Breastfeeding based on the experience of mothers of tracheostomized children and the use of the Passy-Muir® valve

Aleitamento materno na experiência de mães de crianças traqueostomizadas e o uso da válvula Passy-Muir®

Lactancia materna desde la experiencia de madres de niños traqueostomizados y uso de la válvula Passy-Muir®

ABSTRACT

Objective: To understand the experience of mothers of tracheostomized children between 0 and 24 months old, who resumed breastfeeding with the use of the Passy-Muir® deglutition valve. Method: A descriptive study with a qualitative approach and semistructured interviews conducted from June to August 2017 in which the participants were 11 mothers of tracheostomized children, by follow-up in a rehabilitation and logopedics center, which adapted the Passy-Muir® deglutition valve. The analysis was based on the assumptions of thematic content analysis. Results: the mothers’ experience, after the child's tracheostomy, the use of the Passy-Muir® swallowing valve minimized the difficulties in breastfeeding. Once the valve adaptation process was overcome, its benefits were realized. The mothers' feelings in the process of adapting the valve are described, their expectations with the use of the valve and pleasure and fulness for the woman in the return of breastfeeding. Conclusions and implications for practice: Safety during breastfeeding, reduction in the production of secretions, and reductions in the number of airway aspirations were observed, noticing improvements in the respiratory pattern, in the vocalizations (mumbling and crying), and in the child's sleep quality. Further research is needed to address breastfeeding of tracheostomized children to deepen knowledge in this area.

Keywords: Breastfeeding; Tracheostomy; Infant; Child Care; Public Health.

RESUMEN

Objetivo: comprender la experiencia de las madres de niños traqueostomizados, entre 0 y 24 meses de edad, que retomaron el aleitamento materno con el uso de válvula de deglución Passy-Muir®. Método: estudio descriptivo, de carácter cualitativo, con entrevistas semiestructuradas, de junio a agosto de 2017 en el que participaron 11 madres de niños traqueostomizados, mediante seguimiento en un centro de reabilitación y foniatría, con entrevistas semiestructuradas, en los meses de junio a agosto de 2017. El análisis se basó en los presupuestos del análisis de contenido temático. Resultados: la experiencia de las madres, después de la traqueostomía, la utilización de válvula Passy-Muir® minimizó las dificultades al aleitamento materno. Superado el proceso de adaptación de la válvula, se observaron sus beneficios. Se describieron los sentimientos de las madres con respecto al uso del dispositivo y el placer y plenitud para la mujer en el regreso al aleitamento materno. Conclusiones e implicaciones para la práctica: se observaron mejoras en la seguridad durante el aleitamiento, disminución de la producción de secreciones, reducciones en el número de aspiraciones de vías aéreas, mejoras en el patrón respiratorio, vocalizaciones (mumbled y llanto) y en la calidad del sueño del niño. Se necesita más investigación que aborde el aleitamiento materno de niños traqueostomizados, profundizando los conocimientos en esta área.

Palabras clave: Aleitamento Materno;Traqueostomia; Lactante; Cuidado de la criança; Saúde Pública.

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INTRODUCTION

The increase in the use of tracheostomy in infants under one year of age has been attributed to the increased survival of premature newborns and those requiring prolonged ventilation, but it may also be associated with airway obstruction.¹

Although necessary in some health conditions, tracheostomy can lead to changes in the physiological process of swallowing, and in infants, it compromises breastfeeding.² Constant care for these children and families requires resistance, compassion and understanding. In this sense, children and families require appropriate referral to support services, as they have unique and complex care needs.³,⁴

Tracheostomized infants are considered children with special health needs (Crianças com Necessidades Especiais de Saúde, CRIANES). These present longitudinal and continuous care needs of the family, services and health professionals, involving different conditions that vary in complexity and care demands.⁵

