

Nursing assistance to palliative care infants with diagnoses of Edwards and Dandy-Walker syndromes**Assistência de enfermagem em lactente paliativo com diagnósticos de síndromes de Edwards e Dandy Walker****Asistencia de enfermería en lactante paliativo con diagnósticos de síndromes de Edwards y Dandy Walker**

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In neonatology, the theme "palliative care" is becoming more popular due to the greater frequency of syndromes incompatible with life, as well as the occurrence of congenital abnormalities. This study aims to report the preparation of the systematization of nursing care in palliative infant affected by Edwards and Dandy-Walker syndromes. The study was carried out from September to November 2017, during the practical sessions of the discipline Nursing Care for Children and Adolescents Health of the Nursing course at a university in Minas Gerais. Seeking to provide comprehensive and quality care, after listed nonconformities identified during data collection, nursing diagnoses were listed and relevant care proposed. Providing palliative care requires the implementation of systematization to guide the care to pain relief and suffering. The experience of dealing with life and death requires improvement of knowledge and support.

Descriptors: Palliative care; Nursing care; Pediatrics.

Na neonatologia, o tema "cuidados paliativos" vem ganhando espaço devido à maior frequência das síndromes incompatíveis com a vida, assim como a ocorrência de anormalidades congênitas. Este estudo tem como objetivo relatar a elaboração da Sistematização da Assistência de Enfermagem em lactente paliativo acometida pelas Síndromes de Edwards e Dandy-Walker. O estudo foi realizado de setembro a novembro de 2017 durante as aulas práticas da disciplina de Assistência de Enfermagem à Saúde da Criança e do Adolescente do curso de Enfermagem de uma Universidade em Minas Gerais. Buscando prestar assistência integral e qualificada, após elencadas as não conformidades identificadas durante a coleta de dados, foram listados diagnósticos de enfermagem e propostos cuidados pertinentes. Prestar assistência paliativa requer a aplicação da Sistematização para nortear os cuidados no alívio da dor e do sofrimento. A experiência de lidar com a vida e a morte requer aprimoramento dos conhecimentos e apoio.

Descritores: Cuidados paliativos; Cuidados de enfermagem; Pediatria.

En neonatología, el tema "cuidados paliativos" ha ganado espacio debido a la mayor frecuencia de síndromes incompatibles con la vida, así como la ocurrencia de anormalidades congénitas. Este estudio tiene como objetivo relatar la elaboración de la Sistematización de la Asistencia de Enfermería en lactante paliativo acometida por las Síndromes de Edwards y Dandy-Walker. El estudio fue realizado de septiembre a noviembre de 2017 durante las clases prácticas de la asignatura de Asistencia de Enfermería a la Salud del Niño y del Adolescente del curso de Enfermería de una Universidad en Minas Gerais. Buscando dar asistencia integral y calificada, tras listadas las no conformidades identificadas durante la colecta de datos, fueron listados diagnósticos de enfermería y propuestos cuidados pertinentes. Dar asistencia paliativa requiere la aplicación de la Sistematización para nortear los cuidados en el alivio del dolor y del sufrimiento. La experiencia de lidiar con la vida y la muerte requiere perfeccionamiento de los conocimientos y apoyo.

Descriptorios: Cuidados paliativos; Atención de enfermería; Pediatría.

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INTRODUCTION

The provision of care to a patient requires nursing staff competencies, skills and attitudes based on scientific knowledge, which allows the professional to carry out the planning of its action facing the daily challenges and thus, obtaining relevant data in managing of the care provided¹.

In nursing, the scientific method used to organize the professional work is the systematization of nursing assistance (SAE), which provides a comprehensive and individualized patient care, implementing the Nursing Process (NP), which is guided into five stages: data collection, nursing diagnosis, care planning, implementation and evaluation of results¹.

