

# Maternal care at home for children with special needs

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## Mother's care at home for children with special needs

**Objective.** To identify the feasibility of home care and difficulties of mothers who deliver this care for children with special health needs (CRIANES) and to analyze the role of nurses as facilitators of this care. **Methods.** This descriptive study with a qualitative approach included ten mothers of CRIANES who completed a semi-structured interview at a teaching hospital in the municipality of Rio de Janeiro, Brazil. Data were analyzed using a thematic analysis. **Results.** Participants pointed out as difficulties the accessibility of treatment facilities and the presence of complex disease. The administration of medicines was classified as both easy and difficult. Features that made home care feasible were help of the child and preparation of nurses in the hospital context for home care. Maternal love helped mothers to overcome difficulties. **Conclusion.** Encouragement from the nursing team for centered family care is needed. In addition, mothers should be better prepared for the transition from hospital to home. The health network needs to be reorganized with inclusion of CRIANES in the primary care network in order to reduce the dependency of this population on hospitals and to help broaden the social network for CRIANES.

**Key words:** child health; child care; pediatric nursing.

## El cuidado materno en casa a niños con necesidades especiales de salud

**Objetivos.** Identificar las facilidades y dificultades de las madres en el cuidado domiciliar de niños con necesidades especiales de salud; analizar el papel de la enfermera como facilitadora de ese cuidado. **Metodología.** Estudio descriptivo con abordaje cualitativo. Se obtuvo la información mediante entrevistas semiestructuradas realizadas a diez madres con niños con necesidades especiales en salud en un hospital universitario del municipio de Rio de Janeiro, Brasil. Los datos fueron analizados temáticamente. **Resultados.** Las madres identificaron como principales dificultades la accesibilidad a los lugares de tratamiento y la presencia de patologías complejas en los niños. El tratamiento con medicamentos fue dialécticamente fácil y

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difícil. Entre las facilidades se presentaron la ayuda al niño y la preparación por parte de enfermería en el contexto hospitalario para el cuidado en el hogar. El amor materno ayudó a las madres en la superación de las dificultades. **Conclusión.** Es necesario que enfermería estimule el cuidado centrado en la familia, mejorando la preparación de las madres para la transición del hospital al domicilio. Adicionalmente, es prioritaria la reorganización de la red de salud con el fin de incluir acciones de atención primaria para estos niños, para disminuir la dependencia al hospital y contribuir a la ampliación de su red social.

**Palabras clave:** salud del niño; cuidado del niño; enfermería pediátrica.

## O cuidado domiciliar de mães de crianças com necessidades especiais de saúde

**Objetivo.** Identificar as facilidades e dificuldades das mães no cuidado domiciliar de crianças com necessidade especial de saúde (CRIANES) e analisar o papel da enfermagem como facilitadora desse cuidado. **Metodologia.** Estudo descritivo com abordagem qualitativa, desenvolvida através de entrevista semiestruturada com dez mães de CRIANES em um hospital universitário no município do Rio de Janeiro, Brasil. Os dados foram analisados através da análise temática. **Resultados.** Apontaram que as dificuldades foram à acessibilidade aos locais de tratamento e a presença de patologias complexas pelas crianças. O cuidado medicamentoso foi dialeticamente fácil e difícil. As facilidades foram a ajuda da criança e o preparo da enfermagem no contexto hospitalar para o cuidado domiciliar. O amor materno ajudou as mães na superação das dificuldades. **Conclusão.** É necessário por parte da enfermagem o estímulo ao cuidado centrado na família, um melhor preparo das mães para a transição do hospital para o domicílio a reorganização da rede de saúde com a inclusão da CRIANES na rede de atenção primária, a fim de diminuir a dependência do hospital e contribuir para ampliação da rede social da CRIANES.

