

## THE FAMILY'S EXPERIENCE OF CHILDREN AND ADOLESCENTS WITH GASTROINTESTINAL STOMAS

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### ABSTRACT

Caring for a child with stoma causes impacts on the family and generates great demand for permanent and specific care. This study aimed to understand the experience of families of children and adolescents who have gastrointestinal stomas. It is a qualitative study, which used the Symbolic Interactionism as a theoretical reference and narrative analysis as a method, in order to complain the experience of the family. The data analysis suggests that families go through a dynamic process before indicating the need of the stoma. The acceptance of the condition that in the son it is progressive and, even in before the difficulties, family members suggest optimism and aim this son reintegration into society, preferably without the device. The results of this study allow one to deepen the knowledge about the family's experience in this context, and this allows to improve the health care, advancing in matters of nursing care. In this context, the study highlights the need of support from a structured network for the family to monitor, mentor and solve doubts of the placement process and care to the stoma.

**Keywords:** Surgical Stomas, Gastrostomy, Family, Child, Adolescent, Family Nursing.

### INTRODUCTION

When a child or adolescent has a chronic condition, each member of the family learns to live with the disease and adapts to the new situation in an attempt to rebalance the family dynamics<sup>(1-4)</sup>.

Ostomy is a word of Greek origin which means opening or mouth of a hollow organ, made by means of surgical procedure, in which the organ passes to have contact with the skin surface to allow the removal of secretions, feces and urine; introduction of drugs or suggests of diets. The achievement of a stoma, in addition to characterize a chronic condition, affects the body integrity, functional capacity, social relationships and quality of life, generating great impact in their daily lives and in their families<sup>(1-5)</sup>. In this way, the family, before the process of adaptation, often needs to rethink its structure and organizational form as a group, because the care for the child/adolescent stomized requires special attention and sensitivity of the people in their surroundings<sup>(6,7)</sup>.

In this context, to cope and adapt to care with the stoma depends on the understanding and learning of the family to live a different reality than desired. Thus, this study aimed to understand the experience of families of children and adolescents with gastrointestinal stomas, aiming to understand the changes that this condition causes within the family,

recognizing the coping mechanisms and identify the support networks for the care with the child.

### METHODS

This is an exploratory and descriptive study of qualitative approach, which enabled to understand the meanings of the experience of families of children and adolescents with gastrointestinal stomas, under the supervision of the mother.

To guide this study, it was used as theoretical reference the Symbolic Interactionism, which allows to understand actions and behaviors by means of interactions and meanings<sup>(8)</sup>.

The interactionist perspective allows to understand the human being in his relations with society, himself and the other. In addition, the interaction and symbolic communication established by the same allow the apprehension of meanings, feelings, emotions, behaviors and expectations before the experienced situation. Thus, in the Symbolic Interactionism the human being is understood as an individual who passes through continuous interactions, being an active person who has freedom of choice<sup>(8)</sup>.

The Narrative Analysis was used as a method, because it describes or explains the verbal language, knowledge of the lived experience, according to the perception of one's own person<sup>(9)</sup>.

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All the precepts of Resolution N 466/12<sup>(10)</sup>, which regulates the development of researches involving human beings were respected. This research was approved in this institution's Ethics Committee under opinion N 53018.

The study was carried out in an outpatient service of health of a city in the countryside of the State of São Paulo, which attends patients with gastrointestinal stoma, including children and adolescents. Participated in this study families of children or adolescents with gastrointestinal stoma who met the following inclusion criteria: being from 0 to 18 years old (ECA, 1990)<sup>(11)</sup>; having intestinal ostomy, independent of time; make outpatient follow up in this service; reside in the city or in the microregion of care.

The data collection was carried out in 2013. The health service has provided a list containing families of stomized children under care. In principle, the first contact was made in their own health service, after consultation. When the family did not attend the consultation, contact was made via phone, for subsequent scheduling visits. In spite of all relatives present on the day of the interview were invited to participate, mothers were the ones who contributed with their narratives, because they are the main caregivers of children/adolescents.

Initially, we selected all the families who were active in the register service, totaling 21. There were excluded 5: a child who had done reversal of the gastrostomy almost ten years ago; two families who do not reside more in the region and two others who did not want to participate. Of the 16 participants, 6 were children with intestinal stomas and 10 with gastrostomy. During the first contact (in person or by telephone), there was explained that the meeting for the interview would be with the family; nevertheless, 11 interviews were as participants only the mother, who is seen as the main caregiver and responsible for the child. In other interviews, we also share some parents, grandparents and aunts of the children. The age ranged from 7 months old to 17 years old, and the time of use of the stomy ranged from 7 months to 14 years. All had the achievement of the stoma still in their infancy.

