

REPERCUSSÕES DAS CONDIÇÕES CRÔNICAS NAS NECESSIDADES DE SAÚDE DE CRIANÇAS EGRESSAS DE UNIDADE NEONATAL

REPERCUSSIONS OF CHRONIC CONDITIONS IN CHILDREN'S HEALTH NEEDS EGRESSES FROM NEONATAL UNIT

REPERCUSIONES DE LAS CONDICIONES CRÓNICAS EN LAS NECESIDADES DE SALUD DE LOS NIÑOS DESPUÉS DEL ALTA DE LA UNIDAD NEONATAL

Tatiana Silva Tavares¹, Elysângela Dittz Duarte², Roseni Rosângela de Sena³ (*in memoriam*)

RESUMO:

Objetivo: analisar as repercussões das condições crônicas nas necessidades de saúde de crianças egressas de unidade neonatal, na perspectiva das mães. **Método:** Foi desenvolvida pesquisa qualitativa, com referencial da dialética. Participaram 14 mães de crianças com condições crônicas. Os dados foram coletados por meio de entrevistas semiestruturadas, realizadas nos domicílios em Minas Gerais, e verificados por análise de conteúdo temático e procedimentos do Manual do Inventário de Avaliação Pediátrica de Incapacidade. **Resultados:** Destacaram-se, dentre as consequências das condições crônicas, os atrasos na mobilidade, o uso contínuo de medicamentos para controle de problemas respiratórios e o uso de serviços de reabilitação ou de especialidade médica. **Conclusão:** As condições crônicas repercutiram em necessidades existenciais relacionadas a receber cuidados com complexidade variável e apoio para atividades diárias, obter medicamentos, alimentação especial e dispositivos tecnológicos, além de receber atendimento por profissionais de saúde e de outros setores. Contudo, é preciso considerar também as necessidades sociais que conduzem ao aprimoramento da condição humana, como a oportunidade de desenvolver ações lúdicas, de aprendizado e de lazer, estabelecendo relações de afeto com a família e outras crianças.

Descritores: Unidades de terapia intensiva neonatal; Doença crônica; Crianças com deficiência; Enfermagem pediátrica; Determinação de necessidades de cuidados de saúde.

ABSTRACT:

Objective: to analyze the implications that chronic conditions in children health needs egresses from the neonatal unit, from mothers' perspective. **Method:** We carried out qualitative research using dialectics as a reference framework. The participants were 14 mothers of children with chronic conditions. We collected data through semi-structured interviews carried out in their homes in Minas Gerais and analyzed using thematic content analysis and the procedures of the Manual of the Pediatric Evaluation of Disability Inventory. **Results:** Among the consequences of chronic conditions, the most important ones are those related to delay in mobility, continuous use of medication to control respiratory problems, as well as the use of rehabilitation or medical specialty services. **Conclusion:** The chronic conditions had repercussions on existential needs, related to receiving care with variable complexity and support for daily activities; access to medication, special food and technological devices; besides receiving care from health professionals and other sectors. Nevertheless, we should consider the social needs that lead to the improvement of the human condition, such as the opportunity to develop playful, learning and leisure actions, establishing affective relations with their family and other children.

Descriptors: Intensive care units, neonatal; Chronic disease; Disabled children; Pediatric nursing; Needs assessment.

RESUMEN:

Objetivo: analizar las repercusiones de las condiciones crónicas en las necesidades de salud de los niños después del alta de la unidad neonatal, desde la perspectiva de las madres. **Método:** Se llevó a cabo una investigación cualitativa, con referencial de la dialéctica. Participaron 14 madres de niños con condiciones crónicas. Los datos se recogieron mediante entrevistas semiestructuradas, realizadas en los domicilios en Minas Gerais, y se analizaron a través de análisis temático de contenido y de procedimientos del Inventario para la Evaluación Pediátrica de la Discapacidad. **Resultados:** Entre las consecuencias de las condiciones crónicas, se destacaron los atrasos en la movilidad, el uso continuo de medicinas para el control de los problemas respiratorios y el uso de servicios de rehabilitación o de especialidad médica. **Conclusión:** Las condiciones crónicas repercutieron en necesidades existenciales, relacionadas con recibir cuidados con complejidad variable y apoyo para las actividades diarias; obtención de medicinas, alimentación especial y dispositivos tecnológicos; además de recibir atención por profesionales sanitarios y de otros sectores. Sin embargo, también se debe considerar las necesidades sociales que lleven al perfeccionamiento de la condición humana, tales como la oportunidad de desarrollar acciones lúdicas, de aprendizaje y de ocio, estableciendo relacionamientos afectivos con su familia y otros niños.

Descriptores: Unidades de cuidado intensivo neonatal; Enfermedad crónica; Niños con discapacidad; Enfermería pediátrica; Evaluación de necesidades.

¹Graduada em Enfermagem. Doutora em Enfermagem pela Universidade Federal de Minas Gerais. ²Graduada em Enfermagem. Doutora em Saúde da Criança e do Adolescente pela Universidade Federal de Minas Gerais. Docente na Escola de Enfermagem da Universidade Federal de Minas Gerais. ³Graduada em Enfermagem. Doutora em Enfermagem pela Universidade de São Paulo. Professora Emérita da Escola de Enfermagem da Universidade Federal de Minas Gerais.

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INTRODUCTION

In the last decades, there has been a trend towards increasing chronic conditions in children related to progress in health care, which has made it possible to reduce the mortality of children with serious health problems⁽¹⁾. We highlight the advances in neonatal care, which made it possible to reduce the mortality of newborns due to congenital or perinatal problems. Studies show that many of these newborns, due to their health status at birth and the effects of intensive treatment in neonatal units, develop long-term morbidity and disability that can determine chronic conditions and cause special health needs⁽¹⁻⁶⁾.

The concept of a chronic condition, which includes biological, psychological or cognitive-based conditions that last or have the potential to last at least one year and which produce one or more of the following repercussions: limitations of function, activity or social role compared to children of the same age, with no change in growth and development; dependence on compensatory mechanisms - medicines, special diet and technological devices - or care due to the limitations of functions; need or use of services beyond the usual for the age, such as health services or education⁽¹⁾. These children are part of a larger group of children with special health needs, which includes those with chronic conditions and at risk for developing them⁽¹⁾.

