

Challenges of nursing care for children with chronic conditions in primary health care

Desafios do trabalho da enfermagem no cuidado às crianças com condições crônicas na atenção primária

Desafíos del trabajo de enfermería en el cuidado de niños con condiciones crónicas en la atención primaria

Elysângela Dittz Duarte¹

Kênia Lara Silva¹

Tatiana Silva Tavares¹

Corina Lemos Jamal Nishimoto¹

Cynthia Marcia Romano Faria Walty¹

Roseni Rosângela de Sena¹

1. Universidade Federal de Minas Gerais.
Belo Horizonte, MG, Brazil.

ABSTRACT

Objective: To analyze the nursing work in the care of children with chronic conditions in Primary Health care. **Methods:** A qualitative study was developed through interviews with 23 nursing professionals from 16 Basic Health Units in the city of Belo Horizonte. Data were analyzed from the critical perspective seeking to identify common themes in the empirical material. **Results:** Showed up the contradictions and challenges of a practice that began for the group of children with chronic conditions. Nursing work takes a strategic and transversal place in the care of these children, which is not limited to a specific action, but that merges caring dimension of health work. **Conclusion:** There is a need to advance the care organization offering more coherent actions to the needs of children with chronic conditions in order to allow greater expression of knowledge and own nursing doings.

Keywords: Nursing Care; Continuity of Patient Care; Chronic Disease; Disabled Children; Primary Health Care.

RESUMO

Objetivo: Analisar o trabalho da enfermagem no cuidado às crianças com condições crônicas na atenção primária à saúde. **Métodos:** Estudo de abordagem qualitativa, desenvolvido por meio de entrevistas com 23 profissionais de enfermagem de 16 Unidades Básicas de Saúde do Município de Belo Horizonte. Os dados foram analisados a partir da perspectiva crítica procurando-se identificar os temas comuns no material empírico. **Resultados:** Evidenciaram-se as contradições e os desafios de uma prática que se inaugura para o grupo das crianças com condições crônicas. O trabalho da enfermagem assume um lugar estratégico e transversal no cuidado a essas crianças, que não se limita a sua ação específica, mas que conflui na dimensão cuidadora do trabalho em saúde. **Conclusão:** Verifica-se a necessidade de avançar na organização do cuidado para a oferta de ações mais direcionadas às necessidades dessas crianças, de forma a permitir maior expressão dos saberes e fazeres próprios da enfermagem.

Palavras-chave: Cuidados de Enfermagem; Continuidade da Assistência ao Paciente; Doença Crônica; Crianças com Deficiência; Atenção Primária à Saúde.

RESUMEN

Objetivo: Analizar el trabajo de enfermería dirigido al cuidado de niños con enfermedades crónicas en la Atención Primaria a la Salud. **Métodos:** Estudio cualitativo desarrollado a partir de entrevistas con 23 profesionales de enfermería de 16 Unidades Básicas de Salud de Belo Horizonte (MG). Los datos fueron analizados desde la perspectiva crítica, buscando identificar temas comunes en el material empírico. **Resultados:** Se evidenciaron contradicciones y desafíos de la práctica que se inició en el grupo de niños con enfermedades crónicas. El trabajo de enfermería ocupa un lugar estratégico y transversal en el cuidado de estos niños, algo que ultrapasa una acción específica y resulta en la dimensión cuidadora del trabajo en salud. **Conclusión:** Se necesita avanzar en la organización del cuidado para ofrecer acciones más direccionadas a las necesidades de estos niños con el fin de permitir una mayor expresión de los conocimientos y prácticas de la enfermería.

Palabras clave: Atención de Enfermería; Continuidad de la Atención al Paciente; Enfermedad Crónica; Niños con Discapacidad; Atención Primaria a la Salud.

Corresponding author:

Tatiana Silva Tavares.

E-mail: tatianasilvatavares@gmail.com

Submitted on 08/18/2015.

Accepted on 12/14/2015.

DOI: 10.5935/1414-8145.20150087

INTRODUCTION

It has been evident worldwide, in the last few years, a significant increase in the survival rate of premature infants with gestational ages and weight extremely low due to the incorporation of new technologies and specialization of the professionals in the Neonatal Intensive Care Units (NICU)^{1,2}. In Brazil, a cohort study with 198 premature children identified survival rates at 28 days of 52.5% between 25 to 27 weeks and 6 days of gestation, 67.4% between 28 to 29 weeks and 6 days of gestation and 88.5% between 30 to 31 weeks and 6 days of gestation. In general, morbidity was inversely proportional to the gestational age³.

