



CHARACTERIZATION OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND CAREGIVERS IN A TEACHING HOSPITAL¹

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ABSTRACT

Objective: to characterize children with special health care needs admitted to a pediatric unit of a teaching hospital in relation to their clinical conditions, care demands and sociodemographic situation. Also, characterize the family caregivers of the children regarding their age and degree of relationship. **Method:** a descriptive study with a quantitative approach, conducted with 25 children with special health care needs admitted to the Pediatric Inpatient Unit of a teaching hospital. Data collection was performed using a form and analyzed using descriptive statistics. **Results:** in the period, 44% of the children hospitalized had special health care needs. Regarding the demands of care, all have modified habits of usual care, 36% use some type of technology, 40% have demand for neuropsychomotor development, 92% follow-up with some health service and 80% are in continuous use of medication. **Conclusion:** this study provides data that can be used to support the development of strategies that reorient nursing care practice.

Keywords: Pediatric nursing, Child Health, Health Profile.

INTRODUCTION

The possibility of survival in children with perinatal problems, trauma and carriers of chronic diseases is possible in recent years due to the benefits of the accelerated evolution of drugs and equipment applied to human health. Thus, technological advances, associated with the decrease in infant mortality, have contributed to the emergence of a new group of children, emerging in health services, described as children with special health care needs⁽¹⁾. This group defines children who have or are at greater risk of chronic, physical, developmental, behavioral, or emotional illness and require health services of a type or quantity beyond that required by children in general⁽¹⁾.

According to the Child and Adolescent Health Measurement Initiative (2016-2017), about 18.8% of children and adolescents aged 0-17 years in the United States live with special

health care needs. About 19.5% of these children have four or more types of special health care needs, including the need for more complex services that go beyond a primary need, such as prescription drugs, to keep their health condition. This same survey showed that these children are more likely to be male (21.3%) and older 12-17 years (24.4%)⁽²⁾.

In Brazil, this clientele was named as CRIANES (Children with Special Health Care Needs)⁽³⁾. There are no official epidemiological rates for this clientele in Brazil⁽⁴⁾. Brazilian epidemiological data show that mortality rates have dropped, but the number of newborn deaths in the first 30 days of life is still high, as well as the increase in perinatal complications, such as intrapartum asphyxia⁽⁵⁾. A preliminary study carried out at the outpatient clinic of a teaching hospital and at the emergency room in southern Brazil showed a 36% prevalence of CRIANES⁽⁴⁾. Thus, the absence of epidemiological data or the

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invisibility of this group in the data available in Brazil represents a problem for the design of specific public policies for CRIANES^(3,4).

The CRIANES were classified into five types, according to the type of health care they need⁽³⁻⁴⁾. In the first type, there are children who require some special health care related to their motor or developmental condition; in the second, children who need continuous use of medication to survive and to have quality of life; in the third, those that require the use of technological resources, such as probes, semi-implanted catheters, tracheostomy tubes, among others; in the fourth are those that need modified habits of usual care for their survival, demanding beyond those usually required by children, and finally those with mixed demands, presenting all these demands at the same time⁽³⁾. It is observed that the complex care presented by CRIANES is performed in a solitary way by the parents at home, with frequent hospitalizations and little knowledge of health services about the demands of complex care presented by these children⁽⁶⁾.

In this sense, it is known that there are no official data on CRIANES in Brazil. It is noteworthy that screening CRIANES among the general population, besides measuring the prevalence of these children, can also support the restructuring of services and training of professionals to provide the main care demands required by this clientele⁽¹⁻⁴⁾. In addition, the screening of this clientele can contribute to the design of preventive illness strategies for this age group, and also direct the elaboration of specific public policies to promote care for CRIANES^(3,4).

Given the above, this study aimed to characterize children with special health needs admitted to a pediatric unit of a teaching hospital regarding their clinical conditions, care demands and sociodemographic situation. Also, to characterize the family caregivers of the children regarding their age and degree of relationship.

METHODOLOGY

This is a descriptive study with a quantitative approach, conducted in a Pediatric Inpatient Unit (PIU) of a teaching hospital. The hospital is a health reference for the central region of Rio Grande do Sul and has 16 pediatric beds,

separated into surgical, infant and school-age Children wards.