Studies on the evolution of the health status of children from Neonatal Intensive Care Units (NICUs), the repercussions on their lives and their families, the specificities of the attention they need and the difficulties to obtain it have been verified⁽⁵⁻⁷⁾. In Brazil, there has been an increase in the production of NICU graduates, especially children with chronic conditions (CCC) and special needs, due to the magnitude of these conditions for the daily life of the families and the health system^(8,11-12).

Studies have revealed that the search for care in the health services of the preterm infants, low or very low birth weight infants of NICUs, is marked by barriers to access, fragile attachment and fragmentation of care between the different levels of care, making it difficult to follow-up^(7,10). Other studies have addressed the association between perinatal causes and the special health needs of children, and emphasized that they present, after discharge, complex and continuous care demands for families^(8,11-12).

Although children with chronic conditions present different health states, it is possible to identify common aspects in the experiences of these children and their families and in the factors that influence their quality of life. Therefore, it is pertinent to consider an approach of this group of children, which considers the repercussions of health conditions on their lives and human needs⁽¹⁾.

Human needs, in Agnes Heller's interpretation, are socially and historically determined, and can be classified into existential needs, which are related to the conservation of life, and social needs, which are produced in the relation of the individual to the society and determine the needs individuals. Existential needs include food, clothing, housing, social contact, among others, being the way to satisfy them socially determined. Social needs encompass both the needs for material goods in a society or a group and those that can only be met through social institutions or community life, such as the need for education and health⁽¹³⁾.

Considering an expanded conception of health, we can associate health care with the construction of the individual who, in addition to aiming at the preservation of life, seeks to recreate his or her life. This requires the satisfaction of both existential needs and social needs, which lead to the improvement of the human condition⁽¹⁴⁾, through moral and cultural activities and self-fulfillment in work, friendship and love⁽¹⁵⁾.

In addition to the theoretical-conceptual discussion of health needs related to human life in the social, historical and cultural spheres, there is a predominance of publications with an operational approach in which health needs direct policies and actions in health services⁽¹⁵⁾. In this approach, there is the challenge of understanding and incorporating the concept of human needs by workers in order to humanize and qualify care, taking the users' needs as the guiding principle of the interventions, taking their perspective into account⁽¹⁵⁾.

Because of the repercussions that the chronic conditions in childhood cause in the life of the child and his family, as well as the implications for the practices of health professionals and the organization of services, it is important to study this group of children and their families, health policies that guide public policies and practices that they understand beyond a biopsychic cut of disease-related needs.

The understanding of needs, based on Agnes Heller's framework, makes it possible to recognize beyond this idea and indicates the urgency that this be done from the perspective of the users; thus, it allows advancing in the knowledge produced until then on the care to these children. This study aimed to analyze the repercussions of chronic conditions on the health needs of children who are from neonatal units from the perspective of mothers.

METHOD

This is an exploratory descriptive study, with a qualitative approach. The approximation of reality was guided by the referential of dialectics for social criticism. The experience of the chronic condition of the child and the process of caring for the family, in order to meet their needs, were approached considering the contradictory nature of human subjectivity, its dynamism and the possibility of overcoming historical and social mediations in search of totality⁽¹⁶⁾. The concept of chronicity in childhood⁽¹⁾ and Agnes Heller's approach to human needs⁽¹³⁻¹⁵⁾ guided methodological definitions and data analysis.

The inclusion criterion of the participants was to be the main caregiver of children with chronic conditions from the high risk newborn care units of a hospital in Minas Gerais, Brazil. The choice of these participants was due to their proximity to the child and the possibility of reporting on their needs. The identification of these children was carried out from the retrospective documentary analysis of 1080 patients' records from February 2010 to January 2011.

Information was collected using a documental analysis script based on the repercussions of the chronic conditions, according to the definition presented previously: limitations of function, activity or social role; dependence on compensatory mechanisms; and need or use of above-usual services⁽¹⁾. This script allowed to characterize the repercussions of the condition of birth and care in a neonatal unit in the health condition of the child and to select 138 children with demands for care that indicated chronicity⁽³⁾.

Subsequently, the Questionnaire for Identification of Children with Chronic Conditions (QuICCC-R) was applied by telephone contact with the family member, who presented as the main caregiver of the 138 children, in order to confirm the chronic condition in the interview

phase. The questionnaire is an instrument for the identification of children with chronic conditions, based on the concept of chronic condition adopted⁽¹⁾, being appropriate for telephone application. It was developed by researchers linked to the Albert Einstein College of Medicine in New York, and translated and adapted into Brazilian Portuguese by Brazilian researchers⁽¹⁷⁾. Upon confirmation of the chronic condition of 20 children, an invitation was made to the family's primary caregiver to respond to the interview. There were no interviews with six families due to their unavailability.

A total of 14 mothers of children with chronic conditions participated in this study. The study was developed in Belo Horizonte and in five municipalities in the metropolitan region of Minas Gerais, where the participants lived. The home visits occurred between March and May 2012, when the researcher carried out an individual interview with the mothers, with a mean duration of 45 minutes, recorded in audio by digital recorder. In all the interviews were present the researcher, the participant and his son with chronic condition.

The interview was guided by a semi-structured script that addressed the sociodemographic data of the family and seven questions about their perspective and experience regarding the needs of the children, considering the health condition at the time of the interview, the attendance or not of their needs by the services, the need for daily care and the facilities or difficulties for care.

The script was previously tested to verify compliance with the study objective, and no need for adequacy was verified. The interviews were transcribed and reviewed for their accuracy in relation to the audios by the researcher. The names of the participants and their children were replaced by the letters M and F, respectively, followed by numerical identification of the order in which the interviews took place and the order of appearance of the speech fragment in the interview (example: M3-69).

The Pediatric Invalidation Inventory was also carried out through a structured interview with the mothers, with an average duration of 30 minutes, to characterize the repercussions of chronic conditions on children's functioning. The instrument is suitable for evaluating children from six months to seven and a half years, considering the expected performance for the age of Brazilian children, in the same age group,

without changes in growth and development. The inventory is composed of three parts, with information about the child's functional performance in daily activities, caregiver assistance to the child in activities and the necessary modifications in the physical environment. Each part contains scales of self-care areas (food, personal hygiene, toilet use, clothing, and sphincter control), mobility (transfers, external and internal mobility, stair use) and social function (communication, problem solving, and interaction in play)⁽¹⁸⁾.