It has been found that children discharged from NICU, especially those born in the viability threshold, present higher risks of delays in their psychomotor development, functional disabilities, bronchopulmonary dysplasia, cerebral palsy and visual impairment¹⁻⁴, comprising then the group of children with chronic conditions (CCC). The chronic conditions include those of biological, psychological or cognitive basis that lasted or has the potential to last at least a year and produce consequences as function, activity or social role limitations; dependence on medication, special food, technological devices or technological care; and the need for health services or related, and for educational services and above the usual for the child's age⁵.

It has been verified considerable productions about children with chronic conditions and disabilities who seek to analyze survival¹⁻³, characterize the demands of care^{4,6,7}, measure the repercussions for families⁷⁻⁹ and for health services organizations¹⁰. In Brazil, there has been advances in childcare, as evidenced by the reduction of infant mortality and the development of various public policies, such as the Kangaroo Method, the Agenda of Appointments for Children's Comprehensive Health and Reduction of Infant Mortality and the Stork Network. Nevertheless, the health care for children's health "is in process of construction, along with the health care in general, in a paradigm of changes from the movement of the model based on pathology and in children, to movement of construction of networks, aimed at the inclusion of the family and comprehensiveness of care"¹¹. It is noteworthy, however, that a care model to the CCC in the context of primary health care in Brazil isn't systematized yet and that the actions established by the professionals in this practice are still unclear.

So given the new reality outlined by this group of children, their care is configured as a challenge, especially for nursing professionals who are confronted with a group of children with such profile of morbidity and needs that are little known during prolonged hospitalization and readmissions, and also in home care after hospital discharge. It can be observe a certain distancing of these professionals whether in outpatient services or home care from these children and their families⁷.

Nursing work is part of a collective work process in health, in which each worker holds specific knowledge and develops joint actions with other team members¹². In this collective work process the importance of the nurse's work with the CCC, both for meeting the specific needs of care and the family guidance, highlights the need for further discussion about the actions of specific professional core and complementary actions for these children at different levels of the health care network.

For this discussion, we understand that some knowledges and practices are mobilized in the professional act that these come from a specific professional core and caring dimension that any health professional has. The specific core by problems consists in a very particular knowledge/characteristic that the professional will have to face, and that belongs in their professional field of the action. This, in turn, is covered by a territory that marks the caring dimension over any kind of professional action, constituting then the common dimension as it is to all professionals¹³.

In this perspective, nursing is part of a field which includes other professionals with distinct and complementary doings that work in order to meet the children's health needs. We have taken as the object of this study the nursing work in caring for children with chronic conditions. The aim of the study was to analyze the nursing work at care for children with chronic conditions, in continuity, in primary health care, seeking the specificity of this practice throughout the works in health.

METHODS

It is a descriptive exploratory study with a qualitative approach supported by Mark's dialectical framework. This framework guided the approach of the phenomenon in study in a theoretical and methodological path that points to the contradictions of the society, contextualizing the historical process with its movement, provision and transformation¹⁴.

The inclusion criteria for the subjects of the study were: to be a nurse, nurse technician (NT) or nursing assistant (NA) acting on Basic Health Units (BHU) in the city of Belo Horizonte, Minas Gerais; to be linked to team of family health and cover in their work area, children with chronic conditions. The city of Belo Horizonte has 147 BHU spread over 9 sanitary districts. With regard to children and adolescents health, professional health teams should follow the guidelines for action set out in the "Agenda of commitment to the health of the children and adolescents - reducing child mortality", which proposes 13 lines of care [1].

The inclusion of subjects was based on the identification of children with chronic conditions that came, within the period of 12 months, from care units to high-risk neonate of a federal hospital and a philanthropic city hospital. It

was held on the first stage, the documentary analysis of the medical records of the egresses the application, by telephone, of the Questionnaire for Children with chronic conditions Identification (QuICCC-R). This step made it possible to confirm that the child had a chronic condition and identify the BHU and the family health team to which the child was referred, according to the territorialization adopted by the city. In the second stage, the nurses were identified, NT or NA from these teams, and all the professionals from the health teams were invited to participate in the study.