**Palavras chave:** saúde da criança; cuidado da criança; enfermagem pediátrica.

## Introduction

Recent technological developments have benefitted and enabled the survival of a growing number of children. For a variety of reasons, such as trauma, congenital malformation, chronic disease, and prematurity, these children need technology and care from a multidisciplinary team and their family. This distinguishes them from other children.<sup>1</sup> They have special health care needs, and have been identified in Brazilian literature as children with special health care needs (CRIANES) and in the international literature as children with health care needs (CHSN).<sup>1,2</sup> CRIANES are classified according to five care needs: development, technology, medication, modifications, and mixed routine. The first group includes those who need psychomotor and social rehabilitation; the second includes children who depend on technology (e.g., tracheostomy, gastrostomy, implantable

catheter for chemotherapy); the third includes children with pharmacodependence (e.g., those receiving antiretroviral therapy), those who are bed-bound, who require changes in habitual care manner, including daily activities (feeding, personal hygiene, getting dressed), and those with mixed needs.<sup>1-3</sup>

In a hospital context, CRIANES constitute a permanent population and occupy hospital beds for long periods. They need complex and continuous care 24 hours a day provided by a multidisciplinary team, especially a nursing team. For life maintenance of these children, nurses use scientific and technological knowledge from their professional background, such as preparation and maintenance of venous infusions, handling of intravenous devices inserted into deep veins,

oxygen administration, handling of feeding probes, urine elimination, and removal of secretions. These care activities are developed to maintain the child's life and recover from the disease; therefore, they are centered on the disease, not on the child.<sup>1-3</sup> Upon CRIANES' clinical stabilization and hospital discharge, the care context changes from the hospital to the home. Sociocultural history routes of family care point out that, at home, the care is mainly provided by women, usually mothers, who are constantly present in their son's or daughter's life and are responsible for care of children and family. In this context, therefore, care to CRIANES is predominately provided by a woman. In general, mothers are the main and, sometimes, the only caregiver.<sup>3,4</sup>

Mothers of CRIANES face a care reality that does not belong to their common sense, i.e., the level of care required is not what they expected. At home, these children will need medicines, follow-up at psychomotor rehabilitation services, monitoring of growth and development, and changes in daily life and usual manner of care. In addition, they have to adapt to technologies not experienced before.<sup>4</sup> For nurses, home care presents challenges related to the need to switch from a hospital care context to a home care context and the enlargement of the family social network in order to include other caregivers, promote health for CRIANES and be a facilitator to integrate the child into society.<sup>1</sup> For the government, the challenge is to guarantee public policies and promote integration of these children into society. This infant group has become a significant problem for public health in many countries.<sup>5</sup>

This study was performed because of the clinical and social vulnerability of CRIANES. Clinical vulnerability results from complex pathologies that require differing care approaches, recurrent and prolonged hospital stays, and assistance that is often provided only by the family, considering that nursing care for these children is normally given in the hospital. Social vulnerability occurs in a widescale and programmatic level and in the absence of specific public policies to address the needs presented by CRIANES.<sup>3-6</sup> In this study, we

used Paulo Freire's ideas-strength as a theoretical support for the needs of mothers to find answers for situations-challenges during home care to CRIANES; this study also used a nursing education, reflexive, and dialogical perspective. Freire begins with the conception of human beings as temporal-space routes with a calling to be a subject. By reflection of their own situation and their concrete environment, humans become conscious of their history and temporality, reflect about life itself and seek to overcome the challenges they faced; such reflection also enables them to produce culture and history.<sup>7</sup> On the basis of the problem presented, we sought to identify the feasibility of home care and the difficulties of mothers who deliver this care to children with special health needs and to analyze nurses' role as the facilitator for home care.

## Methodology

This was a descriptive study with a qualitative approach. Participants were ten mothers of children with special health needs who had been hospitalized in the pediatric inpatient unit of a teaching hospital in the municipality of Rio de Janeiro. Inclusion criteria were age older than 18 years, being a mother and home caregiver of CRIANES, and having a child admitted to the pediatric inpatient unit at the hospital where this study was conducted. We excluded families who did not have experience with home care of CRIANES.

Data were collected between October 2013 and March 2014. In the beginning, we consulted medical records to complete a form for and characterize CRIANES. This first step was necessary to learn about the health care needs of these children, and, therefore, to contextualize difficulties and feasibility of home care, as well as to analyze the nurses' role as facilitator of home care. After the characterization of CRIANES, we conducted a semi-structured interview consisting of six open questions with mothers who were accompanying the child during hospital admission.