The importance of applying SAE in Pediatric Units is due to the complexity of care required by a child, being necessary a careful, independent and comprehensive care. There are numerous diseases that affect hospitalized children, requiring the professionals to plan their actions in a systematic way, based on technical and scientific principles².

Among the possible disorders seen in pediatric units the Edwards Syndrome stands out, characterized by the existence of a copy of the 18 autosomal chromosome, generating a characteristic picture of congenital malformation, low weight, bad formation of the skull and congenital heart diseases³. Considered the second most frequent syndrome, its worldwide incidence is about 1 case between 30,000 to 80,000 live births, predominantly in female gender^{3,4}. According to studies, the main cause is the increased maternal age, a factor likely to cause no separation of chromosomes during cell division, and diagnosis is confirmed by chromosome analysis, allowing fast detection in newborns and early prenatal detection. Most fetuses with this condition end up dying before birth or, when born live, 99% end up dying in the first 6 months of year⁴.

The Dandy-Walker syndrome is a classic malformation described by Dandy and Blackfan in 1914, which refers to a development process of the foramina paper of Lushka and Magendie during the fourth month of fetal life, leading to cystic bulging of

the fourth ventricle, with part of the children affected having central nervous system abnormalities⁵.

Due to the requirement of an organized, flexible and coordinated action within the multidisciplinary team, in order to improve the quality of provided palliative care, this study aims to contribute to the discussion on the need for implementation of the SAE. From it, it is known that it is possible an early identification of the complex and multiple needs expressed by the patient in palliative care⁶. This study aims to report the preparation of SAE in palliative infant affected by Edwards and Dandy-Walker syndromes.

METHOD

This is an experience report on the establishment of SAE in an infant under palliative care and carrier of Syndromes Edwards and Dandy-Walker.

The study was conducted from September to November 2017, during the practical sessions of the discipline Nursing Care for Children and Adolescents Health of the Nursing course at a university in Minas Gerais.

The infant was hospitalized, making possible a direct observation. The SAE has been prepared for academic purposes, not running any specific procedure or intervention.

Safeguarding the ethical principles and ensuring the integrity of the child and family, the study does not present names or acronyms and respected the ethical principles established by Resolution 466/12.

RESULTS

The infant, four months old, term birth, small for gestational age (SGA), was admitted to the pediatric ICU after cardiopulmonary resuscitation in the delivery room. Ultrasound examination showed brain malformation with cerebellar hypoplasia and increased cistern magna, confirming the diagnosis of Dandy Walker syndrome and showing the malformation of the central nervous system (CNS). The karyotyping further revealed the existence of Edwards Syndrome.

During physical examination performed by the nursing staff and observed by scholars, the infant presented: active, reactive, icteric, cholestatic, thin aspect, keeping diffuse live do reticularis, and lower limbs and right forearm swollen.

She presented increased anteroposterior diameter of the skull and ears with low implantation with right atrial appendage. She maintained peripherally inserted central catheter (PICC), tracheotomy and mechanical ventilation with gastrostomy antireflux valve. At auscultation, the presence of audible murmur tricuspid. At respiratory

auscultation, presence of diffuse sounds (snores). Upon inspection, ascites abdomen with umbilical hernia and rectus diastasis. Palpable liver to 6 cm from the right costal margin and spleen 2 cm from the left costal margin.

Before medical diagnosis incompatible with life, health staff chose to start the implementation of palliative care.

By the clinical condition, SAE is shown in Table 1, with the main nursing diagnoses prepared by students under faculty supervision, based on the NANDA⁷.

Table 1. Nursing Diagnoses *. Uberaba, 2017.

