Original Article

Nursing actions for the dehospitalization of children under mechanical ventilation

Ações de enfermagem para a desospitalização de crianças em ventilação mecânica

Acciones de enfermería para la externación de niños con ventilación mecánica

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Abstract

Objective: To understand nursing actions for the dehospitalization of children dependent on mechanical ventilation.

Methods: This is a qualitative study, with 15 nursing professionals from a reference unit in this health care. The data were obtained through interviews, submitted to content analysis and interpreted by the foundation of Roy's Adaptation Model.

Results: The actions took place by surveying the problems, planning care and assessing the adaptation process for care after hospital discharge of children with mechanical ventilation breathing. These activities were permeated by valuing individual needs, observing the behaviors and stimuli experienced during the preparation for home care.

Conclusion: The actions focused on the support and training of caregivers to meet children's needs and revealed the importance of the theoretical foundation of nursing to strengthen and scientifically improve the actions carried out.

Resumo

Objetivo: Apreender as ações de enfermagem para a desospitalização de crianças dependentes de ventilação mecânica.

Métodos: Estudo qualitativo, com 15 profissionais de enfermagem de uma unidade de referência nesse cuidado de saúde. Os dados foram obtidos por entrevistas, submetidas à análise de conteúdo e interpretados pela fundamentação do Modelo de Adaptação de Roy.

Resultados: As ações ocorreram pelo levantamento dos problemas, pelo planejamento do cuidado e na avaliação do processo de adaptação para o cuidado após alta hospitalar de crianças com respiração por ventilação mecânica. Essas atividades foram permeadas pela valorização das necessidades individuais, pela observação dos comportamentos e estímulos vivenciados ao longo do preparo para o cuidado domiciliar.

Conclusão: As ações se concentraram no apoio e capacitação dos cuidadores para atender as necessidades das crianças e revelaram a importância da fundamentação teórica de enfermagem para fortalecer e aprimorar cientificamente as ações realizadas.

Resumen

Objetivo: Comprender las acciones de enfermería para la externación de niños dependientes de ventilación mecánica.

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Conflicts of interest: nothing to declare.

Métodos: Estudio cualitativo con 15 profesionales de enfermería de una unidad de referencia en este tipo de cuidado de la salud. Los datos se obtuvieron mediante entrevistas, que fueron sometidas al análisis de contenido e interpretadas mediante la fundamentación del modelo de adaptación de Roy.

Resultados: Las acciones se realizaron a través de la recopilación de los problemas, la planificación del cuidado y la evaluación del proceso de adaptación para el cuidado luego del alta hospitalaria de niños con respiración por ventilación mecánica. En estas actividades estuvo presente la valorización de las necesidades individuales, la observación de los comportamientos y estímulos vividos a lo largo de la preparación para el cuidado domiciliario.

Conclusión: Las acciones se concentraron en el apoyo y la capacitación de los cuidadores para atender las necesidades de los niños y revelaron la importancia de la fundamentación teórica de enfermería para fortalecer y perfeccionar científicamente las acciones realizadas.

Introduction

The number of children in chronic health conditions who are dependent on mechanical ventilation is increasing, requiring training and preparation in planning for care actions.[1,2] In the United States, one in five children has a special health need.[3] In Germany, it is estimated that 2000 children live with mechanical ventilation dependence.[4] In the last Brazilian demographic census, about 24.1% of the population under the age of 14 years old, had some type of disability.[5] Although it is a relevant data, it is important to highlight that the epidemiological data referring to this population are shared, according to the compromise of the organic systems, standardized by the International Classification of Diseases (ICD), providing for different degrees and types of technological dependencies due to multisystemic diseases, which makes it difficult for these children to be recognized on the national scenario.[6]

Technological advances and multiprofessional activities have favored the quality of life of these children with special health needs (CRIANES) who survive with dependence on devices, invasive interventions, and demand specialized services and qualified professionals.[7,8]

Among health professionals, the nursing team is responsible for long-term care and continues to be with its clientele. The core concepts of the profession, systematized and scientific based on a theoretical framework, facilitate the understanding of human experiences and their interfaces in health and disease.[9]

In this way, nursing is part of the group of professional categories that teach and assist family members to adapt to the care of CRIANES. The family that experiences the experience of having a child with special health needs, will need to reorganize and adapt to new care routines. In addition to these activities, family members will need to be available to learn how to handle invasive devices that are associated with maintaining their children's vital functions, such as mechanical ventilation, among others.[10]