The study population consisted of children classified as CRIANES, according to the diagnostic history and the identification of the demand for continuous care, through the screening of medical records at the time of hospitalization. As selection criteria, the following were considered: CRIANES under 12 years of age according to the classification proposed by Article 2 of the Statute of the Child and Adolescent (ECA), Law n. 8.069, of July 13, 1990 (BRAZIL, 2006). There were no excluded participants.

From the confirmation that the hospitalized child was a CRIANES, data were collected using a previously developed form, which was filled with data collected from the medical record and through a structured interview with the family caregiver at the time of hospitalization. The form contained variables related to the child's birth, sociodemographic and clinical characterization, previous hospitalizations and specific care related to the child's health care needs. The free and informed consent form was presented to the family members participating in the research.

Regarding the clinical variables related to CRIANES, the number of hospitalizations and previous diagnosis, current diagnosis, we questioned; the reason of the special health care need. Regarding the child's care demand, continuous use of medication, use of some health technology, demand for neuropsychomotor care, modified habits of usual care and need for follow-up with health services were questioned.

The complications during hospitalization and discharge guidelines were classified and questioned as: Probe care, colostomy care, medication administration guidelines, bladder catheterization guidelines, aspiration guidelines, tracheostomy care, oxygen therapy care and modified habits of usual care guidelines. The date of hospitalization, discharge and destination of the child were also described in the form.

Data collection took place in the second semester of 2013. Data were entered into spreadsheets in the Microsoft Office Excel® version 2010 program, under independent double typing, and afterwards were submitted to descriptive statistical analysis by the Epi-info®

program version 3.5.2 of 2010. Data were analyzed using quantitative descriptive analysis.

In the data analysis regarding the caregiver, it is noteworthy that one of the participants was under 18 years of age at the time of the interview. Thus, this participant's data were excluded from the results, totaling 24 for the analysis of caregiver data.

The ethical principles of the research were observed according to Resolution n. 466 of December 12th, 2012. The research project was approved under number CAAE: 20813613.9.0000.5346.

RESULTS

After using the selection criteria, in the data collection period, 25 (N=25) CRIANES were hospitalized, which corresponded to 44% of the total hospitalizations in the unit during the data collection stage. Regarding the gender of the child, 64% (n=16) of the CRIANES in this study were male.

Regarding birth weight, 30.4% (n=7) of the children in this study were classified as underweight; 13% (n=3) as insufficient weight; 52.1% normal weight (n=12) and 4.3% (n=1) overweight. For this variable, two children did not have information on their birth weight in their medical records or vaccination books, and their relatives were unable to give such information, resulting in 23 children in the analysis.

For gestational age, 68% (n=17) of CRIANES were born at term; 24% (n=6) were born premature and 8% (n=2) were born post-term. Regarding the type of delivery, 60% (n=15) were cesarean section and 40% (n = 10) vaginal delivery.

Pregnancy/delivery complications occurred in 36% (n=9) of CRIANES pregnancies/deliveries in the present study. The types of complications ranged from fetal distress (n=4), eclampsia (n=2), cord prolapse (n=1), preeclampsia (n=1), oligodramnia (n=1), delay in expulsion with meconium aspiration (n=1), induction failure associated with fetal distress (n=1), intercurrent problem in vaginal delivery and consequent risk caesarean section (n=1).

As for readmissions, it is noteworthy that only one CRIANES did not have history of

previous hospitalization. For the others, all had at least one hospitalization prior to the current hospitalization.

Thus, about 55% (n=13) of CRIANES had 5 or more previous hospitalizations, and of these, 21% (n=7) had 10 or more numbers of hospital admissions. For this variable, there was no information in the child's medical records about the number of previous hospitalizations, as well as the relative could not inform, resulting in a total N of 24 for the analysis. The time of hospitalization of CRIANES during the current hospitalization ranged from 1 to 31 days, with an average of 10 days and standard deviation of 6.7 days.

Regarding the origin of the special health care need, it is described that 64% (n=16) of the CRIANES in this study have some special health care need (NES) since birth, and 24% (n=5) developed NES older than one year old.

Chart 1 presents the previous and current diagnoses/reason for hospitalization of the CRIANES under study (N=25).

The table shows the relationship between the previous and current diagnosis of CRIANES in this study, and the present diagnosis/reason for hospitalization is a consequence of sequelae or worsening of the previous diagnosis.

