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EXPERIENCE REPORT

Applicability of Orem: training of caregiver of infant with Robin Sequence

Aplicabilidade de Orem: capacitação do cuidador do lactente com Sequência de Robin

Aplicabilidad de Orem: capacitación del cuidador del lactante con Secuencia de Robin

Cleide Carolina da Silva Demoro[I], Cassiana Mendes Bertoncello Fontes[II], Armando dos Santos Trettene[I], Tamara Iwanow Cianciarullo[I], Ilza Marques Lazarini[I]

[I] *Universidade de São Paulo. Bauru, São Paulo, Brazil.*
[II] *Universidade Estadual Paulista Júlio de Mesquita Filho, Botucatu Medical School. Botucatu, São Paulo, Brazil.*

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ABSTRACT

Objective: to report the nurses' experience in relation to the training of caregivers of infants with Isolated Robin Sequence (IRS) for maintaining care after hospital discharge from the perspective of Self-Care Theoretical Framework. **Method**: the following categories were considered in this experience report: self-care action, self-care capacity, therapeutic self-care demand, self-care deficit, and nursing system. The nursing system was wholly compensatory and supportive-educative. **Results:** caregivers' training by nurses results in the acquisition of technical skills and specific knowledge related to the infant's positioning in elevated ventral decubitus, nasopharyngeal intubation, feeding-facilitating techniques and care with the feeding tube. **Final considerations**: the continuity of home care is guaranteed from caregivers' training for the therapeutic demand.
Descriptors: Pediatric Nursing; Nurse; Self-Care; Caregiver; Pierre Robin Syndrome.

RESUMO

Objetivo: relatar a experiência dos enfermeiros em relação à capacitação dos cuidadores de lactentes com Sequência de Robin isolada (SRI) para manutenção dos cuidados após alta hospitalar na perspectiva do Referencial Teórico do Autocuidado. **Método**: as seguintes categorias foram consideradas neste relato de experiência: ação de autocuidado, capacidade de autocuidado, demanda terapêutica de autocuidado, déficit de autocuidado e sistema de enfermagem. O sistema de enfermagem foi do tipo totalmente compensatório e por meio de apoio educativo. **Resultados:** a capacitação do cuidador pelo enfermeiro resulta na aquisição de habilidades técnicas e conhecimentos específicos referentes ao posicionamento do lactente em decúbito ventral e elevado, intubação nasofaríngea, técnicas facilitadoras da alimentação e cuidados com a sonda alimentadora. **Considerações finais**: a continuidade dos cuidados domiciliares é garantida a partir da capacitação do cuidador para a demanda terapêutica.
Descritores: Enfermagem Pediátrica; Enfermeiro; Autocuidado; Cuidador; Síndrome de Pierre Robin.

RESUMEN

Objetivo: relatar la experiencia de los enfermeros en relación a la capacitación de los cuidadores de lactantes con Secuencia de Robin Aislada (SRA) para mantener los cuidados después del alta hospitalaria en la perspectiva del Referencial Teórico del Autocuidado. **Método**: las siguientes categorías se consideraron en este relato de experiencia: acción de autocuidado, capacidad de autocuidado, demanda terapéutica de autocuidado, déficit de autocuidado y sistema de enfermería. El sistema de enfermería fue del tipo totalmente compensador y por medio de apoyo-educación. **Resultados:** la capacitación de los cuidadores por el enfermero resulta en la adquisición de habilidades técnicas y conocimientos específicos relacionados al posicionamiento del lactante en decúbito ventral y elevado, intubación nasofaríngea, técnicas facilitadoras de la alimentación y cuidados con la sonda para alimentación. **Consideraciones finales**: la continuidad de los cuidados domiciliarios está garantizada a partir de la capacitación del cuidador para la demanda terapéutica.
Descriptores: Enfermería Pediátrica; Enfermero; Autocuidado; Cuidador; Síndrome de Pierre Robin.

CORRESPONDING AUTHOR **Cleide Carolina da Silva Demoro Mondini** E-mail: cmondini@usp.br

INTRODUCTION

The Robin sequence is characterized by the presence of micrognathia and glossoptosis with associated posterior cleft palate in 90% of cases. It may occur alone (Isolated Robin Sequence - IRS) or associated with other syndromes or malformations (Syndromic Robin sequence)[1].

Infants with IRS usually develop with respiratory and feeding difficulty. Self-care activities include nasopharyngeal intubation (NPI), nasogastric tube feeding (NGT), and feeding-facilitating techniques (FFT)[1]. However, these infants do not need to remain hospitalized as long as their caregivers learn the care in order to perform it at home. The process of empowering caregivers is part of self-care promotion.

Caregivers accompany children throughout the hospitalization period with the objective of acquiring knowledge and skills to ensure continuity of care after hospital discharge, since the treatment is long term[2].

