

# **Children with Congenital Zika Syndrome:** the complexity of nursing care during hospitalization

Crianças com Síndrome de Zika Congênita: a complexidade do cuidado de enfermagem durante a hospitalização Niños con Síndrome de Zika Congénito: la complejidad de la atención de enfermería durante la hospitalización

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#### **ABSTRACT**

Objectives: to classify the degree of dependence on nursing care required by children with Congenital Zika Syndrome during hospitalization and to analyze their complexity. Methods: this is a descriptive, observational and quantitative study carried out in a pediatric ward of a public hospital in Rio de Janeiro. Data were collected from hospitalization records between June 2017 and April 2018. Results: 54% of the population studied showed a degree of dependence equivalent to semi-intensive care. On 37.5% of hospitalization days, patients required non-invasive or invasive mechanical ventilation; 31.5% had spontaneous breathing requiring airway clearance by aspiration and/or oxygen therapy. Conclusion: Congenital Zika Syndrome represents a challenge for health professionals due to its uniqueness. In this study, it is expressed by demands for complex and continuous care in hospitalization and in preparation for discharge, requiring semi-intensive nursing care.

**Descriptors:** Zika Virus Infection; Pediatric Nursing; Nursing Care; Child; Hospitalization.

Objetivos: classificar o grau de dependência de cuidados de enfermagem requeridos por crianças com Síndrome de Zika Congênita durante a internação hospitalar e analisar a complexidade destes. Métodos: estudo descritivo, observacional e quantitativo, realizado em uma enfermaria pediátrica de um hospital público do Rio de Janeiro. Os dados foram coletados a partir dos registros de internação entre junho de 2017 e abril de 2018. Resultados: 54% da população estudada apresentou grau de dependência equivalente a cuidados semi-intensivos. Em 37,5% dos dias de internação, os pacientes necessitaram de ventilação mecânica não invasiva ou invasiva: 31.5% tinham respiração espontânea com necessidade de desobstrução de vias aéreas por aspiração e/ou necessidade de oxigenoterapia. Conclusão: a Síndrome de Zika Congênita representa um desafio aos profissionais de saúde devido à sua singularidade. Neste estudo, é expressa por demandas de cuidados complexos e contínuos na hospitalização e no preparo para alta, requerendo cuidados de enfermagem semi-intensivos. Descritores: Infecção por Zika Vírus; Enfermagem Pediátrica; Cuidados de Enfermagem; Criança; Hospitalização.

Objetivos: clasificar el grado de dependencia de los cuidados de enfermería que requieren los niños con Síndrome de Zika Congénito durante la hospitalización y analizar su complejidad. Métodos: estudio descriptivo, observacional y cuantitativo, realizado en una sala de pediatría de un hospital público de Rio de Janeiro. Los datos se obtuvieron de los registros de hospitalización entre junio de 2017 y abril de 2018. Resultados: el 54% de la población estudiada presenta un grado de dependencia equivalente a cuidados semi-intensivos. En el 37,5% de los días de hospitalización, los pacientes requirieron ventilación mecánica invasiva o no invasiva; el 31,5% presentaba respiración espontánea con necesidad de despejar las vías respiratorias por aspiración y/o necesidad de oxigenoterapia. **Conclusión:** el Síndrome de Zika Congénito representa un desafío para los profesionales de la salud debido a su singularidad. En este estudio, se expresa por demandas de cuidados complejos y continuos en la hospitalización y en la preparación para el alta, que requieren cuidados de enfermería semi-intensivos.

Descriptores: Infección por el Virus Zika; Enfermería Pediátrica; Atención de Enfermería; Niño; Hospitalización.



#### **INTRODUCTION**

Zika virus infection is an emerging theme in Brazil. The first case was described in 2015. Since then, increasing numbers have been published; Since the Zika epidemic in Brazil, health services have been working with a new profile of children exposed and diagnosed with Congenital Zika Syndrome (CZS).

From 2000 to 2014, 2,464 newborns with microcephaly were registered in Brazil, an average of 164 cases per year. In 2015, there were 1,608 cases, a much higher increase than previous data<sup>(1)</sup>.

CZS is a set of anomalies that cause severe neurological and developmental problems in children, being associated with the occurrence of microcephaly $^{(2-4)}$ .

