Journal of Nursing
Revista de Enfermagem
UFPE On Line
ISSN: 1981-8963

ORIGINAL ARTICLE

# FAMILY CARE PROCESS WITH COLOSTOMY CHILDREN IN THE HOME ENVIRONMENT

# PROCESSO DE CUIDAR DA FAMÍLIA COM CRIANÇAS COLOSTOMIZADAS NO ÂMBITO DOMICILIAR

## PROCESO DE CUIDADO DE LA FAMILIA CON NIÑOS CON COLOSTOMÍA EN EL ÁMBITO DOMICILIARIO

*Raquel Machado Leite[1], Emilly Karoline Freire Oliveira[2], Viviane Mamede Vasconcelos[3], Denise Maia Alves da Silva[4], Mariana Cavalcante Martins[5]*

**ABSTRACT**

***Objective:*** to describe the family care process with colostomy children in the home environment. ***Method:*** this is a descriptive study with a qualitative approach, which involved 15 families of colostomy children from birth to 12 years old, developed into a children's public hospital in Fortaleza/CE and children domiciles. The analysis took place through thematic categorization. ***Results:*** after data analysis, four empiric categories had emerged << Knowledge about the colostomy >>; << The new reality of family >>; << Family daily moments with the child >>; and << Familiar concept about colostomy prevention >>. ***Conclusion:*** families should be included in care, underscoring the concern about the mission assigned to them in the home care process of a colostomized child, considering that its practices, theories and knowledge provide well-being and health for their members. ***Descriptors***: Colostomy; Family; Child.

**RESUMO**

***Objetivo:*** descrever o processo de cuidar da família com crianças colostomizadas no âmbito domiciliar. ***Método:*** estudo descritivo, com abordagem qualitativa, no qual participaram 15 familias de crianças colostomizadas de zero a 12 anos, desenvolvido em um hospital público infantil em Fortaleza/CE e domicílios das crianças. A análise deu-se por meio de categorização temática. ***Resultados:*** após análise dos dados, emergiram quatro categorias empíricas: << Conhecimento sobre a colostomia >>; << A nova realidade da família >>; << Momentos diários da família com a criança >>; e << Conceito do familiar sobre prevenções da colostomia >>. ***Conclusão:*** as famílias devem ser inseridas no cuidado, ressaltando a apreensão com a missão que lhes é atribuída no processo de cuidar domiciliar da criança colostomizada, levando-se em consideração que as suas práticas, teorias e conhecimentos proporcionam bem-estar e saúde para seus membros. ***Descritores:*** Colostomia; Família; Criança.

**RESUMEN**

***Objetivo:*** describir el proceso de cuidado de la familia con los niños con colostomía en el ámbito domiciliario. ***Metodo:*** estudio descriptivo con un enfoque cualitativo, en el cual participaron 15 familias de niños con colostomía desde el nacimiento hasta los 12 años, en hospital público infantil en Fortaleza/CE y domicilios de los niños. El análisis se llevó a cabo a través de categorización temática. ***Resultados:*** tras el análisis de los datos surgieron cuatro categorías empíricas << Conocimiento sobre la colostomía >>, << La nueva realidad de la familia >>, << Momentos cotidianos de la familia con el niño >> y << Concepto familiar acerca de prevenciones de la colostomía >>. ***Conclusión:*** las familias deben ser incluidas en el cuidado, resaltando la preocupación acerca de la misión que se les atribuye en el proceso de cuidados domiciliarios del niño con colostomía, teniendo en cuenta que sus prácticas, teorías y conocimientos proporcionan bienestar y salud de sus miembros. ***Descriptores:*** Colostomía; Familia; Niños.