Families of CRIANES are responsible for a significant range of home care measures and, in the case of families of tracheostomized infants, they even face the challenge of maintaining breastfeeding, avoiding early weaning due to swallowing disorders.⁶ Early weaning can interfere with oral motor development, as it affects the normal functions of chewing, swallowing and posture of the tongue and lips, in addition to interfering with the correct muscle action that has a preponderant role in facial growth and bone development, enabling the installation of malocclusion, oral breathing and motor-oral alteration.⁷

Therefore, in this population, continuity of breastfeeding should be a priority and be based on the perspective of the triad that involves protection, promotion and support, with the engagement of health professionals to prevent early weaning.⁸ In this sense, speech therapy can contribute to rehabilitation and minimize changes in orofacial motricity, which can arise as a result of the tracheostomy and the absence of stimulus for suction in the mother’s breast.⁹

Infants with orofacial deficits, including those using a tracheostomy cannula, have greater difficulties in maintaining breastfeeding, and swallowing and lactation disorders have an impact on their well-being and that of their families. The parents experience the stress of caring for children with special needs, concerns about choking or sucking milk, stunting and social isolation.¹⁰ It is noteworthy, however, that the interruption of breastfeeding among these children can be reversed, as long as the mothers are guided, supported and monitored and specialized techniques and care measures are applied, including relactation and induced lactation.

The mother-infant binomial must receive guidelines, monitoring and support from the health professionals, who can use auxiliary instruments in rehabilitation. In relation to tracheostomized infants, special attention should be paid to the device called the Passy-Muir® swallowing valve, which is adapted to the tracheostomy cannula and allows breastfeeding to continue without complications.

The Passy-Muir® swallowing valve is a plastic piece, cylindrical in shape, with a hollow interior, containing a silicone membrane in its anterior portion, which allows for unidirectional passage of air (only the entry of inspired air). When coupled to the outside of a tracheostomy cannula or in line with a respirator circuit, it allows only inspired air to enter through the tracheostomy cannula and redirects the air to be exhaled into the upper airways, passing through the larynx (vocal folds), pharynx, mouth and nose, thus improving swallowing, secretion management, smell and taste and voice emission due to the restoration of subglottic pressure.¹¹

In view of the above, the following question was asked: What is the experience of mothers of tracheostomized infants in their relationship with the use of the Passy-Muir® valve? This study aimed to understand the experience of mothers of tracheostomized children, between zero and 24 months of age, who resumed breastfeeding with the use of Passy-Muir® swallowing valve.

METHOD

A descriptive and exploratory study with a qualitative approach, developed from June to August 2017, with the participation of mothers of tracheostomized children, who adapted the Passy-Muir® swallowing valve and resumed breastfeeding. It followed the recommendations of the Consolidated Criteria for reporting Qualitative Research (COREQ).

13 mothers of tracheostomized children aged between zero and 24 months were included, monitored in a specialized and rehabilitation service, who resumed or were in the process of resuming breastfeeding with the aid of the Passy-Muir® swallowing valve, and residing in municipalities on the triple border between Brazil, Paraguay and Argentina. Of these, two mothers were excluded: one because the child died and the other for having moved to another city, totaling 11 mothers.

For data collection, the selection of the participants was made by convenience. The interviews were conducted by a master’s student, in the service in question, through individual meetings lasting a mean of 30 minutes, guided by a semi-structured script submitted to a pilot test and initiated by the following guiding question: Tell me about your experience of your child resuming breastfeeding with the use of the Passy-Muir® swallowing valve.

Data was audio-recorded and field notations were taken after each interview. The interview transcripts were not returned to the participants. The saturation phenomenon allowed data collection to end.

The analysis was performed using the thematic content analysis technique.¹² In the pre-analysis, a fluctuating reading was performed for the understanding of the data set, followed by an exhaustive reading for organization and theming in the light of the study objective. In the exploration of the material, the analysis contents were aggregated and classified to establish the thematic categories. In the treatment and interpretation of the results obtained, it was possible to put the data in evidence, and to observe the agreement and the justification of the thematic categories supported by literature pertinent.