Among the neurological abnormalities observed in these children, severe global hypertonia with hyperreflexia, irritability, hyperexcitability, excessive crying, swallowing disorder, and impaired auditory and visual responses stand out<sup>(5)</sup>.

There is no specific treatment for this syndrome. Assistance should be aimed at global children's development according to its complications through actions of early stimulation of neuropsychomotor development from birth to three years of life<sup>(6)</sup>.

Hospitalization needs may be frequent due to worsening health needs. In these circumstances, the nursing team has the role of assisting, guiding and carrying out direct actions for recovery of this population group's health. However, very specific health demands are still part of a new scope of action that is complex and challenging in the daily care.

Patients' complexity does not only include the pathophysiological process of subjects involved, but nursing care and socio-family and environmental factors, clearly highlighted or, eventually, obscure, that can interfere with care practice<sup>(7)</sup>.

To recognize nursing care demands, the "Patient Classification System (PCS)" is used in order to determine the degree of dependence of a patient on nursing care, aiming to establish the time spent on direct and indirect care, and, consequently, the quantity and quality of personnel to meet patients' needs<sup>(8)</sup>.

Therefore, PCS is a useful tool in supporting decision-making related to the organization and planning of nursing actions in health organizations.

In the current world context, with the technological advancement of the means of communication and information, health services have been demanding a higher standard of efficiency and quality to meet the demands of specific clients. Thus, it is necessary to recognize and assess issues such as demand, supply and quality of service provided<sup>(9)</sup>.

#### **OBJECTIVES**

To classify the degree of dependence on nursing care required by children with Congenital Zika Syndrome during hospitalization and to analyze their complexity.

### **METHOD**

# **Ethical aspects**

The study was guided by Resolution 466 of 2012 of Regulatory Guidelines and Norms for Research with Human Beings of the

Brazilian National Health Council (*Conselho Nacional de Saúde*). It was approved by the Institution's Research Ethics Committee and CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration).

#### Study design, place, and period

This is a descriptive, observational, retrospective, quantitative study that followed the guidelines of STrengthening the Reporting of OBservational studies in Epidemiology (STROBE)<sup>(10)</sup>.

The study was carried out in a pediatric infectious disease ward (PeID) of a referral hospital for monitoring CZS in Rio de Janeiro. Outpatient care for children with CZS at the institution in question is performed once a week. Babies are referred through the maternity ward of the institution when they were exposed to the Zika virus during pregnancy, or even through the pediatric outpatient clinic when there is any suspicion of CZS in children. Outpatient follow-up of these patients involves a multidisciplinary team and several complementary exams. In situations of need for hospitalization for some type of clinical treatment, patients are referred to the PeID ward. This is an inpatient sector that consists of four apartments for isolation and another seven beds arranged in two wards - one for children and one for adolescents.

Data from children hospitalized with a diagnosis of CZS were collected from June 2017 to April 2018 from the records in the pediatric patient classification book, used by the institution's nursing teams.

### Sample, and inclusion and exclusion criteria

The research population consisted of all children with CZS admitted to the PeID ward during the study period, which is the inclusion criterion. The total number of hospitalizations in this sector during the study period was 333. Of these, 41 corresponded to hospitalizations of children with CZS, being the final sample of the study.

# Study protocol

The pediatric patient classification book used for data collection consists of the "Pediatric Patient Classification Instrument (ICPP – *Instrumento de Classificação de Pacientes Pediátricos*)"(11). ICPP is an instrument that has three major areas of dominance: family, patient and therapeutic procedures.

Each large area is composed of 11 indicators that measure the degree of nursing care dependency of each hospitalized patient and that constituted the study variables, which are: "companion's participation; support and family support network; activity; oxygenation; mobility and walking; food and hydration; eliminations; hygiene and body care; control calibration interval; drug therapy; cutaneous-mucous integrity". Each indicator has four situations of care dependence<sup>(12)</sup>.

