoma;<br>• Wash with water after administering diet and medication to GTT and NET;<br>• Check the presence of leakage of gastric secretion and diet on the button;<br>• Change NET fixation whenever necessary;<br>• Be careful not to pull the probe accidentally;<br>• Check the correct positioning of the tube, examining the oral cavity, if there are gastric residues, or listening to the moment of the injected and aspirated air, according to the institution's protocol;<br>• Assess nostril integrity. | Restorative care |

Continue...

Continuation.

| CSHCN's typology | Actions | Collière's typology |
|---|---|---|
| **Management of oxygenation, nutrition and skin integrity needs** | | |
| By delegation of competence, NT2 prepares the materials available in C2's bed (10 years) (0.9% SF, probe, gauze, and sterile glove) for lower airway aspiration (LAA) of TCT. Then, she disconnects the mechanical ventilation (MV) tube from TCT and opens the aspiration vacuum system. In response to the vacuum noise, C2 blinks his eyes rapidly. NT2 touches his face affectionately, reassuring him. In response, C2's eyes blink less when touched. NT2 aspirates once and reconnects the MV tube to TCT. Then, while aspirating the nostrils, C2 reacts by arching the upper lip, and the face turns red. (Fieldwork Note. Observation, Case 2). | | |
| Technological care | Care in maintaining the patency of the lower and upper airways<br>• Determine the need for airway aspiration (upper and lower) by the presence of secretion and bullous breath sounds;<br>• Inform the child and family about aspiration, explaining the procedure;<br>• Monitor the child's oxygenation condition (SaO2 levels);<br>• Interrupt tracheal aspiration and offer supplemental oxygen if the child has bradycardia and/or desaturation;<br>• Observe the type and amount of aspirated secretion.<br>Care with food by technological devices<br>• Identify the prescribed diet;<br>• Monitor for the presence of bowel sounds at each diet administration;<br>• Monitor the child's water and electrolyte condition;<br>• Consult other members of the health team to choose the type and nutritional value of enteral nutrition.<br>• Elevate the head of the bed/crib between 30 and 45 degrees while feeding.<br>• Check the feeding pumping flow every hour;<br>• Check gastric residue before each intermittent feeding.<br>Skin care around ostia:<br>• Examine the skin around the tracheal stoma for secretions, redness, and irritation;<br>• Clean the area around the tracheal stoma, after bathing, at the end of tracheal aspiration and whenever it is wet;<br>• Keep the skin around GTT stoma clean and dry;<br>• Remove secretions from TCT ostia and from GTT implantation, whenever present. | Compensation care<br>Maintenance care<br>Restorative care |
| **Coping with vulnerabilities** | | |
| C2 (3 years old) has been with us for a long time [1 year], and he is super responsive to interactions. We have much affection for him. He talks, sees his response, responds to our commands, and interacts well. Talking to him is a way of minimizing that moment when he is left without a companion. (Interview, N2). | | |
| Social demand care | • Determine caregivers' level of knowledge, acceptance and role;<br>• Investigate with caregivers the positive and negative points of daily care;<br>• Support caregivers' decisions;<br>• Encourage acceptance of interdependence among family members;<br>• Monitor family interaction problems with child care;<br>• Strengthen caregivers' social network;<br>• Inform caregivers about health and community service resources;<br>• Contact the social service to access the Income Transfer Program;<br>• Expand the social network of coexistence. | Maintenance care<br>Restorative care<br>Stimulation care<br>Compensation care |

Source: Góes FGB, Cabral IE. Discourses on discharge care for children with special healthcare needs. Rev Bras Enferm. 2017;70(1):163-71
.Colliére MF. Cuidar: a primeira arte da vida. 2ª ed. Loures: Lusociência; 2003. Wilson D, Hockenberry MJ. Wong Manual clínico de enfermagem pediátrica. 8ª ed, 4ª tiragem. Elsevier: 2012.[17,18,21]

that varies between BRL 13,000 and BRL 19,000 related to hospitalization. These values include the cost of special food, ventilation, and continuous use of medications, which are known to be insufficient to cover all the expenses children need.

