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## RESEARCH

Ações de enfermagem no cuidado à lactente com síndrome de WEST: um relato de caso

Actions of nursing care in the infant with WEST syndrome: a case report

Acciones de enfermería en el cuidado de los bebés con síndrome de WEST: un informe de caso

Gyl Dayara Alves Carvalho <sup>1</sup>, Odinéia Batista Lima <sup>2</sup>, Vanessa Costa Melo <sup>3</sup>, Kenya Lima Silva <sup>4</sup>

### ABSTRACT

**Objective:** Systematizing nursing care to an infant with West Syndrome, using the Nomenclature of Diagnoses/Results and Nursing Interventions. **Methods:** A descriptive study, of case type study, conducted in a teaching hospital in João Pessoa/Paraíba in October 2010, following the phases of the nursing process. The diagnoses were identified using the Nomenclature of Diagnoses/Results and Nursing Interventions developed and validated for the referred hospital as terms of ICNP®. The project was approved by the Research Ethics Committee of the hospital, under CAAE: 0052.0.126.000-09. **Results:** There were identified six nursing diagnoses: psychomotor impairment, seizures, impaired oral hygiene, respiratory pattern changes, risk of infection, family routine changed. **Conclusion:** The use of a classification of diagnoses / results and interventions directs nursing actions for efficiency in the care of children with West syndrome. **Descriptors:** Child hospitalized, Infantile spasms, Nursing processes.

### RESUMO

**Objetivo:** Sistematizar a assistência de enfermagem a uma lactente com Síndrome de West utilizando a Nomenclatura de Diagnósticos/Resultados e Intervenções de Enfermagem. **Métodos:** Estudo descritivo, do tipo estudo de caso, realizado em um Hospital Escola em João Pessoa/Paraíba em outubro de 2010, seguindo as fases do processo de enfermagem. Os diagnósticos foram identificados utilizando-se a Nomenclatura de Diagnósticos/Resultados e Intervenções de Enfermagem desenvolvidos e validados para o referido hospital conforme termos da CIPE®. O projeto foi aprovado pelo Comitê de Ética em Pesquisa do hospital, sob CAAE: 0052.0.126.000-09. **Resultados:** Foram identificados seis diagnósticos de enfermagem: comprometimento neuropsicomotor, convulsão, higiene oral prejudicada, padrão respiratório alterado, risco de infecção, rotina familiar alterada. **Conclusão:** A utilização de uma nomenclatura de diagnósticos/resultados e intervenções direciona as ações de enfermagem, proporcionando eficiência no cuidado a criança com síndrome de West. **Descritores:** Criança hospitalizada, Espasmos infantis, Processos de enfermagem.

### RESUMEN

**Objetivo:** Sistematizar la atención de enfermería a un bebé con síndrome de West utilizando la nomenclatura de diagnósticos/resultados y intervenciones de enfermería. **Métodos:** Estudio descriptivo, del tipo estudio de caso, realizado en un hospital universitario en João Pessoa/Paraíba, en octubre de 2010, siguiendo las fases del proceso de enfermería. Los diagnósticos fueron identificados con la nomenclatura de diagnósticos/resultados y intervenciones de enfermería desarrollados y validados para el hospital como términos de CIPE®. El proyecto fue aprobado por el Comité de Ética de Investigación del hospital, bajo CAAE: 0052.0.126.000-09. **Resultados:** Se identificaron seis diagnósticos de enfermería: deterioro neuropsicomotor, convulsiones, higiene oral deficiente, cambios en los patrones respiratorios, riesgo de infección, la rutina familiar cambiada. **Conclusión:** El uso de una clasificación de diagnósticos/resultados e intervenciones dirige las acciones de enfermería para la eficiencia en el cuidado de los niños con síndrome de West. **Descriptor:** Niño hospitalizado, Espasmos infantiles, Procesos de enfermería.

