

## The family in the care of people with an ostomy of elimination: functions of the social network

A família no cuidado à pessoa com estomia de eliminação: funções da rede social

La familia en el cuidado de la persona con estoma de eliminación: funciones de la red social

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The objective of this study was to describe the functions of the social network with the family, in the care of the person with an ostomy of elimination. Qualitative and descriptive research carried out in the first semester of 2013, at the home of seven families of people with elimination ostomies, in a city in the interior of Rio Grande do Sul, totaling 16 participants, which occurred through semi-structured interviews and observation recorded in a field diary. Thematic content analysis was used, with three categories identified: *"My family was going to get it for me"*: material help and services; *"You are normal, you will learn to live with the ostomy"*: emotional support and social companionship; *"I didn't know how to cut and put the bag"*: cognitive and advice guide. As functions of the social network it was verified: the material and service help, the social company, the emotional support and the cognitive and advice guides. The investigated social network performed its functions linked to the development of daily care provided by the family to the person with an ostomy.

**Descriptors:** Social support; Family health; Ostomy; Chronic disease; Nursing.

O objetivo deste estudo foi descrever as fun es da rede social junto   fam lia, no cuidado   pessoa com estomia de elimina o. Pesquisa qualitativa e descritiva realizada no primeiro semestre de 2013, no domic lio de sete fam lias de pessoas com estomias de elimina o, em um munic pio do interior do Rio Grande do Sul, totalizando 16 participantes, o que se deu por meio de entrevista semiestruturada e de observa o simples registrada em di rio de campo. Utilizou-se a an lise de conte do tem tica, sendo identificadas tr s categorias: *"A minha fam lia ia buscar para mim"*: ajuda material e de servi os; *"Tu  s normal, tu vais aprender a conviver com a estomia"*: apoio emocional e companhia social; *"Eu n o sabia cortar e colocar a bolsa"*: guia cognitivo e de conselhos. Como fun es da rede social verificou-se: a ajuda material e de servi o, a companhia social, o apoio emocional e os guias cognitivo e de conselhos. A rede social investigada exercia suas fun es interligadas ao desenvolvimento dos cuidados realizados diariamente pela fam lia   pessoa com estomia de elimina o.

**Descritores:** Apoio social; Sa de da fam lia; Estomia; Doen a cr nica; Enfermagem.

El objetivo de este estudio fue describir las funciones de la red social junto de la familia en el cuidado de la persona con un estoma de eliminaci n. Esta es una encuesta cualitativa y descriptiva realizada el primer semestre de 2013, en el hogar de siete familias de personas con estomas de eliminaci n, en un municipio del interior de R o Grande do Sul, con un total de 16 participantes, que se realiz  mediante una entrevista semiestructurada y observaci n simple registrada en el cuaderno de campo. Se utiliz  el an lisis del contenido tem tico y se identificaron tres categor as: *"Mi familia me lo consegu a"*: ayuda material y de servicio; *"Eres normal, aprender s a vivir con el estoma"*: apoyo emocional y compa a social; *"No consegu a cortar y poner la bolsa"*: gu a cognitiva y de consejos. Las funciones de la red social fueron: ayuda material y de servicio, acompa amiento social, apoyo emocional y gu as cognitivas y de asesoramiento. La red social investigada ten  sus funciones ligadas al desarrollo del cuidado diario de la persona con estoma de eliminaci n.

**Descritores:** Apoyo social; Salud de la familia; Estom a; Enfermedad cr nica; Enfermer a.

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## INTRODUCTION

Chronic illness promotes biological and relational changes in people's lives, and this creates the need to (re)organize their activities in society, at work and in daily activities; in doing so, they need to activate their social network. Personal social networks<sup>1</sup> represent all the relationships established between human beings, which can help in: coping with the problem, adapting to crisis situations or even situations that inspire care.

In the face of a reliable and sensitive social network, there is an offer to exercise various functions, such as: social company, when there is coexistence or shared activities; emotional support, when those involved rely on mutual help; cognitive guide and advice when sharing ideas and positions; in addition to material, intellectual or physical help<sup>1,2</sup>. When families deal with a chronic condition, they look for ways to produce care and adapt for this task, finding in social relationships the trust and support necessary to develop the actions of care aimed at their family member<sup>3,4</sup>.

Faced with this scenario, permanent elimination ostomies stand out as a chronic health condition, in view of the need for continuous care. In a study, the social network of families of people living with an ostomy was identified, in one study, as being composed of the family itself, whether nuclear, extensive or expanded; friends; neighbors; health workers and services; support groups and religious community<sup>5</sup>.