In the data collection we have tried to address the diversity of sanitaries districts in the city. Thus 8 from the 9 districts were contemplated, and one of them was included because didn't have any egress patient that fit the profile aimed by this study. Data collection was interrupted after ensuring the diversity of the districts and observing the convergence in the obtained speeches. Study participants were 15 nurses, 6 NT and 3 NA, who worked in 16 BHU in the city. The whole empirical material is composed of five hours of recorded interviews, each one lasting an average of 15 minutes.

The data were collected through interviews, guided by semi-structured script, with questions about the identification and monitoring of the CCC in the covered area, the role of nursing professionals, their care actions to these children and the challenges for care. All researchers who participated in the collection had experience in conducting interviews; all of them participated in a training section to the alignment as for our understanding of the aspects of the object intended and of what was meant to be grasped by each of the interview questions; and none of them had prior contact with the interviewees. Data analysis was guided by the thematic content analysis proposed by Bardin¹⁵. Successive reading of the recordings' transcriptions of interviews were carried out to identify significant statements with consideration to the research objectives. These were organized according to their subject, and after described as in an attempt to articulate them, then we performed the further development of ideas and established their relations through a reflection about the empirical material and the theoretical framework. In this work, the themes that enabled the explanation of the nursing work on the care of children with chronic conditions in primary care were addressed.

In the results are presented excerpts from reports of the participants where they were encoded with the letters N for nurses, NT for nursing technicians and AN for nursing assistants, followed by an Arabic numeral indicating the order the interview was carried out.

All stages of the research were carried out in accordance with the regulatory guidelines for research involving human subjects of the National Health Council and the study was approved on the ethics committee on the opinion number

0004.0.439.000-10A. There was no refusal to participate in the study and all participants signed the informed consent form.

RESULTS

The results indicate that the work of nursing in care for children with chronic conditions is characterized by a multiplicity of doings that are subdivided into specific actions of nursing, by a mix of private activities and featured activities that are common of the nursing work in primary health care; and by actions made by nurses even if they don't correspond to their specific core.

In the first set are included the nursing consultations as part of the monitoring of the growth and development, vaccination actions, administration of medications, the application of bandages and use care technological devices. In the second set are the services of spontaneous demand through the welcoming, the supply of inputs and articulations to ensure the logistic support for care. It can also be mentioned in this set the nursing interventions focused on educational activities and those related to the care organization, through visits and scheduling of appointments and examinations, in a logic scheme that approaches the management of the cases. In both sets, challenges and contradictions were revealed and they picture a way of doing that is presented in a conformation of movement of a care logic still under construction, geared to health promotion and disease prevention in the assistance of the population.

Children with chronic conditions, like other children, are inserted into the child care visits, which include nursing consultation, as an action to guarantee the continuity of care. Participants report that the moment of care is marked by link relationships that allow apprehending the child care needs, schedule future appointment and establish priority for scheduling.

[...] We can do that, talk ... the stimulation they need, evaluate the development, the growth, in what the child is being stimulated, [...] we assess if they are evolving with regards to their motor, cognitive skills, we assess the diet, the emotional part... [...] We talk... because the physical examination is only a part of that nursing consultation. The rest is checking... sometimes the mother is in need of help (N2).

Our monitoring and participation, in the care of each case requires, is through the monthly child care visits, that we think it's possible to make in shorter time... and we open the agenda for that... But I think we still, also, are still limited somewhat within what we could do, that is the question of prevention and promotion, improving the general state because of the absurd demand that we have (N7).

The reports of the participants reveal the challenge of organizing work in primary care to equate the service to the spontaneous demand and the scheduled appointments. The participants recognize the limits of their action in health promotion and disease prevention stating that there are other aspects related to the practices in this field that could be worked out, but do not occur due to work overload of these professionals.

For children with chronic conditions, the care to the spontaneous demand appears as an action performed during the welcoming or the access to the routine services of the BHU - vaccination, newborn screening, among others - when it is possible to capture the attention-seeking motives and provide care:

In the welcoming it's us who perform the first contact. For example, we see the case of a child who're really crying and we prioritize this case, we pass it in front of everyone [...]. And in newborn screening we already have the guidelines, all of us who are there do a mother listening, ask the mother, we check the child, if they're yellow, we check navel (NT21).

