

Professional attention to the families of people with elimination stoma: the duality experienced

Atenção profissional às famílias de pessoas com estomia de eliminação: a dualidade vivenciada

Atención profesional a las familias de personas con estoma de eliminación: la vivencia de la dualidad

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ABSTRACT

Objective: To know how professional attention occurs for the family in the care of the person with elimination stoma. **Methods:** Qualitative, exploratory and descriptive field research conducted from January to April 2013 with seven families, totaling 16 participants. Semi-structured interview, minimum map of relationships and observation were the methods of data collection in families' domiciles. After analyzing the thematic content, the categories were established: *The support is very strong! It's everything to me:* benefits of professional attention; and *They don't have wisdom for it there:* difficulties of professional attention. **Results:** As a benefit, it has the multidisciplinary service offered by the Service of Health Care of the Person with Stoma, with notoriety for the nursing. The lack of knowledge of some nursing professionals from other services and the difficulty to handle the stoma and the device collectors were difficulties identified. **Conclusion:** The web of professionals and health services form both positive and negative nodes in the care of the families of the person with elimination stoma, characterizing the professional attention to the families of people with stoma as a duality experienced.

DESCRIPTORS: Family Health; Stoma; Patient care; Nursing care; Stomatherapy.

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RESUMO

Objetivo: Conhecer como ocorre a atenção profissional para a família no cuidado à pessoa com estomia de eliminação. **Métodos:** Pesquisa de campo qualitativa, exploratória e descritiva realizada de janeiro a abril de 2013 com sete famílias, totalizando 16 participantes. Entrevista semiestruturada, mapa mínimo das relações e observação foram os métodos de coleta de dados nos domicílios das famílias. Após análise de conteúdo temática, estabeleceram-se as categorias: *O apoio é fortíssimo! É tudo para mim:* benefícios da atenção profissional; e *Eles não têm sabedoria para isso aí:* dificuldades da atenção profissional. **Resultados:** Como benefício, tem-se o atendimento multiprofissional ofertado pelo Serviço de Atenção à Saúde da Pessoa com Estomia, com notoriedade para a enfermagem. A falta de conhecimento de alguns profissionais de enfermagem de outros serviços e a dificuldade de manusear a estomia e os dispositivos coletores foram dificuldades identificadas. **Conclusão:** A teia dos profissionais e serviços de saúde forma tanto nós positivos quanto negativos no cuidado às famílias da pessoa com estomia de eliminação, caracterizando a atenção profissional às famílias de pessoas com estomia como uma dualidade vivenciada.

DESCRITORES: Saúde da família; Estomia; Assistência ao paciente; Cuidados de enfermagem; Estomaterapia.

RESUMEN

Objetivo: Conocer cómo se realiza la atención profesional a la familia en el cuidado de la persona con estoma de eliminación. **Métodos:** Estudio de campo cualitativo, exploratorio y descriptivo llevado a cabo de enero a abril de 2013 con siete familias, con un total de 16 participantes. Entrevista semiestructurada, mapa mínimo de las relaciones y observación fueron los métodos de recolección de datos en los domicilios de las familias. Luego del análisis de contenido temático, fueron establecidas las siguientes categorías: ¡El apoyo es fuertísimo! *Es todo para mí:* beneficios de la atención profesional; y *Ellos no tienen sabiduría para eso:* dificultades de la atención profesional. **Resultados:** Como beneficio, se cuenta con la atención multiprofesional que ofrece el Servicio de Atención a la Salud de la Persona con Estoma, especialmente para la enfermería. La falta de conocimiento de algunos profesionales de enfermería de otros servicios y la dificultad en el manejo del estoma y los dispositivos recolectores fueron las dificultades identificadas. **Conclusión:** El entramado de los profesionales y servicios de salud forma tanto nodos positivos como negativos en el cuidado de las familias de personas con estoma de eliminación, caracterizando la atención profesional a las familias de personas con estoma como una vivencia de la dualidad.