For the analysis of the data, successive readings of the transcriptions were carried out in order to identify the significant statements, considering the research objectives. The excerpts from the transcriptions selected to compose this analysis were validated by two other researchers. The statements were organized according to their theme. Their description was followed, seeking to articulate them, followed by the deepening of ideas and the establishment of relations based on a reflection on the empirical material and the theoretical reference⁽¹⁹⁾. The data obtained through the inventory were analyzed according to the procedures proposed in the Manual of the adapted Brazilian version⁽¹⁸⁾.

The study was developed in compliance with the standards set forth in Resolution 466 of 2012 of the National Health Council for research involving human beings. The project was submitted to the approval of the Research Ethics Committee (Opinion 0004.0.439.203-10).

RESULTS AND DISCUSSION

Characterization of mothers

The mothers who participated in the study were between the ages of 19 and 47 at the time of the interview, with a mean of 31 years-old. From 14 women, six completed primary education and six completed secondary

education. Only one attended higher education. Eleven women reported that they are married; one is separate; and two ones are single. The number of children varied between one (M2, M3, M4, M6, M9 and M10) and three, and the child with chronic condition was the last, except in one family. Nine women reported attending household chores and child care at the time of the interview, while five said they were gainfully employed outside the home (M2, M6, M8, M11, M14). Household income ranged from 1.0 to 6.4 minimum wages, with the average income per family being 2.5 minimum wages. Five mothers received the Continuous Social Assistance Benefit (BPC) (M3, M4, M7, M12, M13) and three obtained the free pass (M1, M4, M7) for CCC. Four children had health insurance.

Characterization of children

The CCC had corrected mean age of 18 months-old at the moment of the interview with the mothers, being the minimum age of 14 months-old and the maximum of 23 months-old. Seven children had complications during labor and delivery. At birth, three had presented prematurity and low weight; five, hypoxic-ischemic encephalopathy, two of them with prematurity and low weight; three Down syndrome, two of them with prematurity and low weight; and two with malformation. During the neonatal period, all were hospitalized in NICUs, remaining from four days to five months. Until discharge, these children presented several health alterations, and after discharge some of these were resolved, while others remained and new alterations were identified. At the time of the interview with the mothers, the health status of these children was mainly determined by respiratory problems, cerebral palsy and malformations. Figure 1 presents characterization data of CCC.

Figure 1- Characterization of children with chronic conditions regarding health status, Belo Horizonte, Minas Gerais, 2012.

Children	Chronological / corrected age	State of health from birth to hospital discharge	State of health at the time of data collection
FM1	16 months / 16 months	Down syndrome, ventricular septal defect	Down syndrome, asthma, adenoid hypertrophy
FM2	23 months / 23 months	Myelomenigocele, hydrocephalus	Hydrocephalus, malformation of the feet
FM3	21 months / 20 months	Preterm / Low weight, Encephalopathy, seizures	Cerebral palsy, seizures
FM4	16 months / 16 months	Encephalopathy, seizures	Cerebral palsy, microcephaly, asthma, strabismus
FM5	18 months / 15 months	Preterm / Low weight, extensive periventricular leukomalacia, bronchopulmonary dysplasia, gastroesophageal reflux	DNPM delay, asthma, strabismus
FM6	14 months / 14 months	Seizures	Adenoid hypertrophy
FM7	25 months / 21 months	Preterm / Low weight, peri-intraventricular hemorrhage, hydrocephalus, bronchopulmonary dysplasia, persistent ductus arteriosus, allergy to cow's milk	Hydrocephalus, cerebral palsy, bronchopulmonary dysplasia, cow's milk allergy
FM8	21 months / 21 months	Encephalopathy, seizures	Delay Neuropsychomotor development, asthma
FM9	14 months / 14 months	Encephalopathy, seizures, seizures	Asthma
FM10	23 months / 20 months	Preterm / Low weight, bronchopulmonary dysplasia	Bronchopulmonary dysplasia, strabismus
FM11	23 months / 21 months	Pre-term/Low weight	DNPM Delay
FM12	19 months / 18 months	Down Syndrome, preterm / low weight, bronchopulmonary dysplasia, Persistence of ductus arteriosus	Down syndrome, asthma, strabismus
FM13	24 months / 23 months	Down syndrome, preterm	Down's syndrome
FM14	19 months / 19 months	Posterior cleft	Posterior cleft

Source: Elaboration of the author from the research data, Belo Horizonte (MG), 2012.

It was possible to recognize, among the five patterns of stability and permanence of the consequences of chronic conditions⁽²⁰⁾, the pattern in which the condition is permanent and manifests consequences with regular stability; the pattern in which the diagnosis persists, but its consequences gradually improve, being able to present long intervals of quietude or are solved; and the pattern in which the consequences of the condition are episodic, involving recurrent periods of activity alternating with periods of silence.

Repercussions of chronic condition in children's needs

The repercussions of the chronic condition on children's health needs were organized into three groups, considering the concept adopted in the study: changes in functionality; dependence on compensatory and care mechanisms; and use of services above expectations for the age. It was verified that the option for a criterion based on the consequences of the health conditions for the identification of CCC allowed recognizing varied alterations in the state of health of the children. It was possible to identify mild, moderate or severe chronic conditions by the number of consequences they presented and their

severity⁽²⁰⁾. It should be noted that even when children presented different chronic conditions, there were common aspects in their repercussions on health needs.

Regarding the functionality, there was agreement between the results of the Pediatric Disability Assessment Inventory and the discourses of the mothers. In the results of the inventory, there was performance within the expectation for Brazilian children of the age group at all scales in the parts of the functional abilities assessment test and caregiver assistance (FM2, FM9, FM10 and FM14); adequate performance in all scales of functional skills, but with below-expected performance on the social function scale of the caregiver's care part (FM6); below the expected three-item scales of the two parts of the test (FM3, FM12) were below the evidenced significant impact of the chronic condition on the performance of daily activities and tasks. It is worth noting the presence of varied impairments in both parts of the test, especially in mobility, considering the expected performance for age (FM1, FM4, FM5, FM7, FM8, FM11 and FM13).

The mothers' reports in the interviews made it possible to apprehend their evaluation of the children's development from what they consider expected for the child's age and health condition, as well as comparing the current stage of their development with previous stages. Only M11 evaluated the development of the daughter by comparison with her other children, who had no developmental changes.

Four mothers (M2, M6, M9 and M14) emphasized the activities that the children performed, revealing the perspective that their development is within the expected for the age, which corroborates the results of the functional abilities part of the Pediatric Assessment Inventory Disability, except for M10. The statement of the mother M14 reveals this understanding, even if associated with the recognition that the daughter still does not speak, due to malformation on the palate, which needs surgical correction: She did everything in age [...] The only difficulty I think it's just her speech ... (M14-25).