Regarding the demands of care of CRIANES, all children in this study have modified habits of usual care, including care with medication administration, care with feeding, risk for infection, among others. Still regarding the classification of demands, 36% (n=9) use some type of technology, being 90% (n=8) gastrostomy tube and 10% (n=1) peritoneal ventriclebypass valve; 40% (n=10), have neuropsychomotor development demand such as: mobility help, feeding help, among others; 92% (n=23) of the children follow-up with some health service, including physiotherapist, speech therapist, nutritionist, and medical specialties such as: nephrologist, cardiologist and infectology service; 80% (n=20) continuous use of medication.

The medications used by CRIANES in this study had, within a group of twenty types of medication, 40% (n=8) of anticonvulsant medications, followed by 20% of antihypertensive drugs, and 10% of antidiabetic drugs.

Chart 1: Previous and current diagnoses/reason for hospitalization of the CRIANES under study (N=25).

| CRIANES | PREVIOUS DIAGNOSIS | CURRENT DIAGNOSIS/REASON FOR HOSPITALIZATION |
|---------|---|---|
| C1 | Down's syndrome | Gastrostomy tube obstruction |
| C2 | HIV, Repeating Pneumonia | Pneumonia |
| C3 | Chronic constipation | Abdominal pain, Syncope |
| C4 | Nephrotic Syndrome (Post kidney transplant) | Urinary tract infection |
| C5 | HIV vertical exposure | Diarrhea, fever |
| C6 | Neonatal anoxia, Epilepsy | Increased Respiratory effort |
| C7 | Congenital cardiopathy, Repeating pneumonia | Urinary tract infection |
| C8 | Stevens Syndrome Johnson Epilepsy, | Drug reactions |
| C9 | Microcefalia, Hidrocefalia | Pneumonia |
| C10 | Cerebral Palsy | Lobar Atelectasis |
| C11 | Hydrocephalus | Awaiting placement of bypass, Ventriculo peritoneal valve |
| C12 | Bronchospasm | Asthma, Asthmatic crisis |
| C13 | Congenital hypothyroidism | Bronchospasm |
| C14 | Type I | Airway infection, Decompensated, Diabetes Mellitus |
| C15 | Nephrotic Syndrome | Decompensated Nephrotic Syndrome |
| C16 | Neonatal Anoxia | Infected Dermatitis |
| C17 | Scleroderma | Urinary tract infection |
| C18 | Asthma | Atypical pneumonia |
| C19 | Neonatal Anoxia | Pneumonia |
| C20 | HIV, Premature puberty | Poor adherence to Antiretroviral treatment |
| C21 | Diabetes Mellitus tipo I | Decompensated Diabetes Mellitus |
| C22 | Corpus callosum agenesis, Ventriculomegaly, Diabetes Insipidus | Hydronephrosis |
| C23 | Cerebral palsy, Hydrocephalus, Microcephaly | Pneumonia |
| C24 | Cerebral Palsy, Epilepsy | Infection to be clarified |
| C25 | Preterm newborn infants with respiratory distress syndrome, acute bacterial neonatal meningitis | Hydrocephalus with Ventriculo peritoneal bypass valve placement |

Regarding complications during hospitalization, the need for intensive care was present in 12% of children (n=3), with later return to the pediatric unit and discharge home. Probes and drains were needed in 8% (n=2) of the children in this study and 20% (n=5) of the children required continuous use of medication. Discharge guidelines included 36% (n=9) of medication administration, 16% (n=4) of probe care, 4% (n=1) of aspiration, and 80% (n = 20) for modified habits of usual care.

Regarding the characteristics of the caregiver, the main caregiver is the mother, totaling 88% (n=21), followed by the father with 8% (n=2) and 4% (n=1) the grandmother. The age of the primary caregiver ranged from 19 to 47 years, with the highest percentage in the 30-40 age group. Regarding education of the caregiver, 12% (n = 3) of the caregivers had less than five years of formal studies.

For the family income variable, it was found that 41.6% (n=10) had income of more than one minimum wage and 29.1% (n=7) less than one minimum wage. Similarly, it was found that in

37.5% (n=9) of families, four people depended on this income and in one case, eight people lived on the same family income. All families included in the results of this study (N=24) had basic housing conditions such as the presence of electricity, running water and sanitation, and 45.8% (n=11) of them live in a masonry house.

DISCUSSION

In this research, it was found that 64% of CRIANES hospitalized in the PIU (n=16) were male, corroborating findings from other studies on this population^(3,7). According to the study, there is a higher risk of morbidity and mortality in male children, this is due to slower lung maturation when compared to females, increasing the chances of these children becoming CRIANES⁽⁸⁾.