This instrument makes it possible to define patients into care categories: Minimum (PCM) - for those from 12 years old, with age-appropriate development, stable from a clinical point of view, performing all self-care actions under supervision; Intermediate (PCI) - for those from 7 years old, with age-appropriate

development, clinically stable, requiring nursing assistance for self-care and/or support to cope with the disease situation and hospitalization; High dependency (PCAD) - for those, stable from a clinical point of view, who depends on nursing to meet his organic/physical, emotional and social needs; Semi-Intensive (PCSI) - for those, clinically unstable, with no imminent risk of death, who requires permanent and specialized assistance; Intensive (PCIT) - for those, unstable from a clinical point of view, with imminent risk of death, who needs permanent and specialized assistance<sup>(9,12)</sup>.

ICPP is part of the daily work process of nurses in the hospital unit in the study. Thus, this data collection is performed daily for all hospitalized patients, helping to define the degree of nursing care dependency of children admitted to the unit for the systematization of care.

In addition to the variables that make up ICPP, a questionnaire was developed with sociodemographic and clinical variables of patients who made up the study sample.

# Analysis of results, and statistics

For analysis of the quantitative data of this research, the data were tabulated in Microsoft Excell spreadsheets\*, using univariate descriptive statistical analysis. Categorical variables were presented from their absolute (N) and relative (%) values.

#### **RESULTS**

The data corresponded to the records referring to 41 hospitalizations of 17 children. That is, each child in the study was readmitted more than once. A total of 797 days of hospitalization were obtained, which were assessed daily regarding the degree of dependence on the required nursing care.

Sociodemographic and clinical characteristics are shown in Table 1.

The average age of these patients was 15 months, with a minimum of 8 months and a maximum of 2 years and 5 months. They were born between the years 2015 and 2016, from the Zika epidemic in Brazil.

The average hospital stay was 19.4 days, with a minimum of two and a maximum of 205 days.

The predominant nursing care demand category was semiintensive care (430 days - 54%), according to Table 2.

Tables 3, 4 and 5 will illustrate the distribution of the classification of pediatric patients with CZS during hospitalizations from each domain and their indicators.

Stratifying the classification shown in Table 2, the first domain is defined as "family" and consists of an assessment of two indicators "companion's participation" and "support network and family support" (11) (Table 3).

The second domain is defined as "patient" and consists of assessment of "activity", "oxygenation", "mobility and walking", "food and hydration", "eliminations" and "hygiene or body care"<sup>(11)</sup> (Table 4).

The last domain, defined as "therapeutic procedures", consists of assessment of "control measurement interval", "drug therapy" and "cutaneous-mucous integrity" (Table 5).

**Table 1** - Sociodemographic characterization of pediatric patients with Congenital Zika Syndrome (N=41 hospitalizations), Rio de Janeiro, Rio de Janeiro, Brazil, 2018

Variables	Frequency	%
Sex		
Male	26	63.4
Female	15	36.6
Age group		
Infants	38	92.7
Preschoolers	3	7.3
Length of stay		
1 to 5 days	10	24.4
6 to 10 days	13	31.7
11 to 20 days	09	21.95
21 to 35 days	05	12.2
> 36 days	04	9.75
Reasons for hospitalizations		
Gastrointestinal tract	13	31
Respiratory system	11	27
Nervous system	6	15
Urinary system	2	4
Others	9	23

**Table 2** - Distribution of the degree of dependence on nursing care to pediatric patients with Congenital Zika Syndrome during hospitalization (N=797 days), Rio de Janeiro, Rio de Janeiro, Brazil, 2018

Care demand category	Frequency	%
High dependence care	299	37.5
Semi-intensive care	430	54
Intensive care	68	8.5

**Table 3** - Distribution of the classification of the "family" domain of pediatric patients with Congenital Zika Syndrome during hospitalizations (N=797 days), Rio de Janeiro, Rio de Janeiro, Brazil, 2018