DESCRIPTORES: Salud de la familia; Estoma; Asistencia al paciente; Cuidados de enfermería; Estomaterapia.

INTRODUCTION

The creation of an elimination stoma causes a significant change in the body, especially after surgery, since people have difficulties in accepting the changes that have occurred. Thus, in the process of rehabilitation and reintegration of these people into society, the relevance of the role of the family and health professionals¹ is highlighted. In this context, it is observed that families establish new interrelations and go through different periods of adjustment, in which they reinforce their relationships with the people with whom they live². At times, the family nucleus needs to activate mechanisms that help in its reorganization and stability³.

In these adaptive moments, the assistance of the health service professionals can be decisive for the families' confrontation. This fact directly implies the safety, rescue and rehabilitation of those involved⁴. In this perspective, is that the personal

social networks are found. These can positively or negatively affect a person's health, from interrelations that are in constant building and deconstructing during life⁵.

Nursing, in this scenario, it is inserted in the promotion of practices that promote the interaction with families, in order to alleviate the anguish and discomfort resulting from the chronic illness of their relative⁶.

In the proposal of health attention for people with stoma, the necessity to guarantee integral care through individualized and interdisciplinary actions is underlined, which requires a specialized structure with trained human and material resources. The health attention of these people should be developed in basic care and in the Service of Health Care of the Person with Stoma (SHCPS), which is composed of a multidisciplinary team, with doctor, nurse, social worker, psychologist and nutritionist⁷.

In front of this, the proposal of this study is justified, since the recognition and improvement of care provided

by health professionals to this population is fundamental. Thus, it is questioned: how do families identify professional attention in the care of the person with elimination stoma? Therefore, the objective of this study was to know how is the professional attention to the family in the care of the person with elimination stomas.

METHODS

It is a qualitative research, exploratory and descriptive, realized with seven families of people with stomas, totaling 16 people who accepted to participate through a previous telephone appointment and after explaining the objectives of the research and signing the Term of Consent Free and Clarified. The project was approved by the Ethics Committee in Research of the university of linkage, with the Certificate of Presentation for Ethical Appraisal nº 11245612.0.0000.5346 and the opinion nº 171.345. This research complied with the ethical recommendations current for conducting studies with humans⁸.

The minimum map of relationships (MMR)^{5,9}, the semi-structured interview and the observation were used as data collection methods from January to April 2013, and these were worked through thematic content analysis¹⁰.

The MMR is formed by four quadrants that represent the social relations of the family; the friendships; community relations and creed (with the subdivision of relations with health systems and social agencies); and work or study relationships. The quadrants are subdivided into three concentric circles that indicate the degree of proximity of the relationships, the former representing relationships with a higher degree of commitment; the middle circle, relationships with less degree of commitment; and the external, the occasional relationships^{5,9}.

To participate in the study, families should have a person with an elimination stoma higher than 18 years; that the patient has permanent, intestinal or urinary stoma; that the stoma had been made more than six months ago; and that the person was resident in the collection municipality. This time of preparation was established, since it was considered that if the stoma was made less time, the family could have difficulty answering the questions, since it would be in a recent process of adaptation. The family that had a member with a speech-restricted stoma was excluded from the study.

Participants were identified in this study with the letter F, family, followed by the number corresponding to the interview order (F1 to F7). In addition, to identify the members of the family was added the degree of relation. The code composed of the letters PS was used to designate the person with the stoma.

From the analysis, two categories are elaborated: *The support is very strong! It's everything to me: benefits of professional attention*; and *They don't have wisdom for it there: difficulties of professional attention*.

RESULTS AND DISCUSSION

Of the seven families interviewed, five were caring for their family member with a colostomy and two with a urostomy. The creation time and consequent care ranged from eight months to 12 years and five months. Families were composed of children and spouses, and there is one case where a friend was referred to as a family member.