In this regard, the Callista Roy's Adaptation Model demonstrates itself as an adequate theory to guide this care, as it considers people as an adaptable system, capable of adjusting to changes in the environment, affecting it, with nursing having the role of promote adaptation in situations of health and illness, increasing interaction with the environment and promoting health.[9]

We identified gaps in scientific production related to the factors that influence the care for the dehospitalization of children under mechanical ventilation and in the nursing actions to perform this care.[8,10] With regard to children under mechanical ventilation, there is a lack of data available in developing countries on the provision of services that offer prolonged mechanical ventilation in the home for pediatric patients.[11] An American study found that there is limited evidence on the impact of the quality of care provided to children with special health needs, when there are social and financial difficulties for family members.[12]

Thus, knowing how the nursing actions for planning the adaptation of family members have been for the hospitalization of children dependent on mechanical ventilation can help to minimize the challenges of this care and enhance the nursing actions for practice of qualified assistance. Given the above, the objective of this study is to apprehend nursing actions in preparing family members for the dehospitalization of children dependent under mechanical ventilation.

Methods

This is a descriptive study with a qualitative approach, developed in a unit for dehospitalization

of a Pediatric Hospital, located in a large municipality in Bahia State. This unit is a reference for training caregivers of children in mechanical ventilation who are in the process of being hospitalized. Approximately 45 children are accompanied by the unit that includes an inpatient unit and a Home Care service with multidisciplinary teams made up of nurses, nursing technicians, doctors, speech therapists, nutritionists, physiotherapists, psychologists, and social workers.[13] With 28 nursing professionals and 15 beds, the inpatient unit is organized and adapted to receive family members and children dependent on mechanical ventilation who will undergo the adaptation process for dehospitalization. In this scenario, it is possible to carry out with the family the simulation of care for children under mechanical ventilation at home.

Fifteen professionals participated in the study, 10 nursing technicians and five nurses. Only professionals from the nursing team with experience in the dehospitalization process were included in the study (understood as the period of admission until the children's discharge). Nursing professionals who performed temporary functions at the unit were excluded.

The invitation to participate in the research was carried out during the work shift and after acceptance, the date, place and time of the interviews that took place individually were scheduled in a place that guaranteed participants' privacy and comfort. Data collection was carried out through a semi-structured interview, the first part relating to participant characterization (age, length of service, professional training, training and graduate courses) and the second part with the following guiding questions: what actions do you take to prepare the process of dehospitalization of children dependent on mechanical ventilation? How does the process of dehospitalization of these children occur?

From June to September 2017, interviews were conducted by the researcher herself, in a private meeting room, at the hospital, with an average duration of one hour. The interviews were recorded in MP3 format and transcribed in full. At the end of each interview, there was feedback with each participant in order to guarantee the initial impressions of the data collected and after the end of the study, the researcher presented the results to the participants for validation. The completion of collection was due to data saturation, i.e., when the responses during the interviews started to be repetitive according to the description of different participants, and therefore, reaching the proposed objective. This step occurred through continuous data analysis, from the interviews, the transcriptions, readings and discussions between the researchers for the valorization of the information obtained. The data were submitted to the content analysis proposed by Bardin, with the phases: analysis organization; coding; categorization; treatment of results, inference and interpretation of results.[14] For this study, data interpretation occurred in the light of the conceptual principles of Callista Roy's Adaptation Model (CRAM).[15] In this theoretical model, individuals are considered as an adaptable system due to their behaviors (physiological, self-concept, real life function and interdependence) and the environment in which they are inserted, with the influence of focal, contextual and residual stimuli.[9,16] Focal stimuli are subjective conditions, such as life experiences and feelings. Contextual are the environmental elements that interfere with the individual and contribute to the effect of the focal stimulus. Residual stimuli are factors, which are not central and people may or may not be aware of their influence on lived experiences.[15,16]

The nursing process according to CRAM constitutes an approach to problem solving, through the identification of people's needs, the implementation of approaches to nursing care, as well as the assessment of this, consisting of six steps: behavioral assessment; stimulus assessment; nursing diagnosis; goal setting; intervention and assessment.[15,16] From analysis of nursing professionals' speeches, the actions taken by this team to prepare family members formed the following thematic categories, following the axes proposed in Roy's theoretical model, as described in Chart 1.