Ten mothers (M1, M3, M4, M5, M7, M8, M10, M11, M12 and M13) described the skills their children acquired but also cited those they have not yet developed. They highlighted the children's ability to hold objects, sit, crawl, and walk; also spoke about the ability to

communicate, through facial expressions, gestures, body postures, and the development of speech: From the waist up, I think he's great, but his legs, until now, he does not stand up, he crawls, but does not lift alone [...]. I think this is a delay [...] (M12-98). The M1 mother emphasized that the delay in the development of the child does not interfere in his ability to play: But it does not disturb anything, he plays in another way, plays in bed, sits here on the floor, rolls, plays ball (M1 -140).

The mothers revealed the perspective of their child's dependence on their care. The reports of M1, M3, M4, M5, M7, M8 and M12 showed a greater dependence of their children on M2, M6, M9, M10, M11, M13 and M14 mothers, mainly on mobility, which is according to the data of the caregiver's part of the Pediatric Disability Assessment Inventory.

Most of the children presented a delay in the performance of the functional abilities and demanded greater care from the caregiver, as expected for the age group, a result similar to other studies that used the Pediatric Disability Assessment Inventory⁽²¹⁻²²⁾. Delayed mobility, coupled with delays in communication and cognition, will probably contribute to the perception of the caregiver's dependence on children with permanent conditions for daily activities to increase with growth, considering what is expected for the age group.

The mothers' expectation was shown for the children to be able to walk because of the increased difficulty with the child moving as they grow: Now, we usually go walking, but I just cannot stand because he cannot walk, but when he can, we will do it a lot! (M1-71); My difficulty is that he is walking, that makes me very difficult. I have to do housework, and stay with him because he does not want to walk, he stays on the ground, but does not walk, he wants to lap (M8 -64).

The concordance between the inventory results and the mothers' reports indicates that they are informed about the child's development and its particularities, which may be related to an adequate orientation by health professionals. Mothers having access to this information can foster the ability to identify and address children's needs, and are also influenced by their life experiences, coping skills and problem solving, access to social support, and socioeconomic conditions, among others. Considering that the family is generally the main

provider of care, its ability to identify CCC needs, provide visibility, and mobilize resources to care for them is paramount to resolute care.

Regarding the dependence of compensatory mechanisms and care, the health condition of these children demanded the use of medications, type or differentiated consistency of

feeding and technological devices, as well as specific care, as shown in Figure 2. Only M11 and M13 mentioned that children had a lower demand for home care at the time of the interview.

Figure 2 - Characterization of children with chronic conditions regarding the dependence of compensatory mechanisms and care, Belo Horizonte, Minas Gerais, 2012.

Children	Medication for continuous or intermittent use	Special food	Technological device	Care
FM1	Beclometasona, Salbutamol, Disodium cromoglycate	Whipped or crushed food	Tutor	To administer medication, to clean nostrils with FS, to prepare food, to use tutor, to clean house dust
FM2	Ointment for perineal rash	–	DVP valve	Care DVP, motor exercises, care for the prevention of diaper rash
FM3	Vigabratin, Valpróico acid, Clobazam	Liquid or pasty food	Gastrostomy, tutor for legs, wheel chair	Caring for gastrostomy, preparing food, administering medication, monitoring seizures, motor exercises
FM4	Beclometasona, Salbutamol, Homeopathic medication	–	Tampons	To administer medication, to use tampons, motor exercises
FM5	Beclometasona, Salbutamol	Children's formula	Tampons, adapted table	To administer medication, to use tampons, motor exercises
FM6	Sambucos	–	–	To administer medication, to clean nostrils with SF
FM7	Budesonida, Salbutamol	Soy milk	DVP valve, hand bracing and tutor	DVP care, to administer medication, to use guardian, to restrict food with cow's milk
FM8	Prednisolona, Salbutamol	–	–	To administer medication, to clean dust at home
FM9	Beclometasona, Salbutamol	Children's formula	–	To administer medication
FM10	Beclometasona, Salbutamol, Singulair Baby®	–	tampons, glasses	To administer medication, to clean nostrils with SF, micronebulization, to use tampons and glasses, exercise for speech
FM11	–	–	–	–
FM12	Budesonida, Salbutamol	–	TQT, tampons, glasses	TQT care, to aspirate airways, to administer medication, to use tampons and glasses
FM13	–	Crushed food	–	To prepare food
FM14	–	Crushed or chopped food	–	To perform maneuver to disengage

Source: Elaboration of the author from the research data, Belo Horizonte (MG), 2012.

Drug dependence was the most frequent; 11 children needed continuous medication at home. From these children, nine used medication to control the respiratory problem (daily or intermittently during asthma attacks), one used to control seizures and one used topical medication to prevent dermatitis. Mothers

showed the frequency of daytime medication administration: every six hours, every eight hours, every 12 hours or once daily. Eight mothers addressed the use of medications daily or intermittently, during bouts of bronchitis and asthma, as has been reported: He uses Salbutamol, the doctor prescribed, she said

'When he is coughing', so he began to feel sick, began to want to cough, [...] I already use Salbutamol, [Beclomethasone] it takes continuously (M1-50). Administration is by nasal airway or by tracheostomy, oral or by gastrostomy and topical probe: It is compressed, [the Vigabatrin], so I dissolve it in the water and give the syringe [by gastrostomy] (M3-98).

From the seven children who needed special nutrition, four needed to change the consistency, which should be liquid, pasty or in small pieces. The mothers of these children mentioned the care with the food preparation due to difficulties in the ingestion: If we are eating, depending on what is doing, if it is something I can give him, and I can crush it with the fork, and if I cannot, I take a food there and defrost it ... [...] he eats everything... I cook, knead or put it on that potato masher (M1-93); [...] it has to be a small piece, that if it is a big piece, [...] then it goes there in her throat and she chokes, she begins to vomit (M14-45). The mother M3, whose daughter uses gastrostomy, approached strategies developed to facilitate the supply of food to the daughter outside the home: I started to buy box juice, box vitamin, not to take too much, that already has to take a lot (M3-78) [...] We go out there, how do we do it, there's no way, we go to the fair? Come on, you have to give [diet] on the street, I just top it up, if someone comes and asks I say, I have no problem with that, I never had, and I talk and explain (M3-83). The other three children needed infant formulas because of difficulty in gaining weight or restricting cow's milk. In these cases, the mothers mentioned vigilance regarding food restriction.