The constitution of the families participating in the study is in line with the concept of the adopted family, which is not necessarily composed of consanguineous relations, but of matrimony, adoption and affection, which may be considered to define the family of each person¹¹.

The support is very strong! It's everything to me: benefits of professional attention

After analyzing the MMR, it was identified that the families received assistance from different services and health professionals. It was observed that the professionals who worked in the Health Care Service of the Person with Stoma of the municipality were referenced by all families as components of their web of interpersonal relationships (Figs. 1 and 2).

When constructing the MMR, the reference of the families to the specialized service was unanimous, regarding the quadrant of community relations and creed, in the subdivision of the relations with the health system. These relationships were marked in the circle of greater proximity to the family, which indicates a relationship with a greater degree of commitment.

In order to illustrate the support received from health professionals, the F3 and F7 MMRs were chosen to be presented and discussed in this article because they had, respectively, eight months and 12 years and five months of

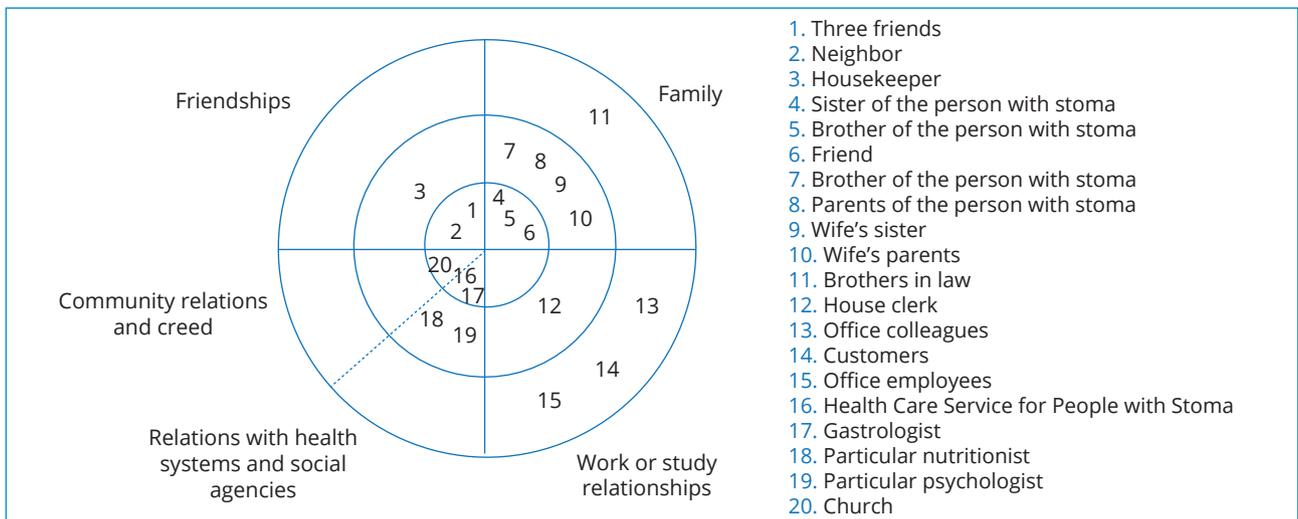


Figure 1. Minimum map of family relationships 3 (F3). Rio Grande do Sul, Brazil, 2013.

