

Home care challenges facing families of children using a tracheostomy cannula

Desafios de familiares no cuidado domiciliar da criança em uso de cânula de traqueostomia

Desafíos de familiares en el cuidado domiciliario al niño en uso de cânula de traqueotomía

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ABSTRACT

Objective: to describe the challenges faced by family members in providing home care for children with tracheostomy. **Method:** this qualitative, descriptive study, applied content analysis from the perspective of Collière's theoretical framework. Eight family members of children with tracheostomies, aged between 3 and 9 years, treated at a pediatric outpatient clinic in Rio de Janeiro city, were interviewed between January and May 2016. **Results:** the main challenges found were coping with the new situation, new care demands, difficulty acquiring material, and limitations on social life. To overcome the difficulties, family caregivers reinvent care strategies in order to preserve lives. **Conclusion:** behaviors that pose risks to these children's health were identified, pointing to the need to equip families' care practices so that they can maintain airways properly and safely at home. **Descriptors:** Pediatric nursing; child; tracheostomy, family.

RESUMO

Objetivo: descrever os desafios enfrentados por familiares para cuidar da criança com traqueostomia no domicílio. **Método:** pesquisa descritiva, qualitativa, desenvolvida através da análise de conteúdo, pela perspectiva do referencial teórico de Collière. Foram entrevistados oito familiares de crianças com traqueostomia, na faixa etária entre 3 e 9 anos acompanhadas em um ambulatório pediátrico no município do Rio de Janeiro, no período de janeiro a maio de 2016. **Resultados:** os desafios envolveram principalmente o enfrentamento da nova realidade, as novas demandas de cuidado, a dificuldade com a aquisição de materiais e a limitação no convívio social da criança. Para superar as dificuldades os familiares cuidadores reinventam as estratégias de cuidado a fim de preservar a vida. **Conclusão:** foram identificadas condutas que oferecem risco à saúde dessas crianças, apontando a necessidade de instrumentalizar as práticas dos familiares para a manutenção adequada e segura das vias aéreas no ambiente domiciliar.

Descritores: Enfermagem pediátrica; criança; traqueostomia; família.

RESUMEN

Objetivo: describir los desafíos enfrentados por familiares para cuidar al niño con traqueotomía, en el domicilio. **Método:** investigación descriptiva, cualitativa, desarrollada a través del análisis de contenido, desde la perspectiva del marco teórico de Collière. Se entrevistaron ocho familiares de niños con traqueotomía, con edad entre 3 y 9 años, cuyo seguimiento tuvo lugar en un ambulatorio pediátrico situado en el municipio de Río de Janeiro, de enero a mayo de 2016. **Resultados:** los desafíos involucraron principalmente el enfrentamiento de la nueva realidad, las nuevas demandas de cuidado, la dificultad en la adquisición de materiales y la limitación en la convivencia social del niño. Para superar las dificultades, los familiares cuidadores reinventan las estrategias de cuidado con fines de preservar la vida. **Conclusión:** se identificaron conductas que representan riesgos a la salud de estos niños, lo que señala la necesidad de instrumentalizar las prácticas de los familiares para el mantenimiento adecuado y seguro de las vías respiratorias en el entorno del hogar.

Descriptorios: Enfermería pediátrica; infantil; traqueotomía; familia.

INTRODUCTION

Technological sophistication and the development of drug and therapeutic resources have resulted in a new group of children surviving perinatal disorders, chronic diseases and trauma, who are referred to as *Children with Special Health Care Needs* due to the fragility and dependence on care in order to survive¹.

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In Brazil, this population was called *Crianças com Necessidades Especiais de Saúde* (CRIANES). Usually, this group requires long-term rehabilitation follow-up and special care from the nursing team at all levels of health care, due to the need for multiple, complex and continuous care².