Two children used a peritoneal ventricle bypass valve (DVP), a gastrostomy, and a tracheostomy (TQT), and the care of these technological devices was mentioned by the mothers. The mother M3 addressed the need to exchange the gastrostomy tube as her daughter grows: We change this probe every three months, because the child grows, I even change here at home [...] (M3-29). The mothers M2 and M7, whose children have a DVP valve, have addressed the need to monitor episodes of fever, to watch for signs of valve malfunction, and to avoid trauma in order not to spoil it: The valve cracks, it's a hose, so it cracks, there you have to go and change or sometimes it clogs, that's all he [doctor] said, do not let him hit her, take that care. And when he has gone badly to observe this side here, he said like this 'When you see that he

has a fever, these business, you pass the hand like this on the side', that when it stops, it kind of fills the water know and the belly grows, he becomes pale, he knows, does not want to eat, only vomits [...] (M7-129).

The valve, it is a crack hose, then she cracks, there she has to go and change or sometimes she cramps, that's all he [doctor] said, do not let him hit it, we have to take that care. And when he is bad, we should see this side here, he said like this 'When you see that he has a fever, these kind of problems, you pass the hand like this on the side', that when it stops, it kind of fills the water and the belly grows, he becomes to be pale, he does not want to eat, he only vomits [...] (M7-129).

The M12 mother talked about the routine of caring for the child due to the tracheostomy, including the need to perform the aspiration and change the fixation: During the day, I let him cough, if he can cough and put the secretion out, I do not aspire. I aspire only in the morning, that I do not aspire him [during] the night, and the night before he sleeps. In fact, when he is very secretive, I aspire more often [...] (M12-134). As for assistive technology resources, three children required the use of guardianship; four, tampon or eyeglass; and a wheelchair. The mothers emphasized the difficulty of the child to accept the use of glasses and, mainly, tampon.

Mother M2, whose son was born with myelomeningocele, and mothers M3, M4 and M5, whose children had cerebral palsy, adopted care with their son's posture and performed exercises to stimulate motor development at home, following the guidelines of the professionals of the services. Rehabilitation: You have several exercises that you have to do, you have ways to carry it because you cannot let her leg loose, so as not to increase the tone, you cannot raise her arm [...] (M5-125). The M10 mother mentioned exercising to stimulate her daughter's speech.

Four mothers approached caring for the home environment to reduce the child's exposure to dust and strong odors, which can trigger respiratory attacks. The report showed constant attention to children and daily precautions, revealing strategies to promote vigilance, such as keeping the child's bed at the bedside: I was worried about him until his breath; [...] with that snoring on the side of the bed, his crib is on the side of my bed (M1-98).

Functional limitations have led to dependence on medication, special diet and technological devices, as identified in studies with preterm and low birth weight children^(3,5) and children with special health needs^(8-9,12). In this and other studies, drug administration is a frequent care to compensate for functional limitations^(3,8-9,12). The dependence of compensatory mechanisms has repercussions on the needs of these children of more complex and frequent care. At home, mothers perform care for prevention, treatment and rehabilitation, and remain vigilant with their children to monitor changes in health status. Studies carried out on the care of children with special needs have identified the performance of similar care, which is repeated throughout the day^(8-9,12). To perform certain care, mothers need to acquire knowledge and perform activities in the field of knowledge and practice of health professionals, according to the demands presented by each child^(12,23-24). The mothers' reports showed the daily learning in relation to the apprehension of the child's needs and the development of strategies to attend them. This process could be provided by nurses through health education actions on care to meet the needs of children. It should be emphasized that the routine of the child described by the mothers is directed towards the care related to the biological dimension, being less approached those related to the psychosocial dimensions, such as the importance of the child playing, emphasized by M1.

Regarding the use of services, the mothers' report on care by health professionals showed that the follow-up of the children was carried out by different professionals, with a greater or lesser performance of each one, depending on the chronic condition of the child and their stage of evolution. As for medical care, in health centers or outpatient clinics of public or contracted specialties, 12 children had follow-up with pediatricians; one with a general practitioner (FM13); and one did not perform (FM11): When I left the hospital, it was almost a month; As soon as I arrived, I went to the health center, talked to them, had nursing care, checked the pediatrician's appointment (M1-23); I take him every three months to the doctor, who is usually not a pediatrician. At my health center here, there is no pediatrician, there is a general practitioner. But he looks at children in the same way (M13-26); Because there in the service, it is more so specialty, if the boy needs more thing.

And at the health post, here, there is nothing, just have the general practitioner and look there! (M7-140). It was also identified the attendance of 11 children (FM1, FM2, FM4, FM5, FM6, FM7, FM10, FM12, FM13, FM14) by specialist physicians such as neurologist, orthopedist, cardiologist, surgeon, pulmonologist, geneticist and homeopath: He left Hospital A with his neurological appointment, at Hospital A (M4-15); From the beginning, he came from the first hospitalization in [Hospital A], the pediatrician asked for all this, asked to make an evaluation with physical therapy, with ... I know she gave me a lot of request. [...] Cardiologist had already recommended there [Hospital A] that, by the medical report, he would have to be evaluated, to be cared, by ophthalmology, by otolaryngologist, by speech therapist, all [...] (M1 -63).

The rehabilitation was performed by eight children (FM1, FM2, FM3, FM5, FM7, FM10, FM12, FM13). The rehabilitation services were mainly performed by a physiotherapist, speech therapist and occupational therapist. He had, his little head was growing very little, his pediatrician said that he was with his legs very hard [...] there she said that it could be a problem that he would have, that he would have to have a special treatment. Then I went back there [rehabilitation service] (M4-18); it was referred for rehabilitation by TO of Hospital A, when I returned there, they said that she had no performance, she was very slow (M5-48); In the week that she [occupational therapist] placed the talon [on hand], he was discharged [from Hospital A]. Then, she sent me, she gave me this address where he has to go to the physiotherapy and said that there was a vacancy, that was for me to go there. [...] Their neurologist there [Hospital A] has already put in the prescription for me to look for occupational therapy, physiotherapy and phono (M7-13,48).