Questions addressed issues related to feasibility and difficulties of mothers delivering home care and about nurses' role as facilitator of home care.

The field study was conducted after approval of Ethical and Research Committee (number 421062) and mothers signed the consent form. To guarantee privacy, interviews were conducted in a room outside of the hospital inpatient unit; confidentiality of participants was ensured by using the word "Mother" along with a number corresponding to the order in which they were interviewed. We followed Brazilian resolution number 466/12 of the National Health Council<sup>8</sup> concerning studies with human beings.

Data collection was finished when theoretical saturation occurred; this was verified by repetition of experiences related to challenges and feasibility in care delivery to CRIANES.<sup>8,9</sup> A thematic analysis was applied to empiric data from the interviews; it enabled discovery of the meanings, both manifested and latent, brought by participants. This is the best format with which to perform a qualitative investigation of health-related material.<sup>10</sup> This analytical method was used in three stages.<sup>10</sup> In the first stage, a fluctuant reading of the transcripts of digital recorded interviews was done, which makes up the textual corpus of the study. In the second stage, material was explored with identification of thematic units. In the third and last stage, data were grouped in the following four thematic units: dialectic of feasibility of/difficulties in care to administer medication to CRIANES, difficulty accessing health care facilities, difficulty in providing care due to the complexity of the child's disease, and nurses' role to prepare the mother to deliver home care.

## Results

The children ranged in age from 2 years and 11 months to 9 years old. Eight CRIANES had special health needs because of congenital causes, such as syndromes and malformations, and two had acquired causes. All children had a history of

more than one hospital admission. The child of Mother 4 had the fewest readmissions at 2, and the child of Mother 1 had the most readmissions at 9. Seven children had mixed care needs, and three children had needs related to medication, modified habits, and growth. In the testimonials of the mothers of CRIANES, we sought to identify the features that made home care feasible and the difficulties they faced delivering such care, as well as to analyze nurses' role as facilitators of home care delivery to children. These characteristics are presented in the following thematic needs:<sup>10</sup>

### **Dialectic of feasibility of/difficulties in providing care through administering medication to CRIANES**

Mothers reported that medication administration to CRIANES is a dialectic feature: sometimes it is presented as easy and sometimes as difficult. Therefore, this type of care entails a challenging and limiting situation for mothers delivering home care: It requires me to also observe medications because sometimes I forgot to give my child the medicine. I also talk with him (the child) a lot and sometimes I ask him to help me to remember and he reminds me about it (Mother 2); The phenobarbital has a very bad taste and he (the child) does not like it, it's very difficult. He (the child) coughs, chokes and vomits and many times he did not take the medicine (Mother 3); For me the easiest thing is to administer the medicine. He (the child) got used to his medicines. So, you just ask him to open his mouth, and he does it automatically despite being an 11-month-old child, he got used to taking it, got used to the pace, he knows on that time he needs to take his medicines (Mother 5).

In the testimonials of Mothers 2 and 3, difficulties with administering medication included forgetting times to administer the medicine, the bad taste of the medicine and non-acceptance of the medicine by their children; for Mother 5, the routine of taking the medicine is something that makes this care feasible. The involvement of the child in his/her medication care as reported by Mother 2 places medication care in a dialectic field, between

easy and difficult. It can be considered easy when the child with special health needs reminds the mother about the time to take the medicine; it can be considered difficult when the caregiver forgets and must remember to provide the care without the child reminding her. The routine of medicine administration, every day at the same time, can be a feature that facilitates caring, as reported by Mother 5.

### **Difficult accessing health care facilities**

The accessibility of treatment facilities that are distant to the mothers' home were difficulties discussed by two mothers, as can be seen in following reports: When the consultation is scheduled in the outpatient unit, I can't come because I can't afford the transportation. I took two buses to go the hospital, I just can't afford it! (Mother 6); My greatest difficulty is when he becomes ill at home—there are no hospitals near my house, a good hospital for my child. The hospital closest to my house lacks a cardiologic emergency service, but I go there for first aid and then he (the child) gets transferred (Mother 5). Because of clinical weakness, the CRIANES present dependency at the hospital where they receive treatment. In emergency situations, Mother 5, who lives 40 km from the health institution where her child attends ambulatory follow-up, seeks a hospital near her home because she knows that the child will be transferred and the hospitalization of the child will be facilitated. The distance between home and hospital also is a difficulty and a challenging situation<sup>7</sup> in home care when more than one type of transportation is needed to travel there; this generates a cost that some mothers cannot afford. These facts limit follow-up appointments scheduled at ambulatory facilities.