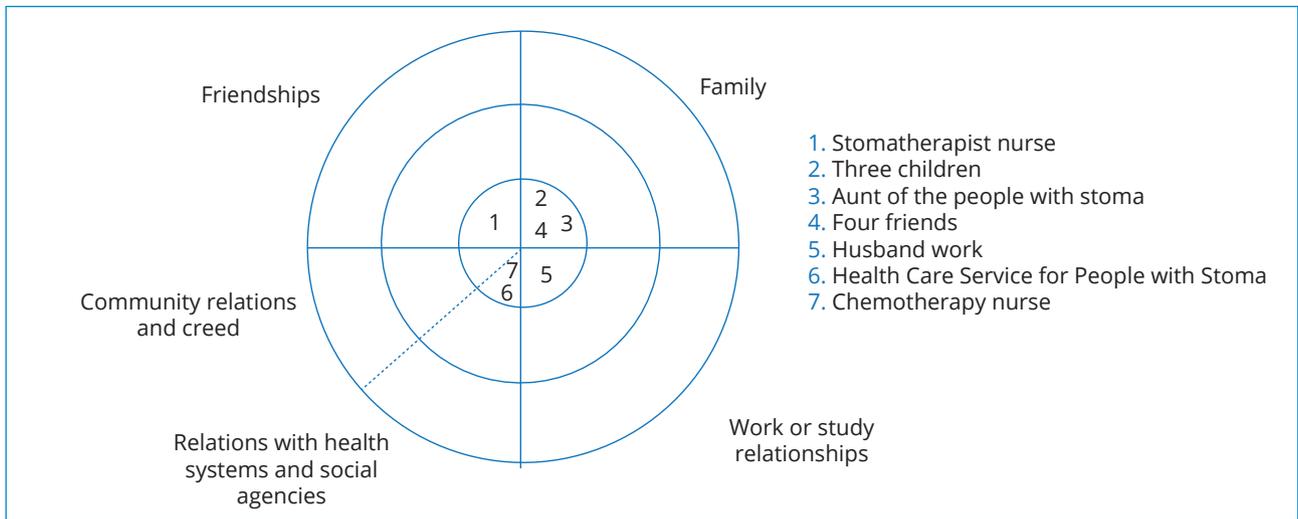


Figure 2. Minimum map of family relationships 7 (F7). Rio Grande do Sul, Brazil, 2013.

contact with the health service attention, with the families taking part in the study with shorter and longer follow-up in the service. This reveals that, regardless of the phase of confrontation and adaptation to the stoma that the family is, the support received and the reference to the service have the same intensity, which indicates the recognition of the importance of the work of the professionals who work there.

The identification of health services in the circle closest to the family was also found in a study with family members of children who used MMR as an instrument¹². However, in a study performed with teenage parents, health services appear in the outer circle, revealing relationships that are not as strong and less supportive¹³.

In the analysis of the interviews, the assistance to the families was provided by the multidisciplinary team of the

Service of Attention to the Health of Person with Stoma of the municipality:

“I have already spoken with a nutritionist [of the SAHPS service] and she has already passed me the guidelines very similar to the [particular] nutritionist. Now it’s a large intestine, it’s different, before it was small, thin, it was another situation.” (F3, wife)

“[...] I did a lot of follow-up with a psychologist, too. I had a lot of support from the psychologist!” (F1, PS)

“The support is very strong! It’s everything to me, that’s all. All the staff there, the [stomatherapist], the [nursing technician], the other, the [social worker].” (F5, mother)

The creation of an elimination stoma requires the care of a multidisciplinary team in the various dimensions, among them: psychological, social and biological, as can be observed in the testimonies. It is noted that for F3 (wife) the nutritional guidelines were fundamental, since before her husband had an ileostomy and, at the time of the study, had a colostomy. This fact becomes fundamental in care, because it is known that, depending on the location of the stoma, eating habits and care need to be modified and adapted.

This reality differed from the situation identified in a study realized in Santa Catarina, in which the assistance received was restricted to the specific care of the gynecologist, excluding the alimentary aspects, physical and labor activities, clothing and social reintegration. This practice of care limits the autonomy of people with stoma¹⁴.

The attendants of specialized services in the care of the stoma, with multidisciplinary service, present a greater security in the handling of the devices, better adaptation to this new characteristic and they are able to prevent the complications^{2,4}.

With the fragments “*I had a lot of support*” and “*is everything for me*” present in the testimonies, it is noticed that the help of the multidisciplinary team establishes itself as a relevant factor facing the new situations experienced.