DIAGNOSIS	DEFINING CHARACTERISTIC	RELATED FACTOR / RISK FACTOR
Impaired Gas Exchange	Abnormal breathing pattern	Imbalance in the ventilation-perfusion relation
Ineffective breathing pattern	Vital capacity decreased	Neurological damage
Ineffective Clearing Airway	Change in breathing pattern, restlessness	Neuromuscular Impairment, excessive mucus
Aspiration hazard	-	Depressed level of consciousness, impaired swallowing ability
Decreased cardiac output	Edema, decreased peripheral pulses, presence of the 3rd heart sound	Altered contractility
Infection Risk	-	Invasive procedures, change in skin integrity
Risk of falling	-	Age ≤ 2 years
Comfort impaired	Restlessness, suffering symptoms	Symptoms of the disease
Breastfeeding interrupted	Not exclusive breastfeeding	Child's hospitalization
Arrangement for paternity or maternity improved	Father / mother express desire to improve the emotional support to children	-
Neonatal jaundice	Yellow sclera, yellowish mucous.	Difficulty of making the transition to extra-uterine life, unintentional weight loss

* Based on NANDA⁷.

DISCUSSION

In Pediatric ICU, SAE application is of fundamental importance because, through it, the nursing staff is able to provide qualified assistance not limited to ensuring the survival, but also planning actions to reduce the level of stress, anxiety and foster the bond between parents and child⁸.

It appears that the majority of clinical findings are justified by the syndromes presented by the infant. In the presence of Edwards Syndrome it is found malformations, cerebral included: dysmorphic skull with reduced bifrontal diameter, and prominent

occipital region; triangular face; narrow palpebral fissures; small nose and mouth; high-arched, narrow palate; micrognathia; dysplastic ears, with low implantation and presence of pre-auricular appendages⁴.

The infant also had the Dandy-Walker syndrome, characterized by the triad: complete or partial agenesis of the cerebellar vermis; cystic dilatation of the fourth ventricle; posterior fossa enlargement with lateral displacement of the lateral sinuses, tentorial and confluence of the dura mater sinuses upwards. In addition, common findings of Dandy-Walker Malformation

included cerebellar hypoplasia and increased cisterna magna, with a possible compression and hypoplasia of the brainstem; weight loss and bulging of occipital bones⁵.

One of the manifestations presented by the child was Lived reticularis, resulting from a physiological vasospastic response to cold or systemic diseases characterized by a pattern of cyanotic discoloration, or erythematous cyanotic, which assumes a lace aspect to the skin⁹. Also, the infant showed up cholestatic and it emphasizes bile formation deficiency and/or bile flow, explaining the jaundice¹⁰.

The tricuspid heart murmurs was, possibly, caused by a change in cardiac muscle¹¹ and the presence of diffused adventitious sounds were by thick secretion adhered to the walls of large diameter bronchi with snoring during pulmonary auscultation¹².

Furthermore, it was observed that infants had abdominal ascites, characterized by the free liquid accumulation in the peritoneal cavity. This factor causes increased intra-abdominal pressure, justifying the development of rectus diastasis and umbilical hernia presented by her¹³. The swelling in the lower limbs is seen as a consequence of changes in the homeostasis of sodium and water in the body of the child¹⁴.

At birth, the child was considered SGA, and such status can be attributed due to hypoplasia of skeletal muscles, and subcutaneous adipose tissues characteristic of Edwards syndrome⁴.

In the delivery room, there were assistance maneuvers to maintain the life of the newly born. Intubation was required due to the need for invasive ventilatory support¹⁵ and inserting the PICC was due to the need for rapid and effective intravenous therapy⁴.

Later, hospitalized in the ICU, the child tracheotomy was to conduct prolonged mechanical ventilation. This measure has been attributed to increased survival in patients dependent on long oxygen therapy¹⁶. It was also necessary to perform gastrostomy with antireflux valve due to severe respiratory problems of neurological causes, being it a device for dietary supplementation

in debilitating diseases able to reduce the risk of respiratory infection subsequent to suction gastroesophageal reflux aspiration¹⁷.

To provide the child a comprehensive, holistic and quality care, the nursing diagnoses listed during the SAE sought to cover non-compliances identified in data collection, as it is recommended to ensure the effectiveness of the Nursing process¹.

