



THE PREPARATION OF THE FAMILY MEMBER FOR THE CARE OF THE PERSON WITH OSTOMY

O PREPARO DO FAMILIAR PARA O CUIDADO À PESSOA COM ESTOMIA EL PREPARO DEL FAMILIAR PARA EL CUIDADO A LA PERSONA CON OSTOMÍA

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ABSTRACT

Objective: to know how happens the preparation of the family member for the care of the person with ostomy. **Method:** it is a descriptive study, of qualitative approach, with Thematic Analysis. Data collection was conducted by semi-structured interviews recorded, with five caregiver family members of people with ostomies, of a hospital from the Brazilian South, as approval of the Ethics Research Committee of Universidade Federal do Rio Grande do Sul, under Protocol nº 38/2007. **Results:** after the analysis two categories have emerged << “The caregiver faced with the need of stomization” >> and << “The preparation of the family member for the care of the person with ostomy”>>. **Conclusion:** It was possible to verify that the caregiver family member of the person with ostomy is unprepared for the care and without knowledge about the stomization process, but assumes care despite its own unpreparedness. So, it needs to be assisted by the nursing professional, in order to be qualified to carry out this care in a safe manner. **Descriptors:** Family; Ostomy; Nursing.

RESUMO

Objetivo: conhecer como se dá o preparo do familiar cuidador para o cuidado à pessoa com estomia. **Método:** estudo descritivo, de abordagem qualitativa, com Análise Temática. A coleta de dados foi realizada por entrevistas semiestruturadas gravadas, com cinco familiares cuidadores de pessoas com estomias, de um hospital do Sul do Brasil, conforme aprovação do Comitê de Ética em Pesquisa da Universidade Federal do Rio Grande do Sul, sob Protocolo nº 38/2007. **Resultados:** após a análise duas categorias emergiram << O cuidador frente à necessidade da estomização >> e << O preparo do familiar para o cuidado à pessoa com estomia >>. **Conclusão:** foi possível verificar que o familiar cuidador da pessoa com estomia é despreparado para o cuidado e sem conhecimentos acerca do processo de estomização, mas assume o cuidado, apesar de seu próprio despreparo. Assim, necessita ser auxiliado pelo enfermeiro, no sentido de ser instrumentalizado para desempenhar esse cuidado de forma segura. **Descritores:** Família; Estomia; Enfermagem.

RESUMEN

Objetivo: conocer como ocurre el preparo del familiar cuidador para el cuidado a la persona con ostomía. **Métodos:** estudio descriptivo, de enfoque cualitativo, con el Análisis Temático. La recolección de datos fue realizada por entrevistas semiestructuradas grabadas, con cinco familiares cuidadores de personas con ostomía, de un hospital del Sur del Brasil, según lo aprobado por el Comité de Ética de la Universidad Federal de Rio Grande do Sul, de acuerdo con Protocolo nº 38/2007. **Resultados:** tras el análisis dos categorías emergieron << El cuidador frente a la necesidad de proceso de ostomización, >> y << El preparo del familiar para el cuidado a la persona con ostomía>>. **Conclusión:** se pudo verificar que el familiar cuidador de la persona con ostomía es despreparado para el cuidado y sin conocimientos del proceso de ostomización, pero cuida a pesar de su falta de preparación. Por lo tanto, necesita ser ayudado por el enfermero, para estar en condiciones de llevar a cabo ese cuidado de forma segura. **Descriptores:** Familia; Ostomía; Enfermería.

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INTRODUCTION

The execution of ostomy, artificial opening surgically performed in the abdomen, causes numerous disorders to the ostomized person, having a limiting, mutilating and transforming outcome to the body and its functioning.¹ In addition to changes in patterns of elimination, eating habits and hygiene, their carriers need to adapt themselves to the use of a collector bag for feces and / or urine adhered to the abdomen, resulting in diminished self-esteem, impaired sexuality and, often, in social isolation.²

The ostomized person and its caregiver family member start to deal, daily, with the ostomy and its accessories, requiring professional support for facing it.^{3,4,5} In a study on the role of the caregiver family member to the person with ostomy, it was found that this relative plays a key role in care. Generally, it is he who seeks guidance that allowing him to take care and do presence, along with the person with ostomy, improving his knowledge.

Nonetheless, many people feel insecure with regard to their ability as caregivers. The authors found that the ostomized person is bearer of the physical pain caused by stomization, but the family absorbs and reflects their psychological pain, also requiring aid to be enhanced as caregiver.⁶

It should be verified that working with ostomized people and their family members must occur in an integral way, allowing the improvement of their situation and their living process. In this sense, the nurse, as health educator, must guide the family for the provision of care to the family member with ostomy, considering it as integrant part and inseparable from the work practice in the health care field. So, the question that guided this study was: how is the preparation of the caregiver family member for the care of a person with ostomy? From this questioning, we aimed at knowing how is preparation of the caregiver family member for the care of the person with ostomy.