Families of people with a stoma, faced with the new routine of life, sought information and support to better develop care for their family member, causing a different confrontation¹⁵.

The representatives of the laboratories, suppliers of the bags collector, were mentioned in the interviews as beneficial factors for the care:

“At first, he had some wounds on the back of the bag, because his skin is sensitive. Now it’s resin, before it was a glue. The resin bag is wonderful. There is a very dear person in the supply [representative of the laboratory] who sends it to my son, because it is the one that he has most adapted to. I’ll go get him, come in the little box for him.” (F5, mother)

“The real support is [the stomatherapist] and the [laboratory representative]. Those that bring the most advantages in their area.” (F7, husband)

Adapting to a chronic health condition is difficult, especially when it depends on devices, such as the use of the bag collector. It is then elucidated the importance of obtaining materials that facilitate daily care, a fact that was

identified by the appreciation of the representatives of the laboratories. The technological evolution in the development of the products used for the care of the elimination stomas has become fundamental to promote the health and the quality of life of the people with stomas and their relatives.

Referrals for specialized services to families occurred prior to discharge.

“Before him [husband] discharged, she [the stomatherapist] went there and explained everything. She gave the address [of the service], telephone, everything for him.” (F4, wife)

“[...] it was there in the hospital itself, they gave me to the address. It was the nurse who told me: go there they will tell you how they will provide you with these bags. There will be no bag left for [son]. Oh, it was great for me [she sighs] because it’s very expensive.” (F5, mother)

During the interviews, it was noticed that the continuity of the care provided by the families at home caused less concern, since they had already received information about the care and accreditation in the Service of Health Care of the Person with Stoma of the municipality even during the hospitalization. This referencing was fundamental, expressed in the fragment “*it will not lack bag*”, because it is the guarantee that the bags collector and adjuvants will be acquired, allowing comfort and practicality.

The data corroborate with another study, which reported that the majority of its participants had already been oriented about the registration and referenced to the service by the hospital in which the surgery of the manufacture of the stoma was done¹⁴.

The research participants highlighted, in this context, the performance of the nursing professionals of the specialized service. The care given to families is mainly due to the guidelines regarding the handling of devices:

“At first it was very difficult because I did not know it, but then, every fifteen days I would go and ask for [stomatherapist] quite right what it was like, and for [nursing technique] and they taught me. I took it easy, I had no problem changing.” (F1, PS)

“At the first moment I went there to get it, he could not go together, he was very weak, he could not go, but they guided me, they showed up there in the mannequin.” (F3, wife)

“When he had the wounds [peristome], she [the stomatherapist said,] take your son there that I want to see. You clean with it, do so, and it was wonderful. There, it was, was, that the [stomatherapist] said: this type of glue does not give to him “. (F5, mother)

In the families interviewed, it was identified that some of the people with stomas performed self-care and others depended on a relative. Thus, the information provided during the nursing consultations and the dispensing of materials were fundamental in the development of the skill and formed webs with strong nodes, safety enhancers and reliability for the care.

Within a multidisciplinary team, nursing plays a preponderant role so that the person with the stoma is safe and feel more autonomous for self-care. Among the nursing actions to promote care were: guidelines on care with the stoma, hygiene and frequency of exchange of the bag, social reintegration, insertion of the family in care, work activities, leisure and sexuality¹⁶.

In this way, nursing helps to promote better adaptation and independence by encouraging the person with the stoma to participate in the caring process. In identifying the complexity and problematic, it is reinforced that acquiring manual skills for the development of self-care is essential for the process of daily life¹⁷.

In order to pass the guidelines, the nursing team used different instruments that aided in the understanding of the people, as, for example, by the speech of F3 (wife), one can intuit that the adoption of a mannequin facilitated the understanding of how to make the exchange of the bag.