In these circumstances, health professionals - especially nurses - need to recognize the support offered by these relationships to individuals and families who experience chronic conditions, in order to identify both the potential and the weaknesses that come with the situation. With this assessment, it is possible to indicate alternatives that can contribute to reducing the burden of care and, consequently, promote the quality of life of those involved, assisting them in coping and treating the disease<sup>6</sup>.

Experiencing a chronic situation is complex, it involves multiple dimensions, which are inherent to the physical, social, psychological and spiritual factors of the human being<sup>6,7</sup>. When taking care of a family member with an elimination ostomy, the family may have the necessary support to develop care in the components of its social network, which helps them experience the chronic condition in a more pleasant way.

Based on this, the following question arises: "*How does the social network work with the family to care for people with an ostomy?*". Thus, this study aims to describe the functions of the social network with the family in caring for people with an ostomy.

## METHOD

This is a qualitative and descriptive research, carried out from January to April of 2013, in the homes of seven families of people with an elimination ostomy, in a city in the countryside of the state of Rio Grande do Sul. As a concept for "family", concepts that go beyond consanguineous ties were considered, such as adoption and marriage<sup>8</sup>.

The access to people with ostomy was granted through the *Serviço de Atenção à Saúde das Pessoas Ostomizadas - SASPO* (Health Care for People with Ostomy Services), in the municipalities where they lived. In this perspective, when they came to the service for medical appointments or to collect the ostomy bags and adjuvant treatments, those who showed interest in participating in the study were checked in the *Gerenciamento de Usuários com Deficiências - GUD* (Register of Users with Disabilities), followed by the initial approach. From that, the proposal and invitation for the research were presented. Upon acceptance, the interview was scheduled later, through a telephone call.

As study participants, were considered necessary the presence and participation of at least two people, including the person with an ostomy, in order to be able to characterize themselves as family<sup>8</sup>. Family members were indicated by the person with an ostomy and, of the ones present on the day of data collection, gathered at home.

For the selection of participants, the following criteria were adopted: families living in the municipality of data collection; all are over the age of 18; one family member living with a permanent ostomy, which characterizes chronicity, and may be of intestinal or urinary origin, for more than six months. This period was established because it is believed that, in the first postoperative months, the family would be in an adaptive process of care and could have difficulties in detailing situations regarding the support received.

Families with a member suffering from cognitive and speech difficulties were excluded, as this could interfere with the understanding of the interview, were excluded, as well as cases in which the person living with an ostomy did not indicate someone to participate.

For data collection, semi-structured interviews were used. These interviews had an average duration of one hour and were recorded on a digital recorder and simple observation, and registered in a field diary. The guiding themes of the interview were: care for the family member; who assisted in this care; types of help received and in what situations; neighborhood services and locations that contributed to care; clarification of doubts; financial aid to perform care. For observation, an adapted script<sup>9</sup> was used, which included four elements: internal and external home environment, behavior of people in the group, verbal and non-verbal language, relationships.

The study was approved by the Research Ethics Committee, under filing number 171,345. The ethical aspects related to research with human beings were respected, and the Free and Informed Consent Term (ICF) were read and then delivered, in two copies, to be signed by the participants, before the beginning of data collection. Families had their anonymity preserved, using the codes "F", referring to the family, plus the cardinal number, corresponding to the interview order (F1, F2, F3 ...), added "PO", when referring to the person with an ostomy, in addition to the degree of kinship to identify family members.

For data analysis, thematic content analysis was used; to undertake it, three steps were followed: pre-analysis, exploration of the material and treatment and interpretation of the results obtained<sup>10</sup>.

## RESULTS

Seven families participated in the research, with a total of 16 participants (seven people with ostomy and nine family members); of these, ten were female, with an average age of 48 years; most were married; as for education, eight had finished elementary school. Regarding the types of elimination ostomy, there were five colostomies and two urostomies; still, it was observed that, in five people, the neoplasm was the cause of the ostomy.

The following are the three categories resulting from the content analysis: *"My family was going to get it for me"*: material help and services; *"You are normal, you will learn to live with the ostomy"*: emotional support and social companionship; *"I didn't know how to cut and put the bag"*: cognitive and advice guide.