[1]Nurse (egress), Integrated Faculty of Grande Fortaleza (FGF). Fortaleza (CE), Brazil. E-mail: mais.raquel@hotmail.com; [2]Nurse, Specialist in neonatology, Family Health Strategy of Itapipoca. Fortaleza (CE), Brazil. E-mail: e.karoline@hotmail.com; [3]Nurse, Ph.D. Professor, Nursing Program Coordinator, Integrated Faculty of Grande Fortaleza (FGF). Fortaleza (CE), Brazil. E-mail: vivienfermagem@hotmail.com ;[4]Nurse. Master's Degree in Public Health. A server of the City Hall of Fortaleza - Dr. José Frota Institute (IJF). Fortaleza (CE), Brazil. E-mail: denisefmail@gmail.com; [5]Nurse, Ph.D. Professor, Nursing Department, Federal University of Ceará (UFC). Fortaleza (CE), Brazil. E-mail: marianaenfermagem@hotmail.com

## INTRODUCTION

The ostomy is a term of Greek origin meaning mouth or opening, and a surgical, provisional or definitive therapeutic measure, according to the conditions and underlying pathology of the patient. It consists of opening an anatomically appropriate hole in the abdominal region, where there will be an artificial communication between two organs or between a viscus and the abdominal wall permitting adjustment of a collecting bag adhering to the abdomen to protect the skin and collect the waste with minimal discomfort to the patient.[1]

Some people develop changes in bowel or bladder that impair the elimination of feces or urine that leads to the need to carry out an ostomy for artificial exit (surgical) of these effluents. The factors that most contribute to an ostomy confection are: neoplasias (rectum cervical cancer), Crohn's disease, gastrointestinal tract obstruction, fecal diversion when there is terminal colon obstruction caused by imperforate anus and weapon fire or gun injuries.[2]

Ministry of Health data shows that new cases numbers of rectum cancer in Brazil in 2010 was 28,110, 13,310 for men and 14,800 for women, values corresponding to a risk of 13 new cases per 100,000 men and 15 to 100,000 women.[3] Facing the increasing ostomy number, the nurse needs to know care strategies, such as guidance about the adaptation process and use of the collection bag; ostomy care and proper nutrition, as well as referral and encouragement for the participation of a support group that can help ostomates to live with this new situation, which becomes part of the whole that composes the living process.[4]

The most frequent complications that can occur with ostomy are: a hernia (bulging around the ostomy), prolapse (part bowel output by stoma), stenosis (narrowing of the ostomy) and retraction (there is a sink in the ostomy within the skin).[5]

Given the complications with the ostomy, it is essential to have an appropriate and quality care with ostomy children aiming to prevent them or to promote the treatment properly and that meets the needs presented during the treatment and follow-up.

Therefore, families should be effectively guided to act directly in the process of care, new, in the family context. Thus, nursing should conduct health education appropriately, individualized and plausible, so that family care would be improved day by day.

Nursing care also plays an important role in the lives of mothers with colostomy children, as they receive guidance and speciallized assistance, clarify doubts of how to live socially with others, with or without ostomy, and they are also guided about ostomates core or programs, as these groups facilitate the rehabilitation of the ostomate.

By the above, this study aims to describe the family care process with colostomy children in the home environment.

## METHOD

Descriptive study, with a qualitative approach,[6] conducted in two study places. The first place was a children's public hospital in the city of Fortaleza/CE, a reference in childcare. The choice of this hospital was to identify families with children undergoing the colostomy, discharged in 2010. The second research place was the domicile of the colosyomy child, identified in the hospital mentioned above to conduct interviews through visits.

15 families were selected, by lot, among the families identified by records analysis, which care for colostomy children from birth to twelve years old, residents in the city of Fortaleza - CE, using the following criteria: family of children who underwent colostomy in the cited hospital, family of colostomy children who were discharged from the hospital in study or those that are accompanied by the HCP (Home Care Program) and family with more than or equal to 18 years old.

After approval by the Research Ethics Committee, the identification of the study population was started and then, home visits to family caregivers of colostomy children, from March to April 2011.

The data production was conducted through semi-structured interviews, with a form consisting of two stages, namely: socio-demographic data and guiding questions, formulated as: Do you know why this child and/or your child has a colostomy? How is your family before the new reality? Which is the best moment of your day/which is the worst moment of your day? What do you think could be done to this situation (colostomy) did not happen? And finally, do you want to say something?

The content analysis technique was used, which consisted of three stages: pre-analysis, material exploration, treatment and interpretation of results, based on the

theoretical framework, which is enhanced by results.[7]

The names of the interviewed participants were kept confidential and for the protection of identity we chose fictitious names identified with the letter F in the order of interviews (F1, F2,..., F15). The research was submitted to the assessment of the Ethics Committee of the Children's Hospital Albert Sabin - HIAS and approved under Opinion Nº 009/2011.