The research followed the ethical precepts of Resolution No. 466/2012, of the National Health Council, Ministry of Health, with approval by the Committee of Ethics and Research with
Human Beings of the State University of Western Paraná, opinion number 2,135,506. To guarantee anonymity, the participants were identified by the letter M, relative to the mother, followed by Arabic numbers in the order of the interviews: M1, M2... M11.

RESULTS

The mothers participating in this study were between 31 and 44 years old, most had a partner and had completed elementary school. Among the infants, six were female and five were male, most of whom underwent tracheostomy in their first year of life and resumed breastfeeding within two months after the procedure.

Data analysis substantiated the construction of three thematic categories: experiencing the tracheostomy and the benefits of the Passy-Muir® swallowing valve; the adaptation process using the Passy-Muir® valve: feelings and expectations; and returning to breastfeeding: the fullness and pleasure of the act.

Experiencing tracheostomy and the benefits of the Passy-Muir® swallowing valve

When faced with children undergoing a tracheostomy, the mothers had difficulties in dealing with the condition of the child, who was crying asking for the mother’s chest and lap. This mother lacked the emotional support and security to breastfeed her son, who was now tracheostomized.

[...] I cried, I didn’t stay with him, my husband did. I was absent from the room, because he wanted to breastfeed and couldn’t, that whole anguish. (M1)

Bronchoaspiration is more frequent in a tracheostomized child, as the reflex cough is lost, increasing vulnerability to complications. As a result, the mothers were afraid to breastfeed.

When I tried to breastfeed him, everything came out through the tracheo, he had bronchoaspiration, I gave up because of fear. (M2)

[...] I even tried, but milk came out of the trachea and the speech therapist who took care of her there in São Paulo didn’t indicate breastfeeding because of the risk of choking and bronchoaspirating. (M9)

In this condition, the swallowing valve proved to be a technology that brought benefits to the care of the tracheostomized child and provided safety to the mothers, in addition to being an effective alternative in resuming the breastfeeding process. The child himself could see that the resource brought him benefit and comfort, showing a state of relaxation.

[...] After he put the valve on, he sucked. When he saw us put the valve on, he sucked and already relaxed to the point of sleeping [...], I brought comfort to him. We saw that it was already a benefit. (M1)

The use of the valve brought benefits in the daily care routine for tracheostomized children. Particularly to the mothers, it allowed greater tranquility, rest and satisfaction in the interaction with the child. The mothers were able to identify and meet the physiological demands of sleep and hunger, enjoy speech sounds and perform leisure activities without worries. Consequently, it provided better quality of life to the families.

[...] It was very good. Didn’t need to aspire many times [...]. Our life changed a lot after the valve, I was less tired, less nervous, less sad [...]. It was better to take care of him, there was no more phlegm coming out of the trachea [...]. He slept all night [...] The valve only helped, he coughed less, he could suckle again, and best of all was hearing him cry. (M4)

[...] After the valve he started to make sounds, I started to hear his crying. It’s exciting to hear his voice [...]. After the valve, he was already breastfeeding and he was calmer [...]. I know he’s not suffering, coughing and secretion coming out of the trachea [...] His quality of life has improved a lot. (M2)

It changed her life a lot, because in the first days she aspirated 15 to 20 times, as soon as she put the valve on it decreased a lot [...] at night, she only wakes up when she wants to breastfeed, no longer sucks [...] when she makes a movement we listen, she screams, when she’s hungry she cries [...]. We are more relaxed [...]. (M8)

In short, quality of life for him and for me [...] she’s able to breastfeed without choking and even traveling is easier because she doesn’t need to suck on the way [...] she already makes noises sometimes in the throat and is a way of exercising and I believe it’s a benefit. (M1)

The adaptation process using the Passy-Muir® valve: feelings and expectations

The proposal to use the valve was received by the mothers with disbelief, since it was a technology they did not know about, without generating expectations of success.