### ***"My family was going to get it for me": material help and services***

Some family members organized themselves to retrieve the necessary material for the care of the person with an ostomy in SASPO, and they were referred to and guided by the professionals of the hospitals where the surgery took place. Such mobilization was important to assist in the recovery of the family member:

*At the beginning, my sisters, my daughters went there (ostomy sector), they took it for me, because I was recovering. (F1, PO)*

*[...] we traveled to my brother's city and there was no bag. My brother went to the health center with me to get some bags. (F2, PO)*

With regard to the acquisition of bags and materials, all interviewed families acquired these devices exclusively either through the *Sistema Único de Saúde - SUS* (Unified Health System), or through associations of people with ostomy or cancer:

*[...] I always took the bags there at the service (from the health department). (F1, PE)*

*He goes here in the neighborhood. He has diabetes, so he goes there, checks glucose and blood pressure, takes the medication, the gauze to help clean better to put on the bag. (F4, wife)*

*[...] I get help from (name of the institution), which is in the cancer league! My medication treatment is all from there, but there is that product that (the stoma nurse) gives to clean, that is very good. And there are bags too. (F4, PO)*

For the interviewed families, one of the main functions of the personal social network was the care with the collection bag, carried out mainly by wives, children, mothers and brothers:

*I had to learn, because I had never lived with it, when he comes out of the bathroom, I make him lie on the bed, dry and put the bag on. Sometimes he says how should I stick the bag better. My daughter has also learned. (F2, wife)*

*In the beginning, my daughter did it, because I didn't want to change. The colostomy prolapsed; so it was horrible, it was terrible! When she (daughter) went on a trip, I already asked her to leave a few bags cut neatly. Now this (urostomy) is very easy. (F4, wife)*

*In this care? It's just me and him here. If we are in Porto Alegre, and he is going to take a shower, my daughters help to cut and put the bag on [...]. (F5, mother)*

*[...] it was my son who dressed it, when it was open. (F6, PO)*

With regard to material and service assistance, receiving assistance in relation to mobility, housing and financial support was also considered important:

*Right at the beginning, I had to dress the cut, so my uncle would take me there (stoma nurse) by car and at the appointments, to get the bags. Because I was weak, and they didn't want me to walk. When he couldn't, he lent the car to a neighbor. (F1, PO)*

*[...] sometimes, even this neighbor (walking along the street) helps to take him, to take him by car, to take me there at the hospital for appointments. (F6, wife)*

*In a more complicated time, which was right after the surgery, for seven months, we stayed in the city (center), in the same building as my brother; we lived there, during treatment, every time there was an exam, monitoring [...]. So, there was also this support from him, from his family. (F3, PO)*

*[...] he was our neighbor on the hill (where they used to live) [...] when our mother was really bad, he gave us financial support and a friend too. (F1, daughter b)*

### ***“You are normal, you will learn to live with the ostomy”: emotional support and social companionship***

The functions of emotional support and social companionship, offered by the personal social network to the families of this study, are organized in order to complement each other. Thus, these two functions arose, mainly, with webs created by the circles of family and friends:

*What they (mother and brother) can help us with. It is encouraging support! (F1, PO)*

*[...] support (from friends) always! Just by trying to find out how you are, it is already important for us. (F3, PO)*

In addition, people living with an ostomy and some of their family members participate both in the support group for individuals with ostomy in the municipality, and in the support group for people with cancer. In this perspective, group activities were perceived as a form of support that contributes to care:

*[...] it is good for him, especially for him to live with it, because there (in groups) he sometimes sees people and says to me: there are much worse people! This is good, because sometimes we think that our (problem) is the biggest, and it is not. He is also very friendly. (F4, wife)*

*During the interview, (F4, wife) seeks the calendar of the group of people with cancer with the dates set for the meetings and stresses the importance of her husband's participation in these activities. (Field diary 01/21/2013)*

*[...] (the group of people with ostomies) is wonderful, I had never thought that I would have such great support, I loved that support. At first, my son did not accept the ostomy, then in the group they talked to him, he went to a psychologist, so he accepted the situation. Today he is a happy person for that. (F5, mother)*

In cases where it was difficult to return to social activities, the emotional support of close people became relevant:

*[...] when we started dating, I realized that he wanted to isolate himself from everything, he didn't want to leave the house anymore. So I started to support him and encourage him to leave the house. Today he goes out, lives with it, but he was much more isolated than usual. (F2, wife)*

*My mother doesn't go out anymore, she used to before, she went to a lot of places, now she doesn't even want to go outside (rural area). There are some friends who invite her to go out, but she doesn't. (F1, daughter b)*