These children present care demands classified into six types. The first one is developmental, which includes children with developmental delay. The second, of technological care, with children who use life-sustaining devices. The third, with children who make continuous use of drugs. The fourth, regarding the modified habits, the children need adaptations in routine activities. In the fifth, regarding mixed care, children have one or more of the previous demands, excluding the technological one. Finally, the sixth summarizes the demands of clinically complex care, with all of the above including the management of life-sustaining technologies^{3,4}. Among the groups of children with special health needs, we highlight in this study those in need of technological care, using a tracheal cannula.

The child using this device has an inherent fragility arising from exposure of the lower airways through the stoma and the constant presence of the cannula, and when at home requires continued vigilance and especially specific care by family caregivers in order to preserve their life and promote their well-being⁵. Sometimes, these family members do not have adequate knowledge to perform such care, which may imply complications in the child's clinical condition and the consequent return to the hospital⁴.

The technological device is a protective element that avoids non-elective hospitalization; however, it requires the implementation of educational actions related to the handling and specific care of each device⁶. Nevertheless, it is important to know the daily challenges faced by caregivers. Thus, the study aimed to describe the challenges faced by family members taking care of the child using a tracheostomy cannula at home.

THEORETICAL REFERENCE

The theoretical framework of this study was based on Collière's contributions on care. In her theory, two types of care of a different nature named life-sustaining care and repair care were identified. The first deals with daily and habitual actions related to the maintenance and continuity of life, which contribute to the development of the human being, such as eating, excreting and getting around; or of a psycho-affective nature. On the other hand, repair care provides the continuity of life, seeking to control the disease, to fight against it and against its causes and to treat it⁷.

When there is a predominance of reparative care over daily and usual care, there is a gradual decrease of the person's living forces, resulting in physical, mental or social exhaustion⁷.

The child using a tracheostomy cannula at home is inserted in a context of significant changes for him/her and the family, with care demands that do not belong to common knowledge.

METHODOLOGY

A descriptive study with a qualitative approach. Eight family members participated in the research, the inclusion criteria were the following: being a family member caregiver of children using a tracheostomy cannula, aged between 3 and 9 years old, attended at a pediatric outpatient clinic, located in Rio de Janeiro.

Of the nine family members caregivers attended at this outpatient clinic and met the inclusion criteria, eight agreed to participate. Family caregivers of children using a tracheostomy cannula who were hospitalized and family caregivers under 18 years old were excluded.

In this study, family caregiver is understood as the person who takes responsibility for the care of someone who is sick or dependent due to a parental bond, not necessarily by a blood connection⁸.

As a strategy for gathering the participants, a telephone contact was made from the child's data registered by the institution. This first contact provided identification of the family caregiver and the opportunity for making an appointment according to their convenience.

Data were collected from January to May 2016 through semi-structured interviews with the following guiding question: Do you find any difficulty in taking care of your child with tracheostomy? Tell me about it.

All interviews were conducted by the first author in a reserved place, lasting an average of 30 minutes. The interviews were fully recorded and transcribed. In order to ensure the privacy of the participants, they were identified by the letter E, followed by an Arabic numeral according to the order of the interviews. For closing the interviews, the theoretical data density criterion was applied⁹, considering the scope of the study objectives.

The analysis of the empirical material took place in three phases, following the thematic modality¹⁰: pre-analysis; material exploration and data categorization, which resulted in four analytical categories: Adaptation to the tracheal device; Changes in the care management of children with a tracheostomy cannula; Acquisition of materials for the child home care; The tracheostomy cannula limiting the child's social life.

The research project was approved by the Research Ethics Committee of the institution, under the number 1,349,663. All participants signed the Free and Informed Consent Form.

RESULTS AND DISCUSSION

Among the eight study participants, most of them belong to the maternal group, aged 40 years old, with low education and family income of up to two minimum wages. Regarding the children, four are preschoolers under 6 years old, and four schoolchildren aged 6 to 9 years old. Regarding the time of cannula use, it ranged from 8 months to 9 years.

Data handling resulted in four analytical categories, which are discussed below.

