PARENTS' PREPARATION FOR THE DEHOSPITALIZATION OF CHILDREN USING TRACHEOSTOMY AND GASTROSTOMY

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ABSTRACT

Objective: to report the experience of an educational action for the preparation of parents for the dehospitalization of children using tracheostomy and gastrostomy. Method: experience report on an educational action, which is part of a Training Program of a public hospital of high complexity reference in pediatrics, from December 2017 to December 2018. Results: the preparation of those responsible for the dehospitalization of children using tracheostomy and gastrostomy was made from 5 stages: 1) Instructions to parents; 2) Training of parents to handle the device used by the child; 3) Manipulation of the devices by parents under the supervision of the nurse; 4) Feedback offered by Nursing; and 5) Evaluation of educational action. Final considerations: It is believed that the therapeutic education provided to those involved contributed to the qualification of care for children using tracheostomy and gastrostomy, favoring their quality of life and reducing home complications related to inadequate handling of the devices in question.

Keywords: Patient Discharge. Education. Homebound Persons. Child Health. Health Education.

INTRODUCTION

Tracheostomy (TQT) and gastrostomy (GTT) refer to surgical procedures in which cannulas are placed that allow gas exchange (in the case of TQT) and feeding (in the case of GTT), when the individual cannot perform such functions naturally.

As evidenced in the study by Góes and Cabral⁽¹⁾, conducted with relatives of children with special health needs, the use of complex and technological devices by these children reveals a social practice marked by the need for learning by caregivers regarding the replacement and/or modification of daily and habitual care to maintain the lives of their children, given the complexification of demands.

Difficulties related to the handling of complex devices when dehospitalization children with special care needs were deepened by research on the subject⁽²⁻⁴⁾, as is the case of the study by Rodrigues et al,(2) which was

performed with caregivers of children using GTT and pointed out as difficulties the insecurity about knowledge and practices that were not previously part of the routine and the fear of handling the catheter for feeding and pointed out as difficulties the insecurity about knowledge and practices that were not previously part of the routine and the fear of handling the catheter for feeding and cleaning, emphasizing the importance of the preparation of parents of children using these devices when dehospitalization of the child, favoring the socalled Family Centered Care, which has 04 central axes: 1) dignity and respect, 2) sharing of information, participation collaboration(5).

Family-Centered Care emerges in the current health scenario as a profound change in the way care is provided to individuals and their families. With an approach focused on the planning, provision and evaluation of care, which is based on mutually beneficial partnerships between

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health professionals, patients and families, this modality of care redefines the relationships between the parties, making patients and family members active in care and decision-making, since these are essential allies for quality and safety⁽⁵⁾.

Therefore, we highlight the importance of the multiprofessional team's role in guiding caregivers of children using complex devices for a successful transition to home care, with reduced morbidity and mortality, which is directly related to the team's performance for the training and guidance of caregivers.

In addition to the relevance of the multidisciplinary team in contributing to the parents' learning about the management of these devices so that they feel safe in the child's home care, it is essential to conduct studies that reveal strategies used by health professionals in the empowerment of the family after dehospitalization, since the dissemination of successful experiences has the potential for reproducibility, improving the care and care of children using special devices at home, favoring qualified and evidence-based care.

In the face of the above, this study aims to report the experience of an educational action for the preparation of parents for the dehospitalization of children using TQT and GTT.

METHOD

Descriptive study of the type of experience report, which is characterized as an important scientific product in contemporaneity, since it is a theoretical-practical construction that unfolds in the search for innovative knowledge from the perspective of the subject-researcher in a given cultural and historical context⁽⁶⁾.

The experience described here was carried out from December 2017 to December 2018 in a philanthropic institution of high complexity reference in pediatrics in the state of Bahia, whose care occurs entirely by the Unified Health System (SUS). This reference hospital, consolidated as the largest exclusively pediatric hospital in the North and Northeast, was inaugurated in 1965 and has a structure of 220 beds, with care in 28 medical specialties, with emphasis on areas of high complexity, such as

oncology, cardiology and neurology⁽⁷⁾.

The experience is part of a training program Training promoted bv the Unit Dehospitalization (UTD) of the hospital in question, which was created in 2012 in partnership with the Health Department of the State of Bahia (SESAB) and aims to train family members of children with chronic diseases so that they can be discharged from the hospital without having their treatments interrupted, once their caregivers receive all the necessary therapeutic guidance to promote safe care at home⁽⁸⁾.