Our expectation was simple, that he could at least with the valve give more protection, because we were very concerned. (M1)

So, as I didn’t know, nor knew anything about it, I didn’t generate any expectations, but at first we already noticed that there was an improvement. (M11)

For some mothers, the use of the valve, an alternative that could facilitate care, generated feelings of fear, anxiety, anguish and insecurity during the adaptation process.
For me it was always fear, this whole process, of course, with all the expectations that could improve [...] it was a difficult choice, it brought us anguish. (M1)

I confess that it was difficult and frightening, because fear haunted me, even though I knew the benefits of the valve [...]. In the first feedings I was a little anxious, but I felt safer when I could see that it was safe to breastfeed with the valve. (M7)

However, immediately after starting using the valve, the mothers noticed the child's progress, whose observed benefits exceeded their expectations.

I thought he would never leave the tube [...] he started to breastfeed orally [...] I started to see that he was developing [...]. It did live up to my expectations. (M3)

The expectations were met for sure, it was more than I expected. (M9)

Then, they began to express satisfaction with the use of the valve and recognize the improvement of their children, in several aspects, such as breathing, breastfeeding and feeding, the emission of sounds and speech.

[...] I hoped she could improve her breathing and it went beyond that, she was able to breastfeed again and then she started eating and then talking, listening her calling me mother was the most exciting day for me. (M9)

[...] it was much more than I expected, it was painful for me to see my daughter suffering. (M6)

Returning to breastfeeding: the fullness and pleasure of the act

The use of the Passy-Muir® valve, as an alternative to overcome the difficulties of breastfeeding, showed that this technology provided the mothers with regaining their self-esteem and made them feel capable of breastfeeding and caring for their child safely and calmly.

For me it was a very good feeling, breastfeeding my son was a feeling of fullness [...]. It was crucial for me at that time, emotionally, to feed him. (M1)

Being able to breastfeed, it was an experience that I thought I wouldn’t live [...] it was very special to breastfeed him after all, [...] feeding him with the valve was much easier for the two, me because of the fear of him choking and him because he wasn’t panting and coughing any more. (M2)

The return to breastfeeding with the aid of the Passy-Muir® valve allowed the mothers of tracheostomized children to recover the feeling of pleasure during the act of breastfeeding.

Breastfeeding her again was the most important of all for me [...] it was the happiest day, such a joy that I cannot explain [...]. When she was sucking my breast I didn’t want it to end, I wanted to breastfeed the whole hour to place her on my lap and feeling her suckling and laughing for me. (M5)

After she put the valve on and sucked on the breast I was looking to see if milk would come out of the trachea and it didn’t. I cried with joy [...]. This changed from one day to the next and only a breastfeeding mother knows what it is, it was wonderful for me [...]. (M6)

Resuming breastfeeding represented more than nourishing and offering food to the child, it involved feelings of hope, comfort, and gratitude to God, a new beginning. Family and professionals established a bond during the valve adaptation process and the success of breastfeeding led to mutual satisfaction.

Being able to breastfeed was the miracle that brought me hope. I even forgot the time when I was breastfeeding, it was my best gift, gift from God [...]. The day I removed the feeding tube was the happiest day, I cried, my husband, the nurse, the speech therapist [...]. Having a successful experience after experiencing a great struggle was comforting, it was a new beginning to breastfeed her. (M7)

The support and encouragement of the health professionals were decisive for the return to breastfeeding and the adaptation of the child and family with the valve. The mothers expressed recognition and importance of the actions of the health professionals in this process.

I was always supported by the speech therapist, it was not a public health service, it was personal, because we built a bond. (M1)

The speech therapist instructed me very well, let us go home when she was sure he was fine, she saw him suck, she didn’t give up on seeing him suck [...]. I was very well assisted by the health team [...] all the professionals supported me. Without support I wouldn’t be able to go ahead. (M2)

She [child] was very well taken care of, it was very important because I wouldn’t be able to do it without you (professionals). (M5)

DISCUSSION

Understanding the experience of mothers of tracheostomized children during the resumption of breastfeeding through the use of the Passy-Muir® swallowing valve is essential for the structuring and the performance of actions aimed at serving these children. This study presents successful experiences of these mothers in
introducing strategies for the care of tracheostomized children and in the innovations that should be available.