The research instruments used were the open interview, to better understand the family structure and its support networks. With the guiding question: "Tell me since the beginning how was recognizing that it would be necessary to perform the ostomy, and how it has been for you to take care of the ostomy of your son?", the interviews were conducted in the household, after signing the Informed Consent Form and the

testimonies were audio-recorded.

After the interviews were fully transcribed and analyzed their narratives, the statements were cut out and grouped into major themes that corresponded to the family's experience in the situation of children/adolescents with ostomy. Then, a new reading of cutouts of narratives were seized the points in common, and thus emerged six categories: 1. Impact of unexpected illness; 2. Acceptance of the stoma; 3. Changes in family life; 4. Helplessness in the course of the walk; 5. Benefits of the stoma; 6. Search for social integration.

The statements were identified with the letter M for the mothers and the numbers corresponding to the chronological order of the interview (eg.: M1 corresponds to the first mother interviewed).

## RESULTS

In this article we evidenced that even in the face of all challenges and obstacles, the family faces the situation to offer a better quality of life to the son. The categories described below report the everyday family life in coping with the chronic condition.

### 1. Impact of unexpected illness

The surprise of a disease causes suffering and shakes the emotional, spiritual, physical and financial spheres of the family, which needs time to assimilate what is happening with the child. In both intestinal stomas as in the stomach, the procedure is only performed in critical situations of child health, with therapeutic purpose. Whether chronic or acute, in both cases, before making the stoma, the family is faced with the disease situation of the child. The diagnosis and the communication of the need for a physical intervention mark the family in a negative way, which intensifies the fear and anguish due to the risk of death or sequel.

"In the beginning was difficult, because we knew nothing. The time that I saw I didn't believe that there was a person with so many problems. We suffered a lot, but then you will learn and get used. He was born with cleft lip, cleft palate, spina bifida, without the esophagus and imperforated anus. Did the surgery of the lip and reconstruction of the palate. After made the surgery of the esophagus, and now will make the intestine and will perforate the anus." (M1)

The path followed by the family is obscure and vague, because it does not know the procedures performed and the need to repeat it. In this context, the

prolonged hospitalizations are very frequent. In children with gastrostomy, several hospitalizations occur before the completion of the stoma, in the great majority of times because of respiratory tract resulting from aspiration dysplasia. Already with children with intestinal stomas, occur previous admissions, by prematurity or serious infections, and after the creation of the stoma, in attempts to reverse. The family lives long periods within the hospital and the child suffers with the various invasive procedures.

The constant episodes of hospitalization of the child mark the family in undesirable ways, and often believe that the hospital procedures, including the construction of the stoma, did not help the child to overcome the situation.

"Signaled the surgery and he opened the channel, then returned home, some days passed he closed again. When signaled to close the colostomy, arrived there, the channel was closed, then opened again and returned home. He made enough surgery to open the channel, however, he did 11 surgeries." (M3)

"It was just a second shock (make a gastrostomy). Within three months was diagnosed with West Syndrome, but fed orally. When she was 1 year and 3 months old, she began to have pneumonia and did not have what to heal. We went to investigate and discovered that she was vacuuming. It was there that was made in the stomach. We already knew all her weakness, all the difficulties, but we did not expect to happen." (M16)

## 2. Acceptance of Ostomy

The family goes through the process of denial from the need of surgical procedure; tries to alternatives to avoid an 'aggressive' surgery, because it believes that make the stoma implies in compromising the development of the child away even more from the 'patterns' of healthy childhood, since children eat by mouth and are evacuated through the anus.

Furthermore, the family is concerned with the prejudice that will face when using such technology. The labels placed by society and by their own family members extensive torment the experience of this in accepting the procedure.

In this context, the acceptance of the need of the gastrostomy is only complete when the family believes that the device is placed to save the life of her child or to improve its health conditions, but is not an easy process. The confection of the stoma, in most cases, is performed when the child's situation is at the limit, with signs of severe malnutrition, for example, and the family has almost no option of choice.

"Because I didn't accept, I thought that my son had to eat. And also because I had never seen it in my life. It was something he never imagined that existed probe in my life." (M9)

"In the beginning it was difficult, because my sisters even did not want to accept because they spoke that he was okay, that he would eat by mouth. They said: 'take it hence', 'no'." (M8)

"For he (the father of the child) was very difficult, because he didn't have the courage to look. You know, he didn't have the courage to look at her gut it out." (M12)

## 3. Changes in family life

Having a child with any level of dependence generates changes in the family context and requires learning and adaptation to the care in the management of technological device. The stoma tract requires specific care with hygiene, with the skin, with the power to be infused with the own infusion. Despite not being a difficult implementation, the lack creates uncertainty on who cares. The changes are continuous, because as the child grows, it requires new adaptations, in addition to financial matters and relating to professional life, because often the mother leaves the job to live in function of the child care.