When it comes to the nature of its activities, UTD is unique in Bahia and considered a reference throughout Brazil. It consists of 20 beds, which are occupied by children referred via the State Regulatory Center and evaluated by the hospital's technical team, so that, when considered in a stable health condition and subject to discharge, children and their parents are accommodated in the unit for a period of one month to one year, in which caregivers accompany their children until they can be reintegrated into the family and social environment. It is noteworthy, however, that the time to train caregivers and dehospitalization the child is variable.⁽⁸⁾

The educational action was directed to parents of children using TQT and GTT and occurred during all days of the week, in the hospital facilities, with an average duration of 30 minutes, in the morning and night shifts. It is important to mention that the time of participation of each of the families in the educational activities described in this experience was variable (from one month to one year), depending in addition to the child's discharge, the acquisition of aptitude for home care by their guardians.

For being an educational activity, which is part of an institutional training program, it was not necessary to sign the free and informed consent form or submission and approval of this study by a research ethics committee.

The following is the operationalization and evaluation of this educational action, which are described in five stages.

Step 1) Instructions to parents about the device being used by the child

A priori, the multidisciplinary team — composed of nurses, nursing technicians, nursing undergraduates, nutritionist, speech therapist, physiotherapist, psychologist and physician — sought to instruct parents about the child's condition, importance and need for the device in question.

This stage occurred during the hospitalization of the child and was implemented from conversation wheels with an average duration of one hour between members of the health team and parents, in which the participants had space to verbalize their doubts and, parallel to this, were informed about the demands presented.

Step 2) Parent training to handle the device used by the child

After being informed about the child's condition and the device in use, the parents were admitted to the home care training unit. The length of stay of these in the training unit was peculiar, varying according to the understanding of these people regarding the correct techniques for handling the device used by the child, building a unique form of care, centered on the family and supported by scientifically based knowledge, seeking to provide caregivers with greater security and tranquility in the management of the child and his device.

During the first weeks of training, the nurse individually followed the caregivers, demonstrating in a practical way how to handle the device used by the child. In the case of TQT, those responsible were taught about sterile cleaning and cannula fixation, in addition to being instructed about the identification of clinical signs of desaturation, respiratory distress, oxygen therapy, use of the vacuum cleaner, detection of complications and emergency techniques⁽⁹⁾, in order to avoid complications related to this prosthesis, such as the occurrence of lung lesions and infections. (10)

Regarding the management of GTT, the guardians were instructed on the administration of diets and medications, dressings, skin care, cleaning of the probe, as well as on the signs of gastric fluid leakage and diet, infection of the site of insertion of the probe, presence of flogistic signs and possible complications that may occur at home.

Step 3) Handling of devices by parents under the supervision of the nurse

After participating in the orientation and observation sessions on how to handle the TQT and GTT, those responsible for these children were encouraged to manipulate such devices under the supervision of the nurse, since therapeutic education is an essential factor in dealing with the new health condition and in the acquisition of skills that help patients and caregivers to achieve an efficient level of self-care⁽¹¹⁾.

At this stage, it was observed that the participants had understood the process of manipulation of both devices, according to the guidelines provided, but they still felt unsafe given the absence of manual dexterity, since until that time they had never had approached with such modality of child care. Therefore, stimuli to the manipulation of the devices were intensified, which occurred individually assisted, resulting in the progressive improvement of the correct management of TQT and GTT.

Step 4) Feedback offered by Nursing

After supervised manipulation, the nurse gave the family feedback about the procedure performed, resuming important and previously addressed contents such as maintenance of aseptic technique, cleaning of the cannula, change of the fixation shoelace and evaluation of possible abnormal ventilation pattern when it comes to TQT and administration of the diet according to the prescription of nutrition and cleaning of the catheter when it comes to GTT.

Step 5) Evaluation of the educational action

This stage occurred in two different ways: 1) evaluation by the multidisciplinary team; and 2) evaluation by the participants.

Regarding the multidisciplinary team, it was agreed that the objective of the educational action was achieved from the means used, since unanimously the professionals involved concluded by the success of the program participants with regard to the manipulation of the TQT and GTT cannulas, so that, at the end of the period of this experiment all participants

were discharged from the UTD, considered as "able" to provide home care to the child.

Likewise, the evaluation by the participants was positive, and there were reports of greater security for the promotion of child care at home.

Throughout the training program, facilities and difficulties related to the educational process were listed. Among the first, one can mention the team's commitment to provide family-centered care and the qualification of child and parent care, who year longed to learn the techniques, being open to receive all the guidance provided by the professionals involved.

Regarding the difficulties, these were mainly related to the fact that many parents had a low sociocultural level, so that some of them were not even literate, which made it difficult to understand what was addressed. As a coping mechanism for this problem, the word used was adapted to the recipient, besides using resources such as prescriptions adapted for the administration of safe drugs at home.

RESULTS AND DISCUSSION

Right at the stage of instructions to the parents, it was observed the impact that the therapeutic condition of the child generated on their parents, who were fearful of the child's situation and afraid about the ability to promote home care properly.

