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## Stomized patients' perception of the stomatherapy service: a descriptive study

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### ABSTRACT

**Aim:** To understand the importance of the stomatherapy service through the perception of stomized patients. **Method:** a descriptive, exploratory study using a qualitative approach, performed in 2011 in the stomatherapy department of a hospital in southern Brazil. Twelve patients with a stoma participated in the study. Data was collected through semi-structured interviews and analyzed using Thematic Analysis. **Results:** The service provided is perceived as a place for patients to learn about living with a stoma, to teach them self-care procedures, to have contact with other people with a stoma and to establish relationships of mutual support and exchange experiences. **Discussion:** The service provides patients with knowledge about the disease and why an ostomy was required, the care measures needed and how to achieve a better quality of life through self-care. **Conclusion:** The stomatherapy service promotes health, and is part of the social support network for people with ostomies.

**Descriptors:** Ostomy; Nursing Education; Self-care; Nursing.

## INTRODUCTION

An ostomy is an artificial opening of any hollow viscera in the body, created by surgical means<sup>(1)</sup>. Ostomy surgery is performed when there is an alteration in the referred tissue caused by cancer, trauma in the viscera region, or due to other syndromes, in order to divert the natural path of effluents, such as feces and urine<sup>(2,3)</sup>. After surgery, this elimination process is not controlled voluntarily, and the person with a stoma will require special collection bags, adapted in the abdomen.

With the breakup of their usual pattern of elimination, stomized patients usually face psychological difficulties associated with fear, shame and insecurity, often leading them to experience sickening feelings about themselves<sup>(4,5)</sup>.

The dependence of the bag, the fear about the smell, the changes in some lifestyle habits, the change of body image and low self-esteem result in worry and can transform a patient's life into a painful process<sup>(6)</sup>. After surgery, stomized patients can experience a number of physiological, psychic or social difficulties<sup>(7,8)</sup>.

The challenges of living with a stoma begin with the diagnosis and continue with the process of adapting to the new condition after release from hospital; the rehabilitation process can be difficult<sup>(9)</sup>. Thus, people with stomas need to receive support, advice and specialized assistance that visualize the specific issues of their daily living, in order to help them get on with their lives<sup>(10)</sup>.

In 2009, the Brazilian government approved Ordinance No. 400 of November 16<sup>th</sup><sup>(11)</sup> which considers the importance and needs of people with a stoma for comprehensive health care procedures from specialists in appropriate healthcare fields. It also takes into account the need for essential material resources and trained

professionals for the development of assistance. Through the Stomized Patient Assistance Program, the stomatherapy service (SS) offers specialized care, providing information, specific measures and full attention to the needs of these individuals. In this context, the ordinance also defines the minimum number of professional staff that should cover the stomatherapy service: a general practice physician, a nurse and a social worker.

In a multidisciplinary team at the SS, the nurse helps people with a stoma with their reintegration into society, by developing facilitating strategies for the process of accepting their new condition. The basis of the work in the SS is the dialogue and exchange of experiences and information, to help patients understand their situation. The SS can be seen, therefore, as a major source of social support for people with stomas and their family caregivers.

In the role of health educators, health professionals need to teach the family about therapeutics, in order to allow them to provide care to the patient with a stoma. This stimulates patients to perform self-care and regain their autonomy<sup>(11)</sup>. Building a bond of trust between nurses and patients is essential for the success of SS interventions. The effectiveness of these actions depends on a continuous and thoughtful approach, with constant changes based on the needs expressed by the stomized patients.

In this context, the question that guided this study was: what is the importance of the SS for the person with a stoma? The goal was to understand the importance of the service from the point of view of the patient. The knowledge generated in this research will enable the professionals at the SS, especially nurses, to rethink their practices among people with stomas, and provide better quality care.

## METHOD

This is a descriptive and exploratory research with a qualitative approach, performed in the second half of 2011. The research is descriptive and exploratory because it describes the phenomenon under investigation and explores the problems experienced; and it is qualitative because it responds to specific questions, making use of social sciences on a level of reality that cannot or should not be quantified. It covers the universe of meanings, motives, aspirations, beliefs, values and actions of people<sup>(12)</sup>.

The study was conducted in a SS at a university hospital (UH) in southern Brazil. The UH has 185 beds reserved for the Public Health System. The SS at the UH has 21 years of experience, with approximately 100 stomized patients and their families. It aims to develop teaching, research and extension activities.

The study included 12 patients with a stoma, who were being looked after by the SS. After receiving guidance on the goals and methodology of the study, they signed the Consent Form. The criteria for inclusion in the study considered the time living with a stoma (for a period greater than or equal to one year) and considered those who had participated in both individual nursing consultation and group activities in the SS. We considered that, after that time, they would have enough experience of the SS to express their views on the service<sup>(13)</sup>. Patients registered at the SS, who did not attend for more than two monthly appointments or were in ill health, were excluded from the study.