After the tracheostomy, the mothers experienced breastfeeding difficulties related to the fact that breast milk came out of the cannula, which caused a feeling of insecurity in the face of the new situation, also implying the possibility of bronchoaspiration. The mothers showed dual feelings about breastfeeding because they claimed to have breast milk, but they were unable to breastfeed their children, since this act, concomitant to silent aspiration, put the child at greater risk.

The act of breastfeeding the tracheostomized child exposes the infant to risk factors for respiratory aspiration in view of the presence of dysphagia, impaired or absent cough reflex, decreased or absent vomiting reflex, pharyngeal motor dysfunction, delay in the reflex of swallowing, stasis in pharyngeal recesses (vallecula and/or piriform sinuses) and changes in the pharyngeal closure mechanism.\textsuperscript{10,13}

However, with the introduction of the valve, there was a better mother-child interaction considering that this technology provided symptom relief, since there was a decrease in the production of secretions and, consequently, reduced the aspirations of the tracheostomy. Also noteworthy is the occurrence of prolonged sleep and the emission of sounds due to the benefits of using the valve that promotes greater comfort for children and mothers. With the expression of these benefits, it can be considered that the Passy-Muir\textsuperscript{®} valve is a technology that can favor the control of salivation, recovery of smell, taste and the air flow starts to be directed to the upper airways, also favoring decreased airway secretion in tracheostomized people.

The use of the Passy-Muir\textsuperscript{®} valve allowed the mothers to resume the breastfeeding process and promoted benefits such as readaptation for feeding, as well as improved swallowing and communication. In addition, there is a significant improvement in swallowing due to the restoration of subglottic pressure; the positive increase in pharyngeal sensitization reducing the risk of penetration of food into the lower airways; in addition to the fact that it favors ventilation and oxygenation, it helps in the early weaning process of mechanical ventilation and increases the chances of decannulation of the tracheostomized patient.\textsuperscript{7}

A number of studies show that the use of the valve favors the communication of the tracheostomized person, an important factor for them and their family, as well as it excludes the need for digital occlusion for oral communication, reduces secretions, prevents risks of infections, and improves the senses of smell and taste.\textsuperscript{14,15}

Infants tracheostomized and in use of the Passy-Muir\textsuperscript{®} valve are part of the group of Children with Special Health Needs (CRIANES) because they demand habitual modified care measures in addition to those of others in the same age group, and are dependent on technology.\textsuperscript{16} It is emphasized that, to meet the care needs of these children, the families must be prepared to deal with this new condition as well as they must be supported in the care load that they should offer the child in that condition.\textsuperscript{17}

Therefore, the management of the tracheostomy is complex care and is not part of the care repertoire of an infant child, triggering multiple feelings in the mothers. Among them, fear was the most evident. The lack of more consistent knowledge about their child’s condition or disease makes the experience of these parents a distressing and suffering condition. This condition remains, even when faced with alternatives that could have positive results in care, due to fear of the unknown, a fact observed in the mothers’ statements when they introduced the use of the Passy-Muir\textsuperscript{®} valve. These feelings are recognized in families with sick children and, often, for assuming the role of primary caregiver, the mothers feel insecure, frightened and powerless in the care process. Therefore, the more complex the care, the greater the demand for support of the families.\textsuperscript{18}

Insecurity stems from fear of the unknown. This feeling can go through the adaptation process in the child’s care, when sudden changes occur in the daily routine, in the child’s general condition, associated with the need to learn new procedures. The family needs to partner with the professionals and have knowledge on how to access the health services to ensure improvements in the health and well-being of their child.\textsuperscript{19}

Although the mothers showed a mixture of uncertainty and fear, they were able to try the new technology proposed for their children and trust the evolution process of the child’s clinical condition. With the possibility of using the Passy-Muir\textsuperscript{®} valve to care for the tracheostomized child, a feeling of hope is reborn in these mothers.