Feelings of stress, overload, sadness, shock and fear were also evidenced in the researches by Bossa et al⁽³⁾ and Mai et al⁽¹²⁾, conducted with parents of children using TQT cannula, and Zacarin, Borges and Dupas⁽⁴⁾, conducted with families of children with gastrointestinal stomas, revealing that adaptation to the child's situation permeates the impact of the discovery of the new reality, in need of guidance on the child's condition.

Therefore, it is noteworthy that the stage of offering instructions to parents is considered fundamental, because communication in addition to being configured as an essential part of the support offered to the family is also a mechanism to reduce emotional stress and help manage the situation, as received by the study by Terp, Weis and Lundqvist⁽¹³⁾, conducted with parents of children hospitalized in an Intensive Care Unit (ICU) in Sweden, which with the

objective of describing the parental view on family-centered care, revealed that despite the satisfaction of the approach related to this type of care, the person-centered communication was a point of improvement for the family-health professional partnership to be, in fact, improved.

It is also noteworthy that the stimulus to proximity between parents and children is capable of generating positive psychological responses, as observed by nurses neonatologists who participated in a study developed in neonatal units in Estonia, Finland, Norway, Spain and Sweden, which concluded by the importance and need to expand measures that approximate parents and children within neonatal units. (14) In this same direction, the communication between the team and the family was pointed out by a study conducted with families of neonates hospitalized in the ICU⁽¹⁵⁾ as something capable of providing relief and placating feelings of unwanted responsibility, positively influencing the experience of parents in the context of their child's hospitalization.

Thus, the essentiality of communication is emphasized in the creation of bonds between those involved in the care and in the process of acceptance of the family about the child's condition and the use of the device, allowing them to understand the whole process and feel able to participate in care, which were put into practice already in the training stage.

In the second phase of the experiment, with emphasis on the exercise of family-centered care, the exchange of roles and responsibilities was promoted, so that parents were trained to properly handle the devices in use by the child⁽¹⁶⁾, thus avoiding possible complications for the patient and his family at the time of dehospitalization.

Regarding the preparation of the family for the care of children using TQT, the literature⁽⁹⁾ highlights the importance of the nursing team's work regarding the provision of guidance and as a facilitator of family contact with the hospital and the medical team. In addition, it stresses that the child cannot be discharged from the institution before the guardians have learned all the care with the TQT and about performing emergency procedures with the tracheostomized child when they are necessary.

Therefore, it is highlighted that the

performance of the health team with gastrostomized patients assumes an essential position based on specialized care directed to both the patient and his family. This care relationship between the child, the caregiver and the professional should also begin during hospitalization, ranging from the preoperative period until the discharge of the child to his/her home, thus building a collaborative relationship in the teaching of care with the GTT tube, so that everything that has been taught and learned in the hospital environment can be perpetuated in the extra-hospital environment⁽¹⁷⁾.

The inclusion of parents in the care of children who need complex support, besides being characterized as a mechanism to guarantee patient safety is also a way to bring the family closer to the health team and the patient, creating bonds between those involved, reducing stress, providing optimal care⁽¹⁶⁾ and promoting the humanization of care, as well as autonomy for non-professional care after dehospitalization, such inclusion is essential when considering the potential of caregivers to feel incapacitated and unprepared for child care after discharge^(12,3).

As evidenced in a systematic review⁽¹⁶⁾, the involvement of parents in the care of children in special support of even hospitalization increases their preparation for hospital discharge, preventing complications related to the child's device, as was verbalized by a participant in the research by Bossa et al⁽³⁾, according to which the ignorance about the need for aspiration of the TQT cannula caused the child to be taken to the hospital on the first day after discharge. In the context of GTT, in a study conducted in Ceará, the mother reported that the accidental externalization of the tube generated a feeling of despair for having made her think that this would culminate in the death of her son⁽¹⁷⁾.

Regarding specifically the handling of the devices mentioned in this study, despite the insecurity initially observed, given the fact that it is an innovative care, very different from care practices so far dispensed by the family⁽¹⁾, the participants demonstrated a progressive scope of the ability to properly manipulate the devices necessary to maintain the child's life, revealing the success of the individual therapeutic guidance provided by the multidisciplinary team.

A similar result was disclosed in a study

conducted in the United States⁽¹⁸⁾ with caregivers of children using a TQT cannula, which said that despite the difficulties related to the transition from hospital care to home care, families felt prepared to go home when receiving therapeutic guidance, emphasizing the importance of individualized training. At the same time, in a study conducted in Brazil⁽²⁾ it was demonstrated that the mother of the child using GTT experienced feelings of despair and fear, which can be defeated from the educational process enterprise that makes the family autonomous to cope with the process of dependence on technologies by children⁽¹⁸⁾.

It is important to highlight the relevance of stimulating family participation, which should be assisted individually by health professionals involved in care, in order to offer emotional support and guide the proper manipulation of the device, returning feedback about the practice performed by the caregiver.