*The mother of (F1, daughter b) is moved, her eyes are filled with tears and points out that people have a lot of prejudice against those who have an ostomy, that, therefore, she does not go out and is afraid to connect to people,*

that even avoids wearing some clothes. But she emphasizes that her daughters support her going back to her leisure activities. (Field diary)

On the other hand, some participants, when asked about relationships in society, reported remaining with a good social life, even after the ostomy:

[...] *the group of ostomy patients has already taken a tour to the mountains and also to the ruins (locality). (F6, PO) I work, I teach Bible studies, I take care of the community center of the church and of Our Lady the one who visits the homes. I was fine, I suffer from nothing, I do not deprive myself of anything. Now the irrigator appeared, it's very quiet, with that plug there, I'm not afraid of anything, the beach, anything, the pool. (F7, PO)*

### ***"I didn't know how to cut and put the bag": cognitive and advice guide***

The clarification of doubts or the receipt of information about the needs for care with the ostomy occurred mainly through the nursing professionals of SASPO:

*At first I did not cut and put the bag. I cut too much, then the (stoma nurse) helped me. Because you measure there and have that little hole, you can't open too much, you can't close too little, so that was a question for me, it was so complicated. (F5, mother)*

*First, they (stomatherapist and nursing technician) always changed it; later, I trained and she (stomatherapist) taught me well. (F7, PO)*

[...] *With the (stomatherapist), we seek information. That group is always asking if it is better (which is the best bag), if anything is necessary. (F2, PO)*

The guidelines received by other health professionals also contributed to the family care for the person with a permanent ostomy. In addition, only one family mentioned also seeking guidance on the internet ”:

*A doctor at the meeting (support group) said that germs could enter through the ostomy. So you must be very careful. (F2, PE)*

[...] *On the internet and there's the doctor (gastrologist) that we go to almost every week. Anything he has, I have his phone number, he calls me whenever he wants, answers me, gives me guidance, any time any day ! So the doctor and the internet that we have, and the nutritionist as well. (F3, wife)*

## **DISCUSSION**

After hospital discharge, the person with an ostomy is weakened as a result of the stoma surgery. At this moment, the function of material help and service, performed by the social network with the family, becomes essential, since there is a need to register and, consequently, to obtain, via SUS, the collection bags and others devices for care.

It was observed, in all interviews, the presence of information that, during the first weeks at home, it was the family who went to the Health Department sector for registration and search for the other adjuvant treatments, which was evident as an important care aid. However, it was identified that even the family member who does not live daily with the person with an ostomy feels sensitized and lends their assistance, both in acquisition of these devices and in organization for care.

Most of the time, when a family member falls ill, the family instinctively organizes to develop immediate care<sup>3,11</sup>. In documentary study, it was identified that care in the home environment is mainly developed by family members<sup>12</sup>.

As a result of the new way of life, the person with an ostomy and their family live with numerous changes, which begin with the diagnosis of a chronic health condition, with the etiology, often, of a neoplasm or inflammatory disease, which involves financial expenses. Thus, obtaining collection devices, adjuvant treatments for the care of the ostomy and medications, through SUS or associations, are actions that contribute to the continuity of care.

Thus, when they are registered with SASPO, people know that they have the right to receive this assistance, a fact that provides less concern in relation to the acquisition of devices. Such a condition is beneficial because, in some cases, the sick person is the main provider of family income, and their illness is the factor that makes it impossible to work, culminating, many times, in disability retirement.

The family nucleus is affected by changes arising from the confection of an ostomy and by the care required for an ostomy. This involves psychological, social and financial spheres,

in addition to restriction or loss of work activity. Such issues trigger changes in quality of life and, in some cases, lead to the need for rearrangements of family dynamics<sup>3,13</sup>.

As one of the alternatives that can ease the costs of chronicity, SUS offers a monthly kit, which content is the collection bag, the protective skin barriers and cleansers<sup>14</sup>. The supply of these materials mainly facilitates the initial post-confection phase, since it preserves the continuity of care and prevents the family from creating unnecessary itineraries in search of collection bags<sup>15</sup>.

Care with the collecting device and peristomal skin was performed by wives, children, mothers and brothers. This occurred, mainly, in the initial period of use of the collection bag, due to the physical conditions to adapt it.

Thus, even with the initial difficulties of handling the devices and without the necessary knowledge to correctly perform care, the family organized to do so. Thus, it develops care for the skin, food habits and bag changes<sup>16,17</sup>.