Some mothers and children were attended, according to the need identification, with a psychologist and social worker; however, in a timely manner, during hospital admissions and rehabilitation services. The mothers' reports also showed the nurses' performance, especially in the hospital setting in health education actions: [...] every time they go there [Hospital E], they look, if I complain about anything, a pediatrician comes to see it, even if I do not have an appointment, they take a look at it, a nurse comes and looks, teaches you to do something you need, then it is very easy [...] Thank God! (M2-99). Some mothers cited the nurse's role in

primary care in meeting spontaneous demand, scheduling consultations or referral to other services, as reported by M1, mentioning that she "was cared by the nurse" to make appointments for the child at the clinic.

The need to use more health services that what is expected for the age for these children was demonstrated, reiterating the findings of other studies with CCC, with difficulties in guaranteeing the right to health, of universality of access^(11-12,23). The constant professionals were pediatrician, physiotherapist, occupational therapist, speech therapist and medical specialists according to the condition of each child. Psychologist, social worker, nurse and nutritionist are restricted and discontinued, depending on both the identification of this need and the possibility of attending services. It is worth mentioning that the knowledge of each professional of the health team, as well as that of the mother, allows us to apprehend different needs and to construct ways of attending them. In this sense, it is important to highlight the seriousness of the situation of the daughter of M11, who was not performing continuous follow-up with health professionals from one month of age, evidencing obstacles to access to the health care network: She was consulted in the first month of her life, at the Post, with her pediatrician. [...] after she was discharged [...] when I came, the first thing I did was take her there to get the consultation. Even on the same day that I got there, I already went in and I consulted, because, at that time, the pediatrician was there (M11-30).

The mothers also mentioned the use of services in the moments of exacerbation of the child's condition through the recognition of signs and symptoms that evidence the worsening of the condition. They sought, mainly, the urgency services, being public or contracted to the health plans. The report of eight mothers allowed us to understand that the moments of exacerbation were related to the aggravation of respiratory problems: When my daughter started to have these bronchitis attacks, I took her to the UPA [...] I already took her there twice. The last time I took her, she had a fever of 39 degrees. (M9-43,59). In the case of M11's daughter, emergency medical care at the municipal hospital is the only one the child has access to: In the emergency room, you stay there all day, you can get [care], get there early in the morning and get out of there at night. When I get a car, I take her at night. At 10 p.m.,

11 p.m. I leave home [...] Because it is much emptier, and then I can be assisted faster. But this is the only fast way! If it is not so [...] (M11-37). The exacerbation or complication of the health condition of five children led to hospitalization in a pediatric hospital unit, one (FM2) due to complications related to DVV valve and four due to respiratory problems (FM1, FM7, FM10 and FM12): [with 9 months] he was hospitalized at Hospital D for another seven days, with two of us already in the UPA, a total of nine days. It was pneumonia again [reference to pneumonia that the child had in the neonatal period], infection, he took that much of antibiotic again (M1-39); When we came home from the hospital, he came home from the hospital, he started to turn purple, cyanotic, they said, he was usually like that, and then his mouth used to be black, one day he lost his breath [...] so I took him there to the polyclinic, they said that he had dysplasia, he needed to be hospitalized, and we went to the hospital. When we arrived at Hospital G the left lung closed and also the right one, we stayed there a month, we stayed there a month and eight days, having a treatment because of the pneumonia also that he gave. [...] But the respiratory was about eight times, only respiratory, and all of us go to Hospital F and stay fifteen, twenty days. For oxygen he stays for a couple of weeks, but he never came home with this problem and always keep quiet (M7-30). The importance of the use of asthma medications on an ongoing basis, associated with environmental care, is emphasized in order to avoid asthma causing functional limitations and to control exacerbations of the respiratory tract, a major cause of urgent care or hospitalization hospital⁽²⁾.

It was possible to identify, in the mothers' speeches (M2, M4, M7 and M12), the discontinuity of the periodic follow-up of the children due to the exacerbation and complications of the condition, preventing attendance at services or care delivery. In addition, the mothers' reports showed the suffering caused by the moments of exacerbation that lead to hospitalization. Mothers expressed fears about the possibility of new hospitalizations associated with invasive procedures, pain, and delayed child development: If you do not need to change [the valve] before then, it is a simple but it is a surgery, and child ends up suffering, and he went through several of them very fast, went to the block and came back, went to the block came back, difficult, right, and he was thank God only

growing and strengthening, difficult! And he also does not develop as much, stays there in the hospital, just lying down [...] (M2-68).

It was also possible to seize the use of services from other sectors for the care of CCC, such as Social Assistance, Education and Sports. The mothers talked about the process of obtaining BPC (M3, M4, M7, M12, M13) and the Free Pass for public transport (M1, M4, M13): I could not work anymore and only my husband, even more taking medicine and things were increasing, I went and got the entrance. [...] I was like this, let's see what happens. Thank God, it was very quiet; at first so, they supported. [...] My husband changed company, I availed that his job was not formal and I got it. We were both unemployed (M12-75); Since he had been hospitalized for ten months, going in and out, going in and out, that's where he came in. In that last time, that he got it, it was the hospital, there in Hospital E, [...] the assistant there also helped me, to get it again [...] And because he had paralysis, he said 'He has the right, you have other children, you do not work, so he needs'; at the time, he was taking much medicine, these stuff [...] (M7-4). The situation of the CCC in the country is aggravated by the social vulnerability of their families, who, in the majority, have insufficient income to buy special food, medicines^(8-10,11), technological devices and follow up on services. Studies have shown financial disruption in the families of these children^(8-9,11) in a context of difficulty in accessing health services and insufficient specific public policies^(9,11-12). In this way, the BPC and the free pass are important to protect the beneficiaries and their families from the situation of social vulnerability.

The activities in education and sports services were recommended by the health professionals to favor the development and to enable the socialization of the child. FM2 attended the nursery, FM8 the municipal education unit, where he had accompaniment with physiotherapist, and FM3, water aerobics. The mothers M2 and M8 reported the stimulus for the development of children and the positive aspects of living with other children: He developed a lot [...] it is, his feeding, I found it easier to feed, it is, living with other children, helped a lot (M2-113); He was developing. But he had more difficulty, we worked hard on it. She [pediatrician] asked me for him in the school, to see if he could advance, how he reacted (M8-28); I put him in the school, he reacted very well, he

advanced a lot. [...] they play, have a lot of little children in his classroom, there is everything about his age, he develops a lot with the other boys, he has all day like that, they have snack, lunch, everything at the right time, activities during the day. In the course of the day, he does activities, he eats, puts him to walk around, as they say, he has to be independent there (M8-30-53).