A study carried out in the United States of America showed that MCC, with a mean hospital stay of 7.2 days, has hospitalization costs of around US$3,928 with continuous and prolonged care. Children with neurological or neuromuscular diseases accounted for 40.5% of those with the highest number of days in hospital.[23] Many hospitalizations are associated with the social vulnerability of low-income families, low levels of education, and precarious housing conditions.[23]

In Brazil, comparing hospitalization costs between children with and without chronic conditions showed a higher cost in the medically complex subgroup. Furthermore, these costs increased among those with more than one chronic condition (respiratory and neuromuscular diseases more prevalent), with technological devices (drains and or catheters and GTT) and the need for long periods of hospitalization.[6]

The quantity and variety of medications and supplements for continuous use stand out. It determines care demands involving scheduling appointments to avoid incompatibility and drug toxicity, adequate volume management, and compatibility with children's growth stages. These data corroborate other studies carried out with mothers of CSHCN dependent on technological care and medication (anticonvulsants, muscle relaxants, antibiotics, vitamins, corticoids, and bronchodilators), determining total dedication to these children and overload of continuous and complex care. They also report that physicians prescribe drugs that are not standardized and costly, in addition to a formal request for their acquisition and the need for case-control.[24,25]

Medications, especially anticonvulsants, indicated for children with chronic encephalopathy or cerebral palsy aim to compensate for the effects of permanent and non-progressive damage to the central nervous system, which compromises the global development (cognitive, motor, sensory, and personal-social). of individuals. Two cases were caused by cerebral hypoxemia and one by microcephaly associated with congenital Zika.

Children have different trajectories of special health needs; however, they all determine high loads of modified usual care. There is total dependence on hygiene (bath in bed, changing diapers, oral hygiene, scalp, and hair), grooming, maintaining skin integrity, lubrication and ocular occlusion, mobility, positioning, and transfer. Ensuring TCT patency demands technological care implies appropriating knowledge from the fundamental nursing field to meet the need for oxygenation without additional risks to children's safety. In enteral feeding by NET and GTT, the aim is to ensure that the nutritional need is met, maintaining the proper functioning of technological devices, implying the need for training by the nursing team.

A study with caregivers of children with TCT reinforced the importance of receiving adequate guidance, especially in emergencies and for those who use mechanical ventilation[26] Another study with mothers of children with GTT demonstrated the need for device handling and maintenance training compared to those who did not receive guidance. The results showed the difficulties with administering the diet and medication through the tube, ostium and button care, and tube fixing.[27]

Thus, for continuous care, there is a need for technical-scientific knowledge due to its complexity, with overload for caregivers. This finding is consistent with a study in which mothers of children with mixed care demands experienced a more significant burden when compared to those who presented demands for medication or modified usual care, separately.[28]

This set of care corresponds to what Collière calls life maintenance, compensation, and reparation care.[18] They are associated with maintaining patency of the upper and lower airways, which guarantee life, as well as cutaneous-peristomal integrity, fixation, and cleaning of technological devices (GTT, TCT, NET, and mechanical ventilation circuit) aimed at restoring vital functions.

Restorative care should not predominate over other types of care, nor should it paralyze or limit the dynamics of life in the event of an illness. Thus, caring needs movement and diversity regarding health needs that make sense in people's lives, regardless of health condition and hospitalization. [18]

Indeed, the institution replaces the coexistence at the family's home with health professionals in prolonged hospitalizations. By limiting the chronic condition or the connection to the ventilation system or continuous monitoring devices, bed restrictions can limit children's comfort and well-being, interactive needs, and social participation.[29]

The limited social participation of a CSHCN can lead to isolation from contact with other children since they begin to interact only with adults, especially those who care for them. They are children who live in the hospital, two of whom spend most of their time unaccompanied due to interrupted family ties. These findings are in line with a study that revealed the impossibilities of social interaction that can be enhanced when children move away from those usual activities of daily living that are common for children in general, depriving them of relationships with other family members.[30]