"Is that direct exchange. Also at night. During the day everything well because I am already agreed, but during the night has to put into service from hour to hour. During the night I've noticed that it dissipates less, then as night it dissipates less I put to service an hour to two hours, more that it does, because I do not know if this evacuated or not. The night is tiring. During the day will still, but at night it is tiring, because if we do not exchange gets worse." (M10)

In the gastrostomies, when the family goes home, the sudden departure of the device is the greatest cause of stress and fear. All families have gone through at least one episode in which the abdominal probe comes out of the hole, and after going through this a few times, realize that with calm can cope with this setback.

"There is a 'beast has seven heads'. To start I thought, I had never seen. Everyone ignores much, I had never seen such a situation. I knew, too far away, who had people who wore pouches, but as everyone thinks that it is only in the case of cancer. I mean, I never heard of a child. Then, I saw that there is all this. Of course that is not what I wanted, is not what i want yet, but gives to go leading." (M14)

It realizes in the statements that the family, in the first moment, is unprepared to deal with the possible complications of gastrostomy. None of them mentions

a training or a guideline on how to deal with a complication at home and where to take the child if there is a problem with the stoma. Despite this, the daily experience with the child or adolescent with ostomy or gastrostomy leverages the family to provide the necessary care, performing movements that seek to improve the quality of life of the child. The experience of daily care reveals to the family that the technology used is not an instrument which harms the walk of the family nucleus, but a facilitator for the quality of life of the child.

“So, I exchanged (colostomy bag) every day at the time before bath. When I had more than one bath on the day, so I left. Had a few times that I could leave from one day to the other, but when I left the night, I do not know if began scratching or upset, he even snatched at dawn.” (M15)

#### 4. Helplessness during the walk

Caring for a child with a stoma causes strangeness to the family that sees inserted in an unknown situation. In this context, the family makes changes, in order to seek a support network to experience the new situation. However, the family feels lack of support and guidance of qualified persons. In addition, reveals that the relationship established with these people tend to be confrontational, with vague communication, i.e., little understood.

In the case of families in which the child has intestinal ostomy, besides the helplessness, experiencing situations of prejudice when the child begins to attend school. The lack of preparation and knowledge of professionals who deal with children in daycare centers and schools is striking in this context, and is cited in the narratives as prejudice.

The family feels insecure in putting the stomized son in school, because they are afraid that the professionals are not prepared to receive and meet the needs of their children while they are there. In addition, they are afraid of the reaction of colleagues, which often influence on the decision of the parents not to enroll their children.

“Ah, I think that most of the times is laziness, others have loathe to care. In fact it is prejudice, I think it has a lot of prejudice. The way the director spoke. She can be a great person, but deep inside I feel that has prejudice. Because he couldn't stay in the small room together with the boys because sometimes disappeared. I took the bags all cut, leaving everything separately. The backpack was going all prepared. I sent a glove box closed for there. All cut, but even so the other day she cared for me, and ‘ah, because the bag of your son is leaking’; ‘ah because it

does not good he stay in small room’; ‘ah, because it is with bad smell in the small room’.” (M3)

“So I have to go behind the bags straight and nobody is going with me, nobody takes. The woman who took care of him was only for care, only to take it at school so I could work, because even care (pause) I do everything.” (M4).

#### 5. Benefits of Ostomy

After acceptance and adaptation, the family recognizes the benefits with the improvement and recovery of health. With the stoma means to lessen the risk of falling ill. The child has a visible improvement of clinical condition and in intestinal stomas family experiences the possibility to revert this situation in the future, which brings hope. It is a phase in which there is a joy to see the welfare of the child.

In addition to observing the improvement of the child after the ostomy, the family perceives that with the completion of this procedure, the child does not need frequent hospitalizations. This fact reassures the family unit and generates hope for a better future for the child.

“Ate everything that was soaked. Took milk, he ate, but then began to breathe with difficulty, because going to the lung. He was hospitalized with pneumonia, but then (gastrostomy) went no more.” (M5).

“It was good, thanks God. She gained enough weight. I think it became easier. In addition to not choke too, nor have pneumonia, these things.” (M11).