However, mothers did not always insert children into these activities because of difficulty in accessing public services, not being able to include the amount to be paid in the family income, doubts about the appropriate service for their child or fear of leaving it under the care of others people: I tried, but I could not [swim] [...] They gave me the phone number of one university, I could not, and the other one they gave me was also very expensive, it was R \$ 95 per section. She said he would need about three sections a week. Because the physiotherapist said that it would be very good for him, that he has his arms very tight (M4-91); I'm sorry for, he tried, tried so much, I was afraid, I think it's just me who take care of him, for me I think if I have to leave him in day care, it has to be a doctor childcare, I think I left [laughs] I left there, I do not trust, no, I'm afraid. [...] Wait longer, wait for him to walk. I'm scared, she [neurologist] said 'don't think about fear,' says that it is for him to develop more he knows [...] For me, for him at day care I have to be working there! [laughs] (M7-133).

The mothers' report showed that most are afraid to put their children in day care or school at the moment, choosing to enter the children when they are older. They justified this feeling by the likely difficulties of adapting children to the school environment and by the inability of teachers to provide the attention and care demanded by children. Mothers assume that the care their children would receive in school would not be the same as their care. It is emphasized that the fear of separation of the children and the tendency to overprotection are contradictory to the mothers' desire that the children develop autonomy and participate socially. The social inclusion of these children requires adequate physical structure and support professionals trained to meet the specifics of their needs. Intersectoral action can promote inclusion as mentioned by M2: The Hospital E went to the kindergarten school, they like it, saw the little school, taught me how to give soup, as he walked at the baby walker at the time to train [...] (M2-

61) In addition, the mothers' report showed the relevance of the public sports service offer. In this study, the need to use services from sectors such as education and sports still appears incipient, which is related to the age of children. However, as these children grow, new demands will arise in other sectors, so that they can have cultural, leisure and work opportunities with accessibility conditions, fundamental to meeting their social needs related to the recreation of life⁽¹³⁻¹⁴⁾.

In Brazil, there are no national or regional studies of CCC prevalence or their needs; so there is the risk of becoming invisible to policy makers, managers and service professionals. The health professionals' discourses reveal that these children have needs beyond the use of drugs, other inputs and health services, which tend to increase according to the severity of children's functional limitations⁽²⁵⁾. The reports also showed difficulties in guaranteeing the right of access to health care of universality, which can prevent the fulfillment of existential needs of these children, highlighting the commitment of its functionality and its potential for social inclusion, which also make it impossible to meet their social needs⁽¹²⁻¹³⁾.

The analysis of the impact of chronic conditions in children's life allows grasp existential and social needs, especially the following: have an informed caregiver to identify their needs and seek to meet them, making this caregiver throughout life for those with permanent condition; have a caregiver with capacity to carry out activities of the field of knowledge and practice of health professionals for those with complex care; have their development recognized by comparison of their own stages; obtain compensatory mechanisms and receive care related to their use; vigilance regarding exacerbations and complications; play; monitoring by multi-professional team; receive social protection benefits; have the possibility of social participation; and have visibility in society. These needs go beyond ensuring the survival of children born at risk, implying the guarantee by the State and society of possibilities to enjoy their potential life.

FINAL THOUGHTS

Chronic, mild, moderate and severe conditions have led to a variety of consequences in the lives of children, especially delays in mobility, continuous use of medicines for respiratory problems, and the use of

rehabilitation or medical specialty services. These conditions had repercussions on existential needs, related to receiving care with variable complexity and support for daily activities, obtaining medicines, special food and technological devices, receiving care by health professionals and other sectors. However, it is also necessary to consider the social needs that lead to the improvement of the human condition, such as the opportunity to develop play, learning and leisure activities, establishing relationships of affection with family and other children.

It is emphasized that addressing these children as a group with common needs and seeking to meet their needs can contribute to reduce their invisibility, encouraging the elaboration of public policies and the organization of the service network, both in the health sector and in other sectors. It is observed the urgency of a greater role of nurses in the various spaces of care to meet the existential needs of these children, but also favoring the fulfillment of human needs. As potentialities of the study, the adoption of comprehensive approaches of chronic condition of theoretical reference of health need and of different instruments for the approximation of reality, which allowed that the analysis of the needs of these children was not confined to the biological aspects.

The limitations of the study are acknowledged because the results represent a unique reality, being important to carry out other research involving CCC in other age groups.

REFERENCES

1. Stein RE. The 1990s: A decade of change in understanding children with ongoing conditions. *Arch Pediatr Adolesc Med.* 2011;165(10):880-3. DOI: [10.1001/archpediatrics.2011.165](https://doi.org/10.1001/archpediatrics.2011.165)
2. Rover MMS, Viera CS, Silveira RC, Guimarães ATB, Grassioli S. Risk factors associated with growth failure in the follow-up of very low birth weight newborns. *J Pediatr.* 2016;92(3):307-13. DOI: [10.1016/j.jpmed.2015.09.006](https://doi.org/10.1016/j.jpmed.2015.09.006)
3. Tavares TS, Duarte ED, Silva BCN e, Paula CM de, Queiroz MPM, Sena RR de. Caracterização do perfil das crianças egressas de unidade neonatal com condição crônica. *R Enferm Cent O Min.* 2014;4(3):1322-35. DOI: [10.19175/recom.v0i0.802](https://doi.org/10.19175/recom.v0i0.802)
4. Liu L, Oza S, Hogan D, Perin J, Rudan I, Lawn JE, et al. Global, regional, and national causes of child mortality in 2000–13, with projections to

inform post-2015 priorities: An updated systematic analysis. *Lancet* 2015;385(9966):430–40. DOI: [10.1016/S0140-6736\(14\)61698-6](https://doi.org/10.1016/S0140-6736(14)61698-6)

5. Blencowe H, Cousens S, Chou D, Oestergaard M, Say L, Moller AB, et al. Born too soon: The global epidemiology of 15 million preterm births. *Reprod Health* 2013;10(Suppl 1):S2. DOI: [10.1186/1742-4755-10-S1-S2](https://doi.org/10.1186/1742-4755-10-S1-S2)

6. Aires LC dos P, Santos EKA dos, Costa R, Borck M, Custódio ZA de O. Baby follow-up in primary care: Interface with the third stage of the kangaroo method. *Rev Gaúcha Enferm.* 2015;36(nesp):224-32. DOI: [10.1590/1983-1447.2015.esp.56805](https://doi.org/10.1590/1983-1447.2015.esp.56805)