Chart 1. Presentation of clippings of participants' experiences and formation of thematic categories

Shared Experiences	Roy model axles	Thematic categories
We observe the mother... some are fearful... They don't know what to do... how to take care of. (P03).	Behavior assessment	Problem recognition
There is a team preparation to meet children's and their families' demands. We know their needs and from there we started training (P01).	Assessment of people's stimuli	
From the demands identified by our assessment, we started training and resolving the mishaps for dehospitalization (P15).	Nursing diagnoses	Planning of care for dehospitalization
We take care of children until their mothers are ready. Every day we do the procedures and ask her to observe, we explain the step-by-step and the purpose of each care. As they feel safe, they start helping us and then they can do it themselves (P08).	Goal setting	
We teach the mother to bathe in the bed ... to use the mechanical ventilation device. When they are ready, they go to a simulation bed to assess the safety of care (P02).	Intervention	Assessment of the adaptive process for dehospitalization
	Assessment	

The study was submitted to and approved by the Research Ethics Committee of the School of Nursing of *Universidade Federal da Bahia* (Consubstantiated Opinion 2,125,417). An Informed Consent Form was drawn up in accordance with Resolutions 466/12 and 510/2016 of the Brazilian National Health Council (*Conselho Nacional de Saúde*). To guarantee anonymity, participants were identified by the letter P, numbered from 1 to 15.

Results

All study participants were female, aged between 25 and 50 years, with more than 5 years of professional experience. Among the ten nursing technicians, six reported having updated pediatrics. Among the nurses, two were specialists in intensive care.

Considering that the promotion of the adaptation of caregivers of CRIANES in the process of dehospitalization occurs, sometimes, simultaneously, we present the following categories with the intention of elucidating the nursing actions in this process: problem recognition; planning of care for dehospitalization; process assessment.

Problem recognition

Among the actions of nursing to promote the adaptation of caregivers to children's needs, it was identified that the team sought to carry out a survey of stimuli and behaviors of caregivers. The focal stimuli in this study were recognized for nursing team's actions in valuing and recognizing the importance of the impact of the disease in the family's life, of the family's feelings, desires and expectations:

> *When mothers arrive here, they are afraid to bathe, they are afraid of making mistakes, of taking care because of children's mechanical ventilation, we show every day the technique of giving the boys a bath, how to cover the bed, how to cut nails and after they watch a lot; they start performing care (P05).*

> *Parents arrive here afraid to take their children, to bathe, to take care. Gradually we go on winning this, teaching, and when they realize they already know how to even aspirate the tracheostomy (P10).*

The team carried out a survey of the contextual stimulus that proved to be challenging situations for planning nursing actions such as economic/social/educational needs. Illiteracy or low education were exemplified by participants:

> *We went to teach the mother how to administer the medications and we realized the difficulty in understanding the names and volume of medications, even though she said she knew how to read. We talked to her, little by little, and she assumed she couldn't read (P13).*

> *If the mother has any difficulty reading, we talk to her and organize the training in another way (P01).*

The study participants brought observations that we can interpret as 'residual stimuli', which are other factors that influence the preparation for dehospitalization, such as the tiredness of family members.

> *Child care training is easier when the family is really committed... and does not leave all care to the mother alone. When there are several family members involved in the dehospitalization process... father, grandparents, uncles... it is better, they are not too tired, they have the possibility of relay (P11).*

There are mothers who have been in this situation for years, without going home, without contact with other family members, and this tiring hospital routine sometimes impairs the concentration of training (P03).

We have to deal with the mother who, due to being in the hospital for a long time, is stressed, tired and is not always available to learn (P07).

Uncertainty of hospital discharge, unpredictability, and the unstable situation of children were shared by participants as factors that influenced the behavior of caregivers and consequently in the planning of team's actions.

We realized that the mother or father who is not expected to be discharged seems not to dedicate enough when compared to those who have a scheduled hospitalization, they change... I don't know if they get discouraged (P04).

Sometimes the family is doing well in training and the child's condition worsens, due to the disease itself, going to the ICU. The family destabilizes, becoming afraid to go home, to take care (P06).

The experiences shared by nursing professionals revealed that assessment of focal, contextual and residual stimuli were decisive for understanding the adaptive behaviors of caregivers and guided the planning of their actions.

Planning of care for dehospitalization

In the nursing team, nurses must carry out care planning and process. Nurse participants reported carrying out the survey, interpreting the identified problems and carrying out the planning of their care activities.

From the demands identified by our assessment, we started training and solving the challenges for dehospitalization. We carried out a survey of the problems, identified the needs, planned the interventions, carried out and assessed the actions (P15).

Mothers come in here one way and leave the other, prepared, safe. Usually when it is necessary to return to the hospital and hospitalize, it is not due to failure in the care of family members ..., but it is due to the severity of the disease (P12).

Although the nurses in this study do not use a taxonomy to describe the diagnoses, it was possible to identify in their reports that they perform the interpretation of the identified problems.