### **Difficulty in care due to disease complexity**

In this category, mothers reported difficulties providing care due to disease complexity and fear of the child's death: *So, at home, I have to*

*check my child's blood pressure to see if his blood pressure is low or high. The biggest fear of a mother of a child with cardiomyopathy is to wake up and have your child dead. After he was discharged, I spent many nights awake. I was exhausted and reaching my limits (Mother 5); My son has to drink plenty of water during all day in order to not die, he needs to drink more or less 10 cups. This is difficult and stressful for me and also for him because he doesn't like water, and I have to combine water with sugar, juice, things like that, and now he will undergo a gastrostomy and the procedure will help in this part, because he suffers with that, but he doesn't like water, he never did (Mother 3). We found that care provided by mothers of CRIANES at home goes beyond the care needs of most children, and, as time goes by, they discover how their child's body works and overcome technological care difficulties.<sup>7</sup> In the past, I have had problems with tracheostomy, but now I deal with this situation easily. I also do not have more problems with gastrostomy because she (the child) has had a gastrostomy since she was 3 months of age (Mother 1).*

### **Nurses' role in preparing the mother to deliver home care**

When mothers were asked about the orientation they received by the nursing team for home care, some reported guidance<sup>7</sup> but others reported having received no guidance. *First, the nurse explained everything. How to change the gastrostomy probe, and how to feed my child. I was very afraid of aspiration of her tracheostomy, and also to clean it, but now the ICU (intensive care unit) staff gave all instruction. Today I got the way to do it, after receiving the orientation from the nursing team (Mother 1); Yes, they provided information, and it helped a lot, I left the hospital feeling totally trained! (Mother 7); No, I never received information! You know, my son was born and I adapted myself to the routine he needs, you understand? To me it was easy, because I love my son (Mother 4).*

During the hospital stay, mothers of CRIANES must be taught by nurses and other health professionals

about child care needs and how to meet these needs. These orientation sessions must be done during the hospital stay, not only when discharge is approaching. This behavior would help reduce events such as the one reported by Mother 4, who affirmed not receive any information from the nursing team. Her testimonial show that approximation and strengthening of the bond with her child gave her the skills and that such feelings worked as a mediator in care. On the other hand, Mother 1 received nursing team orientation and, therefore, showed more self-confidence and security in delivering care, especially for activities related to aspiration and cleaning of the tracheostomy of her son.

## Discussion

Home care provide by mothers of CRIANES can be defined as life preservation.<sup>6</sup> This care is developed through constant, intensive, 24-hours-a-day surveillance of the child that is facilitated by the knowledge acquired at the hospital or encouraged by maternal love. The fear of the child's death is constant in a mother's life; the mothers have given up their social life<sup>11</sup> to devote their life to all home care needs. Maternal love gives the mother the ability to overcome difficulties and take care of the child even when she does not receive orientation from the nursing team. For mothers, this love is acquired and developed daily and helps them to overcome difficulties presented in the care routines of CRIANES. Common sense suggests that this love originates from an unconditional feeling that is not reinforced by the myth of maternal love, where existence of this feeling between mother and child can be fragile, can exist or be absent, and can appear or disappear.<sup>12</sup> Difficulties for developing home care go through a dialectic of feasibility and difficulty related to medicine administration.<sup>1,2</sup> For some mothers, medication care is difficult because it requires rigorous timing and dealing with the child's lack of acceptance. The caregiver can forget to give the medication, and the child can react to the bad taste of the medicine by coughing, choking, and vomiting, which can compromise the treatment.<sup>13,14</sup>

To help mothers overcome this difficulty, nurses can negotiate, based on Freire's dialogic education,<sup>7</sup> such strategies as use of schedules, an alarm clock, individual pill boxes, and administration of medicines that taste bad along with food (if the food does not interfere with medicine absorption).<sup>15</sup> For other mothers, the facility exists when the child helps them to remember the time of medicine administration and accepts it. In this sense, encouraging the child to engage in self-care and respecting their biologic age and cognitive development can be a feasible action for medication administration. Therefore, children become co-responsible in their care process, can help the mother, and may promote changes in their daily life to improve their well-being.<sup>16</sup> These assumptions corroborate with Freire's theoretical presuppositions<sup>7</sup> stating that all educational processes make sense only when they are based on genuine concern with real needs and the autonomy of individuals, who are understood as subjects in the learning-teaching process.