#### 6. Search for social integration

The family wants to reinstate the son to the routines of the house and, despite the recognition of the benefits, see the stoma as limiting the social life. Therefore, creates expectations around the supply for gastrostomized children. The family want the child to continue feeding orally, because the ‘not feel the taste of the food’ is something that afflicts. With this, seeks to bring to life the child a routine called ‘normal’ and, therefore, reinstate it to social life.

“Sometimes I give a little bit of yogurt, juice or water. In the mouth I give a little, not much, just to feel the taste.” (M11)

In intestinal stomas expectation by reversal of the stoma strengthens the hope of being able to take to school as other children, without it being necessary to conduct trade nor sanitization, and thereby protect the son of prejudices. The reversal brings hope; however, despite this desire, the fear of surgery there.

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"I took the pediatrician and he said it was already released. I am afraid, but I hope that she put into and that it is well. I'm afraid she do the surgery and I'm afraid after she quit from thence. I am afraid because (pause-crying) I think that if anything happens with it happens to me too. Because the doctors say that has risk, all surgery is risky. (Crying)" (M12).

## DISCUSSION

The results of this study allowed to understand that the family of the child and adolescent with stoma tract passes through a process of gradual acceptance of the condition of the child. Symbolic Interactionism<sup>(8)</sup> permitted to visualize the experience of these families by means of the actions they have performed, directed by the meanings of interactions established in this ongoing process.

Having a child in a situation of chronicity produces adverse psychological, social and changes the family functioning, because in addition to the impact, changes and constants readaptations are required. The overrun comes with experiences and their interpretations, as well as the recognition of the new situation, a dynamic process that guides the actions of individuals<sup>(12)</sup>.

The experience of having a son in chronic condition is lived with great fear of losing him. The families of this study express that the stoma is done only when the situation is at the limit, and symbolizes for them the dependence of the son. With the experience of specific care to this, the situation will be ressignified until the parents realize that it was a necessary procedure for the welfare of the child. The time between denial and acceptance varies with the type of ostomy and with the urgency of the procedure. The situation for the intestinal stomas is usually described with the clinical critic of the child, and many times with risk of death<sup>(13)</sup>.

After the creation of the stoma, the family sees the need to learn and cope with the new reality<sup>(14)</sup>. Research conducted with families of newborns with congenital anomaly revealed that the family is insecure with the lack of practice to perform actions related to child care, causing fear and anxiety<sup>(15)</sup>.

The maternal experience with the son ostomized highlights the need and the lack of emotional support

to the conviviality and child care, which is limited to the nuclear family. The customer service needs is centered on the mother, often distancing the father of care<sup>(16)</sup>. In this context, the family has a role in the development of this child, because the way is seen the stoma can interfere directly in the definition of self-esteem and the child or adolescent, since the acceptance of the ostomy is related to positive responses from their parents.

Prejudice and the difficulties arising from the surgical procedure, after going through the process of acceptance and adaptation, have the return of the benefits of the stoma, which serves as a consolation. The experiences after completion of the procedure make the family give new meanings to the stoma, because evaluating the benefits that the child has with the use of technology. In the process of acceptance and adaptation, difficulties and prejudices still occur, but they are relative by gains in quality of life; and thus the family makes a new interpretation of experiences.

Study on the topic reveals that 91% of the participants' families reported high satisfaction and recognize the considerable improvement of the child after the beginning of the use of gastrostomy, especially in regard to nutrition, the reduction of respiratory infections and the reduction in the time of power<sup>(17)</sup>.

Among the results of this study, it is observed that the family, the mother's voice, feels alone, because it does not consider sufficient the support received from health professionals. The few interlocations are usually done during the hospital stay, after the completion of the stoma, when they receive some guidelines on how to make and administer the diets (gastrostomies), or on placement and exchange of device manifold and some skin care (in intestinal stomas), but without systematic monitoring, which makes the family often finishes developing ways of dealing with the ostomy, without specific guidance.

The new daily routines and care also modify the leisure moments of family that isolates of socializing with other people and remains too long inside the house. Experience the chronic condition is an intense suffering, with changes in everyday family, because the family is overloaded due to the availability required for activities related to child care<sup>(18)</sup>.

The health condition of the child/adolescent, whether permanent or temporary, just interfering in the whole family dynamics, once the child with ostomy has changes in their day-to-day due to physiological changes, psychological and social, which can generate

on familiar feelings of irritability, frustration, anxiety and guilt. In this way, it is important that health professionals also understand the needs of the families of these children, broadening the spaces of reception and interaction, receiving the doubts and allowing the manifestation of anxieties. The search of the family for information appropriate for the care to child and adolescent is due to the need to develop actions that promote the integration of the son in social life, without stigma and prejudice<sup>(18)</sup>.

