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EXPERIENCE REPORT

Nursing care for pediatric patients with Down Syndrome and congenital heart disease

Atención de enfermería al paciente pediátrico con Síndrome de Down y cardiopatías congénitas

Assistência de enfermagem ao paciente pediátrico com Síndrome de Down e cardiopatia congênita

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Abstract

This study aimed to describe the application of the Systematization of Nursing Care to a pediatric patient with Down Syndrome and congenital heart disease. This is a descriptive, cross-sectional, qualitative study, based on an experience report during the undergraduate nursing internship at a public children's hospital in Piauí. The study addressed the care provided to a pediatric patient with congenital heart disease and Down syndrome, based on the NANDA, NIC, and NOC taxonomies, which represent, respectively, Nursing Diagnoses, Interventions, and Expected Outcomes. The multiple health care needs of the child were identified to ensure adequate oxygenation and nutrition. Thus, the following NANDA criteria were used: Excessive fluid volume associated with impaired regulatory mechanism; Ineffective infant feeding dynamics associated with congenital heart disease; Ineffective airway clearance related to retained secretions; Risk of infection associated with the invasive procedure; Risk of aspiration associated with impaired swallowing ability. NIC: Remove secretions by stimulating coughing or suctioning; Monitor respiratory status and oxygenation, as appropriate; Monitor calorie, carbohydrate, vitamin, and mineral intake. This experience allowed for clinical and critical assessment of quality nursing care.

Descriptors: Nursing; Nursing Assistance; Pediatrics; Heart Disease; Trisomy 21.

Resumén

El objetivo de este estudio fue describir la aplicación de la Sistematización de la Atención de Enfermería a un paciente pediátrico con Síndrome de Down y cardiopatía congénita. Se trata de un estudio descriptivo, transversal y cualitativo, basado en un relato de experiencia durante la pasantía de enfermería de pregrado en un hospital público infantil de Piauí. El estudio abordó la atención prestada a un paciente pediátrico con cardiopatía congénita y síndrome de Down, con base en las taxonomías NANDA, NIC y NOC, que representan, respectivamente, Diagnósticos de Enfermería, Intervenciones y Resultados Esperados. Se identificaron las múltiples necesidades de atención médica del niño para asegurar una oxigenación y nutrición adecuadas. Por lo tanto, se utilizaron los siguientes criterios NANDA: Volumen excesivo de líquidos asociado con un mecanismo regulador deteriorado; Dinámica ineficaz de la alimentación infantil asociada con cardiopatía congénita; Depuración ineficaz de las vías respiratorias relacionada con secreciones retenidas; Riesgo de infección asociado con el procedimiento invasivo; Riesgo de aspiración asociado con la capacidad de deglución deteriorada. NIC: Eliminar secreciones estimulando la tos o la succión; Monitorizar el estado respiratorio y la oxigenación, según corresponda; controlar la ingesta de calorías, carbohidratos, vitaminas y minerales. Esta experiencia permitió la evaluación clínica y crítica de la atención de enfermería de calidad.

Descriptores: Enfermería; Asistencia de Enfermería; Pediatría; Cardiopatía; Trisomía 21.

Resumo

Objetivou-se descrever a aplicação a Sistematização da Assistência de Enfermagem em paciente pediátrico com Síndrome de Down e cardiopatia congênita. Trata-se de um estudo descritivo, transversal, de abordagem qualitativa do tipo relato de experiência vivenciado durante o estágio de graduação em enfermagem, em um hospital público infantil localizado no Piauí, acerca da assistência a um paciente pediátrico com Cardiopatia Congênita e Síndrome de Down sob a luz das Taxonomias da NANDA, NIC e NOC que representam, respectivamente, Diagnósticos, Intervenções e Resultados Esperados em Enfermagem. Foram constatadas as múltiplas assistências em saúde que o infantil necessitava a fim de garantir uma oxigenação e alimentação adequadas. Assim, empregaram-se o NANDA: Volume de líquidos excessivo associado ao mecanismo de regulação comprometido; Dinâmica ineficaz de alimentação do lactente associado à doença cardíaca congênita; Desobstrução ineficaz das vias aéreas relacionado às secreções retidas; Risco de infecção associado à Procedimento invasivo, Risco de aspiração associado à capacidade prejudicada para deglutir. O NIC: Remover secreções estimulando a tosse ou aspirando; Monitorar a condição respiratória e a oxigenação, conforme apropriado; Monitorar a ingestão de calorias, carboidratos, vitaminas e minerais. A presente vivência permitiu o exercício clinico e critico de qualidade da assistência em enfermagem.