7. Aires LC dos P, Santos EKA dos, Bruggemann OM, Backes MTS, Costa R. Reference and counter-reference health care system of infant discharged from neonatal unit: Perceptions of primary care health professionals. *Esc Anna Nery* 2017;21(2):1-7. DOI: [10.5935/1414-8145.20170028](https://doi.org/10.5935/1414-8145.20170028)

8. Alves GV, Lomba G de O, Barbosa TA, Reis KMN, Braga PP. Crianças com necessidades especiais de saúde de um município de Minas Gerais: Estudo descritivo. *R Enferm Cent O Min.* 2014;3(4):1310-21. DOI: [10.19175/recom.v0i0.778](https://doi.org/10.19175/recom.v0i0.778)

9. Okido ACC, Cunha ST da, Neves ET, Dupas G, Lima RAG de. Technology-dependent children and the demand for pharmaceutical care. *Rev Bras Enferm.* 2016;69:718-24. DOI: [10.1590/0034-7167.2016690415j](https://doi.org/10.1590/0034-7167.2016690415j)

10. Klossowski DG, Godói VC de, Xavier CR, Fujinaga CI. Integral care to premature infant: implications of practices and public policy. *Rev CEFAC* 2016;18(1):137-50. DOI: [10.1590/1982-021620161814515](https://doi.org/10.1590/1982-021620161814515)

11. Nóbrega VM da, Silva ME de A, Fernandes LTB, Viera CS, Reichert AP da S, Collet N. Chronic disease in childhood and adolescence: Continuity of care in the Health Care Network. *Rev Esc Enferm USP* 2017;51:1-8. DOI: [10.1590/S1980-220X2016042503226](https://doi.org/10.1590/S1980-220X2016042503226)

12. Neves TE, Silveira A da, Arrué AM, Pieszak GM, Zamberlan KC, Santos RP dos. Network of care of children with special health care needs. *Texto Contexto-Enferm.* 2015;24(2):399-406. DOI: [10.1590/0104-07072015003010013](https://doi.org/10.1590/0104-07072015003010013)

13. Carone I. Necessidade e individualização. *Trans/Form/Ação* 1992;15:85-111. DOI: [10.1590/S0101-31731992000100005](https://doi.org/10.1590/S0101-31731992000100005)

14. Melo-Filho DA de. Repensando os desafios de Ulisses e Fausto: A saúde, o indivíduo e a história.

Cad Saúde Pública 1995;11(1):5-33. DOI: [10.1590/S0102-311X1995000100002](https://doi.org/10.1590/S0102-311X1995000100002)

15. Petersen CB, Lima RAG de, Boemer MR, Rocha SMM. Health needs and nursing care. *Rev Bras Enferm.* 2016;69(6):1236-9. DOI: [10.1590/0034-7167-2016-0128](https://doi.org/10.1590/0034-7167-2016-0128)

16. Gelbcke FL, Peña YF, Gallo E. Dialéctica y materialismo histórico: Su aproximación al estudio del fenómeno salud/enfermedad. In: Prado ML (Ed). *Investigación cualitativa en enfermería: Contexto y bases conceptuales*. Washington: Organización Panamericana de La Salud; 2008.

17. Duarte ED, Tavares TS, Nishimoto CLJ, Azevedo VMG de O, Silva BCN e, Silva JB da. Questionário para identificação de crianças com condições crônicas (QuICCC-R): Tradução e adaptação. *Acta Paul Enferm.* 2018;31(2):144-52. DOI: [10.1590/1982-0194201800022](https://doi.org/10.1590/1982-0194201800022)

18. Mancini MC. Inventário de Avaliação Pediátrica de Incapacidade (PEDI): Manual da versão brasileira adaptada. Belo Horizonte: UFMG; 2005.

19. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 2005;15(9):1277-88. DOI: [10.1177/1049732305276687](https://doi.org/10.1177/1049732305276687)

20. Stein RE, Bauman LJ, Westbrook LE, Coupey SM, Ireys HT. Framework for identifying children who have chronic conditions: The case for a new definition. *J Pediatr.* 1993 [citado em 13 jun 2017]; 122(3):342-7. Available in: [http://www.jpeds.com/article/S0022-3476\(05\)83414-6/fulltext](http://www.jpeds.com/article/S0022-3476(05)83414-6/fulltext)

21. Maggi EF, Magalhães LC, Campos AF, Bouzada MC. Preterm children have unfavorable motor, cognitive, and functional performance when compared to term children of preschool age. *J Pediatr.* 2014;90(4):377-83. DOI: [10.1016/j.jpeds.2013.10.005](https://doi.org/10.1016/j.jpeds.2013.10.005)

22. Silva VF da, Medeiros JSS de, Silva MNS da, Oliveira LS de, Torres R de MM, Ary MLMRB. Análise do desempenho de autocuidado em crianças com Síndrome de Down. *Cad Ter Ocup UFSCar* 2013;21(1):83-90. DOI: [10.4322/cto.2013.012](https://doi.org/10.4322/cto.2013.012)

23. Zanello E, Calugi S, Rucci P, Pieri G, Vandini S, Faldella G, et al. Continuity of care in children with special healthcare needs: A qualitative study as family's perspectives. *Ital J Pediatr.* 2015;41:7. DOI: [10.1186/s13052-015-0114-x](https://doi.org/10.1186/s13052-015-0114-x)

24. Nishimoto CL, Duarte ED. Family organization for the care of children with chronic conditions, discharged from the neonatal intensive care unit.

Texto Contexto-Enferm. 2014;23(2):318-27. DOI:

[10.1590/0104-07072014001330013](https://doi.org/10.1590/0104-07072014001330013)

25. Duarte ED, Silva KL, Tavares TS, Nishimoto CLJ, Silva PM, Sena RR de. Care of children with a chronic condition in primary care: Challenges to the healthcare model. Texto Contexto-Enferm. 2015;24(4):1009-17. DOI: [10.1590/0104-0707201500003040014](https://doi.org/10.1590/0104-0707201500003040014)

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Mailing address:

Tatiana Silva Tavares

Hospital das Clínicas - UFMG/CTI Pediátrico

Ave. Professor Alfredo Balena, 110 – Santa Efigênia

ZIP CODE: 30130-100 - Belo Horizonte/MG - Brazil

E-mail: tatianasilvatavares@gmail.com