The knowledge produced in this study may help nurses in their daily practice with the caregiver family member of the person with ostomy, directing their educational practice in order to help it to acquire skills and competencies for the care act.

METHOD

The current study was extracted from the final report of the Research Project of Scientific Initiation / CNPq / FURG, entitled "*The preparation of the family member for*

the care of the bearer of ostomies", in force from July 2007 to August 2008. This is a descriptive research, with qualitative approach. The descriptive research addresses the description of the investigated phenomenon, enabling to know the experienced problems.⁷ A qualitative approaching considers, as a source of study, the perspective of individuals who experience a given phenomenon, its universe of meanings, aspirations, beliefs, values and attitudes.⁸

The study was conducted in the first half of 2008, in a Stomatherapy Service (SS) of a University Hospital (UH) of the Brazilian South. This service has 17 years of working with people with ostomies and their family members, working in the areas of care, teaching, research and extension.

The participants of this survey were five family members of people with ostomy served in SS. The inclusion criteria were: being a caregiver family member of person with ostomies and accept to participate in research, by signing the Free and Informed Consent Form (FICF) and allow recording of the interview and dissemination of results. This consent form was signed in two copies, and one copy was given to each participant.

Data collection was conducted through semi-structured interviews, single with each participant. The interview is an activity in which occurs a successive approximation of reality that never runs out, making a particular combination between theory and practice.⁸ They were conducted individually during nursing consultations and recorded for later analysis. The number of interviews was limited by data saturation and the caregiver family members were asked about the impact of the news on the necessity of stomization of the relative, the reasons that made it becomes the caregiver, the available resources for the care and their preparation for the care of the person with ostomy.

We proceeded to the content analysis, technique in which the focus is the speech of individuals, since it considers that there is a correlation between the type of speech and the characteristics of the individual or reality in where it is inserted.⁹ This method was operationalized by means of the following stages: pre-analysis, in which the organization of the empirical material was proceeded; exploration of content; treatment of the results and interpretation, in which the results become meaningful and valid, generating empirical categories, revealing the constituting elements of the investigated phenomenon.⁹

The research project was approved by the Ethics Research Committee of the Association of Charity *Santa Casa do Rio Grande*, receiving a favorable opinion with the number 38/2007, as determined by the Resolution 196, of October 10th, 1996, from the Brazilian Ministry of Health.¹⁰ For ensuring the anonymity of the study participants, they were identified by the letter F, followed by the sequential number of the interviews.

RESULTS

The people with ostomies were three females and two males, all of them with more than 60 years old, with permanent ostomies, which were caused by adenocarcinoma stomization of the rectum (three) or sigmoid (two). The five caregiver family members who were participants in the study were female. Three caregivers were daughters of people with ostomy; one was niece, but when asked, she called himself as daughter; and the fifth subject was a professional caregiver, who was hired by the family to care for the patient. Nevertheless, when asked, she also considered herself as a daughter. Their ages ranged from 30 years old, the age of the younger caregiver, and 54 years old, the age of the older caregiver. Regarding the length of care, this ranged between three and six years.

From the data analysis two categories have emerged: *"The caregiver faced with the need of stomization"* and *"The preparation of the family member for the care of the person with ostomy"*.

• The caregiver faced with the need of stomization

In our environment, cancer is seen as stigmatizing disease and, usually, related to death. The receiving of a cancer diagnosis for the family presents itself as something appalling.

When I noticed he had stomach cancer, I got scared, scared, scared, scared. (F1)

Caregivers are surprised by this diagnosis and, when they are notified on the need for execution of an ostomy in his family members, get unable to measure the meaning of this procedure, taking into account that it is a little known process of the general population. Furthermore, impacted by the diagnosis, they may present themselves emotionally shaken up, and it decreases their ability to understand the situation.

It was suddenly, I got surprised, because he, in certain time, he was fine and suddenly came to feel cramps and did not keep stand up. He came to the hospital and has already collapsed. It was diagnosed that he had a malignant cancer; he would suffer a surgery, would use a colostomy bag. (F2)

It was a very quick thing, what happened to him. He was a strong and well-disposed person. Rode a bike, did everything. Suddenly, he felt sickness and it was a quick thing, a cancer. I stayed thirty-three days with him in the hospital. He had a surgery and the doctor told him to return in three months that, probably, would take off the little colostomy bag. But, he got worse [...] the doctor said he could not stand that any longer, he sent him to home and told to take good care, because he might not last more than three months. Indeed, a person who weighed seventy kilos ends up with thirty-seven. He lost too much body mass and we did not understand and got frightened. (F1)

They believe that the support of family members to the person with ostomy is indispensable, especially, soon after the stomization, since the person experience moments of intense emotional disorder, in addition to having to (re) learn to care for itself.