Confirming the continuity of SAE, an assistance plan consisting of care was prepared, which are justified scientifically and theoretically. In this context, it is known that in the case described, evaluation of arterial blood is an important factor for the interpretation of the basic acid balance, pulmonary oxygenation and alveolar ventilation, to normal gas exchange¹⁸.

Monitoring the neurological condition is essential to ensure the brain is receiving oxygen to avoid a possible cerebral hypoxia¹⁹. It is necessary to monitor offered values of fraction of inspired oxygen (FiO₂) to maintenance of appropriate tissue oxygenation²⁰.

Adopting Semi-Fowler positioning facilitates the work of breathing, ensures comfort, besides promoting lung expansion collaborating with breathing²¹. Performing airway aspiration, keeping them patent, constitutes an important factor in restoring gas exchange, thus favoring respiratory function²². The respiratory therapy also increases the capacity of the lungs through the recovery of the respiratory condition²³.

In the context of comprehensive care, vital signs should be monitored, since they indicate the health status and functioning of the circulatory, respiratory, neural and endocrine functions of the body. They contribute to the prevention of damage and signal events that may impact the quality of care. When checked serially, these parameters give the nurse the ability to evaluate the implemented interventions, making decisions towards the patient therapy response²⁴.

Complications resulting from aspiration, such as pneumonia, can be avoided by keeping the diet off during procedures and placing the child in the supine position during and after the power supply up to the eructation²⁵⁻²⁷. The

airway aspiration technique is essential to keep it patent, restoring gas exchange and consequently, favoring respiratory comfort²². The implementation of this technique is an essential factor to maintain oxygenation, avoiding obstructions and, possibly, the occurrence of aspiration²⁸.

The water balance is a fundamental importance tool in assisting the infant, since at this age the child is susceptible to considerable water loss. It allows one to see whether there's water balance and is an early indicator of the occurrence of cardiovascular and renal complications in critical patients²⁹.

Cardiac physical examination of the infant in this study has its need based on the presence of the 3rd heart sound, the thin wrists and present edema. Such changes indicate circulatory compromise and require detailed cardiac assessment, paying attention to pattern changes and observing pulses regarding the frequency, rhythm and depth³⁰.

Evaluating and ranking edema semiotic conditions as to the place, evolution, intensity, consistency, sensitivity and temperature is required. One should check if its cause is related to other circulatory factors, so that appropriate measures are taken³¹.

Maintenance of perfusion and oxygen delivery to cells is the main function of the cardiorespiratory system. Thus, unstable patients tend to develop tissue hypoperfusion, which is directly related to organic and multiple organ dysfunction injury, justifying the need to monitor the capillary refill time (CRT) 32.

When the patient's clinical condition requires the insertion of a catheter, it is necessary to pay attention to a number of associated risks, including priority to infection and device obstruction^{33,34}. These complications contribute directly to the increased hospitalization period, mortality rates and hospitalization costs³⁵. Thus, handling, maintenance and optimization of devices requires the nursing staff knowledge and skills to enable them to handle the devices safely³⁶.

The appearance of signs of inflammation such as pain, heat, erythema and edema at the insertion site or in the vascular path, may

signal the presence of superficial access infection. Thus, the dressings exchange should be performed regularly, so that the local view is facilitated and a favorable environment for bacterial growth³⁷ avoided.

In the safety of the patient, it is known that children aged ≤ 36 months must be accommodated in cribs with high grades to the maximum height, as the falls contribute to the increased length of hospital stay and, in severe cases, death³⁸.

The changing positions in bedridden patients contributes to reduction of respiratory infections, helps in dermatologic prevention dermatological in ischemia and pressure areas, improves oxygenation and facilitate mechanical respiration, also promoting mobilization of tracheobronchial secretions³⁹.