Domain: Family	Frequency	%
Companion's participation:		
<ol> <li>Companion recognizes the physical and emotional needs of pediatric patients and manages to meet them.</li> </ol>	620	77.8
<ol><li>Companion demonstrates availability to incorporate new information and skills for pediatric patient care.</li></ol>	52	6.5
<ol> <li>Companion demonstrates difficulties or unavailability to incorporate new information and skills for caring of pediatric patients and/ or manifests anxiety and/or fear and/or anger and/or withdrawal behaviors.</li> </ol>	105	13.2
<ol> <li>Companion absent or who demonstrates unavailability or aggressiveness to care for patients and/or patients requiring highly complex technical care.</li> </ol>	20	2.5
Support network and family support:		
<ol> <li>Presence of a companion involved in providing and planning care at all times.</li> </ol>	656	82.3
2. Presence of a companion involved in providing and planning care for more than 12 hours a day.	48	6.1
3. Presence of a companion involved in providing and planning care for less than 12 hours a day.	9	1.1
<ol> <li>Absence of family support or psychiatric illness of a companion or presence of a companion that demonstrates stress or alienation from the provision of patient care.</li> </ol>	84	10.5

**Table 4** - Distribution of the classification of the "patient" domain of pediatric patients with Congenital Zika Syndrome during hospitalizations (N=797 days). Rio de Janeiro, Rio de Janeiro, Brazil, 2018

Domain: Patient	Frequency	%
Activity:		
Demonstration of affection and interest in stimuli and activities compatible with the age group.	-	-
<ol><li>Demonstration of affection and interest in stimuli, with limitation for carrying out activities compatible with the age group.</li></ol>	-	-
<ol> <li>Disinterest in stimuli due to pain, sadness, anger, psychomotor agitation or apathy; language difficulty; visual impairment or developmental deficit.</li> </ol>	797	100
<ol> <li>Severe cerebral palsy or coma vigil or unconscious or totally sedated.</li> </ol>	-	-
Oxygenation:		
<ol> <li>Spontaneous breathing, without the need for oxygen therapy or airway clearance.</li> </ol>	222	27.9
<ol><li>Spontaneous breathing, with the need to clear the airways by installing a saline serum.</li></ol>	25	3.1
<ol> <li>Spontaneous breathing requiring airway clearance due to aspiration of secretions and/or oxygen therapy.</li> </ol>	251	31.5
4. Mechanical ventilation (Non-invasive or invasive).	299	37.5
Mobility and walking:		
Walking without assistance.	-	-
2. Rest in bed and mobilize without assistance.	-	-
<ol><li>Rest in bed and mobilize with assistance or walk with direct supervision.</li></ol>	277	34.8
<ol><li>Restricted in bed, totally dependent on changing position.</li></ol>	520	65.2
Food and hydration:		
1. Orally independently or effective breastfeeding.	-	-
2. Orally with assistance and collaborative patient.	30	3.8
<ol><li>Orally with a non-collaborative patient or at risk of aspiration or at probes or ineffective breastfeeding.</li></ol>	736	92.3
4. Parenteral nutrition/hydration.	31	3.9
Eliminations:		
1. Toilet without assistance.	-	-
2. Toilet with assistance.	-	-
3. Use of diapers or through bedpan or urinal.	774	97.1
4. Bladder catheter or stoma.	23	2.9
Hygiene or body care:		
Shower bath without assistance.	-	-
2. Shower bath with partial aid.	-	-
<ol> <li>Immersion bath or shower bath in chair or with total assistance.</li> </ol>	176	22.1
4. Bed or in incubator or heated crib bath.	621	77.9

**Table 5** - Distribution of the classification of the "therapeutic procedures" domain of pediatric patients with Congenital Zika Syndrome during hospitalizations (N=797 days). Rio de Janeiro, Rio de Janeiro, Brazil, 2018

Domain: Therapeutic Procedures	Frequency	%
Vital signs and others controls calibration interval:		
1. 6/6 hours.	231	29
2. 4/4 hours.	05	0.6
3. 2/2 hours.	-	-
4. Less than 2 hours interval or continuous monitoring.	561	70.4
	To be continued	

Table 5 (concluded)

Domain: Therapeutic Procedures	Frequency	%
Drug therapy:		
1. Do not need medication.	-	-
<ol><li>Topical, ocular and/or oral medications with a collaborative patient.</li></ol>	36	4.5
<ol><li>Medicines via parenteral, enteral, inhalation or topical, ocular or oral routes with non-collaborative patient.</li></ol>	720	90.3
<ol> <li>Blood products and/or chemotherapy and/or Absolute indication for the use of an infusion pump.</li> </ol>	41	5.2
Skin-mucosa integrity:		
1. Whole skin throughout the body area.	-	-
<ol><li>Need for low complexity care: skin hydration, treatment of simple dermatitis, renewal of peripheral venous catheter fixation.</li></ol>	176	22.1
<ol> <li>Need for medium complexity care, such as dressings in: wounds limited to the dermis, drain insertions, tracheostomy, gastrostomy or central venous catheter.</li> </ol>	585	73.4
<ol> <li>Need for highly complex care, such as: debridement, disseminated dermatitis, extensive burns; complex stomas or deep wounds.</li> </ol>	36	4.5