CRIANES present clinical fragility<sup>3-6</sup> that makes them dependent on professional care, follow-up at outpatient units and frequent hospital admission. The care that these children need is available from a variety of sources and in the hospital because these institutions have concentration of health professionals and fundamental technologies to address their health needs. However, when mothers need to go to the hospital they find accessibility difficulties due to the geographic distance from their home<sup>17</sup> and also financial expenses stemming from bus fares. According to the guidelines of universality, equality and integrality stated by the Brazil Unified Public Health System (SUS, acronym in Portuguese),<sup>18</sup> CRIANES must be assisted at any health unit, not only at the hospital at which they receive outpatient unit. The child's health network, however, is limited to a referral hospital, which may cause inadequacies in care and functioning of SUS. In theory, SUS is a structure in a hierarchical care network with a referral and contra-reference system among varying levels of complexity; as a result these children can be invisible at primary and secondary care levels. In this way, the referral

network of SUS works in a singular manner, and therefore no contra-references exist because the child is always referred to the hospital where he/she is treated, regardless of the geographic distance or whether he/she is assisted in the emergency unit in other health institutions.<sup>1,4,6</sup>

Mothers of CRIANES can face sadness and financial difficulties because of the specialized care required by CRIANES that involves high costs due to constant coming and going to the hospitals and rehabilitation services, medication expenses, special diets, and consumption, among others. The fact that at least one member of the family, often the mother, stops working to dedicate herself to the integral care of the child at home reduces the family income and may cause financial problems.<sup>1,4,6,19</sup> A way to evaluate the economic impact on the family of CRIANES would be for the Brazilian government to provide financial support and to establish a specific public policies for this population. Social programs and benefits, however, are not diffused for the general population, and this leads to a lack of knowledge about the rights of the child; health law is also needed. Therefore, it is important to popularize and facilitate access to existing benefits for families with CRIANES.<sup>20,21</sup>

Nurses, as facilitators of home care, must attempt to reduce the distance between scientific knowledge, created and imparted at the hospital, and common sense knowledge, which belongs to the environment of mothers who deliver care at home. To reduce this distance, health professionals, especially nurses, need to promote training for care, based on respect for existing knowledge of caregivers, and manage the understanding and fundamental practices to assist the multiple needs required by these children.<sup>6,7,22</sup> Nurses have an educational role in health care. Through nurses' knowledge, management, care and dialogical skills, nurses must assume the role of discharge coordinator to prepare the mother and the family for home care.<sup>21-23</sup> This care must be organized and planned by the mother, family and health professionals in a manner that considers the inter-relation between popular knowledge

and scientific knowledge toward guidance and educational practices in order to promote health and facilitate care outside of the hospital.<sup>21</sup> These actions must be planned and implemented in a deliberate manner with actions centered on development of skills and maternal competencies; the goal would be to prevent a hospital discharge in which mothers leave the hospital without mastery of or no knowledge about their child needs. The approximation of mother with nursing and care needs of the child is a facilitator because knowledge is required to delivery care.<sup>22</sup> In this way, the nurse will help to manage all care needs, including how to administer the medicines, and all other home care actions needed in order to coordinate them with the family's life routine.<sup>1,15</sup>

We conclude that home care to CRIANES may pose some difficulties because of the invisibility of this group, along with public policies, the weakness of health network and lack of guidance and training for nurses on how to deal with and prepare mothers for the transition from hospital care to home care. Centered family care should be encouraged in order to reduce the overload of mothers as single caregivers; the health network should also be reorganized to include CRIANES in the primary care network in order to reduce their dependency on hospitals and, consequently, help broaden the social network of CRIANES.

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