Feedback, a tool pointed out as simple and essential in the evaluation process⁽¹⁹⁾, is indispensable to evaluate whether the guardians of the child actually learned the correct techniques of handling the TQT and/or GTT, allowing modifications and improvement of the techniques used, when necessary. When positive, the feedback serves as a reinforcement to stimulate the skill learned and, when negative, it acts as a starting point for the reorientation of care, with new attempts — all assisted individually — to put into practice the skill in question.

In addition to the training for the acquisition of skills necessary for dehospitalization, given the complexity of the demands of these children and their families, the UTD continues to accompany the families in their homes after discharge from the hospital institution⁽⁸⁾, an essential factor to ensure the readaptation of the patient and his caregivers to the home environment, ensuring safe care in that niche.

FINAL CONSIDERATIONS

It is concluded that the training program achieved its objective of preparing the parents of children using TQT and GTT for the dehospitalization of their child, since the interventions performed with the families have

the potential to favor the empowerment of those involved, resulting in the effective and effective care of the child, in addition to the proper handling of the devices after hospital discharge as a result of the experience acquired.

The applied methodology was evaluated as positive by the participants, due to the fact that therapeutic guidance was initially offered about the child's condition and the device in use and, later, after depending on the existing doubts, practical care was performed to the cannula, with individual follow-up by the nurse, offering feedback at the end of the process.

It is expected that the participants involved in

this educational action can assume their autonomy for self-care, safely and efficiently in providing care to their children using TQT and GTT as a result of the knowledge acquired from this training program.

It is worth mentioning that given the impacts of the absence of planning and guidance for the dehospitalization of children using complex devices, the reproducibility of this experience in other scenarios is important to strengthen the autonomy of caregivers in providing safe care, reducing the rate of readouts due to complications resulting from inadequate handling of the device.

PREPARO DOS PAIS PARA A DESOSPITALIZAÇÃO DE CRIANÇAS EM USO DE TRAQUEOSTOMIA E GASTROSTOMIA

RESUMO

Objetivo: relatar a experiência de uma ação educativa para o preparo dos pais para a desospitalização de crianças em uso de traqueostomia e gastrostomia. **Método:** relato de experiência sobre uma ação educativa, que é parte de um Programa de Treinamento de um hospital público de alta complexidade referência em pediatria, no período de dezembro de 2017 a dezembro de 2018. **Resultados:** o preparo dos responsáveis para a desospitalização de crianças em uso de traqueostomia e gastrostomia foi feito a partir de 5 etapas: 1) Instruções aos pais; 2) Treinamento dos pais para manuseio do dispositivo utilizado pela criança; 3) Manipulação dos dispositivos pelos pais sob supervisão do enfermeiro; 4) *Feedback* oferecido pela Enfermagem; e 5) Avaliação da ação educativa. **Considerações finais:** Acredita-se que a educação terapêutica fornecida aos envolvidos contribuiu na qualificação do cuidado à criança em uso de traqueostomia e gastrostomia, favorecendo sua qualidade de vida e reduzindo as intercorrências domiciliares relacionadas ao manuseio inadequado dos dispositivos em questão.

Palavras-chave: Alta Hospitalar. Programas de Treinamento. Pacientes Domiciliares. Saúde da Criança. Educação em Saúde.

PREPARACIÓN DE LOS PADRES PARA LA DESHOSPITALIZACIÓN DE NIÑOS EN USO DE TRAQUEOSTOMÍA Y GASTROSTOMÍA RESUMEN

Objetivo: relatar la experiencia de una acción educativa para la preparación de los padres para la deshospitalización de niños en uso de traqueostomía y gastrostomía. **Método**: relato de experiencia sobre una acción educativa, que hace parte de un Programa de Entrenamiento de un hospital público de alta complejidad referencia en pediatría, en el período de diciembre de 2017 a diciembre de 2018. **Resultados**: la preparación de los responsables para la deshospitalización de niños en uso de traqueostomía y gastrostomía se hizo a partir de 5 etapas: 1) Instrucciones a los padres; 2) Entrenamiento de los padres para manejo del dispositivo utilizado por el niño; 3) Manipulación de los dispositivos por los padres bajo supervisión del enfermero; 4) *Feedback* ofrecido por la Enfermería; y 5) Evaluación de la acción educativa. **Consideraciones finales**: Se cree que la educación terapéutica proporcionada a los involucrados contribuyó en la calificación del cuidado del niño en uso de traqueostomía y gastrostomía, favoreciendo su calidad de vida y reduciendo las complicaciones domiciliarias relacionadas con el manejo inadecuado de los dispositivos en cuestión.

Palabras clave: Política de salud. Educación. Capacitación de recursos humanos en salud. Atención primaria de salud.

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