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## INTRODUCTION

**T**he West syndrome is a severe epileptic encephalopathy of early presentation, beginning between 4 and 10 months of age. The estimated incidence is 1 per 2000-4000 born alive, with a predominance in males, representing between 2-10% of all cases of childhood epilepsy.<sup>1,2,3</sup> Study published in Japan brings an incidence of 1 to 2380 born alive.<sup>4</sup>

This syndrome can be characterized by a triad of infantile spasms, consisting of rapid contractions of flexion, extension or mixed, being this last the most frequent. Contractions are usually bilateral and symmetrical, and biphasic, with a duration of 0,5 to 2 seconds, starting in isolation, but may evolve into hundreds of spasms. Associates, still, the occurrence of hypsarrhythmia in the electroencephalogram (EEG), those are peaks and slow waves and jumbled and of large amplitude, ranging in duration and location. The triad is completed with the occurrence of the delay or stop of the neuropsychomotor development.<sup>1,2</sup>

In this sense, it is known that epilepsy is a chronic disorder characterized by the occurrence of seizures repeat, resulting from abnormal electrical discharges of neurons in areas of the brain. These can be classified as partial, when the process of depolarization is restricted, or generalized, when they hit large areas of the brain, and is therefore more complex.<sup>5</sup> In children less than one year old, there is a significant risk due to brain development, with strong relation to permanent neurological damage.<sup>6</sup>

The etiology of the syndrome is diverse, and its classification has three categories: symptomatic, cryptogenic and idiopathic.<sup>2</sup> Among the causes, is the occurrence of malformations, trauma during delivery, incompatibility ABO and Rh, hemorrhage, meningitis, abuse alcohol and/or drugs during pregnancy, brain tumors, head trauma, stroke and vascular metabolic changes.<sup>5</sup> Research developed in Cuba has sought genetic relationships associated with the syndrome, presenting a new path of research.<sup>7</sup>

Although West syndrome has come under investigation, there is a gap in the literature when seeking reports on nursing care to this group of patients. Thus, by understanding the importance of continued vigilance, especially in children with seizures of repetition, it is worth noting the importance of nursing care to children with West syndrome and their families, structured through the nursing process, based on theoretical assumptions of Horta, in order to subsidize humanized and individualized care guided by comprehensive care.

Before the exhibition, it aimed to systematize nursing care to an infant with West syndrome, using the nomenclature of diagnoses/results and Nursing Interventions, developed for the teaching hospital, based on the International Classification for Nursing Practice (CIPE®).

## METHOD

This is a descriptive study of a case type study; performed on a Teaching Hospital, in the city of João Pessoa/Paraíba/Brazil, in October 2010, during the hospitalization of an infant diagnosed with West syndrome, accompanied by its mother. The institution is a reference in care for children with chronic and rare diseases in the Coastal Region and of the Forest Zone of Paraíba.

The data collection was supported by a data collection instrument for children 0-5 years old, used in service, based on the theoretical principles of Horta about Basic Human Needs, still in propaedeutic techniques of physical examination, in addition to data recorded in the patient medical record but data were also obtained through conversations with the mothers' infant.

After the stage of data collection, the indicators were analyzed and identified diagnoses prioritized in the care process, using the nomenclature of diagnoses/results and Nursing Interventions<sup>8</sup> developed and validated for the hospital as the ICNP<sup>®</sup> terms. After the definition of nursing diagnoses, there were proceeded the care planning and, therefore, the implementation of care.

It is noteworthy that the researchers only began collecting data after those responsible for providing clarifications on the infant research objectives, and after signing the consent form, being guarded him the ethical principles of the law of the country with Resolution 196/96 of the National Health Council and the COFEN Resolution 311/2007.<sup>9,10</sup>

It is noted, also, that this study is part of a research project for the systematization of nursing care to children and adolescents with chronic illnesses, approved by the hospital's Research Ethics Committee under CAAE: 0052.0.126.000-09, which is a bound to the Group of Studies and Research Grounds of Nursing Care component of Postgraduate Nursing, Federal University of Paraíba (PPGENF/UFPB).

## RESULTS E DISCUSSION

- **Nursing Historic**

The infant, R.A.O., 8 months old, female, residing in the district Bonito de Santa Fé-Paraíba, admitted to the Pediatric Clinic in October 2010, from his residence, with a diagnosis of West syndrome, accompanied by their mother. This report has presented during pregnancy induced hypertension syndrome of pregnancy (SHEG). Prolonged labor, eutocic, using forceps; NB had a cardiac arrest shortly after birth and cerebral hemorrhage after five days of life;



spent the first forty-five days of life hospitalized in the Intensive Care Unit (ICU), the mother reported that the first episode crying child was out of the ICU and, after discharge, the child underwent frequent readmissions. It is noteworthy that the family received the diagnosis of West syndrome at four months of age of the infant. Since then, the mother stopped working and began to devote herself exclusively to care for her, so that, throughout the period of hospitalization, it remained beside the child.