The initial contact with the ostomy is hampered by the strangeness with the devices, in addition to the externalization of the intestine and/or the ureter, via the abdominal cavity. However, the physical and instrumental help that the person with an ostomy receives from their family members, from the beginning, is essential to help them live with this process and adapt to it. As much as the family has difficulties in relation to the exchange of the collection bag, over time, they will be overcome, which provides the family with more security and greater comfort.

The daily care provided by the family is interconnected with the social relationships from which they receive support<sup>4,12,18</sup>. A survey found the benefit of an educational video to assist families in these early years of home care - that is, the material was configured as an alternative to be used, in order to illustrate, didactically and complementarily, the nursing guidelines<sup>17</sup>. In this case, the family is mobilized and undergoes a learning process in view of the need to care for their family members, which often leads to changes in their own routine and imperatives to acquire new habits<sup>12,16,17</sup>.

In addition to the technical obligation related to the ostomy, the social network also helped the families participating in this study in other activities: transportation of the person with an ostomy, housing, and financial support. These results converge with an investigation carried out with men with neoplasia, which referred to the benefit received by them from friends, neighbors and family members, in helping with mobility and financial support. These aids were fundamental for coping with illness, promoting family members the hope of betting on recovery<sup>19</sup>.

The social network acts as a generator of health, since stable and active relationships protect individuals from illness, assist in the use of health services and promote an acceleration in the healing process<sup>1,2</sup>.

The assistance with transportation was pointed out as a relevant aid, as verbalized by the participants, since many of them did not have a car and, if they had not received this support from family and friends, perhaps the treatment and care necessary for their recovery would have to be made possible in another way, which would require mobilizing different strategies by the family. In addition, the care provided was strengthened by material and service aids, received through interpersonal relationships. These networks were woven in the moments that passed through hospitalization periods; hospital discharge; continuity of treatment, medical appointments and examinations; searching for devices and handling with the collection bag; besides information about the ostomy.

Other types of social network functions found were emotional support and social companionship. Thus, it is reiterated that, in situations of chronic illness and, especially, at times when the disease brings bodily changes, such as an ostomy, families feel supported by the fact that they know that someone encourages them and cares about them, which characterizes the function of emotional support in such a difficult time.

Emotional support can be equated with "*being there*"; the social company, in turn, is characterized by experiencing moments together<sup>2</sup>, or "*being present*". The presence, at the time of suffering, does not need to be physical, as support can overcome these barriers and be offered by the family members themselves<sup>19,20</sup>.

Participation in support groups was another form of emotional support signaled by families. In these places, there is recognition of the new body identity generated by the ostomy. The fact that people share the same anxieties and similar concerns regarding the care for their family members makes the group's meeting moment act as a "*being present*" and helps in the acceptance of this process.

The interactions with the other, within the support groups, become useful by enabling the sharing of joys, anxieties, ways of caring, in addition to being a listening space. The fact of relating to others and also belonging to a group helps in the recovery of health problems<sup>1</sup>.

On the other hand, some participants expose the difficulties of living in society again. However, even if the person with an ostomy has limitations to return to social activities, they receive stimuli for social interaction, which characterizes a practice of emotional support through the incentive to rescue interactions in society.

The ostomy changes in biopsychosocial aspects are notorious, but, mainly, this is more noticeable in body image. Allied to this, five participants had an ostomy caused by neoplasms. Thus, when faced with a society that imposes body standards, people with an ostomy can often suffer from the stigma of having a body that does not follow the standards.

Suffering, feelings of sadness, social withdrawal and mutilation, resulting from the use of the collection bag, were also reported feelings, found in a survey of families of people with cancer stomas<sup>16,21</sup>. In view of the affected self-esteem, the person with an ostomy feels depreciated in the social environment, which causes a reduction in their sociability<sup>22</sup>.

It was identified, through testimonies and by records in the field diary, that the family members (wife and daughters) act as stimulators of social interaction, favoring the resumption of activities previously carried out. In this context, it is through dialogue that they seek to encourage the recovery of social relationships prior to illness.

Emotional support can be a preponderant factor to provoke social reintegration after the construction of the ostomy<sup>4,23</sup>. Thus, encouragement, willingness to help and the development of close relationships facilitate the daily lives of families affected by chronicity<sup>11</sup>. In the face of chronic illness, social networks can also act positively, in order to strengthen and expand family and friendship bonds, as well as to unite people to cope and treat the disease<sup>1</sup>.