Children and their families come from other services and what we do is to assess the knowledge they have, the activities they develop and the weaknesses presented. Based on this analysis, we outlined our care plan (P04).

Some children returned from their homes because they formed a bladder. We realized that it was necessary to improve training, reinforcing the bladder catheterization for all families (P14).

It is noticed that participants are involved in the process of judgment and interpretation of family members' and children's needs, establishing objectives and goals so that the caregiver and their child are able to return to their home with the necessary skills for assistance.

Assessment of the adaptive process for dehospitalization

Assessment of the steps for preparation of caregivers was carried out from the moment of admission. Participants share the experience of this action, revealing their commitment and attention to children and family members:

First, we observed how the family takes care, then we conduct training and assess everything they do (P09).

We assess each caregiver when we allow them to carry out the activities we teach. We consider it as fit or not fit, as the family member is able to perform care for their child with skill and safety (P12).

Another aspect in the assessment phase carried out by nursing was the existence of a bed simulating the reality of the home, in the unit, where the family is accompanied, recreating an environment similar to the home, including also the equipment, so that caregivers can be assessed regarding the safety and dexterity in care.

> *For the family to enter simulation, they need to be prepared and present safety in child care (P02).*

> *After we teach..., and the social and financial conditions are favorable to hospital discharge, the child goes into simulation. Care becomes the father or the mother. If he asks us or shows us a lot of doubts, the child goes back to training again (P08).*

Discussion

The analyzed data revealed that the nursing actions for discharging children under mechanical ventilation aim to promote adaptive care. They contemplate from the technical preparation so that caregivers learn to manipulate equipment, perform specific care with ventilatory support and airway maintenance, as well as prepare caregivers with respect to focal, contextual and residual stimuli that permeate family members' experiences.

It is possible to realize the steps proposed by Roy's theoretical model, due to the team's attention in valuing the demands of family members to plan assistance, corroborating the study findings with asthmatic adolescents from Roy's perspective, conducted in Iran, unveiling that family involvement has important contributions to strengthen the adaptive process, with a reduction in the impact of the disease.[17]

Social, economic aspects and low schooling, contextual stimuli, interfere in the process of adaptation and preparation for discharge. Such factors need a dialogical relationship that welcomes the doubts and demands of the family for an effective and quality planning in the provision of care.[18,19] The lack of social network that permeates the daily lives of children leads to the wear and tear of their parents, especially the mother, who is considered in most studies to be the main caregiver of children with special needs.[8] The appreciation of relational knowledge that underlies caregivers' affective and social needs must be present in actions to promote adaptation by the nursing team, as support and strengthening and preservation of physical and mental health of caregivers.[20-22]

As an integral part of the nursing process, the diagnoses were made unsystematically without a method or use of taxonomy. This factor can weaken assessment of the results of assistance. The use of standardized terminology in the identification and representation of the nursing diagnosis favors communication between nurses and other team members, improves continuity of care, favors the registration, documentation, and makes nursing actions standardized.[23]

The intervention activities carried out by the team were based on observation, carrying out care in partnership with family members and through continuous assessment playing the role of educator and learning mediator, whose teaching process is centered on procedural care and mediation of knowledge.[8]

The planning and assessment of results of nursing interventions were aimed at correcting the possible flaws and weaknesses of family caregivers. It was not revealed the attitudes of professionals who reinforced the positive actions carried out by caregivers, in contrast to what the theory recommends that adaptive behaviors are valued and increased to strengthen and promote assertive attitudes.[15] Although the study participants do not refer to the stages of the nursing process according to CRAM, the principles of theoretical foundation in care practice are perceived.

Conclusion

Nursing actions took place through the preparation of family members of children dependent on mechanical ventilation and were unveiled by surveying and recognizing problems, planning care and assessing the adaptation process for discharge. The

actions developed by the study participants considered individuals in an adaptive manner, understanding the various stimuli and interferences that affect children and their families. Understanding the needs evidenced in the transition from hospital to home can provide autonomy and security for the family. The limitations of this study are related to the scenario, which reflects the image only of the universe studied. Moreover, family caregivers' perceptions about their adaptation to dehospitalization were not explored, which directed the discussion in only one perspective. The use of a nursing theory strengthens actions in clinical and care practice.

Collaborations

Ulisses LO, Bispo TAS, Caldas AB, Camargo CL, Oliveira MMC, Silva EA, Gomes NP and Whitaker MCO contributed to the project design, writing of the article, relevant critical review of data intellectual content, analysis and interpretation and final approval of the version to be published.

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