The examination and evaluation of the needs of breastfeeding: Vital signs and anthropometric data: T: 36,4°C, FC: 11bpm; FR: 59 irpm; P: 95bpm; Weight: 7.050Kg; Height: 71cm. Need for Neurological Regulation: conscious, hypoactive. Computed tomography suggestive result of anoxic/ischemic encephalopathy, diffusely affecting the cerebral hemispheres, cranial ultrasound revealed signs of bilateral cerebral injury hypoxic- ischemic, with signs of periventricular encephalomalacia, especially in the occipital region; presence of glabellar reflexes and suction, and unresponsiveness to stimuli, evidence during the application of certain valuation techniques (Search reflexes, Babinski, hold Palmar and Plantar, March). Throughout the review infant had mild spasms in upper and lower limbs; Need for Sleep and Rest: Sleep and rest preserved in using Nitrazepam; Nutritional Need: accept well the diet; Need Electrolyte Regulation: Serum Therapy in MSE for infusion of medications, Need for body Care: body care satisfactory and impaired oral hygiene (whitish tongue), absence of teeth; Need for Physical Integrity and mucocutaneous: Skin and mucous normocored, acyanotic, anicteric, afebrile, preserved elasticity and turgor; Need for oxygenation: eupneic typical chest (pigeon chest), breath sounds present with presence of scattered rhonchi over both lung fields, productive cough without expectoration; Need for Vascular Regulation: Normocadiac, BCNF in all outbreaks of auscultation, RCR in 2Q; Need elimination half- distended abdomen, RHA + in 4Q, without reference or expression of pain superficial and deep palpation, tympanic sounds in all quadrants; bladder deletions present with normal characteristics; bowel eliminations gifts, stool yellowish and pasty, observed during the period of data collection. Need for Love/Gregarious: mothers' reports that father and brother have good relationship with the infant, and that all are confident with the improvement in the clinical picture of it. Genitor further stated exclusive latent dedication, so after admission daughter was rarely home, leaving his other son in the care of his grandmother.

After investigation of the history of the child followed the other steps of the nursing process, being performed six nursing diagnoses and interventions selected, aiming to improve the quality of care, which are shown in Table 1.

Table 1. Planning of nursing care to a child with a diagnosis of West syndrome. João Pessoa-PB, October 2010.

Needs identified	Nursing diagnoses	Nursing interventions
Need of Neurological adjustment	Neuropsychomotor commitment	Be aware of the forms of communication used by the child. Monitor the development progress at regular intervals. Guide the mother to make monthly monitoring of the child.
	Convulsion	Keep possible objects of hurting the baby. Aspire to secretions from the oral cavity. Place the infant in lateral

		decubitus to facilitate drainage of saliva. Observe the signs and symptoms in the convulsive crisis. Protect the infant's head, putting, if necessary, pillow at the head.
<b>Need for body Care</b>	<b>Impaired oral hygiene</b>	Guide the mother principles of good oral hygiene. Commend and encourage the mother regarding the continuity of care with hygiene. Use feedback technique to assess the understanding of the mother on the guidelines.
<b>Need for Oxygenation</b>	<b>Altered breathing pattern</b>	Evaluate the frequency and respiratory depth every four hours. Monitor for the beating wings of the nose, chest retractions and cyanosis. Stay with the child and provide peace of mind during periods of difficulty breathing. Monitor pulmonary and cardiovascular State, every six hours. Provide treatment with nebulizer as prescribed.
<b>Need for immune regulation</b>	<b>Risk of infection</b>	Teach protective measures (diet, immunization) to minimize the risk of infection. Monitor vital signs. Guide the mother about the signs and symptoms of infection. Guide the mother about the importance of washing hands and maintain personal hygiene. Supervise the skin.
<b>Need to love/gregarious/attention/safety</b>	<b>Family routine changes</b>	Encourage parents to treat the infant. Support mother, listening to their needs, trying to help her. Identify and reduce the multiple environmental stressors (personal).