These children create emotional bonds with health professionals by staying in the hospital for a long time. Additionally, there is limited autonomy for families to make decisions that may pose a risk to the safety and integrity of children due to the complexity of technologies that improve or prolong life.[7, 31]

Chronic encephalopathy in the three cases determined their motor and sensory limitations, requiring demands for developmental care and pleasurable, interactional activities stimulating their senses. For Collière, hands and voice pacification, comfortation, and provide security, which can be care that stimulates the senses and desires through touch, singing, rocking, for instance.[18]

In this regard, the findings of this study demonstrate the importance of, in mediating care for

CSHCN, communicating with them through the voice with a soft and melodious tone, the affectionate touch, and calling for affectionate nicknames. Such actions can promote well-being and comfort, decrease anxiety during invasive and painful procedures, [32-34] and promote stimulating, appeasing, and comfortation care in addition to promoting stimulating, pacification and comfortation care.[18]

The analysis of the nature of medically complex care demands reveals that, in terms of caring for this subgroup of CSHCN, complexity implies a diversity of activities that aim to sustain and or maintain life, allowing it to live to its full potential. However, in the literature, it is seen that most of the care provided by family members is centered on technological devices, such as TCT, GTT, or colostomy bags, as they report feeling insecure about their handling and maintenance.[34]

The awareness of the type of care associated with the demands allows guiding nurses' practice in providing care to sustain life and promote well-being and comfort in hospital environments. In addition, the three cases generated lines of convergence with the care demands of children with special health needs, providing survival, well-being, and comfort. These cases extracted continuous and complex care demands of stimulation, pacification, and comfortation; and seemed convergent with developmental and modified usual (bath, grooming, feed, and mobility) care. Compensation care in managing bodily technologies and administering continuous-use medications converged to demands for technological and medication care. Although these last two types of care are essential for the survival of medically complex CSHCN, it is necessary to consider the other developmental and social care demands, integrating them with the medically complex ones. Therefore, it is necessary to ensure a set of care encompassing actions that promote interaction and comfort, management of oxygenation needs, nutrition and skin integrity, and coping with vulnerabilities as part of social care.

Developmental care demands need to be better integrated with those that are part of modified usual care. Social care demands, however, need to be reinforced to expand these children's social network and coexistence beyond professionals and family members (siblings, pet therapy, hospital class). Therefore, it is recommended to carry out studies that broaden the focus and analysis of the nature of medically complex care in other health contexts.

As a methodological limitation of this study, there is the restriction to a single reference hospital scenario for CSHCN-MCC care, which could not reflect the reality of other hospital contexts. Moreover, due to the COVID-19 pandemic, fieldwork was interrupted to ensure health protection, especially for these medically fragile and vulnerable children. Another limitation is the limited number of children, not allowing an intersectional analysis of ethnicity, race, and gender.

## Conclusion

Multiple case studies allow for a deeper understanding of chronic morbidity that determines clinical complexity. The three cases of children with special healthcare needs who require medically complex care (CSHCN-MCC) aged three, ten, and 11 years remained hospitalized for four months to six years. The reason for long-term hospitalization was an intensive demand for continuous and medically complex care due to their fragile medical and social vulnerability. The need for survival, determined by children's medically complex nature, directs the priority of care in the continuous use of multiple medications and the management of technologies in the safety of hospital environments. In all three cases, there is technological dependence and medication use for survival, given their history of special health needs and diagnosis of chronic encephalopathy. These are children who, regardless of age, remain bedridden with functional limitations and total dependence on care. Care demands, classified as modified usual, regardless of age, will imply in this group continuous dependence on an adult to transfer CSHCN-MCC from the bed to a wheelchair, in addition, to care in the administration of continuous use medications (anticonvulsants), body technological care for feeding through gastrostomy and NET and airway maintenance to breathe through TCT.