Study participants did not refer the scheduled appointment with actions geared especially for children with chronic conditions. These children are assisted in the same model of other children even though there is the recognition of their specific needs. This recognition directs the sort of professionals to compose a different arrangement in the organization of care with less spacing between the appointments or even a single meeting with mothers and caregivers, marked by the attempt to capture their aspirations and resolve questions about the care of the child.

I think there isn't, I do not know if I can say there is an action that is different from what we do with the other children. Despite the fact that we try to check the patients individually, each child, we see what they need, even if it is not a child with chronic conditions, but they will have needs that are different from the children who are from another child, neighbor, cousin... [...] The kind of support that mother has to create the child. And we try to identify the individual needs and adequate them to the guidelines (N17).

Still in the programmatic actions, nurses report the completion of the actions of the fifth day and vaccination for children with chronic conditions, in the same way that is done for other children who seek the unity of primary care.

We're doing the action of the fifth day. [...] But, nothing different (N15).

We take really good care of the vaccines [...] normal measures for any other children (N13).

In the work of nursing assistants and technicians stands out a reference on the technical procedures aimed at administering medications and care with technological devices, as mark of a care that is made for children with chronic conditions. The application of bandages and care with gastrostomy, tracheostomy and tubes are actions that in the health service are assigned to the nursing. When the care is continued in the home care, it is up to the nursing to guide and prepare mothers for the maintenance of the care:

The care with the tube ... the care with the bandage of the tube ... we provide them. But we could give some orientation [...] if they have a bladder catheterization we can give them directions. If it's a tracheotomy ... which is a care with aspiration, we can give directions (NT6).

The wrong drug use is frequent, because usually these chronic kids, they make use of medication [...]. It is very important the mother to be well oriented (N1).

The orientation of care, whether is a matter of feeding, or a general care, for example, a child that has reduced mobility. Orienting the mother as for the decubitus change (N11).

In guidance and preparation for the care, nursing puts in action the know-how that comes from the common core of health professions: education in health. Despite being in a territory shared by occupations, health education here evoked turns primarily to the portion of the care given to the nursing, composing then their specific core of action. So it is the nursing responsibility to perform the educational practice that provides opportunities for mothers and their families to have a better understanding of a chronic condition and guidance on the care with the use of drugs and diets, handling devices for this purpose, positioning and stimulating the child, as well as guiding them on the characteristics of growth and development of a child with chronicity.

In the same vein, the educational groups with actions that are not specific to nursing are also included, but participants report that only these professionals perform the primary care:

So these collective actions that we do are punctual evaluations. In the example of malnutrition, the most punctual assessment on the development that the child had in that period of growth, is whether their

gained weight or not. But we always direct health education actions that are connected with this issue of the problem that the children are presenting, targeting both parents and children. For individuals with asthma we have also created groups, collective actions to guide and correct techniques to sanitize the spacer, to use the medication, the care of dental hygiene... I think that also contributes for the care (N17).

I find it interesting to create groups... children that have to be accompanied because of these risks (NT8).

It stands out in the doing of nurses a set of coordination actions that includes, among others, planning visits, calling other professionals, scheduling appointments, guiding nursing technicians. In more complex cases its required home assistance from the staff, so it is up to nurse the organization of out the care and monitoring of the care carried out. However, the reports of the participants allow us to infer that these actions take place without the potential they can offer as care strategies for children with chronic conditions.

We trace a care plan, but it goes to the nurse ... to the doctor, they interfere in what they think regarding the medication, sometimes with respect to diet, but the environment, care ... usually it involves the prescription of the nurse [...] We established that the visit will be monthly according to the risk, the vulnerability of the child, of that family; or else it [the nursing technician] goes each month to the house and he brings us the feedback, for us to go perform the necessary interferences (N2).

If they are more complex situations, we try to make a home care, with targeted guidelines in terms of care, the prevention of these aggravations to the parents and caregivers. And the nurses always get for themselves the responsibility of coordinating the services these teams. So, for example, chronic conditions such as respiratory, asthmatic conditions, we try to keep a file, a control to monitor these kids. Who isn't all right, who's missing, who was discharged, active search, new additions [...] (N17).