Regarding gestational age, although most CRIANES were born at term (68%) and with adequate weight (60%), a considerable percentage were born prematurely (24%) and underweight (30.1%). A similar study conducted

in the northern region of Brazil by interviewing and evaluating 23,940 postpartum medical records between February 2011 and October 2012 found a strong association between low birth weight and prematurity, and increased neonatal morbidity and mortality⁽⁹⁾.

A Western Australia cohort study in which children were followed from the first hospitalization after birth up to 18 years of age found that preterm infants are at higher risk of readmission compared to full-term infants and that perinatal causes are the most common reason for hospitalization in the first 28 days, infection from 28 days to 12 years of age, and oral cavity-related diagnoses and admissions after 12 years of age⁽¹⁰⁾.

The predominant type of delivery was cesarean section (60%) there were complications in 36% of pregnancies/deliveries, and fetal distress was the most frequent complication. Study conducted in two public maternity hospitals in central Rio Grande do Sul found that 76% of the deliveries were caesarean sections and the main indication for cesarean delivery was fetal distress, followed by preeclampsia and its complications⁽¹¹⁾.

The results showed that only one CRIANES had no previous hospitalization, the others were all hospitalized at least once. The average length of stay was 10 days, ranging from 1 to 31 days. Studies show that children with complex chronic diseases have more frequent and prolonged hospitalizations, fewer days between hospitalizations and greater use of emergency services and intensive care^(12,13).

Regarding the origin of the special health care need (NES), there was a close relationship between perinatal conditions and the child's history of NES, since 64% of CRIANES had NES since birth. Although there has been a decrease in the number of infant deaths due to perinatal conditions in Brazil, with a fall from 9.5/1,000 live births in 2010 to 8.4/1,000 live births in 2013⁽¹⁴⁾, this cause continues to result in the increase in the CRIANES group due to technological advances in child health care that enable the survival of clinically fragile children^(3,5).

The children of this research have many and complex nature diagnoses. More than 25% of them had more than one initial diagnosis, and

several diagnoses related to chronic diseases. It was also possible to observe the relationship between previous and current diagnoses, being the current diagnosis a possible consequence of the previous diagnosis, such as urinary tract infection may be the result of an uncontrolled nephrotic syndrome.

As for the demands of care presented by CRIANES, it was identified that modified habits of usual care constitutes the main one, followed by drugs, developmental and technological care. Study conducted with newborns described that of children with chronic condition from the neonatal unit, 64.9% were depended on medication, 59.5% needed special follow-up for development in relation to children of the same age and 8.1% were depended on technology⁽¹⁵⁾.

Regarding care with medication, the results of a study that characterized technology-dependent children corroborate the findings of this research, citing anticonvulsants as the main medication used by CRIANES⁽⁷⁾. Exchange of continuous use medications and the need for intensive care were identified as the main complications that occurred during the hospitalization of CRIANES.

It is observed that the complexity and multiplicity of diagnoses presented by this clientele ends up making hospitalizations more severe and with more complications. The need for intensive therapy and the exchange of continuous use medications is closely related to children who had chronic diseases in need of drug control. For example, in this study, decompensated diabetes mellitus and inadequate adherence to antiretroviral treatment as factors associated with readmissions. This shows the importance of health education during hospitalization preparing them for hospital discharge, ensuring that these family caregivers can return home safe to perform the care that ensures the survival of these CRIANES⁽¹⁶⁾.

The findings showed that the guidelines at the time of hospital discharge were related to modified habits of usual care and drug administration. After hospital discharge, the family members of CRIANES are faced with the reality of caring for a special child, who uses some kind of device in the body or need medication to survive. These children demand continuous care of a complex nature, requiring

from the family caregiver ability, management and adaptation of the home environment for care, as well as the provision of care different from what is understood by common sense. In this context, the nursing staff needs to mediate knowledge and care practices with the families of CRIANES, so that they feel able to understand the complexity of care of these children at home^(16,17).

The mother is responsible for the care of CRIANES, corroborating a study that showed that although the mother receives the support from her husband, grandparents, children and godfather/godmother, she still takes over a large part of the demand for care and tasks required by the child in the life of the primary caregiver, causes considerable physical and emotional distress⁽¹⁸⁾.