Furthermore, developmental care, mediated by the conversation in a soft voice, promotes social interaction. The restriction of these children's coexistence with professionals and little family members determines a restricted demand for social care. This set of demands is included the emancipation, comfortation, maintenance, restorative, compensation, stimulation, and pacification care implemented safely to ensure the integrity and survival of these children.

## Acknowledgments

We would like to thank the Brazilian National Council for Scientific and Technological Development (CNPq - *Conselho Nacional de Desenvolvimento Científico e Tecnológico*) for granting the doctoral scholarship to Jéssica Renata Bastos Depianti and research productivity scholarship, Process 303149/2019-1, to Ivone Evangelista Cabral, coordinator of the research project funded by Edict Universal 2018-CNPq, Process 430213/2018-2, CREANES VII. Knowledge-in-action in the transition of children with clinical and complex care demands from hospital to home.

## Collaborations

Depianti JR and Cabral IE contributed to the study design, data analysis and interpretation, article writing, relevant critical review of intellectual content and approval of the final version to be published.

## References

1. Cohen E, Kuo DZ, Agrawal R, Berry JG, Bhagat SK, Simon TD, et al. Children with medical complexity: an emerging population for clinical and research initiatives. Pediatrics. 2011;127(3):529-38. Review.
2. McPherson MG, Arango P, Fox H, Lauver C, McManus M, Newachek PW, et al. A new definition of children with special health care needs. Pediatrics. 1998;102(1):137-41.
3. Cabral IE, Jesus SJ, Oliveira DZ, Rezende JM, Conceição ER. A criança egressa da terapia intensiva na luta pela sobrevida. Rev Bras Enfem. 2004;57(1):35-9.
4. Brenner M, Kidston C, Hilliard C, Coyne I, Eustace-Cook J, Doyle C, et al. Children's complex care needs: a systematic concept analysis of multidisciplinary language. Eur J Pediatrics. 2018;177:1641–52. Review.
5. López MP, Fernández AL, Fiquepron K, Meregalli K, Ratto C, Serrate SM. Prevalence of children with complex chronic conditions in PICUs of Argentina: a prospective multicenter study. Pediatric Critical Care Medicine. 2020;21(3):e141-53.
6. Novais MC, Victor DS, Rodrigues DS, Freitas BO, Barreto NM, Mendes DJ, et al. Saquetto Factors associated with de-hospitalization of children and adolescents with complex chronic condition. Rev Paul Pediatr. 2021;39:e2020118.
7. Pinto M, Gomes R, Tanabe RF, Costa AA, Moreira MC. Análise de custo da assistência de crianças e adolescentes com condições crônicas complexas. Cien Saude Colet. 2019; 24(11):4043-52.
8. Cohen E, Berry JG, Sanders L, Schor EL, Wise PH. Status complexus? The emergence of pediatric complex care. Pediatrics. 2018;141(3):e 20171284. Review.
9. Bazemore A, Petterson S, Peterson LE, Bruno R, Chung Y, Phillips RL Jr. Higher primary care physician continuity is associated with lower costs and hospitalizations. Ann Fam Med. 2018;16(6):492-7.
10. de Carvalho AJ, Ferreira HM, Borges EF, Borges Junior LH, de Paula AL, Hattori WT, et al. Analyses of the effectiveness of a Brazilian pediatric home care service: a preliminary study. BMC Health Serv Res. 2019;19(1):324.
11. Ferro F, Tozzi AE, Erba I, Dall'Oglio I, Campana A, Cecchetti C, et al. Impact of telemedicine on health outcomes in children with medical complexity: an integrative review. Eur J Pediatr. 2021;180(8):2389-400. Review.
12. Yin RK. Estudo de caso: planejamento e métodos. 5a ed. Porto Alegre: Bookman; 2015.
13. Silva LA, Mercês NN. Multiple case study applied in nursing research: a case report. Rev Bras Enferm. 2018;71(3):1194-97.
14. Carvalho CC, Pimentel TG, Cabral IE. Child with special health needs at one hospital of the brazilian unified health system. Rev Fun Care Online. 2021;13(1):1296-302.
15. Nowell LS, Norris JM, White DE, Moules NJ. Thematic analysis: striving to meet the trustworthiness criteria. Int J Qual Meth. 2017;16:1-13.
16. Costa AP, Moreira A, Souza FN, "webQDA - Qualitative Data Analysis". MicroIO and University of Aveiro: Aveiro; 2019.
17. Góes FG, Cabral IE. Discourses on discharge care for children with special healthcare needs. Rev Bras Enferm. 2017;70(1):163-71.
18. Colliére MF. Cuidar: a primeira arte da vida. 2a ed. Loures: Lusociência; 2003.
19. Precce ML, Moraes JR. Educative process with relatives of children with special health needs in the hospital-home transition. Texto Contexto Enferm. 2020;29:e20190075.
20. Brasil. Companhia Nacional de Abastecimento (CNA). Tabelas e taxas de diárias hospitalares. Brasília (DF): CNA; 2018 [citado 2023 Fev 5]. Disponível em: https://www.conab.gov.br/institucional/conab-corporativa/assistencia-a-saude/tabelas-referenciais/item/9356-ro-tabela-de-taxas-diarias-servicos-hospitalares-e-gases
21. Wilson D, Hockenberry MJ. Wong manual clínico de enfermagem pediátrica. 8a ed. Elsevier: 2012. 496 p.
22. Berry JG, Hall M, Neff J, Goodman D, Cohen E, Agrawal R, et al. Children with medical complexity and medicaid: spending and cost savings. Health Affairs. 2014;33:2199-206.
23. Ruth AR, Boss RD, Donohue PK, Shapiro MC, Raisanen JC, Henderson CM. Living in the hospital: the vulnerability of children with chronic critical illness. J Clin Ethics. 2020;31(4):340-52