In addition, in the international scenario, the use of a multimedia education program on self-care for people with a post-operative stoma was highlighted as a satisfactory alternative used by nursing. The patients who received the guidelines with this tool improved their knowledge about self-care, attitudes and behaviors, in a statistically significant way, when compared to those who received by the conventional way, by nurses, on the same content¹⁸.

Faced with the lack of knowledge about the stomas and skills for care, the family seeks health care, support and guidance, especially nursing, to acquire knowledge and tools to care for their family member at home^{15,19}. Faced with the follow-up and guidelines received from nursing, people who live with the stoma are better cared for, which implies effective therapy and collaboration for self-care⁴. Thus, the practice of health education by nurses was emphasized in

a study, in situations of chronic illness, to elucidate care alternatives that may help the quality of life of all those involved in this process⁶.

In addition to the nursing orientations, the nurse stomatherapist was related as a source of support:

“The [stomatherapist] gives support! [...] such attention. Even a doctor, if she needs it, she can do it and make a mark for us. “ (F4, wife)

“I always went to the [stomatherapist], I felt safe when she looked and said everything was fine. I think it was strong for me [the support]. Imagine, at the time, [after surgery] if I did not have that support, what would I do? “ (F7, PS)

The nurse stomatherapist became a reference for the participants, since the care provided to the families was essential, reinforce them in the promotion of the care provided, in the continuity of the care and in the acceptance of the elimination stoma.

The international and national literature highlights the importance of nurses acting as promoters in the process of adaptation and transition from life to what is now²⁰⁻²¹.

Chronic health conditions can weaken all people experiencing such a process. The contact with welcoming health services, in which the professionals assist them in a singular way, so that they feel less fragile and have their abilities enhanced for the care²².

The beneficial influence of professional attention to the people in this study made it possible to use them for the development of care for their families. These relationships formed networks of proximity, creation during the interviews the multidisciplinary team was valued, highlighting the performance of the nurse stomatherapist and the nursing technique, which were referenced at all times by name and not by its function. This can be understood as a manifestation of narrowing in this relationship, which was possible through an open stance to the family and effectively supportive actions.

They do not have the wisdom to do this: difficulties of professional attention

Certifying the duality lived by the families, in other health services, outside the SAHPS scenario, there were reports that the nursing care did not meet the expectations and needs for the care of the person with the stoma:

“As soon as I did [surgery], I went there the first few times [the basic unit of the neighborhood] for the nurses to do, so I did not have to go there [service] [...] there they told me that I had to learn that I had to turn around, that it was not difficult. That’s when I said: I just did it, I want it, I’m going to learn how to do it. After that time, I said: do you want to know something? I’ll learn it myself.” (F1, PS)

“Here [basic unit of the neighborhood] has no one to know [handle the bag]. It seems they are disgusted.” (F1, daughter)

It can be seen from the testimonies of the F1 members that the care given to the family and the person with the elimination stoma, as well as the technical ability for handling and health education in primary care did not correspond to the demands presented. The families F4 and F6 reported similar situations that occurred in tertiary care:

“[Husband was hospitalized] I took the bag from the [stomatherapist], then I blew the bag, I got there [public hospital] he was angry, eventually she [technical nurse] consumed with the little bag I had taken. I think she was cut and cut wrong, so put out. The others exchanged it with him lying on the bed, and she wanted him to get up with nothing and go to the sink. I think she did not want to, I do not know, clean it up.” (F4, wife)

“When it clogs [stoma] he has to go to a public hospital because here in MC [municipal medical center] they do not want it anymore because they do not have the wisdom to do it.” (F6, wife)

It permeates, through the testimonies, the idea of the lack of preparation of the health professionals in the different points of attention. It is understood that performing the care with the stoma demands scientific knowledge and technical ability on the part of the professionals, mainly of the nurses who are the ones responsible for the care to the people in these conditions. The acquisition of these domains is indispensable so that the health services can provide attention that promotes the adaptation, the security and the comfort in the first moments. However, the exchange of the bag collector is not only a function of the stomatherapist, it is a practice that transits in all the attention scenarios, and the nursing team must be enabled.