When presenting the family with the opportunity to experience a satisfactory rehabilitation to the child’s health status and when part of this beneficial evolution comes from the use of a resource in the care process, feelings, previously of impotence and fragility, are transformed into hope and satisfaction. To do this, they need to receive adequate guidance, emotional preparation and training to deal with the devices. In addition, at home they need family support and constant professional support.\textsuperscript{20}

The safer and less anxious the mother’s function and the handling of the devices needed by the child, women feel more confident in their ability to interpret and resolve the breastfeeding difficulties, especially when in situations of harms to the child’s health, they are presented with an effective alternative for the control of the disease which still allows the resumption of breastfeeding.\textsuperscript{21,22}

For being children who require complex and continuous health care, the family needs to incorporate new knowledge and practices into everyday life.\textsuperscript{23} The desire to breastfeed the child drives them to overcome the barriers. Being able to breastfeed and establish body-to-body contact maximized the bond and the exchange of affection between mother and child, giving rise to feelings that conferred pleasure, satisfaction, empowerment, joy, accomplishment, and self-confidence, among others. It was observed that, even in the face of fear of the unknown, the mothers wished to help their children, and their satisfaction in reporting the experience is expressed when they said that use of the Passy-Muir\textsuperscript{®} valve exceeded their expectations and allowed
them to face the challenges of the child's health treatment cycles. Similar feelings were also expressed in studies in which the mothers expressed suffering for the unexpected, sadness for their child's suffering but, in return, they expressed hope and a desire to fight for their child's recovery and to see it improve. Being able to breastfeed led the mothers to overcome the difficulties arising from the interruption of breastfeeding. The benefits of using the Passy-Muir® valve acted as a stimulus for the recovery of their self-esteem and self-confidence, expressing the feeling that they were able to nourish their children, even in adverse conditions. The fullness of this experience could be apprehended in the mothers' reports when they returned to breastfeeding, representing a pleasurable moment, of satisfaction, joy, comfort, exchange of affection, fondness and love.

The mothers expressed that the return to breastfeeding was a challenge overcome in the care of their children, confirming that breastfeeding is more than nourishing the child; it is a process of intense emotional connection in the mother/child relationship that affects the mothers' emotional development, since breastfeeding promotes moments of pleasure, contentment, relief, and well-being. The support of the health professionals in the process of helping these mothers and babies to resume breastfeeding was fundamental and indispensable. We emphasize the importance of monitoring these families to reduce early weaning, especially with educational actions.

In this study, it was evidenced that the support of the health professionals was decisive in changing the child’s quality of life, in its development, and that the support received was essential for the success of the rehabilitation actions proposed for the care of tracheostomized infants. This perception of the interviewed mothers points to the importance of professional practices based on respect and attention, valuing dialog as the foundation to encourage co-responsibility and favor shared care directed towards the integral development of children and their families. As a limitation, the fact that this research was carried out with a limited number of mothers who had tracheostomized children in the lactation phase stands out, which prevents the generalization of the results. However, the results can be used in the definition of public policies since, for the technique to be successful, the mothers must have access to the Passy-Muir® valve.

CONCLUSION AND IMPLICATIONS FOR THE PRACTICE

During the rehabilitation process, the benefits observed pointed to the resumption of breastfeeding by the 11 children in this study, safe breastfeeding, reduced secretion production, daily reductions in the number of airway aspirations, improved breathing pattern, vocalizations (babbling and crying), improving the child's sleep quality, readjusting swallowing and sucking, and introducing new foods. The responses to the use of the Passy-Muir® valve were beneficial and satisfactory and promoted a significant change in quality of life, in the daily activities of the children and of their families.

In the care practice for children using the Passy-Muir® valve, daily monitoring by a multidisciplinary team is essential for the mothers to overcome fears and anxiety about resuming breastfeeding of tracheostomized children.

New research studies are needed to address the weaning and relocation of tracheostomized children, solidifying knowledge in this area of action, since there is a limited number of studies that correlate such themes in the literature. Therefore, the study is relevant for the scientific community and for society in general, for professionals and future health professionals, directly or indirectly related to maternal and child health.

AUTHOR’S CONTRIBUTIONS


ASSOCIATE EDITOR

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