Category 1: Adaptation to the tracheal device

The impact of discovering the need of tracheal cannula use in the child was one of the evident challenges in the testimonies of family caregivers, resulting in shock and fear.

In the beginning it was very difficult. Because it was all new to me [...] it was a shock indeed! I faced this [...] because she needed to have surgery and use the cannula. [...] the doctor told me that her life depended on it. (E3)

When realizing a child's health problem, the family caregivers manifest anxiety about the future, fear, internal conflicts, impotence and also the adaptation to the new reality¹¹.

In addition, performing the tracheostomy implies changes in the family's daily life due to the child's dependence on the tracheal device and the care that the device demands.

[...] in the hospital I am sure that if anything happens [...] the nurses come to help us, but what about in our house? Once we got home, he was hardly breathing. I ran to the hospital. When I arrived there they explained that I needed to aspirate the cannula [...] this happened on the first day after hospital discharge. (E8)

Taking care of a technology-dependent child requires training and guidance from health professionals, considering that the responsibility will be of the family caregiver. Care that until then was performed by a specialized hospital team¹².

For Collière, the care for ensuring the maintenance and continuity of life is not simple. The process of caring involves maintaining life ensuring the satisfaction of a set of essential survival needs¹³.

In this perspective, the nurse's performance is paramount, guiding and giving voice to the family caregiver. It is necessary to encourage the caregiver to face the moment, clarifying doubts and yearnings in order to promote the quality of life of children with a tracheostomy cannula⁷.

Category 2: Changes in care management of the child with a tracheostomy cannula

This category addresses the difficulties encountered by family caregivers to perform the care routine that was intensely modified by the presence of the tracheal cannula.

Related to bathing the child with tracheal device, a family caregiver revealed:

It was too hard. Because it was in the small bathtub [...] and with a lot of difficulty, I could bathe him [...] because he has a lot of difficulty sitting [...] and he can't stand up [...]. But soon we found a way! [...] my husband cut a bucket in half and made a huge bathtub for our boy. He painted it [...] it was the most beautiful thing in the world! (E1)

In addition to the care demands related to the use of the tracheal cannula, some of these children also need to face the difficulties arising from the limiting physical condition due to neurological impairment. Thus, according to the last report, in order to provide more comfort to his son's bath, the father made a bathtub with the resources he had available at home, offering care in the perspective that Collière points out as comfort¹⁴.

[...] it was very difficult, because I was afraid of wetting it, of getting water through the cannula, of choking and not realizing it, you know? It was very difficult [...] so I put little water, then I bathed her, very slowly [...] carefully. (E3)

The possibility of water entering the tracheostomy tube and not noticing it and, as a result, causing harm to the child was also a concern of the family. To lessen this problem, their strategy was to put less water in the bathtub and also give the bath slowly, revealing the care of preserving life¹⁴, avoiding risks to the child's health.

Considering that bathing is a child welfare practice, the nurse and the family caregiver need to take a close look in order to develop new practices with the purpose of providing safety and quality of life to the child and his/her relative.

The concern with bath water is part of learning the routine care of the child using the tracheostomy tube. This fear of letting the cannula to get wet comes from the recommendations provided during the training, which reinforce the importance of not letting the child stay in the water for too long and wetting the cannula fixation³.

Family members pointed out strategies used facing tracheostomy tube secretions:

It's way too much secretion! I only aspirate it [...] sometimes, I have to do the nebulization in order to release [fluidize the secretion]. [...] she does respiratory physiotherapy so that it may help [...]. Sometimes I go crazy! (E7)

The uses of medication, nebulization and breathing exercises in an attempt to reduce the accumulation of secretion in the child's tracheostomy cannula are pointed as specific care strategies in this condition.

These actions are recommended for the prevention of cannula obstruction and are indicated for all tracheostomized children and should be emphasized by the nursing staff. These actions include: regular aspiration with the right technique at least three times a day and when there is evidence of airway secretion; secretion humidification; respiratory physiotherapy for better mobilization of the secretions¹⁵.