Descritores: Enfermagem; Assistência de Enfermagem; Pediatria; Cardiopatia; Trissomia do 21.

Introduction

Congenital heart disease is defined as a malformation in the structure and function of the heart. According to DATASUS, the incidence of congenital heart disease in Brazil was approximately 3.6 per 10,000 live births between 1999 and 2015[1]. Technological advances have contributed to early diagnosis and improved treatment, which has significantly reduced mortality and increased patient survival time[2]. The diagnosis of congenital heart disease has a major impact on parents, resulting in recurring invasive treatments, surgery, and a higher risk of death for their child[3]. It triggers stress in caregivers and a greater likelihood of mental health-related illnesses[4].

It is noteworthy that a systematic review and meta-analysis of the functional capacity of the respiratory and circulatory systems of children and adolescents with congenital heart disease found that maximal oxygen consumption (VO2max) was the variable associated with low functional capacity, possibly influenced by impaired chronotropic response. This highlights a complicating factor in the presence of cardiac pathologies in pediatrics, which require a greater supply of O2 for satisfactory respiratory dynamics[5].

Therefore, due to the particular physiological and anatomical conditions of pediatrics, age has also been shown to correlate with functional outcome, with younger individuals presenting a greater risk of dysfunction[6,7]. However, younger children have immature and fragile bodily systems, such as the respiratory system. Furthermore, newborns naturally have lower antioxidants and self-regulatory capacities, which predispose certain systems to injury, especially when associated with major cardiac surgery, as this is a complex and delicate operation. Furthermore, the brain system can be negatively affected, given the changes that occur in brain perfusion and oxygenation[8].

Furthermore, chromosomal abnormalities and complex clinical presentations are common in pediatric patients with congenital heart disease. The prevalence of serious infections, such as pneumonia and sepsis, is also high (70% and 85%, respectively) among children with Down syndrome and congenital heart disease between the ages of six and 48 months. Therefore, clinical monitoring and periodic vaccination, including the use of antibodies against respiratory syncytial virus, are essential[9]. The prevalence of congenital heart disease in children with Down syndrome is known to be 40 to 60%, a higher percentage than that observed in children without the syndrome. This highlights the relevance of studies on this cardiac involvement in pediatrics with this chromosomal abnormality[10].

To specify the cardiological anomalies, a study with 441 children with congenital heart disease, 55% of the cases presented Down Syndrome, and the most common congenital heart disease was also Ventricular Defect (VSD) in 28.3% of the cases[7]. In addition, another study, based on medical record analysis, revealed that more than one heart disease was diagnosed per patient. The patient diagnosed with the highest number of congenital heart defects had eight types of malformations: VSD, T4F, pulmonary stenosis (PS), Down syndrome, atrioventricular septal defect (AVSD), pulmonary atresia (PA), late postoperative Glenn syndrome (LPOG), and late postoperative Blalock-Taussig syndrome (LPOBT)[11].

Another important point to consider regarding the high mortality rates of patients with congenital heart disease in the state of Jalisco is the inadequate referral system. In many cases, it is not possible to transfer patients to a unit that performs life-saving procedures, regardless of whether the patient has a critical heart condition requiring immediate attention. This is a consequence of the patient volume and insufficient resources in public hospitals, which contributes to the increased mortality rate. As mentioned, multidisciplinary teams are needed to care for patients with congenital heart disease to achieve the best outcomes. However, patients often receive primary care from physicians with little training in pediatric cardiology, who often refer and diagnose patients at a very late stage, which interferes with a positive prognosis[12].

In addition to these factors, from the perspective of parents or caregivers, parents of children with congenital heart disease tend to experience more stress than parents of children with other pathologies. This scenario includes dilemmas of normalcy and social integration. In a study on the quality of life of parents of children with heart disease, emotional roles and mental health were among the factors that influence this issue[13].

Therefore, the research question was defined as nursing care for children with Down syndrome and congenital heart disease, and the objective of this study was to describe the application of the Nursing Care Systematization (NCS) in pediatric patients with Down syndrome and congenital heart disease.