Participants also reported that have been responsible for providing the necessary inputs, where these are one of the most common practices in the set of nursing actions.

Equals when it happened, their needed oral health, they asked support or material, [...] I had to make the visit, make a report, program the use of swabs, tubes, day by day material, serum (N13).

Our support depends on the chronic patient, frequently they already have a very structured network. [...] So they have a stand outside the basic attention network. Then we only need to make the the quarterly report to order the inputs (N4).

The report of the participants allow us to apprehend that the care characteristics provided to children with chronic condition requires professional training not only from the nurses, as it constitutes a challenge for them. There is the recognition of the need for investment in training of professionals for the care of children with chronic conditions in primary health care, as they consider the graduation insufficient for such. One of the strategies to overcome this challenge is to seek support from professionals with some knowledge about this population in a mutual aid process:

So, I must have made two childcare in my graduation... So I think we really have difficulties... you face the reality, you have to adapt and pursue try to improve (N5).

I feel a bit outdated as well. Because not all professional are like this... trained to assist such children the health center. I often see that they seek the best person to reference (N15).

Besides the importance of the training of nurses to meet one of the challenges for the care of children with chronic conditions they refer to the composition of a multidisciplinary team that can work together and continuously. It expressed the recognition of the complementarity of different knowledge and contribution it can provide for the care of these children.

[...] we often lack the appropriate professional, for example, if we do not have a nutritionist, that would be from the [Centers of Support for Family Health] CSFH. So we don't have that professional. Then, it's necessary the integration of more professionals to the team. Having the the monitoring of psychologists is also very good, who makes the monitoring of cases that we send them [...] we do team meeting, all our cases are discussed among all professionals of that team and we give the due referrals through these discussions (N21).

DISCUSSION

The analysis of the results suggests that the work of nursing in care for children with chronic conditions in primary health care occurs at the boundary of a making of the nursing area itself which is complemented by unspecific actions, not

the appropriated by other professionals. These nonspecific of care to children, which could be part of the work of different team members, when incorporated into the making of the nursing team professionals, assume a practical character that is a characteristic of this profession.

In this field of, the data indicate that the nursing work in caring for children with chronic conditions reproduce the programmatic actions and attention to spontaneous demand taken in primary care for the health of the kids. In this model, the nursing actions indicated by the participants have few elements that mark the difference in the care offered to the children in general. The difference, if any, is unsystematic and marked by timely intervention of an increase of the actions offered to all children; no evidence of innovative approaches that would be represented by a restoration that combines, besides the programmatic offer, a set of new actions aimed at the specific needs of these the children. Among these, they would include, for example, the systematic home care and timely rehabilitation actions.

The absence of a specific approach hinders the expression of a new model of care, which would advance to a proposal of care sustained by the needs in a perspective of promotion of life. In this context, the work of nursing is not adjacent to the method of organizing care for children with chronic conditions in primary care, which reveals challenges.

Traditionally, do nursing is expressed in three dimensions: watch/care for, manage and educate, that form the technological basis of the profession¹⁶.

In the dimension of the care, It is revealed the magnitude of the procedural intervention for which turns the nursing work to children with chronic conditions. In the specific case of this group, given its condition, we expect increased demand for care due to disability, medication use and technological dependence, determining special care in daily life in relation to other children of the same age without changes in growth and development⁵. Despite this recognition we highlight the contradictions expressed in the organization of care in primary care that does not open spaces to meet the demands and needs apart from the usual way of doing care of the other children.

It is known that chronic condition care requires other than those restricted to recover the biological body. Therefore, the working process should incorporate new technologies. Among these, it stands out in the findings, signs of doing that approaches the management of cases with nurse's responsibilities in mobilizing other professionals and services to meet and monitor the needs of children in chronic conditions. The management of the case is characterized as a cooperative process that included the identification of cases, assessment, planning, monitoring and reassessment of care actions in order to favor a humanized care and of quality¹⁷.

In attention to children with chronic conditions, case management by primary care professionals can be an important provision as it improves the quality of life by reducing the disability, the demand for emergency services because of acute exacerbation of chronic condition, unnecessary hospitalizations and mortality¹⁷. Also it can help reduce fragmentation of care, typical of situations where the demand for specialties is an alternative priority, as it has been for children with conditions chronic. These limitations, show up a weakness of the care model, which is still centered on the care for acute conditions, sending children with chronic conditions for greater technological complexity service, making it difficult to bond with primary care¹⁸. The relevance of strengthening family health strategy, so that the family does not lose its careful reference when their need special assistance, it is also stated in another study¹⁹.