## FINAL CONSIDERATIONS

The results of this study indicate that experiencing the ostomy is an experience that, initially, scares, causes fear and undermines the family. It is a very difficult phase, since in addition to the impact of a finding that points to chronic condition, it is a period full of hospitalizations, tests, treatments and procedures that the family did not understand.

The experiences expressed by the family reveal how the path travelled by her to the understanding of the benefits of technology is vague and obscure. The walk is still hampered by the lack of support and guidance for health professionals.

The results indicate that the family experiences a dynamic process, because having a child with intestinal stoma or gastrostomy generates the need for changes in family routine and in the bond.

As a way to reestablish the family dynamics, ways of coping and adaptive difficulties, but this feels lack of professional follow up and interactions for exchange of experiences. The family, throughout the process of experiencing the insertion of technology in the life of the child and/or adolescent demonstrates the difficulties, pointing to the need of support to cope with the problems that arise.

The understanding of the peculiarities of the families in this condition and professional approach can mitigate the suffering and the non-acceptance of the stomy. The knowledge of the experience of the family with stomy may offer subsidies for health professionals to promote changes in the paradigm of care, reflecting on the quality of health services provided to this child/adolescent.

Thus, we point out the need for research involving health professionals regarding working with families of children with stomas and that address the child's reintegration into society, as well as the difficulties and/or support received by the family forward to chronicity are also required.

This study contributes to add to the literature, the experience of the family, under the gaze of the mother mainly, depicting in detail the findings of the national studies and going beyond the technical concepts, such as surgical methods, effects and complications, strongly covered in international studies.

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## EXPERIÊNCIA DA FAMÍLIA DE CRIANÇAS E ADOLESCENTES COM ESTOMAS GASTROINTESTINAIS

### RESUMO

Cuidar de uma criança estomizada provoca impactos na família e gera grande demanda de cuidados permanentes e específicos.. Esse estudo teve como objetivo compreender a experiência da família de crianças e adolescentes que têm estomias gastrointestinais. Trata-se de estudo qualitativo, em que se utilizou o Interacionismo Simbólico como referencial teórico e a análise de narrativa como método, a fim de apreender a experiência da família. A análise dos dados aponta que as famílias passam por processo dinâmico frente a indicação da necessidade da realização do estoma. A aceitação da condição que no filho é progressiva e, mesmo diante das dificuldades, os familiares apontam otimismo e almejam reinserção deste filho na sociedade, preferencialmente sem dispositivo. Os resultados deste estudo possibilitam aprofundar o conhecimento acerca da experiência da família neste contexto, e isso permite melhorar o atendimento de saúde, avançando nas questões da assistência de enfermagem. Neste contexto, o estudo destaca a necessidade de apoio de uma rede estruturada para a família para acompanhar, orientar e sanar dúvidas existentes do processo de colocação e cuidado ao estoma.

**Palavras-chave:** Estomas cirúrgicos. Gastrostomia. Família. Criança. Adolescente. Enfermagem familiar.

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## EXPERIENCIA DE LA FAMILIA DE NIÑOS Y ADOLESCENTES CON ESTOMAS GASTROINTESTINALES

### RESUMEN

El objetivo fue comprender los significados que profesionales de salud atribuyen a las experiencias de ser paciente o Cuidar a un niño ostomizado provoca impactos en la familia y genera gran demanda de cuidados permanentes y específicos. Este estudio tuvo como objetivo comprender la experiencia de la familia de niños y adolescentes que tienen ostomías

gastrointestinales. Se trata de estudio cualitativo, en que se utilizó el Interaccionismo Simbólico como referencial teórico y análisis narrativo como método, a fin de comprender la experiencia de la familia. El análisis de los datos señala que las familias pasan por proceso dinámico frente la indicación de la necesidad de la realización del estoma. La aceptación de la condición que en el hijo es progresiva, e incluso delante de las dificultades, los familiares demuestran optimismo y anhelan reinserción de este hijo en la sociedad, preferencialmente sin dispositivo. Los resultados de este estudio permiten profundizar el conocimiento acerca de la experiencia de la familia en este contexto, y esto posibilita mejorar la atención a la salud, avanzando en las cuestiones de la asistencia de enfermería. En este contexto, el estudio destaca la necesidad de apoyo de una red estructurada para la familia para acompañar, orientar y sacar dudas existentes del proceso de colocación y cuidado al estoma.

**Palabras clave:** Estomas quirúrgicos. Gastrostomía. Familia. Niño. Adolescente. Enfermería Familiar.

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