We respected Resolution 466/12 regarding the ethical aspects of research with human beings<sup>(14)</sup>, and assured the anonymity of participants, identifying their interviews by the letter P, followed by the sequential number of the interview. The project received a favorable opinion from the Ethics Committee of the Health Area (CEPAS) at the University of Rio Grande (FURG).

After receiving the opinion number 39/2011, we began collecting data through semi-structured interviews. The interview is a method that allows an approximation of reality and a particular combination of theory and practice<sup>(12)</sup>. We raised the issues related to patients' submissions to the SS, activities performed and how they perceived the care provided by the professionals in the service. The interviews took place after nursing consultation on days and at a time previously scheduled with each participant. They were carried out and recorded individually. Interviews each lasted approximately 30 minutes.

The data was analyzed using thematic analysis<sup>(12)</sup>. The focus was on the individual interviews, since it considered the possibility of a match between the type of discourse and the characteristics of the environment or reality in which the patient found themselves. It was performed in three steps:

- 1) Pre-analysis: the selection of documents to be analyzed, a summary of assumptions and goals, preliminary reading, corpus constitution and the determining of the recording unit, with an understanding of the unity and the development of the categories.
- 2) Exploration of the material: the researcher seeks to find categories that are meaningful words or expressions, in which the content of the interviews will be organized.
- 3) Treatment of results and interpretation: proposal for inferences and interrelation with the theoretical framework around new interpretive dimensions<sup>(12)</sup>.

## RESULTS

We observed that the professionals involved in the ostomy surgery (nurses, social workers

and physicians) refer the patient who underwent a recent ostomy and their family caregivers to the SS, hoping that the service absorbs their care demands, showing confidence in the sector.

It was the doctor who operated on me. He sent me to the SS after surgery and said that there I would have all the support to take care of me well. (P1)

When I went to surgery to get this bag I was not even thinking, I had no idea how it was going to be. I knew I'd have a bag, but I knew nothing else. It was after that the hospital's nurse brought me here, and here in the SS I learned everything. (P10)

The free supply by the State Health Department of materials (which are currently not easily accessible in pharmacies and hospital material stores) presents itself as an important point in the decision to seek the SE, as the high cost of these supplies in the market precludes their acquisition by most people with stomas.

[...] I also came to the SS to get the bags and products to protect the skin, since we can't find them in the drugstores. It is the government that provides this and it's all free! (P12)

The certainty of obtaining knowledge about the materials, the procedure for replacing the collection bag and other inputs that support self-care appear as an important reason to join the SS, and patients admit the improvement in their lives.

Look, it's been more than four years now that I have been using the bag. Today I have no difficulty and live

well. It was difficult in the beginning. The nurses used to teach me, they used to change it and ask me to help, but when I came home I could not do the same. It was a gradual and slow process but I got it, and today I live a better life. (P2)

Oh! The nurse explained it to me, he explained what to do. Everything! How I can use it so people don't notice that I'm using the bag. When I go somewhere I use a strap, a lycra band to hold it close. (P8)

The constant updating of care methods and technologies offered by the SS is cited as a motivation for seeking the service. This now represents a reference of care and health promotion for people with a stoma and their families.

Although today I already know almost everything about it, I'm always learning. I keep myself updated, informed about the news regarding the care of the stoma and skin. (P3)

It has helped. I combine new knowledge with what I already have. So I have no difficulty at all. I learn fast! But I learned slowly at first. At first the nurse changed it, then I changed it with her and now I change it quickly. (P9)

The coexistence with other patients in the SS allows the establishment of relationships of mutual support and the exchange of experiences of the same living conditions and the same problems. Feeling supported, understood and seeing that they are not the only ones in that situation, patients realize that they can have a good quality of life.

It is really good. We meet many people, and I need the group. When I come to the group meeting I feel very well. There is a bond between us. It seems that whoever is out there does not understand what we go through as well as we do. We understand each other, we care about each other and we want to come, to be here! The group knows what I'm talking about and what I'm going through, because they are like me. (P11)

In the SS, the stomized patients feel welcomed by professionals. This contact provides the perception that they are not alone in facing their problems and that they can live a quality life. Thus, they feel more determined to adapt to their new situation in a less traumatic way.

I need the nurse and everyone who works here. I feel welcome, I feel at home, among my people. I don't know how to explain! I need to know that they are here. That if I need to, I can come here and I'll be understood. It made me want to improve and live better. (P7)

The link between professionals, the group of people with a stoma and the support of family and friends encourage the patients to face their everyday problems, causing them to mention that without the SS environment they would not have realized the possibility of living a quality life.