All of them accepted. None of us had any problems with it. (F4)

At first, she was hopeful because she thought she would use it only a month and get back to normal. But, her son came from Rio and said it was better to use that little bag than dying. She accepted. But, at that moment, she would not be able to take care of herself, she needed her family there. (F5)

I thought because I preferred my mother alive than she dead. I was aware that if she did not do the surgery, she would die. So, we had to accept. It was very difficult, but we accept. There are times when we look up and say: why? Why, poor woman? Why do suffer, being like this using that bag, why? It was hard for all of us. But, I faced it and take care of her with all of my affection. (F4)

We verified, in this study, that some families present a differentiated way of coping. Upon receiving the diagnosis, they start to act objectively, making use of their defensive mechanisms, going to look for knowledge about the care necessary for the well-being of their family members.

I think it was not so traumatic. If it is one thing for she gets healed. If you have to do, you got to do. If you have to use, you got to use. It is for she gets fine, so it has to be done. Even if it was for me, it would be like this. I'm trying to learn everything I can do for taking better care of her. (F3)

• The preparation of the family member for the care of the person with ostomy

Faced with a situation of illness and need for cares, the family, usually, organizes itself to take care of its relative as a way to

preserve its life, providing comfort and well-being. In most cases, a family member is elected by the others to be the direct caregiver. In this study, there were several reasons listed by the families for the choosing of this person:

The lack of another family member with skills for the care can be determinant for the definition of caregivers.

It's because they came from outside. They have no children; have no one to look at them. So, they rented a house there near my home. (F2)

It's what's closest, living together, later it would be made by me. It's me and my dad. I do not know if it happens because the girls live far away, in Cassino. So, I'm always running after the doctors, of everything. There's no one else for doing it. (F4)

For the family's thought, this caregiver adds characteristics and skills needed for the care due to previous experiences as caregiver.

I do not know if I'm the most dedicated, I'm the oldest. So, it entails more because others are younger, inexperienced. They've been told that I have that habit of leadership. You know, I take the front. If you have to do something, if you have to schedule a laboratory medical test, that's all I try to do. I always took the initiative. They called me leadership. (F1)

I have no disgust, so take care with no problem. (F5)

The availability of time and proximity to the person with ostomy are presented as factors that are determinants in definition of family caregivers.

I think the availability of time and because of being closer, because my brothers live in the city of Porto Alegre and I got together in everything. It's pretty complicated, because none of them have time, work hard, and they would not perform it. (F3)

Other caregivers are chosen for demonstrating willingness and vocation for the care.

I don't know explain to you what I feel. I only know where I see sick people, around me, so I have to take care of them because when I was with them hospitalized here, I not only took care of them. The patients that were in the next hall, I took care them. I think it is a vocation. That's where I see someone sick I'm always helping, always watching out. I like doing that. I am the leadership. [...] But, if anything happened there, they came to me. For making a simple surgery, they came to me, any little thing they would do. The other two, in this case, were living with him. My brother and my sister living until the forty years old with him, and they call me. I had to come, wherever I was. (F1)

When the family has not a person who meets the aforementioned conditions, they search for the professional care as an alternative capable of subsidizing its family member with ostomy through the special cares that he/she needs. When deciding to choose a caregiver outside the family context, the family does it in search of someone who meets the necessary characteristics for the care, especially knowledge and affectivity.

Because I took care of this other old lady. It was another type of operation. They saw my affection for that person. Because each person that I care I feel like it were a relative of mine. I like to take care as if it were my relative. Her son came to me and asked me to take his mother to care for. She is lovely! You got to be lovely and, at the same time, you got to be firm, because you what I mean when I talk about sick people. [...] But I kept visiting her, because I achieved the friendship of the family. I was asked to take care of her. I'm not a nurse, but I was changing her bandages. (F5)

After being chosen as a direct caregiver, the family member, at first, may feel scared and present a great suffering, since stomization is a little known procedure, requires very specific cares as cleaning and exchange of ostomy bags, subjecting this family member to an estrangement in the face of the unknown. Despite his fear, the caregiver family member must win it and, thus, overcome possible internal conflicts in order to play his new role before the responsibility given to him.