Methodology

This is a descriptive, cross-sectional, qualitative study, reporting on the authors' experiences during their undergraduate nursing program at a public university in the state of Piauí in September 2023, during their ninth-semester internship at a large public children's hospital in Teresina, Piauí. Because these are academic experiences related to the case, the use of a Research Ethics Committee (REC) is waived.

Experience Report

The experience took place in September 2023, during the hospitalization of a child with Down syndrome and congenital heart disease. The hospitalization area consisted of wards, divided by complexity levels. The nurse was included in the nursing team through the Supervised I internship, with one of the areas being the ward where the patient was hospitalized. This is a pediatric patient with Down syndrome and congenital heart disease. Therefore, in addition to routine care, the care plan was developed using the Nursing Care Systematization (NCS), which developed Nursing Diagnoses, Interventions, and Expected Outcomes based on the NANDA, NIC, and NOC Taxonomy (Chart 1).

Chart 1. Nursing Diagnoses, Nursing Interventions, and Expected Outcomes for Nursing Care for a Patient with Down Syndrome and Congenital Heart Disease. Teresina, PI, Brazil, 2023

Nursing Diagnosis	Nursing Prescriptions	Expected Results
Excessive fluid volume associated with impaired regulatory mechanism	Remove secretions by stimulating coughing or suctioning.	Use of symptom relief measures from frequently demonstrated to consistently demonstrated. Knowledge of the procedure from consistently demonstrated to consistently demonstrated.
Ineffective airway clearance related to retained secretions	Position the patient to maximize ventilatory potential. Auscultate respiratory sounds, observing areas of decreased or absent ventilation and the presence of adventitious sounds. Monitor respiratory status and oxygenation, as appropriate.	Monitoring the therapeutic effects of treatment from consistently demonstrated to consistently demonstrated. Monitoring changes in disease status from consistently demonstrated to consistently demonstrated.
Ineffective infant feeding dynamics associated with congenital heart disease	Flush the tube every four to six hours, as appropriate, during continuous feedings and after each intermittent feeding. Check the gravity drip flow or pump flow hourly. Monitor fluid and electrolyte status. Monitor calorie, carbohydrate, vitamin, and mineral intake for adequacy (consult a nutritionist) twice a week initially; then reduce to once a month.	Knowledge of the procedure from consistently demonstrated to consistently demonstrated. Knowledge of the risks and potential complications from consistently demonstrated to consistently demonstrated. Adherence to the prescribed diet from consistently demonstrated to consistently demonstrated.
Risk of aspiration associated with impaired ability to swallow	Perform endotracheal or nasotracheal suctioning, as appropriate.	Knowledge of the procedure from consistently demonstrated to consistently demonstrated. Knowledge of the risks and potential complications from consistently demonstrated to consistently demonstrated. Performing skin preparation from consistently demonstrated to consistently demonstrated.
Risk of infection associated with invasive procedure	The responsible professional should wear sterile gloves during procedures, as appropriate. Change central and peripheral intravenous lines, as well as dressings, promptly. Encourage adequate nutritional intake. Encourage fluid intake, as appropriate.	Use of universal precautions. Adapting infection control strategies as needed, from frequently demonstrated to consistently demonstrated. Hand hygiene practices, from frequently demonstrated to consistently demonstrated. Monitoring the environment for factors associated with infection risk, from frequently demonstrated to consistently demonstrated.

Discussion

Organizing nursing care is essential for hospitalized children and their families. Care is structured through the SAE (National Health Assistance System), which guides plans and interventions based on the needs and humanization of care provided by the nursing team[14]. By referring this care to children with Down syndrome, the role of the nursing professional in constructing care based on diagnoses and interventions becomes even more evident, as well as their educational role with the family and patient[15].

It is important to note that early surgical interventions are being recommended to correct physiological defects caused by congenital heart disease, resulting in longer survival and a better quality of life for those affected[16,17]. Aiming to evaluate physiological changes, a study compared executive function between groups of children and adolescents with severe coronary artery disease and controls (ages 10-19 years). The results showed that rates of executive function impairment were almost twice as high for the group with coronary artery disease (81%) compared to the control group (43%)[18].