By taking over the management of the case, as typical of the nursing work, the dimension acquires a broader and systemic perspective that overcomes the dichotomy between care and manager, requiring changes in the training and knowledge and practice of nursing in the organization of care²⁰. Providing inputs and providing logistic support are key functions for the care, in the particular the group of children with chronic conditions. These are the actions for care as well as the support system is for health care networks, ensuring that each service - or professional care - operates single and efficiently. The management of the case will then appear as a care component that can bring together the three dimensions of nursing work in the micro space of care.

The dimension of educating, including family education also makes up the toolbox in the nursing work for children with chronic conditions, which aims to prepare the family for the performance of procedures and the identification of the care needs. The education, in turn, is also a contradictory object, because while it is necessary for the continuity of care at home, should be planned and operated in a balanced ratio not to feature a full transfer and disclaimer of professional care to these the children. So the challenge is to establish the limits expressed in a performance that, in the border care, are faced with weaknesses in the organization of care, creating insecurity for families and contributing to the discontinuity of care^{1,10,18}.

The findings direct to the understanding that the work of nursing in care for children with chronic conditions is concerned in greater proportion to what is common to different cores health professionals, with specific actions to a lesser frequency in their work. This specificity, in part, can be attributed to the blurring of children care model with chronic conditions and logic of the organization of primary health care that is in nursing and, above all, the nurse, the professional who occupies the baseline of all assistance and administrative proceedings in this scenario of care.

Even assuming the critics to this model, the study points out that it is for this reason - being at baseline - that the nursing work takes a strategic and transversal place in caring for children with chronic conditions is not limited to a specific action, but that it overflows and invades the field of other professionals being responsible for ensuring the articulation that converges in the caring dimension of health work¹³.

But there is the challenge to discuss the performance of this professional, which may require modifications to their training in order to instrumentalize it to a technological composition of the work that allows them to deal with the ownership of specific doing and actions that complement the comprehensive care of children with chronic conditions, overcoming the theoretical and technical weaknesses, as well as the limitations for coordination between the different services and sectors, resulting in less resolute care to children and their families¹⁹.

In primary health care, the incomplete implementation of government strategies is related to prioritizing attention to acute diseases and spontaneous demands, which limits the link between health services and follow-up of users with chronic diseases. It's noteworthy that given the increased morbidity and mortality from chronic conditions in the country, the deficiency in the growth and development of children can trigger chronic health conditions¹¹.

Finally, it should be argued that the care needs presented by children with chronic conditions and their families are an interdisciplinary subject that must be met in the articulation with a multidisciplinary work in which the nursing staff is located. In this model, no work is bigger or wider than others, because all are complementary to the comprehensive care¹³.

CONCLUSION

It was concluded that the nursing work in caring for children with chronic conditions is characterized by specific actions and common health work actions in the field of primary care. Although incipient, the convergence of these actions is presented in case management technology that demonstrates the articulation of the dimension of care, educate and manage the work of nursing.

As typical of a construction process process, the results demonstrate the contradictions and challenges of a practice that is opened to the group of children with chronic conditions. It is necessary to advance the care organization in primary care with new or renewed actions including the specificity of this population group in a more coherent care to meet their needs. In another model, it's necessary to discuss the insertion of the nursing work in a harmonious equation of care to spontaneous and programmatic demand to allow greater expression of nursing field nursing.

Consequently, it is necessary to recover the technologies in nursing work that will demand beyond the procedural intervention, the traditional forms of health education and the classic ways of managing the sectors and stocks in primary care, a new toolbox more consistent for the caregiver model in permanent construction.

It is recognized that other studies need to be developed on the theme, in special those that turn to the articulation and multi-professional co-responsibility in the health work in primary health care interface. It's necessary to consider as a limitation of this study not conducting interviews with more participants by professional category in each of the BHU due to the reduced number of professionals who identified themselves as active in meeting the CCC. However, the reliability of the data was obtained by convergence in the speeches of the participants and the results were supported by the scientific literature produced on the subject.

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