In the first few days, I was pretty scared of moving the patient. In the early days, I did not want to look at that. After all, I got used to it, so I realized that this problem had to be my task. Then, I had to face and learn. (F3)

I do not know. I really don't know to say to you, and the way I say. I don't know! I've never seen anyone do that. I never cleaned up anyone or interacted with people who did this. Hence, I do not know. I think that way of care came from me anyway, do you know? I have assumed to me the care act. (F2)

Faced with the physical and emotional fragility presented by the relative chosen by the family for the care, other family members mobilize themselves in order to give him support, even working to collaborate with this, adding efforts for that the person with ostomies is not deprived of care. In some cases, we found that the stomization contributes to a greater family union, keeping in mind that relatives outside the home context will contribute, in this context, in the care. Thus, it was found that the stomization

and the need of care of its carrier can lead the family to expand itself as a way to increase its network of social support.

They do the same thing because I've taught them. All do the same thing I do, because he stays during a month with each one. Before, he just stayed with me. He was during one year and two months with me. When my mother died, I went into depression. I was very close, with them too. They lived with me. I was much attached, went into depression and they obliged themselves, each one, to stay during one month for giving me a relief. I had to do a treatment, to give me a relief, they will stay. But if he could, he would stay definitively with me because he feels very safe. The others do the same, but he has a mania. As I've always been to do everything, he has become accustomed. But, the others also let the things well done. (F1)

No, it has even more united us. All of us are united. There are five adult children, plus the father, and plus my cousin who was raised with us. So it has teamed us well. We're always around. The girls are living in the Cassino, but even so, they are always around. (F4)

In the face of the fact of being the caregiver, the family member needs to prepare itself for the performance of the care. When asked about which knowledge they thought would be necessary, they pointed out, especially, patience and willpower as manners of overcome for the lack of specific knowledge for the care of people with ostomy.

I think, mainly, patience. You got to have patience. You must not feel disgust. I think you got to be careful for taking care of such type of person. Because for caring of a person, for dealing with it, you got to [...] you may not be a stressed person, a person who has disgust, because you will not do that willingly. I think it must be so. (F2)

The willpower is useful. It's my opinion, because I had not any knowledge about colostomy, did you understand? But I wanted to learn. (F5)

Taking into consideration the strangeness of the family member to care and the need for provision of specific cares and acquisition of specific skills, the family seeks, in the health professionals, the knowledge and information that can qualify them for the care.

There has to be a person who knows to teach. After that you perform it with someone else, it is pretty easy. You must have guidance from someone able to do so. In my case, I started with the nurses of the Santa Casa, from the city of Porto Alegre. After, I came here, with the social worker and the nurse of that group. I attended

meetings where they showed slides and talked about it. (F1)

In the first days he left the hospital, he went home, and we call a person who was more used to do this. I have never done, nor seen anyone do that. A person presented itself saying that knew [...]. Before he left the hospital, I came here to pick up the bags. The nurse of the UH explained to me how the things could work well, but I still would not risk it. I let that person who said that know go to his house for I see how it would work. [...] I thought, based on what the nurse of the UH had explained to me, that was not what she was doing, because she did not find a way of doing. So, I decided do not call her any longer. I think I do it better than her. From what she (nurse) told me, I started to do without any fear. (F2)

All kind of knowledge we need to have. You have to learn to be able to help. Learning to put, do the hygiene of the bag. (F4)

DISCUSSION

The causes of execution of ostomy are multiple, but, cancer is the most common pathology that results in the need for this procedure. The census of the Brazilian National Cancer Institute - *Instituto Nacional do Câncer* (INCA) estimated that, in 2010, 28.110 cases of colorectal cancer were diagnosed in Brazil, with 13.310 cases in men and 14.800 cases in women, many of these resulted in ostomies.¹¹

The person with ostomy find in its family the support, comfort and, seeks help for dealing with frequent hard situations, which needs face in its daily live.¹² The family, before this process, often, needs to rethink its structure and organizational form as a group, because the care of the person with ostomies requires the constant presence of a caregiver.¹³

A person with ostomy and its caregiver family member start to deal, daily, with the ostomy and its accessories. Both coexist with the need to directly manipulate feces or urine. This coexistence can present itself as deconstructive and lead them to a decreased feeling of self-esteem, requiring professional support for coping with it.⁶

After the impact of the diagnosis, it is essential the support of family members to the person with ostomy, especially, in the early periods after the stomization, since the person experience moments of intense emotional turmoil, besides of having to relearn how to take care of itself. When they are guided by health professionals on the need of execution of the mentioned procedure, the relatives can understand the stomization as a

possibility of healing, or as a way to avoid the death of its family member. Thus, even anguished, they begin to accept the surgery and prepare themselves for the care.⁴