Furthermore, a study conducted with 448 children undergoing a surgical procedure at a children's hospital in the city of Londrina, in the state of Paraná, 47 children were diagnosed with Down syndrome (10.5%). In this group, Atrioventricular Septal Defect (AVSD) had a higher incidence (27.70%; n=13)[10]. Concurrently, the study conducted in the city of Jalisco showed that although the cardiology care teams (pediatric cardiologists, pediatric cardiovascular surgeons, pediatric intensivists, nurses, and perfusionists)

working in Jalisco hospitals attempt to provide timely and quality care to these patients, this is not sufficient due to significant limitations; much remains to be done to ensure that all children born in the state with cardiac anomalies receive appropriate and timely medical and surgical care[13].

Regarding the physiological conditions of infants undergoing cardiac surgery, studies have shown variations in cardiorespiratory parameters during feeding. No statistically significant differences were found in the variation in cardiorespiratory parameters associated with complications in the clinical swallowing assessment (such as coughing and choking) or with the completion of the swallowing assessment, even though approximately 75% of the EG sample presented dysphagia. Dysphagia presents as difficulty in swallowing related to the functioning of one or more oropharyngolaryngeal and esophageal structures, making safe, effective, and comfortable oral intake of food difficult or impossible, and can cause malnutrition, dehydration, aspiration, displeasure, and social isolation, in addition to more serious complications such as aspiration pneumonia and death[19].

Furthermore, previously published research has shown that patients with heart disease, liver disease, and neurological diseases with prolonged mechanical ventilation and malnutrition are more likely to undergo tracheostomies[20]. Therefore, patients with these diagnoses have risk factors related to the underlying disease and the presence of a tracheostomy for developing dysphagia and alternative feeding methods, such as tube feeding. Another study found that 40% to 70% of children with chronic conditions, such as congenital or acquired respiratory, cardiac, and gastrointestinal problems, have difficulty swallowing and feeding[21].

Parallel to this, patients undergoing enteral tube feeding and their prolonged dependence are also factors associated with the development of food refusal. Broadly speaking, food refusal arises from a decreased motivation to eat due to poor perception of hunger, satiety due to tube feeding, negative experiences such as extreme handling during hospitalization and procedures, impaired child-caregiver interaction, and reduced positive oral stimulation due to lack of experience[22].

Regarding decannulation in hospitalized pediatric patients with tracheostomies, successful decannulation can be considered the final step in the care needs of the child who has undergone tracheostomy. In this study, the authors found a decannulation rate of 31.6% of cases, without process failure and during the same hospitalization. All cases were associated with hospital discharge. A retrospective study of 426 tracheostomized children discharged from the ICU found that older children (over 5 years old) with airway obstruction, acquired neurological disease, or respiratory disease were more likely to be decannulated compared to those with congenital neurological disease[23].

Given these aspects, the care provided by the nursing team to children and adolescents with special health needs is shared with the family. A 2017 study with 20 nursing professionals and 20 family members at two university hospitals in the state of Rio Grande do Sul confirms that the nursing team possesses technical and scientific knowledge focused on patient care. However, it is the family caregiver who can identify and explain to the care team even the slightest changes in the child's health. Thus, the family becomes an important collaborator in the treatment, as they mediate essential information that aids in the care of this hospitalized child, which must be valued and recognized by professionals[24].

Finally, the nursing care described in the literature is often focused on technical procedures; however, children need strategies that improve their quality of life, with comprehensive actions that strengthen bonds and closeness between those who care (team), those who are cared for (pediatricians), and the family caregiver[25,26]. Therefore, care for children and adolescents needs to go beyond technique and include relational and playful strategies that reduce the physical and emotional impact caused by hospitalization[24]. Accordingly, the importance of the nursing process is highlighted for its contributions to the growth of the category, documentation of professional practice, and quality of service provided[27].

Among the limitations of this study, we highlighted the limited number of studies in the literature that address the diagnosis of congenital heart disease combined with Down syndrome in a targeted, up-to-date, and case-specific manner. That said, we inferred from studies conducted before the last five years. Regarding the contributions of this study, we found that the study of nursing care focused on complex pediatric clinical cases benefits the advancement of science by mapping difficulties and identifying the positive and negative aspects inherent in care.

Conclusion

Therefore, it was found that care for children with heart disease and Down syndrome encompasses multiple care delivery approaches, and thus, nursing care gains prominence in identifying and developing therapeutic plans tailored to each individual need. This experience contributed to the systematization of nursing care for patients with Down syndrome and heart disease, enabling a thorough analysis of the clinical presentation, needs, and potential risks for developing diagnoses, interventions, and objectives. This study also enabled a holistic and humanized approach to the health of children and their families.

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