It is noteworthy that the visits were scheduled according to the availability of the participants and recorded on magnetic media through authorization, previously requested through a Consent Form, ensuring the confidentiality and anonymity of the informant and authorizing the participation in the research and publication of results in scientific circles.

## RESULTS AND DISCUSSION

The thematic analysis guided the construction of four empirical categories: << Knowledge about the colostomy >>; << The new reality of family >>; << Family daily moments with the child >>; and << Familiar concept about colostomy prevention >>.

In the category << Knowledge about the colostomy >>, when questioning the family about which was the reason for this procedure in children, stressed that would be a malformation problem during pregnancy, which consequently required the realization of colostomy, as the following reports:

> *[...] It was due to a problem of malformation during pregnancy. (F1)*
>
> *[...] During her formation, this problem happened. (F13)*
>
> *Due to a problem that happened during his forming period [...]. (F15)*

It is known that during pregnancy, important phase for the fetus and the mother, many changes can happen, including malformations, affecting different parts of the body, significantly impacting the future of this child.

The organic condition from a surgical intervention that aims to recover the communication between viscera or organ and the external environment, to repair the damage caused by some disease compensating its functioning, is called ostomy. As the affected area will be corresponding to its name, for example, ileostomy, colostomy, nephrostomy, tracheostomy and ureterostomy.[8]

The colostomy person has an artificial opening in the abdominal wall, performed by a surgical procedure to open a new passage for fecal or urinary transit, as affected segment. The causes for this need are numerous, the most common are: inflammatory diseases, congenital diseases, tumors, bowel and bladder cancer.[9]

Some families, during the interview, were more specific reporting the child's need to be colostomized, justifying an intestinal obstruction.

> *Anomaly was resulting in bowel obstruction. (F5)*
>
> *Imperforate anus. (F8)*
>
> *She was born with the anus closed (imperforate) [...]. (F12, 14)*

It is noteworthy that the cause of colostomy may also be the result of an intestinal obstruction or imperforate anus, where the diversion of the fecal stream may be temporary or permanent. According to the Brazilian Medical Association and Federal Council of Medicine[9], the intestinal obstruction indicative begins with the absence of meconium elimination from the first 24 hours of the newborn whose main causes are anorectal malformations, Hirschsprung disease, intestinal atresia, meconium ileus, intestinal rotation vices and meconium plug syndrome.

It was also noticeable that some families did not know the reason for the colostomy:

> *I have no idea. (F2, 3, 6, 7, 9 and 11)*

Colon and rectal cancer because of its incidence, has become a public health problem in Brazil, since there is the commitment of the normal transit of eliminations, causing most patients have to undergo surgery for realization of colostomy.[10,11]

It is emphasized that this lack of knowledge can cause even more distress to the family because when it is possible to know what caused such damage, it becomes easier to understand and accept.

Regarding the category << The new reality of family >>, it is clear that emotional distress is a situation that affects them, probably due to emotional trauma generated by this type of procedure, accentuated when there is physical and psychological prejudice.

> *We are very surprised and emotionally affected. (F1)*
>
> *Complicated, because my husband abandoned us and now I take care our son alone. (F4)*
>
> *Very sad. (F11)*
>
> *Changed the every day [...]. (F12)*

The disease advent causes imbalance and emotional distress for the family because it is

closely linked to the fact, however, there is an adaptation process in which the family sometimes unconsciously, is encouraged to be able to act and collaborate with the assistance their sick relative.[12]

Each family has its characteristics and is constituted to be a caregiver unit, so the family participation in the care process is so important, since the bonds of trust, respect, love and affection are established between members, and there is, therefore, the strengthening of trust and confidence to be able to assist in the care of their relative.[13]

The family is the first social organization with which the human being comes into contact with and establishes learning ties, since the family is directly related to the care, guide and strengthen process of its members, conducting and participating in this process.[14]

The changes that happen in the life of colostomy related to body image, to self-esteem and self-image, reflect and influence the daily activities of the family because it is essential that they become-trained to carry out the care inherent to child colostomy.[15]

When a family prepares for the birth of a child, a range of feelings is aroused, among them the expectation of healthy growth and development, future and hope. However, when faced with the fact that the child was not born completely perfect, feelings of anxiety, frustration and anger begin to involve the family setting. Given the new reality, there is the need to balance these feelings so that childcare can be full and satisfying:

> *Learning to live with her to make her more secure and confident. (F2)*
>
> *Naturally accept, despite the difficulties, so we can take care of her in the best possible way. (F5)*
>
> *Anxious to learn to deal with him and know when he will return to poop normally. (F6)*
>
> *Very difficult because at the beginning we did not know to handle the situation, but now we take care of him well. (F7)*
>
> *At first, it was an impact, but then, together, we adapt to everyday life. (F8 and 9)*
>
> *Although it is a sad situation, we thank for her life. (F13)*

Soon after colostomy surgery, families may express sadness or discontent due to doubts and uncertainties that arise because of the lack of information, so advise the family about all stages of the process to which the child will be subjected is one of most significant factors to support happen.[15]

On the other hand, this special and difficult moment in their lives ends connecting, even more, some families, since each member seeks to rely on each other, according to reports:

> *More united, all have become concerned more with each other. (F3)*
>
> *Calm [...]. (F10)*
>
> *[...] my family has not changed [...]. (F14)*
>
> *The whole family helps [...]. (F15)*

The involvement of one or more family members allows to resolved and absorbed complications more softlly, which favors the family dynamics about to childcare.[16]

The family can solve different situations of health and disease since each family is unique; each plays their role in the disease situation because contributing to the recovery of their being.[17]

About the category << Family daily moments with the child >>, it was wondered: Which would be the best and the worst moment of the child? And in response, it was shown that the best time was founded on the happiness of the child and the fact they are alive.

> *When we realize that he is happy. (F1)*
>
> *When she is studying or playing with her friends. (F5)*
>
> *Knowing that she's alive and happy. (F2 and 14)*
>
> *The whole day is good. (F3, 4, 6 and 9)*
>
> *When we have no problems [...]. (F11)*

It was noticeable also that the child, even presenting an “imperfection” but that has progressed without many complications, the faciliting adaptation of the family to the situation and even the ability to turn an unpleasant fact more acceptable.

To promote the child's welfare, it is noteworthy that the family becomes to develop actions geared to meet the needs of their being, to collaborate for the care success of the colostomy child.[18]

As the following statements, it is clear that the existence of colostomy does not change the every day of the colostomy child, since they can and must normally live with the new reality facing society, regardless of the permanent or temporary situation.

> *When we realize that his development is equal to that of a normal child. (F8)*
>
> *To see that it is growing healthy. (F12 and 13)*

Families and colostomy children accept the new condition but for lack of choice because even faceing difficulties with the collection bag, food, clothing or social issues, the fact of being alive lessens the severity of reality,[18] however, in the report of the worst moment, it was noted that despite the difficulties

commonly experienced by colostomy due to the limitations to which they are subject, it is necessary to face the complications.

> *There is no worse moment, despite the faced difficulties; we always took the best advantage. (F7, 10, 12 and 15)*
>
> *Normal because his colostomy does not have problems [...], there is no worse moment. (F10)*
>
> *[...] Thank God, we have only good moments with him. (F15)*

It was evidenced by some families that the worst moment was in the period that, beyond the special care involved to colostomy, the colostomy were often affected by other diseases such as flu and infections.

> *When he is sick. (F1, 5, 8, 9 and 14)*

The colostomy procedure is potentially accompanied by complications caused mainly due to the poor adaptation of the skin to external devices or because of dermatitis around the stoma from prolonged contact with the skin or because of infectious processes due to poor hygiene or periostomal delay in emptying the bag.[19]

Continuing, it is known that the body image offers to the human sense of identity and is presented as an element of internal balance and the world; this means that we have a sense of what we are compared to others, distinct.[19]

It was noticeable, in the next lines that complications related to the use of the collection bag contribute to being the worst moment of the day.

> *When the bag does not stick is terrible. (F4)*
>
> *When the bag does not stick and leaks dirtying him. (F11)*

The choice of the bag should be by the particular characteristics of each user, such as the condition of the skin and the stoma size, age, type and amount of drainage.[20]

In addition to attention that a colostomy needs, before their physiological change, we must also consider the need to take care of the colostomy bag; both in order to prevent complications with ostomy, and to avoid possible annoyances leak odor or feces.[20]

Some testimonials bring us a reality view, in which the embarrassment feeling becomes part of the family's daily lives, making them home prisoners.