The data from this research point that 46% of CRIANES caregivers have between 5 and 10 years of education. A study with family members of CRIANES showed that of the six family members interviewed, five had not completed elementary school⁽⁵⁾. Therefore, these children receive care from people who may have a little understanding of the complexity of the care actions to be performed with the child, and a difficulty to have formal jobs with better salary.

CONCLUSION

This study showed that of the 58 children admitted to the Pediatric Inpatient Unit within 50 days, 44% were classified as CRIANES.

The findings of this study confirm that the diagnoses of these children are many and of complex nature. More than 25% of them had

more than one initial diagnosis, and several diagnoses referred to chronic diseases. It was also possible to observe the possible relationship between past and current diagnoses, constituting a relationship between them as chronic diseases that need constant care and cause changes in the child's quality of life, such as decompensated diabetes mellitus.

Of the 25 CRIANES, 68% were born at term and 36% had complications at birth, with the highest rate of fetal distress, demonstrating the need for care during their perinatal phase. In addition, birth weight was inadequate in 30.1% of them and prematurity was present in 24% of CRIANES.

The CRIANES of this study are characterized by having complex care, being 100% of them with modified habits of usual care and four of the 25 CRIANES had mixed care demand, involving drug administration, control and constant care with feeding, follow-up in many health services, care through technologies, among others. In addition, most of these CRIANES have more than one demand for care, requiring constant attention and dedication from caregivers.

At the time of hospital discharge, family caregivers become responsible for maintaining the proper health conditions of these children, facing a therapeutic and care complexity that modify and hinder the family routine. However, it is known that the recognition and knowledge of these demands is still restricted. The health professionals involved in the care process of these CRIANES know these demands due to the constant and long hospital stay they go through, however, there are no concrete and official data that can be accessed by these professionals.

PERFIL DE CRIANÇAS COM NECESSIDADES ESPECIAIS DE SAÚDE E SEUS CUIDADORES EM UM HOSPITAL DE ENSINO

RESUMO

Objetivo: caracterizar as crianças com necessidades especiais de saúde, internadas em unidade pediátrica de um hospital de ensino, em relação às suas condições clínicas, demandas de cuidados e situação sociodemográfica. Ainda, caracterizar os familiares cuidadores das crianças quanto a sua idade e grau de parentesco. **Método:** estudo descritivo, com abordagem quantitativa, realizado com 25 crianças com necessidades especiais de saúde, internadas na Unidade de Internação Pediátrica de um hospital de ensino. Os dados foram coletados por meio de formulário e analisados por meio da estatística descritiva. **Resultados:** das crianças internadas no período, 44% apresentaram necessidades especiais de saúde. Com relação às demandas de cuidados, todas possuem cuidados habituais modificados, 36% utilizam algum tipo de tecnologia, 40% possuem demanda de desenvolvimento neuropsicomotor, 92% fazem acompanhamento com algum serviço de saúde e 80% fazem uso contínuo de medicação. **Conclusão:** Este estudo oferece dados que podem ser utilizados como suporte para a elaboração de estratégias que reorientem a prática assistencial de enfermagem.

Palavras-chave: Enfermagem pediátrica. Saúde da Criança. Perfil de Saúde.

PERFIL DE NIÑOS CON NECESIDADES ESPECIALES DE SALUD Y SUS CUIDADORES EN UN HOSPITAL DE ENSEÑANZA

RESUMEN

Objetivo: caracterizar a los niños con necesidades especiales de salud internados en unidad pediátrica de un hospital de enseñanza con relación a sus condiciones clínicas, demandas de cuidados y situación sociodemográfica. Aún, caracterizar a los familiares cuidadores de los niños en cuanto a su edad y grado de parentesco. **Método:** estudio descriptivo, con abordaje cuantitativo, realizado con 25 niños con necesidades especiales de salud internados en Unidad de Internación Pediátrica de un hospital de enseñanza. Los datos fueron recolectados por medio de formulario y analizados por estadística descriptiva. **Resultados:** de los niños internados en el período, 44% presentaron necesidades especiales de salud. Con relación a las demandas de cuidados, todos poseen cuidados habituales modificados, 36% utilizan algún tipo de tecnología, 40% poseen demanda de desarrollo psicomotor, 92% hacen acompañamiento con algún servicio de salud y 80% hacen uso continuo de medicación. **Conclusión:** este estudio ofrece datos que pueden ser utilizados como soporte para la elaboración de estrategias que reorienten la práctica asistencial de enfermería.

Palabras clave: Enfermería Pediátrica. Salud de INiño. Perfil de Salud.

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