The development of pressure injuries cause significant damage to the patient, since they hinder the functional recovery process and may result in prolonged hospitalization, sepsis and death. In this sense, the use of pads among the bony prominences, changing positions, skin hydration and maintaining the nutritional status act as preventive measures to injuries⁴⁰.

It is known that the pediatric intensive care units are stressful environments to the hospitalized individuals due to several factors, such as lighting and loud noise, excessive handling of the child, and little social interaction. It is true that simple measures such as reduction of these stressors, habit of talking with infants and implementation of non-pharmacological pain management should be implemented, in order to reduce suffering caused by the hospital, making the assistance humanize⁴¹.

The evaluation of pain can be divided into three categories: 1. Measurement of physiological pain responses; 2. Observations of pain-related behaviors; 3. written or verbal descriptions of pain and/or associated variables. There are pain intensity measurements (one-dimensional) and multiple measures of pain dimensions (multi-dimensional), with the latter being the most widely used in newborns and infants, as they

are able to assess the behavioral responses associated with physiological responses⁴².

The interaction among the nursing staff, patient and family is essential for effective care, being communication its main medium. The affective and empathetic relationship provided to families and patients are also essential factors⁴³.

Even lying in a state of emotional weakness or crisis, parents continue to occupy a prominent role, making her feeling protected, safe, loved⁴³.

Leaving the parents comfortable to question the child's clinical condition and guide them regarding this means not only an important element in the care provided, but also a breakthrough in establishing the interpersonal relationship among the nursing staff and the family group. This attitude enables effective communication and the sharing of emerging meanings before the stressful situation of having a family member in ICU⁴⁴.

It is essential to emphasize the importance of developing the SAE, but it is necessary to understand the obstacles that are imposed on professionals.

The development of a planned care becomes, in the opinion of some professionals, a new situation to be added among the many already performed in daily life of those who have an extensive service charge, thus leaving unnoticed the main benefit that the implementation of SAE guarantees, that is, the organization of care, and that from this it is possible to prioritize actions and discard not relevant interventions to the continuity of patient's care, reducing, consequently, the service overload.

The concept of SAE and due consideration of its implementation need to be better worked with professionals. Because of lack of knowledge, there may be bias with SAE. In addition, this methodology ensures the improvement of care, benefits the professional, as well as for the patient, and offers comprehensive care based on individual needs of each patient.

CONCLUSION

Providing palliative care to an infant requires the application of SAE in order to guide the care provided. Assistance should involve not only the patient and his family, but also the team that daily works to relieve pain and suffering, as the experience of dealing with life and death requires improvement of knowledge and support.

For the applicability of the SAE become productive and profitable it is necessary available professional staff. The team needs to be involved in operating procedures and knowledge of the benefits that SAE provides; therefore, it is necessary to solve any doubts that may be occurring in relation to this method of care, in order to prevent an unfavorable concept that might hinder acceptance on the team.

A previously established planning enables the reduction of complications, increased knowledge of the individual patients' needs and the organization of care, generating an action in which the patient will be assisted in their mental, physical and social integrity.

In neonatology, the subject "palliative care" is becoming more popular due to the greater frequency of syndromes incompatible with life, as well as the occurrence of congenital abnormalities. Still, there is a gap to be filled with knowledge aimed at professionals regarding this type of care, for when faced with these situations they feel unable to make decisions due to both lack of theoretical background and the absence of livings practices.

Thus, it is necessary to be better training of professionals, so they can deal with situations without possibility of cure. And so, they can take care to offer comfort to the patient and family up to death.

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CONTRIBUTIONS

Izabela Katiucia Tomaz da Silva, Laís Silva Palmieri and Douglas de Oliveira Silva contributed to the conception, planning, design of the study, collection, data analysis and interpretation and writing. **Bruna Maria Malagoli Rocha** was responsible for the guidance and coordination of the application process of the Nursing Assistance Systematization, design, analysis of data collected and review.

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