The clinical manifestations of West syndrome bring several changes to the lifestyle of the child and his family. The existing cognitive impairment in 90% of cases occur in varying degrees and is frequently associated with motor deficit, conduct disorders, blindness, deafness, autistic behavior, among other comorbidities that result in a change in the lifestyle of the child and his family.<sup>7</sup>

As a result of the needs of the child, family members, especially parents, markedly change their daily routine and suffer from the situation experienced by the child.<sup>11</sup>Situations that can trigger emotional disorders, which are characterized by periods of anger, sadness and discouragement, which can lead to depression.<sup>12</sup>Thus, the binomial child/family needs individualized attention, especially during the hospitalization process, when it is away from social contact.<sup>13</sup>

In this context, it is necessary that the nursing staff seek strategies to minimize the suffering of children and their families, working with the multidisciplinary team in rehabilitation of these two machines. It is important to consider risk related to West syndrome factors and individual needs of the child and his family. To do so, we need to promote emotional and psychological support, guidance regarding possible complications and treatments.<sup>12</sup>

Interventions relating to the education of family members should be directed in the sense that they understand the importance of tests to confirm a diagnosis of West syndrome or monitoring framework.

The course of West syndrome is varied and usually has a poor prognosis, which is closely related to early diagnosis, etiology and treatment of early stage.<sup>14</sup>Thus, it is observed in 90% of cases the presence of mental retardation, half of them with severe retardation.

Psychiatric disorders are common and other epileptic syndromes can arise, with 50-60% of cases progress to Lennox-Gastaut syndrome, multifocal epilepsy or secondarily generalized partial epilepsy.<sup>15</sup>

Whereas the prognosis of the disease, an adequate and effective clinical management to improve the quality of life for patients through the implementation of pharmacological care is not only necessary, but they are facing psychological needs and comfort of patients and their families.<sup>12</sup>

The institution of early treatment for West syndrome has aimed to achieve the abolition of spasms, in order to obtain a better performance neuropsychic.<sup>16</sup> In this context we highlight the administration of adrenocorticotrophic hormone (ACTH), which is effective in both immediate control of spasms as hypsarrhythmia, but no clear evidence of benefit on long-term prognosis.<sup>17</sup>

Furthermore, severe side effects are associated with this therapy, including: excessive weight gain, hypertension, infections, irritability, osteoporosis, electrolyte disturbances. Thus, many other drugs are used in treatment of West syndrome, such as valproate sodium, nitrazepam, vitamin B6 in high doses and vigabatrin. The latter has emerged as initial monotherapy for West syndrome, symptomatic or cryptogenic, since their side effects are acceptable, drug response can be measured quickly, is inexpensive and can be easily acquired in trade.<sup>17</sup>

Therefore, during the administration of pharmacological therapy, it is necessary that the nursing staff is attentive to any changes within the child. Importantly care with venous access, the risk of overdose and drug interactions, with a view to adopting standardized patient safety and adherence to treatment of the family conducts.<sup>18</sup>

The individualized and extended family assistance should be seen as a priority, not a team or service, but on the whole network of health professionals involved in the care. Under this approach, we highlight the role of nursing staff in providing care for children with the West syndrome, with the process of nursing care strategy which improves the bio-psychosocial conditions of children and their families.<sup>12</sup>

Thus, the Nursing Care System (NCS) is an important tool for providing holistic care to children with West syndrome and their families, since the care actions are deployed around the personal satisfaction and well-be causing the family to need to become a partaker of care actions and turning it into a protagonist of the process.

## CONCLUSION

The systematization of nursing care assists in directing the actions of care, allowing nurses to perform interventions in order to minimize or eliminate identified diagnoses and evaluate them using parameters established in the expected results.

In this sense, the use of CIPE<sup>®</sup>, through a classification of diagnoses/outcomes and



interventions, validated for the reality of the Brazilian health service, guiding the activities for efficiency in caring for children with West syndrome, and therefore, nursing interventions to all children attending at the institution, enabling the promotion of individual care and quality, focused on the needs of the patient-binomial family.

Thus, the study raises broader reflections, so that nurse practitioners awaken to the benefits brought by the use of the systematization of nursing care as it provides individualized and comprehensive care. Furthermore, we emphasize the importance that studies be conducted with experts and assistance in order to test nurses nursing actions in order to identify the effectiveness of interventions in the recovery process groups, like children with West syndrome so that they can produce evidence to guide teaching and nursing care.

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