In addition to clinical conditions, caregivers' capacity regarding procedures inherent to infants with IRS is considered for hospital discharge[2]. Nurses and the team should promote caregivers' training, and develop strategies and instruments to formalize this training[3].

The nursing work process in the care of these infants and their caregivers is based on the Self-Care Theoretical Framework[4-5]. Self-care is "the practice of activities by people for their own benefit, in the sense of maintaining vitality, well-being and health". Adults usually take care of themselves, but infants and children need to be assisted[5].

Thus, nurses must be aware of self-care action needs, including for example, deficits related to oxygenation or feeding. Among the performed interventions, are direct infant care, and caregivers' guidance and training[4-5].

In view of the above, emerges the question: how have nurses been acting in the training promotion of caregivers of infants with specific care demands, aiming at maintaining care at home after hospital discharge?

Given the service decentralization according to the recommendation of the Unified Health System, there is possibility of care to infants with IRS in different realities. Hence the relevance of sharing our experience in nursing care to these infants, especially regarding the work process used in caregivers' training.

OBJECTIVE

To report the nurses' experience regarding the training of caregivers of infants with IRS to maintain care after discharge from the perspective of the Self-Care Theoretical Framework.

METHOD

The present study was developed in a public tertiary hospital specialized in the care of patients with craniofacial anomalies and related syndromes. Caregivers are called Self-Care Agents by Orem[5], and remain during daytime period to receive care training.

Orem's theoretical framework is the base of nursing, and composed of three interrelated constructs, namely the Theory of Self-Care, Theory of Self-Care Deficit, and Theory of Nursing Systems[5].

The Theory of Self-Care addresses the care practices performed by individuals or their Self-Care Agents with the aim to maintain vital and health conditions. Orem lists three categories of therapeutic demands or self-care requirements; the universal, developmental and health deviation[5]. In the present study, the oxygenation and feeding of infants with IRS were prioritized within the aforementioned requirements.

The Theory of Self-Care Deficit refers to the performance of nursing in situations where individuals are incapable or have limitations to perform effective self-care. In this context, individuals or their Self-Care Agents need to acquire specific knowledge and skills[5].

The last construct of Orem's Theoretical Framework addresses the Theory of Nursing Systems that establishes the structure and guides nursing practices by encompassing the wholly compensatory system, the partly compensatory system and the supportive-educative system[5]. The supportive-educative nursing system was used in the present study to develop guidelines and training related to the maintenance of care for infants with IRS after hospital discharge.

Description of the experience of caregivers' training

The therapeutic demand for self-care is the set of necessary care identified and learned by caregivers for meeting the universal requirements of care and health deviations of patients in order to maintain their health and well-being. It also includes nurses' actions related to the quality of care.

Capacity for self-care are the skills acquired for effective child care. It is directly related to basic conditioning factors such as age, life experience and sociocultural factors. In addition, the caregiver must be involved and willing to perform the actions[6-7].

The self-care deficit is the reason why the caregiver needs the nurse in order to meet self-care requirements[5]. In the process of caring for infants with IRS, nurses take over the care and articulate caregivers' training as they assess the requirements of therapeutic demand. In this way, the supportive-educative nursing system is used for caregivers' guidance and training[6-8]. In addition to teaching about care, nurses and their staff should supervise and make sure of its effectiveness[4].

Different instruments can be used for caregivers' training. A recent publication evidenced the benefits of using an educational video in the training of caregivers of children with cleft lip and palate on postoperative care of cheiloplasty and palatoplasty[9].

Next, we present the report regarding the process of caregivers' training.

Promotion of self-care related to ventral decubitus (prone position)

In relation to retromicrognathia and glossoptosis, the positioning of infants in ventral decubitus promotes the anteriorization of the tongue, unclogging the airways. In infants with impaired swallowing, there is evident accumulation of saliva

in the oral cavity[1]. In this sense, prone positioning favors the flow of saliva outwards, avoiding for example, choking episodes that can lead to suffocation[1,10].

Thus, positioning infants with SRI in ventral decubitus has been strongly recommended, especially in cases of lower airway compromise[1]. In addition to prone positioning, the child should remain in a recumbent position at 45º. This position favors the treatment of gastroesophageal reflux (frequent in infants with IRS) and a better respiratory pattern[1,10].

The cervical region should also be kept hyper-extended, which favors airway opening with improved ventilation[1] (Figure 1).

Nurses and their staff should advise caregivers and demonstrate the importance of maintaining the decubitus elevated to 45º with the infant in prone position. The position can be achieved by placing pillows or foam recliners (wedges) under the mattress at the head of the bed, or the anti-reflux board resting on the head of the crib. A fabric sling or similar should be used to accommodate infants and prevent them from falling or slipping down on the mattress, impairing the permanence in the ideal position. The 45º positioning should be maintained in all procedures performed with infants, including hygiene, bathing and comfort care.