#### DISCUSSION

The profile of children with SZV predominant in this study, in most days of hospitalization where the classification instrument was applied, was semi-intensive care (430; 54%), followed by high dependence (295; 37%) and intensive care (72; 9%).

The semi-intensive care patient is one who is liable to instability of vital functions, recoverable, without imminent risk of death, requiring permanent and specialized health team assistance<sup>(13)</sup>.

We emphasize that, since ICPP was applied in the study setting daily, these children moved from one category to another during hospitalization according to the evolution of their illness; they generally reduced their demand for nursing care as hospital discharge approached. Despite being described in Resolution 543/2017 of COFEN (Conselho Federal de Enfermagem – Federal Nursing Council)<sup>(14)</sup> that in pediatric inpatient units every child under six years old should already be classified, at least, as intermediate care regardless of the presence or absence of a companion, there were not, at any time during the days of hospitalization, children with CZS requiring intermediate care, not even at the time of hospital discharge.

It is noteworthy that, although the collection site did not consider intensive care beds, in 9% of the days observed there were patients classified as intensive care.

Therefore, we can observe that hospitalized children with CZS, in this study, demanded greater attention, availability and specialized care from the nursing team. The specific health needs of this population group also include the demands of families, who need support and training/awareness to learn how to deal with their children's conditions at home.

In this sense, children with CZS, who is part of a group of complex chronic conditions, will require a readaptation of this family to new realities and the understanding and skills to deal with the limitations imposed by the disease. Thus, the family ends up demanding greater participation in the hospitalization process for better preparation for discharge.

ICPP used consists of 11 indicators that are divided into three major areas of domain: family, patient and therapeutic procedures<sup>(12)</sup>.

In the family domain, the indicator "companion's participation" describes companions' attitude and performance to provide care and meet pediatric patients' needs<sup>(11)</sup>. In this study, in most days the companions of hospitalized patients (620 - 77.8%) were classified as recognizing the physical and emotional needs of pediatric patients with CZS and capable of meeting those needs.

Studies carried out with caregivers of children with complex chronic conditions pointed to the uniqueness of care for these children, such as differentiated feeding or by devices such as tube and gastrostomy, proper positioning, tracheostomy, among others<sup>(15-16)</sup>. It was highlighted that caregivers need to incorporate activities and procedures in their daily care for children, which are mostly nursing<sup>(15)</sup>.

Thus, although the results of this study show that, on most days, companions were able to meet the physical and emotional needs of their children, nurses, as great articulators of the care provided to these children, need to be attentive to a daily assessment of how this care is being performed by the family so as not to miss an opportunity to train them more and more to perform an adequate assistance minimizing risks to patient safety<sup>(15-16)</sup> both in the hospital and at home.

Still in the family domain, the indicator "family support and support network" deals with the possibility of incorporating the knowledge, values, beliefs and culture of the accompanying family member in the planning and provision of care to pediatric patients during their stay in the hospital<sup>(12)</sup>. The results showed that, in most days, the companions of hospitalized patients (656 - 82.3%) were classified as involved in the provision and planning of care at all times.

The importance of family presence during children's hospitalization is unquestionable. The presence of parents or companions is seen as a source of protection, information and security with a very important role in children's recovery<sup>(17)</sup>.

It is important that nurses have the sensitivity to favor the adaptation of caregivers in the hospitalization process, to recognize the need to reinforce the bonds of communication and guidance with family members as a means of preparation for child care<sup>(18-19)</sup>.

This involvement of family members of children during hospitalization is especially important in the case of chronic diseases, which, due to their own pathology, parents/companions end up becoming responsible for continuous and prolonged care at home<sup>(20-22)</sup>.