24. Okido AC, Cunha ST, Neves ET, Dupas G, Lima RA. Technology-dependent children and the demand for pharmaceutical care. Rev Bras Enferm. 2016;69(4):718-24.

25. Pereira HV. Paralisia cerebral. Residência Pediátrica. 2018;8(Supl 1):49-55.

26. Mai K, Davis RK, Hamilton S, Robertson-James C, Calaman S, Turchi RM. Identifying caregiver needs for children with a tracheostomy living at home. Clinical Pediatrics. 2020;59(13):1169-81.

27. Pars H, Soyer T. Home Gastrostomy Feeding Education Program: Effects on the caregiving burden, knowledge, and anxiety level of mothers. JPEN J Parenter Enteral Nutr. 2020;44(6):1029-37.

28. Rodrigues DZ, Ferreira FY, Okido AC. The burden of family caregiver of children with special health needs. Rev Eletr Enf. 2018;20:20a48.

29. Pordes E, Gordon J, Sanders LM, Cohen E. Models of care delivery for children with medical complexity. Pediatrics. 2018;141(Suppl 3):S212-23.

30. Aragão LR, Maia FN, Mitre RM. Os estímulos sensoriais recebidos por crianças com hospitalização prolongada. Cad Bras Terapia Ocupacional. 2018;26(1):45–51.

31. Graaf G, Annis I, Martinez R, Thomas KC. Predictors of unmet family support service needs in families of children with special health care needs. Matern Child Health J. 2021;25(8):1274-84.

32. Gjærde LK, Hybschmann J, Dybdal D, Topperzer MK, Schrøder MA, Gibson JL, et al. Play interventions for paediatric patients in hospital: a scoping review. BMJ Open. 2021;11:e051957. Review

33. Efendi D, Caswini N, Tane R, Kurniasari MD, Hasanul HM, Farid RI. Comparison of mother's therapeutic touch and voice stimulus in reduce pain in premature infants undergoing invasive procedures. La Pediatria Medica Chirurgica 2021;43(259):1-5.

34. Viana IS, Silva LF, Cursino EG, Conceição DS, Góes FG, Moraes JR. Educational encounter of nursing and the relatives of children with special health care needs. Texto Contexto Enferm. 2018;27(3):e5720016.