Source: Mondini CCSD, Marques IL, Fontes CM, Thomé S. Nasopharyngeal intubation in Robin sequence: technique and management. Cleft Palate Craniofac J. 2009;46(3):258-61.

Figure 1 – Infant in prone position and elevated decubitus at 45º

Promotion of self-care related to nasopharyngeal intubation technique

Nasopharyngeal intubation (NPI) is prescribed by the pediatrician. It is the insertion of a soft silicone cannula with nasopharyngeal positioning. The purpose is to improve the respiratory pattern, since the cannula overcomes the barrier formed by the retropositioning of the tongue. In addition to unclogging the airways, this procedure facilitates the food mechanism, in spite of the need for adjustments such as milk thickening[1].

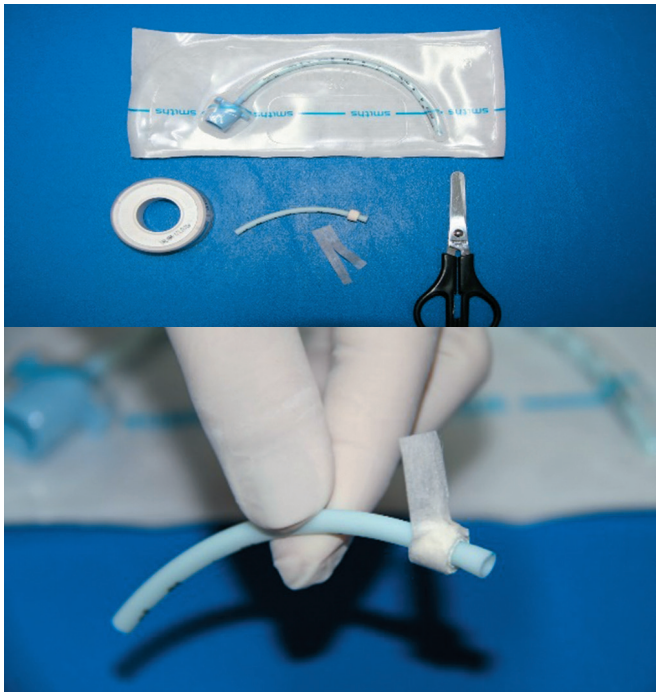
Caregivers' training is initiated by the nurse after 24 hours of NPI. The self-care training procedure is evaluated by means of an instrument prepared and validated for this purpose[8]. This instrument has three different parts comprising physical, mental and motivational capacities. It has scores classifying the Self-Care Agent as unable, requiring training, or able for self-care. For layout reasons, the instrument could not be attached to this manuscript, but it is available upon request.

For hospital discharge, in addition to medical consent, the Self-Care Agent should be considered able to perform the care.

The following materials are used in NPI: nasopharyngeal cannula, medical tape, micropore tape, gauze, medium chain triglyceride emollients or essential fatty acids and scissors[8] (Figure 2).

The cannula should be cut one centimeter longer than the previously checked measurement in order to prevent it from entering the nostril. The distal part of the cannula that will be in contact with the nostril should be covered with 0.5 cm tape strips. A 5 cm narrow micropore tape strip is prepared for fixing the cannula to the nostril. Cut in half about 2.5 cm in lengthwise direction. The full part will be fixed over the infant's nasal dorsum, and the two micropore tape sections will cover the cannula[8] (Figure 2).

After this preparation, the cannula is lubricated with emollient to facilitate introduction into the nostril. The cannula is introduced and its ventilatory permeability is checked using a gauze strip. If the gauze strip moves with expiration and inspiration, the fixation in the nasal dorsum is performed[8].



Source: Mondini CCSD, Marques IL, Fontes CM, Thomé S. Nasopharyngeal intubation in Robin sequence: technique and management. Cleft Palate Craniofac J. 2009;46(3):258-61.

Figure 2 – Materials used in nasopharyngeal intubation

The cannula should remain for 24 hours without being withdrawn for promoting nasal dilatation and the child's adaptation. Insertion of a 0.9% saline solution avoids accumulation of nasal secretion and consequent obstruction. After the first 24 hours, the cannula should be removed for hygiene in running water using a flexible rod without the cotton to remove secretions adhered to its lumen[8].

Hygienization of the cannula should be performed every six to eight hours or as needed. It is very important to check

ventilatory permeability with the gauze strip after the cannula reintroduction. Caregivers are advised about changes in infants' respiratory pattern, the need to monitor the amount of nasal and oral secretion, and to promote clearance of upper airways.