Injuries caused by the tracheostomy cannula in the adjacent region to the tracheal stoma were also reported.

[...] I put the gauze to avoid hurting under the tracheostomy [cannula], because sometimes it hurts a lot [...], because he coughs too much [the cannula moves injuring the skin around the stoma], then he gets hurt a lot. (E1)

Regarding the continuous presence of moisture in the skin, a study points the possibility of developing an erythema, which is why frequent dressing changes are indicated to keep the skin dry and to avoid tissue maceration and skin rupture¹⁶.

Mothers also highlight concerns about the facility of entry of foreign bodies such as insects and airborne debris into the tracheal cannula.

[...] when we go outdoors, I'm afraid of insects [...] we always have to look. Sometimes we walk and see that wind of dust, of garbage [...] then, I put him in the opposite direction of the wind, to avoid it [in order to avoid entering foreign body in the cannula]. (E4)

In this sense, the care of frequently inspecting the tracheostomy cannula when outdoors and positioning the child opposite the wind were mentioned strategies.

Previous study advises to avoid contact with dust, smoke, pet's fur, powders, greasy creams, ointments and *sprays* as they may cause lung irritation. In addition, it indicates keeping away from children small objects or toys that may be introduced into the tracheostomy cannula, also avoiding common causes of obstruction in children¹⁷.

The reports highlighted family caregivers' challenges when facing the tracheal decannulation of their children, denoting emergency situations:

[...] about 15 days after hospital discharge, her [tracheal] cannula loosened; when I woke up, I saw her last breath, [she was] cold, almost breathless! And I was looking for the cannula on her bed. [...] When I found it, I took it fast! I cleaned it quickly and put it back. Then I ran, I turned on the aspirator, my husband helped me aspirating it. [...] after I aspirated, her breath started to return [...]. (E2)

Given this report, this family experienced a potentially life-threatening situation due to the accidental decannulation of the child.

The issue of decannulation also emerged among the participants of another research that showed doubts and concerns regarding emergencies that may occur with the externalization of technological devices⁴. Accidental decannulation requires immediate replacement of the cannula. Although some children have a rigid trachea causing the airway to remain partially open when the tube is removed, other children have malformed or flexible tracheal cartilage, resulting in airway collapse when the cannula is removed¹⁸.

In this context, it is observed that the family caregiver not only performs the care practices of the child with tracheostomy cannula, but also seeks strategies to conserve his/her life¹⁴.

Category 3: Acquisition of materials for the child's home care

In the speeches of family members, it was possible to observe the challenges to acquire the needed materials to take care of the child with tracheostomy tube.

[...] a difficulty is the lack of material, we use these [suction] probes many times! But we find our way to aspire [...] [recently] the probes were over, and where I live there isn't any [to buy], it's very complicated to find them. I met a guy who sells, but he wants to sell me 100 probes! I can't afford to buy 100 probes. (E8)

The difficulty of the family caregiver to find the aspiration probe in the city where he lives is noted, and when he finds it, he can only buy it in large quantities, and thus has no financial conditions to afford it, unveiling a challenging issue for this family.

The financial impact in these families is significant, because most of the time mothers stop working outside and performing paid works, this way the financial resources are only the responsibility of the child's father. It is noteworthy that the cost of the family is higher, given the need for technological supplies to maintain the child's life¹⁹.

Another family member, faced with the need to acquire materials for the care of his child, reveals that he tries to seek donations of materials at the outpatient clinic where his daughter goes.

I got some [aspiration probes] from the outpatient clinic, and I got some [from acquaintances], and sometimes I buy them too [...]. I'm still going to require the public defense to try to get [the materials]. [...] For you to get things is a great bureaucracy [...] it should be easier! (E7)

The difficulty in obtaining the basic materials for the care of these children result in anxiety in the family caregivers. This way, they seek strategies that enable them to acquire the necessary materials and build a support network with their usual health services; they are also willing to fight for judicial means in order to acquire the indispensable resources.