Nurses, in their practice as educators with family members, in preparation for hospital discharge of chronic children, have adopted the model of knowledge transmission through the demonstration of technique and replication, observing the family's ability to absorb and replicate care. However, it is essential that these teachings take into account the living conditions in which families are inserted, as it will directly interfere in the applicability of this care at home<sup>(16)</sup>.

The issue of education and preparation of family members is perhaps one of the most important niches of performance of the nursing team in the admission of complex chronic children, since these families return home with children demanding a high dependence on assistance and technology, requiring training. to perform home care, in addition to a support network. It is also

worth remembering that, many times, these children leave a hospital stay dependent on a new technology for survival.

In the "patient" domain, the "activities" indicator assesses the possibility of interacting with family members, professionals or patients and carrying out activities compatible with the expected development for their age. In this regard, all patients showed lack of interest in stimuli, language difficulties, visual impairments or developmental deficits.

A Brazilian study conducted with children with microcephaly by ZIKV in rehabilitation centers in the Brazilian states of Rio Grande do Norte and Paraíba found, through a functional profile, a complete disability in most categories of body functions, particularly in categories related to mobility and activities<sup>(23)</sup>. Children with CZS, in addition to microcephaly, may have other malformations, such as brain, hearing, visual, neurological disorders, swallowing problems and *artrogryposis* <sup>(24-26)</sup>. All of this will generate a deficit in the motor and cognitive development of these children, in comparison with others of the same age not affected by ZIKV, consequently causing great dependence of children on a caregiver<sup>(27)</sup>.

The "oxygenation" indicator assesses the possibility of children maintaining normal airway permeability, ventilation and oxygenation. It was found that in 37.5% (299) of the studied hospitalization days, patients required non-invasive or invasive mechanical ventilation; 31.5% (251) had rspontaneous breathing requiring airway clearance due to aspiration of secretions and/or need for oxygen therapy.

This result confirms that, in this study, there was a need for respiratory support technology in 69% (550) of the hospitalization days. Thus, the need for specialized nursing care, characterized as semi-intensive, is clear. Sometimes, the use of this respiratory support technology, depending on children's clinical evolution, can lead to dependence on equipment to maintain ventilatory support, which makes it difficult to discharge from the hospital, since in addition to the need for training caregivers to deal with a new life support technology, would need the availability of equipment and a multidisciplinary team to accompany this child and family at home.

The indicator that dealt with "mobility and ambulation" judges the possibility of pediatric patients mobilizing body segments and walking safely. In most of the hospitalization days studied (520 - 65.2%), patients were classified as restricted to bed and totally dependent on changing position; in 34.8% (341), they were classified as those who rest in bed and move with assistance.

These results indicate that although these children are mostly infants, the youngest being 8 months old, they are unable to mobilize without the help of an adult, as they have a high deficit in motor development, which increases their degree of dependency. In the hospital environment, this issue leads us to the planning of nursing care, which is indispensable for the prevention of pressure ulcers and the need for early stimulation by the multidisciplinary team.

The indicator "food and hydration" is based on the possibility of children receiving fluids and nutrients by ingestion or by enteral or parenteral infusion. In the most part of studied hospitalization days (736 - 92.3%), patients were classified with food through tubes (gastric, enteral or gastrostomy), or orally with a

non-collaborative patient or at risk of ineffective aspiration or breastfeeding.

It is characteristic of newborns (NBs) to present what we call primitive reflexes, which are involuntary motor responses presented when exposed to a certain stimulus. Reflex suction is one of the primitive reflexes, which appears when the newborn's lips are touched by some object, triggering the suction movement. These reflexes remain present until about six months of life, and their disappearance is naturally occurring, since these reflexes cease to be involuntary and become volunteers<sup>(28)</sup>.

Children with CZS, who participated in this study, had already passed this phase of reflex of involuntary swallowing; due to the large psychomotor development (PMD) that affects them, they start to have swallowing problems that will impact their diet and hydration daily.

The indicator "eliminations" takes into account the conditions of pediatric patients to present urinary and intestinal excretions. As they are infants and preschoolers (with a maximum age of 2 years and 5 months), on 97.1% (771) of the days observed, patients used diapers like any other child of the same age.