Promotion of self-care related to feeding-facilitating techniques

FFT are effective, and after an average of seven days of treatment, there is possibility of the child being orally fed[3,4]. As cases are evaluated individually and evolution will depend on several factors, results cannot be generalized. The guidelines are provided by the speech therapist after the child's evaluation. From the indication, nursing manages and promotes caregivers' training[1,10].

The training includes stimulation of non-nutritive suckling by using a pacifier, massage to relax and anteriorize the tongue, manual support for the mandible, long and soft bottle teat with hole increased to 1mm, placement of the teat on the tongue, symmetrical global posture, and rhythmic movements of the teat in the oral cavity during nutritive suckling[1,10] (Figure 3).

Using a hypercaloric diet favors overall growth and development and consequently, early withdrawal of the NGT. The feeding tube should be removed when the infant's intake is greater than 70% of the amount established for oral intake, in less than 30 minutes, and without ckoking, cyanosis or coughing[1].

The care to be taught to caregivers and supervised includes the following: caregivers' positioning by reinforcing the importance of doing it in an organized way, the performance of massage to anteriorize the tongue, non-nutritive stimulation with pacifiers, the check of the bottle teat hole (1 mm), thickening of the diet, positioning of the bottle teat on the child's tongue, control of feeding time, observation of coughing, choking and/or noisy breathing, presence of perioral cyanosis and/or extremities when offering food.

Promotion of self-care related to use of the feeding tube

NGT feeding is prescribed by the pediatrician when aspiration risk factors are identified in the swallowing and breathing process. Generally, such factors are related to the lack of maturation or anomalies of these structures. In this case, the speech therapist evaluation contraindicates oral feeding[1,10].

The nurse guides the caregiver about the preparation of materials and the diet, which include slowly filling the equipment with the diet to be administered, attaching it to the container without presence of air, connecting the equipment at the end of the NGT, and opening the equipment clamp to control the drip. The caregiver is instructed to keep the prone position continuously elevated to at least 30º[4].

Care related to this management includes checking the tube marking to verify its correct positioning, and checking the gastric residue prior to dietary administration. If the gastric residue is greater than 30% of the total diet, this volume should be reintroduced into the NTG and discounted of the diet volume to be administered. In case of persistent gastric residue, the caregiver should inform the pediatrician.

The following should also be taken into account: the diet should be in room temperature, and the tube must be washed after administration of diet and medicines to maintain its permeability.

Source: Mondini CCSD, Marques IL, Fontes CM, Thomé S. Nasopharyngeal intubation in Robin sequence: technique and management. Cleft Palate Craniofac J. 2009;46(3):258-61.

Figure 3 – Feeding-facilitating techniques

Limitations of the study

The limitations refer to the fact that the study was developed in a specialized and tertiary institution, including patients with a single medical diagnosis. These factors limit the discussion of results, since publications of this theme in the nursing area are incipient.

This article was developed from the doctoral study titled 'Evaluation of the ability of caregivers of infants with Robin Sequence' completed in 2008 at the Universidade de São Paulo, Hospital for Rehabilitation of Craniofacial Anomalies of USP, with the researcher's own resources.

Contributions to the nursing area

The scientific evidence described in this experience report reinforces the effectiveness of nursing as promoter of self-care, particularly presented here in caregivers' training in the care of infants with IRS. Note that this approach promotes caregiver-patient interaction and the social insertion of these infants, decreases the health system costs, and favors the prognosis and quality of life of all involved.

The benefits of Orem's Self-care Theoretical Framework were evident particularly at a time when nursing professionals seem to distance themselves from the fundamentals of the profession.

FINAL CONSIDERATIONS

The IRS is a complex anomaly with varied clinical manifestations that require preparation of the multidisciplinary team and caregivers for a safe care in order to favor these infants' prognosis. This study corroborates the dissemination and increase of specialized nursing care actions to infants with IRS with the aim to solve the reduced number of publications in this area of knowledge.

The practice of teaching self-care is a reality in the broad spectrum of nursing actions. The Self-Care Theoretical Framework allowed the implementation of teaching-learning actions with active participation of caregivers during treatment, with a view to continuity of care after hospital discharge. The benefits of this practice favor the reduction of hospitalization

time, reduction of risk factors for nosocomial infections, and strengthening of the caregiver-infant-family trinomial.

After caregivers' training by nurses in the hospital context, caregivers have the necessary requirements for continuity of care at home by promoting the child's quality and well-being and the family life. The teaching-learning process contributes to nurses' professional autonomy, and the visibility of the therapeutic demand required by infants with SRI. Thus, the use of this and other theoretical references in nursing care is encouraged as they will certainly contribute to quality of care. It is also noteworthy that nursing care for infants with IRS requires specific and sometimes complex care.

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