In this context, an informal aid network is formed that may include religious institutions, non-governmental organizations (NGOs), and known people who offer help. Families seek alternative resources by appealing for donations of materials that make caring for their CSHCNs possible¹⁹.

Thus, it is clear that although there are legal provisions that guarantee CSHCNs' rights in Brazil, in the practice, family members often live a true pilgrimage in order to assure them. Sometimes needing court orders to ensure proper treatment for their children²⁰.

Due to the difficulty in obtaining the materials for the care practices with their children, the family members revealed the strategy of reusing materials, such as the aspiration probe and the fixation device.

[...] We do not have that support to buy these materials, [so] we have to wash to use them again [...] I always reuse the fixation device. [...] I reuse the probe too, because otherwise it is too much money. And the hospital does not give it. They could give that set of materials every month to take care of him, but we don't have it, so we reuse it [...]. (E4)

Aspiration of the tracheal cannula is a frequent care in the routine of these families. In this regard, according to a study, aspiration probes can be used more than once before being discarded in the trash if the patient needs frequent aspirations. For this purpose, the probe should be rinsed in clean running water and kept clean in its original packaging or an exclusive use container²¹.

Category 4: The tracheostomy cannula limiting the child's social life

Family members pointed out the challenges related to the social life of the child who has the tracheal device. The possibility of the child expelling secretion through the tracheostomy cannula in other people, primarily in public settings, result in anxiety, fear and embarrassment in family members.

[...] there should be a protector for this tracheostomy [cannula] [...] to avoid showing it. [...] sometimes, when we are talking to people, it splashes on you, on others. I think a protector [for the tracheal cannula] would help to avoid this embarrassment [...]. (E4)

Still regarding social concern, it also refers to the feeling of shame when facing such a situation.

It expels too much secretion in others, [...] It's so embarrassing! It's not possible. What a shame! [...]. And it's embarrassing, because it splashes a lot of secretion far away [...]. As we are mother or father, we can handle everything, but the others wouldn't, they would feel a little disgusted! In this way, they wouldn't want to be near him and I wouldn't like it. (E1)

It was noticed that some families choose to avoid going out due to the embarrassment that may occur out of home.

[...] it is very difficult to go walking [...]. I almost don't go out with him anymore. Because I'm afraid something will happen because of this tracheostomy [cannula]. Only indoors. (E5)

The tracheostomy tube has become a decisive factor for the mother to keep her child only in the social space of her house, pointing out that the home is the place where she feels safer to meet the necessary demands to preserve her child's life.

There is also the fear of social confrontation because of the child's aesthetics, which is influenced by culture and social standards. It is noteworthy that the aesthetic consequences influence significantly other people's behavior, such as reactions of strangeness and rejection, causing feelings of shame and/or embarrassment on the part of clients²².

CONCLUSION

The study allowed learning the care practices, the challenges experienced and the strategies created by family members to maintain the child's life using the tracheostomy cannula at home.

Adaptation to the tracheal device requires changes in family routine due to the child's dependence and new demands for care. It also involves a series of feelings, such as suffering to accept the new reality, insecurity facing the new care for life maintenance, as well as the feeling of impotence and fear of the future.

The changes in the care management of the child are related to the acquisition of interdisciplinary knowledge and the adequacy of daily care, which have become complex and frequent, in order to meet the essential needs for their survival.

The acquisition of materials for the home care of children is complex, since most families cannot afford them; if they cannot get donations, they reuse the materials.

The tracheostomy cannula limits social life, as the possibility of the child expelling secretion, the insecurity of taking care of the child outside home, and the social confrontation due to body alteration cause fear of manifestations of stigmas and prejudice, which eventually isolate the child and the caregiver.

This study unveiled the reinventions of ways of caring, as well as highlighted the vulnerabilities of care practices developed by family members of children with tracheostomy cannula, revealing the need to better instrumentalize them.

Specific programs need to be developed to support family members and their children, enabling them to have better quality care, as well as their respected rights of childhood and citizenship.

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