The last indicator of the "patient" domain involves the theme "hygiene or body care", which takes into account the possibility that the pediatric patient can perform alone, need help, direct supervision or depend entirely on oral, body and clothing hygiene. Of the total number of children with CZS in this study, in 77.9% (621), bed bathing was necessary.

Bed bathing is a demand for care that is very common in the pediatric area, and for reasons of patient safety, it is sometimes essential that two nursing professionals act in the procedure, which further increases the degree of dependence on nursing care. A study shows that when the act is performed only by a nursing professional, it is more exhausting, with potential risks for professionals and patients, risks such as falls and displacement of devices for patients and musculoskeletal damage/injuries for professionals<sup>(29)</sup>.

In the "therapeutic procedures" domain, the item "control measurement interval" assesses the need for observation and control of vital signs, O<sub>2</sub> saturation, central venous pressure, capillary glycemia, peritoneal dialysis, water balance. In this study, on 70.4% (561) of the days of hospitalization of children with CZS, was necessary to have a control interval of less than 2 hours or continuous monitoring. This result points to the instability of these children's vital functions and the need for continuous surveillance by the health team.

In the subcategory "drug therapy", the need for children to receive medications is assessed. It can be seen that on 90.3% (720) of the days observed, patients required meditions via parenteral, enteral, inhalation, or topical, ocular or oral for noncollaborative patients.

A study on the use of parenteral medications in a pediatric inpatient unit, whose characteristics of patients attended mostly were carriers of chronic-degenerative and highly complex diseases, showed that the intravenous parenteral route was the most used, thus revealing the need for more time for the nursing staff in the medication administration activity<sup>(30)</sup>.

In the item "cutaneous-mucous integrity", there is a need to maintain or restore cutaneous-mucous integrity. In this item, it

was found, through daily observation, a higher rate of patients in need of medium complexity care, such as dressings in wounds limited to the dermis, drain insertions, tracheostomy (TCT), gastrostomy (GTT) or central venous catheter (585 - 73.4%).

The high index of medium complexity care mentioned above can be attributed to the characteristics of patients with technological dependence, using devices such as TCT and GTT.

All these characteristics of care demands presented by children with CZS include her in the group of children with complex chronic condition (CCC). CCCs include multisystemic, congenital and acquired diseases, presenting with functional limitations, technological dependence and demands for specialized care<sup>(31)</sup>.

This study demonstrated that children with hospitalized CZS presented demands for developmental care (rehabilitation, psychomotor and social), drug and technological dependence and great dependence for common daily tasks. Most of this demand seems to be irreversible and should be part of the lives of these children after hospital discharge.

The results show a complexity of care for children that, even clinically stable, demand semi-intensive care and hours of specialized nursing care and above the typical standard of conventional wards.

# **Study limitations**

As limitations, we recognize that ICPP does not specifically elucidate the type of developmental deficit, technological and drug dependence presented by each child studied. As it is a study carried out in a single center, it may deserve a more extensive analysis of other realities for purposes of generalization.

# Contributions to nursing, health, and public policies

Determining the complexity of care subsidizes the planning of activities and costs of assistance and adequate dimensioning of nursing professionals, contributing to the responses to the demands of the target population with quality, safety and effective and efficient results.

Therefore, the referred study may be of great relevance for improvements in care practice, training of professionals, in addition to contributing to new studies and research in the area addressed.

#### CONCLUSION

The results showed that children diagnosed with CZS have a degree of nursing care dependency, mostly corresponding to a semi-intensive care patient.

Most of these hospitalizations have evolved into children's dependence on a technological device for maintaining life, such as tracheostomy, gastrostomy and peritoneal ventricular bypass. Using these devices increases the demand for nursing care for hospitalized children, not only due to their handling and maintenance, but also due to the need to implement educational actions aimed at family members for daily care and preparation for hospital discharge.

The hospitalization process of these children and families requires health education and preparation for discharge. Families

Novaes MC, Azevedo MSN, Falsett CF, Reis AT,

need to adapt to the new daily life, incorporate specific knowledge and skills in order to improve their children's quality of life in the social and family context. This progressive learning should aim at greater security for families and greater independence in daily care.

Finally, CZS represents a challenge for health professionals not only because it is an emerging clientele for pediatric nursing, but because of its demand for complex and continuous care during hospital and home admissions.

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