The Unified Health System recommends, as one of its principles, integrality. Also, Decree N° 5.296 of 2004 highlights the necessity for an integral and individualized care for people with stomas, involving primary, secondary and tertiary care, in order to guarantee the provision of essential equipment for the promotion, prevention, care, rehabilitation and improvement in quality of life²³. In this sense, we highlight the reality of the state of Ceara, where the stomatherapists perform permanent education actions, in order to provide practical instrumentation to other nurses, enabling all of them to have knowledge to care in this area²¹.

The dissatisfaction with the deficient service signaled can be perceived in the record of the field diary:

When the F1 and F4 families addressed the lack of care by some health professionals and services, their members looked sad, and sometimes excited. (Field Diary 10 and 01/21/2013)

It was noted that the reality experienced by the families does not match the assumptions of health policies. Still, implicitly, families demonstrated, in their daily lives, the desire to receive equal, resolute and respectful assistance, regardless of the place of care.

In this perspective, in another study, it was also pointed out that people with stomas wanted a humanized care, in which they received support and attention²⁰. Thus, when a person’s social network presents problems in their accessibility, and therefore in the support provided, this presents a possibility of greater morbidity and mortality, as well as lesser opportunities for recovery^{5,9}.

Situations that complicate the attention of professionals to families promote the distance of relationships, reflecting in the composition of a fragile social network, between the different points of attention to health, with loose or non-narrowing nodes. This evidences the necessity to build actions that weave a network of assistance, in which people who live with elimination stomas can be attended in an egalitarian way and that their singularities in all points of health care are respected.

CONCLUSION

Regarding the perspective of the relationships with the professionals and health services of the participants of this research, the personal social network is interlaced, mainly,

by the staff of the service of the municipality specialized in attention with stoma. The web of professionals and health services forms both positive and negative nodes in the care of the families of the person with the stoma, characterizing the professional attention to the families of people with stoma as a duality experienced.

As a benefit, the multidisciplinary service offered by the Service of Health Care of the Person with Stoma is presented. Still in this scenario, nursing care for families is well known, including guidelines for the devices and support for adaptation and coping with the new way of living. Regarding the difficulties, the families reported the lack of knowledge on the part of some nursing professionals of other services and the lack of preparation to handle the stoma and the device collectors.

It is important that health professionals, when presenting difficulties in care, seek information with the specialized services that form the social network of care individuals, so that a segment in health care is possible, as provided by health policies.

Faced with the results of the study, the question is: Why do these episodes of duality happen? What are the difficulties faced by professionals? What is the care flow between health services? How is the training of professionals for the care of people with elimination stoma? This work does not intend to bring answers to the questions, but to instigate the reflection

on the part of the professionals regarding the nursing care to the people who live with the stoma.

It is known that stomatherapy is a specialization of the nursing that qualifies for the care to the people with stoma. However, this care should not be centered only on the daily life of professionals with this training, but rather should permeate the practice of all nursing staff. To this end, it is hoped that effective networks of care will be created, in which diffusion of health care will occur according to the particularities faced by families and people living with the stoma.

It is important to emphasize the need to broaden nursing knowledge, as it was verified in this study and is consistent with the social networks used, the network promotes health when it is active and reliable. For this to happen, emphasis must be placed on academic training and lifelong learning.

AUTHOR'S CONTRIBUTION

Conceptualization, Simon BS and Budó MLD; Methodology, Simon BS; Investigation, Simon BS; Budó MLD and Leal TC; Writing - First version, Simon BS; Budó MLD; Schimith MD; Leal TC; Silva MM; Wunsch S and Silva DC; Writing - Review & Editing, Simon BS; Supervision, Budó MDL.

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