On the other hand, it is clear that the chronic condition, for some participants, did not prevent them from maintaining social, family and marital relationships, nor from cultivating life habits. This fact can be corroborated by the emotional support and social company they receive from their personal social networks, which demonstrates the relevance of maintaining interpersonal relationships.

During the F7 interview, both the person with an ostomy, as well as her husband and friend, highlighted the fact that the ostomy irrigation system is a device that acts as a beneficial aid in resuming daily activities. With the development of the irrigation technique, water is introduced through the stoma with the aid of its own system; thus, fecal waste is cleaned and, consequently, the person uses an occluder and can stay up to 72 hours without using the collection bag<sup>24</sup>.

The acts of stimulating self-esteem, encouraging social return and recognizing the similarities in the support groups were contributions generated by the personal social network, in the development of care for family members with ostomy.

The development of care for the families surveyed was intensified based on the role of cognitive guide and advice from the social network, woven by health professionals, with an emphasis on the nursing technician and the stoma nurse in the ostomy sector in the

municipality. The care with the collection bag caused an initial estrangement, but, over time and with the guidelines received at the health service, it was possible to care at home.

With regard to the care and guidance received by nursing, it was identified in this research that, if these occur in a comprehensive manner and adequate to the needs, they are considered essential for the process of acceptance and coexistence with the ostomy.

From the testimony of F2 (PO), it was identified that, in addition to the information, the professionals of the specialized service act with the intention of helping them to better adapt to the devices. In view of the variety of collection bag models, it is essential that the person with an ostomy can identify which one promotes a better adjustment to their body and their way of life.

Thus, the guidelines in the pre and postoperative period for the construction of the ostomy, by the nursing team, need to address the technical issues related to the care of the bag, skin, possible complications and the use of adjuvant treatments. In addition, they also need to address the subjective aspects that permeate the new way of living<sup>22</sup>. Thus, the nurse plays an important role in encouraging self-care, recognizing self-image and resuming social and work activities<sup>4,21</sup>.

The guidance received on how to change the collection bag and how to care for the ostomy was highlighted. This clarity facilitates the understanding of what was part of the body, which allows differentiated care, by combining this with the information previously offered by health professionals.

An easy-to-understand approach was verbalized by the doctor during the support group meeting. This fact helps the other participants, because when using technical terminologies, there may be a gap in the understanding of the participants and, as a result, hamper the care to be performed at home.

A proposal both ministerial<sup>14</sup> and resulting from research<sup>23</sup> points to multidisciplinary care for people with ostomy and their families, whether in an individual or collective approach. These moments of dialogue and group health education strategies operate not only as enhancers for self-care and for daily reflection, but also as promoters of well-being, stimulating the increase in self-esteem and improving quality of life<sup>24</sup>.

A research that evaluated social support received by people with chronic kidney disease found that these entities also receive help from health professionals and that this assistance contributes to the resolution of treatment and necessary care<sup>6</sup>. Thus, it is clear that the personal social network can effectively assist in providing practical guidance and advice<sup>2</sup>.

Faced with what is new, as it is the case with living with an ostomy, families felt empowered, at the moment they were instrumentalized, to exercise care through the function of the social network of cognitive guide and advice, which is given by health professionals.

## CONCLUSION

The results of this research point out through functions performed by social network, that families were able to develop better care for their loved ones with an elimination ostomy. There are, as functions received, material help and services; emotional support and social companionship; cognitive guide and advice. However, the function that was most present - to the detriment of direct care to the family member with an ostomy - is part of material help and services, since having a permanent ostomy demands the need to live forever with the collecting devices.

As a limitation of the study, it was pointed out the difficulty that families had in remembering the people who helped them in the care. At first, in the interviews, the families said that support was exclusively from the family nucleus. However, during the interview, it was noticed that other networks were formed, which contributed with direct and indirect actions in care. This fact can be related either to the process of social isolation caused by the



construction of the ostomy or to the necessary demand for care that often makes the family's perception of their support network unfeasible, involved in this care activity.

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**Bruna Sodr  Simon** and **Maria de Lourdes Denardin Bud ** contributed to the conception of the study, data collection and analysis, writing and revision. **Ang lica Dalmolin, Nara Marilene Oliveira Girardon-Perlini, Raquel P tter Garcia** and **Stefanie Griebeler Oliveira** participated in writing and revision.

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