> *[...] When we have to spend a lot of time away from home. (F3)*
>
> *When we go out, and everyone ask what he has. (F6)*

Because the colostomy has an altered body image, families often avoid public places and social life, due to feelings of fear and panic, reflecting the need to support social networks that act to reinstate this public to society.[21]

The social support networks work as an interaction way between people or groups through educational, religious, motivational activities, among others, which allow users to improve the social life and to feel encouraged working for the quality of life.[21]

The last category was << Familiar concept about colostomy prevention >>, in which families were asked if there was something they could have done preventively, so that the child did not need to have been colostomized and can show that they understood that a more effective pre natal as well as the non-use of medications during pregnancy could have given them a different future.

> *A more rigorous prenatal follow-up. (F2)*
>
> *I think if anything was diagnosed; it may have been a prenatal error. (F9)*
>
> *Having done all the pre-natal consultations, including the ultrasound. (F13)*
>
> *During my pregnancy, I took many medicines, and I think this may have contributed. (F14)*
>
> *Accompanied her pregnancy in a better way. (F11)*

It is worth emphasizing that only one family showed that nothing could have been done to prevent such a situation: *Nothing, it was a malformation problem and this only God can liberate (F8).*

The diagnosis of anorectal anomaly or anus imperforate is not performed during prenatal care, either it is possible to intervene in this situation because the diagnosis is primarily through a well done the physical examination in the delivery room. When the rear part of the anal canal does not recanalizes carries on imperforate anus.[22]

The fact that the family is guided, especially mothers, as other factors that may require the completion of the colostomy, it is essential so that they do not blame and/or do not try to find blame for this situation of their being because they provide subsidies to demystify this feeling. Thus, the suffering that these families spend is softened through belief in God as unique and absolute, able to take them all the sadness comforting and encouraging them to continue life with dignity.[23] The search for God console benefits many families since it is this faith that they hold the intention to strength to endure their vicissitudes.

For many people, faith works as a tool to alleviate the anguish, pain and/or feelings of frustration, since the search for divine help brings comfort and help to accept the problems because the individual feels

strengthened to face their daily struggle[24]. To that end, the families report:

> *I strongly believe in God, and I know if he wants this, it is because he knows my heart. (F1 and 3)*
>
> *God give providences in our lives [...]. (F5)*

Valuing family enables training skills inherent to the care process, since families are owners of the habits and customs of their loved, providing favorable subsidies for child care.[15] And at this moment, to corroborate with the family during this process, the nurse's figure emerges as one that facilitates the articulation, coordination and leads the whole process of support and advice needed to care for the colostomized child as part of contextual situation of the patient and the family.[12]

## CONCLUSION

It could be observed that the literature about pediatric ostomy is rather scarce; it reveals the need to expand the studies in the area.

Given the fact that the family is directly related to the care process, it causes health intitutions to assume their roles concerning the support to the colostomized child family, so they become capable and able to exercise activities that were not part of their routine, and properly guide them, so the colostomized child care can contribute to improving the quality of life of these.

In this analysis, it was noticeable that the changes that occur in the lives of these families significantly reflect in their daily lives, leading them to experience moments of anguish, loneliness, fear and anger. This, enter the families, highlighting the concern about the mission given to them in the home care process of the colostomized child, taking into account that their practices, theories and knowledge provide well-being and health for their members, it is also a key factor in this work.

Families must be recognized by the partner relationship they have with health professionals because of the importance that expresses to the survival of their being, dependent on special care.

It could be observed, during this study, that the performance of health professionals, especially nurses whose nature is being a health educator and wellness promoter, becomes primordial strategy for both adaptation of the colostomized child as to the suitability of the condition patient's family, and contribute to the adaptation of care related to colostomy, also relieves the anguish and brings comfort to the closest ones, thus becoming a main actor throughout the process involving the family and the colostomized child.

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Submission: 2015/09/05
Accepted: 2016/03/02
Publishing: 2016/04/01

**Corresponding Address**

Mariana Cavalcante Martins
Departamento de Enfermagem
Universidade Federal do Ceará
Rua Alexandre Baraúna, 1115
Bairro Rodolfo Teófilo
CEP 60430-160 – Fortaleza (CE), Brazil