It should be considered the family support as a determinant factor for acceptance of the ostomy from the patient. The family is the first source of support and, they are closer to the person with ostomy, thus can better understand its reactions, transmitting important information to the health team that will subsidize the implementation of a therapeutic plan for reinsertion and rehabilitation of this patient.¹⁴

The family, in interaction with its dynamic-social environment, has ability of resilience in facing adversities daily experienced in the living process of the human being. In this sense, it is an indispensable support to the social reintegration of the ostomized patient.^{15,16}

There are multiple factors involved in choosing the primary caregiver in the family ambit. This choice can occur by availability or by obligation, to repay previously received cares, by kinship relations, by physical proximity or time available to care.¹⁵

The responsibility for the care of the person with ostomies can be managed by a family member that, in general, has no preparation that enables it to take care of each other without interfering in its own care. This caregiver usually has other activities, which must be reconciled with the care, such as child care, home and professional activity, and may feel overwhelmed to care, leading it to illness, needing of professional support for this confrontation.^{3,17,18}

A study that assessed the profile of the caregiver family member of patients with ostomies shows that 58% of them did not know what an ostomy was, 42% had not received guidance on the care of the ostomy and 25% of them found it difficult to naturally accept the condition of its ostomized family member.¹⁴ In this sense, the information provided to the caregiver family members cannot be restricted to small and short conversations at the time of the hospitalization, but rather to permeate the entire period before, during and after surgery, recognizing that the family, the support network and the friends are important axes to a positive reframing in this stage of life.¹⁹

To care for people with ostomy, the caregiver family member needs to be enhanced with regard to the acquisition of new skills of care related to the use and exchange of collector bags, procedures after radiotherapy and chemotherapy, diet care,

among others. To guide the caregiver family member, the nursing professional must take into account the objective and subjective aspects of the care that should be provided, in order to fully meet its needs, thus guaranteeing it a better adaptation, life quality, autonomy and empowerment.^{6,20}

The nursing professional needs to recognize the impact of the ostomy for the caregiver family member and implements care strategies.⁵ It should be highlighted the execution of the guidelines on the process of adaptation and use of collector bag; the care of the ostomy and adequate feed, besides of the forwarding and the encouragement for participation in a support group that can help the ostomized people to coexist with this new situation, which becomes part of the whole that makes up the living process of this person and its caregiver family member.^{21,22}

Whereas this is a descriptive study, it should be recommended to carry out further studies on the caregiver family member and its nuances that allow comparing these results with those observed in other realities, seeking effective strategies to minimize the anxiety and the suffering of families who experience the care for the person with ostomy.

CONCLUSION

The study aimed at knowing how is the preparation of the caregiver family member for the care of the person with ostomies. The data showed that, in the face of the need for stomization of its relative, the diagnosis of cancer is recognized as appalling, by surprising the caregiver family member and emotionally shattering it. They (relatives) believe that the family care is indispensable and seek to acquire knowledge to enable them for the care.

Regarding the preparation of the caregiver family member for the provision of the care for the person with ostomies, we found that the family members organize themselves to care as a way to preserve its life, providing it comfort and well-being. Generally, a family member is elected by the family as the primary caregiver. The reasons for this choice were several, such as: lack of another family member with skills for the care, because this action adds characteristics and skills for the care, from previous experiences; for being available and next to the person with ostomies and demonstrate willingness and vocation for the care.

In case of lack of a family member for caring of the sick subject, the family seeks an alternative in a professional caregiver. Many caregiver family members feel frightened and

suffer, because they do not know about stomization process, having to overcome their fears and conflicts to play their role.

When they organize themselves for the care, the family may expand itself as a way to increase its network of social support. In seeking to prepare itself for the performance of the care, they pursue the overcoming through the patience and the willpower and, in health professionals, knowledge and information.

We conclude that the caregiver family member of the person with ostomy is, generally, unprepared for the care and without knowledge about the stomization process. But, in the face of the need to take care of its relative, he/she assumes the care, despite its fragility. The caregiver needs to be assisted by health professionals, in order to be qualified to carry out this care in a safe manner.

Each family experiences the care for the person with ostomies in a singular form, assuming a singular posture, which is generator differentiated needs of support. The caregiver prepares itself for the care in its own daily of caring, presenting doubts, fears and weaknesses. The health professionals, especially nurses, need to understand how the family care happens, individual needs of each family, with the aim at minimizing their weaknesses, helping them to identify ways of coping with everyday situations, allowing them a more independent and qualified living.

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