With the professionals, the group and the family, I think we learn to deal with it. To face it, I think it's very important, right? Because some need it more, and others have more courage. There with

other people, we see that it is possible to live well. We become strong and learn to live. (P4)

Bit by bit I got used to it, because I also read a lot about ostomy. It's like dealing with an amputation [...] So it's hard. But in the SS we have support. We know that the professionals will be there to help us always. It gives us a lot of security and I can live more peacefully! (P5)

I have a lot of support in times of difficulty here in the SS, because I used to have a lot of gas and the bag became bloated, sometimes it popped and there was that bad smell! But I sought the nurse and learned to use the activated carbon that treats the gases with no smell and helps the bag to last longer. Today I feel encouraged to go out and have a social life again! (P6)

## DISCUSSION

The construction of a stoma and the use of the collection bag can cause severe repercussions on a person's body image and self-concept, generating negative feelings about life with a colostomy<sup>(15)</sup>. The changes that the person with ostomy faces range from the removal of an important organ and the consequent deprivation of sphincter control to decreased self-esteem and self-concept, and feelings such as depression, disgust, hatred and self-rejection<sup>(16)</sup>.

This procedure also implies the revision of habits, values and beliefs; the incorporation of professional knowledge; access to specialized health services and disposal devices for the patients' bag; as well as changes in their family, work and daily life<sup>(17)</sup>. These changes, in turn,

affect their family, emotional and social life, as well as reflect on the environment in which the patients receive care or perform their self-care procedures<sup>(18)</sup>.

Besides the stoma repercussions, the care measures require both specific theoretical knowledge for the treatment of stomatherapy, and practical skills to assist these patients and their families<sup>(19)</sup>. In this context, the SS units emerge as a reference for acquisition of knowledge and materials for self-care, improving patient's quality of life.

The focus of the SS is on specialized care that includes education for self-care, evaluation of general biopsychosocial needs of patients and their families and specific needs related to the stoma, including the prevention and treatment of complications, and the recommendation, prescription and supply of collector equipment, as well as protection and safety adjuvant equipment<sup>(1)</sup>.

Establishing a parallel with other global policies regarding the access to stoma treatment materials, developing countries in general have more difficulties accessing the equipment due to the high cost market, which makes its acquisition very difficult without public funding. In contrast, the access to materials is provided partly or fully via public health or private insurance systems, and the patients with a stoma have the possibility to choose the equipment that best suits their needs<sup>(19)</sup>. The increasing demand of collector devices by developing countries, such as Brazil, has led to increased accessibility to these through specialized stores with different types and prices. The difficulty of access to these materials is reduced through laws that guarantee access to these – such as N12.738 Law of November 2012<sup>(20)</sup>, which states the mandatory provision of collectors by health insurance plans, showing an alternative to private health system customers.

The treatment measures for stomized patients are not limited to the provision of care equipment; on the contrary, they seek to cover the complexity of human beings. Thus, the service has an interdisciplinary team. This is crucial to the rehabilitation of people with a stoma, as it provides support that encompasses all their real needs<sup>(18)</sup>. With the help of these, one attains autonomy and can participate in educational workshops and support groups, which are essential for the reconstruction of self-care<sup>(5)</sup>.

Within the context of the acquisition of self-care, the nurse emerges as a transforming health agent, acting as an educator to the people with ostomy and their families. The nurse can use educational technologies that facilitate the acquisition of knowledge, making the learning process simpler and with easier implementation<sup>(18)</sup>.

Thus, nurses are essential elements in the rehabilitation process of people with a stoma, as they are present from diagnosis, participating in the decision to have ostomy surgery in a hospital or outpatient environment, before surgery, during the post-surgery hospitalization, in discharge and in the later postoperative period, either at the SS, health centers or family health teams<sup>(22)</sup>.

Technological innovations regarding the materials and forms of care in stomatherapy are constantly developed, requiring constant updating of knowledge of health professionals, so they can provide skilled care and teach safer and more efficient ways for self-care.

The family provides the support to the fragility of the person with ostomy and helps overcome situations of crises, insecurity, anger, anxiety and fear. To provide help to the patient with a stoma, it is common for the family to put aside all disagreements in order to become united and harmonious to aid in a patient's recovery<sup>(17)</sup>.

The difficulties in maintaining the collection bag and the embarrassment with the odor and gases can demotivate patients with a stoma, leading them to isolation and dependence. However, family and friends can help to provide care and attention in these moments<sup>(23)</sup>. For the people with ostomy, feeling loved is really relevant, because this enables them to feel like an important part of the family unit.

The support groups, in another way, easily provide the interaction between patients at different stages of adaptation to the stoma, allowing the sharing of experiences and strength to face daily difficulties, contributing to improved acceptance and quality of life. Support groups disrupt the existing social paradigms, encouraging social inclusion and the development of innovations to face the health-disease process in a periodic living space and in an educational environment to develop autonomy through information related to their life context<sup>(18)</sup>.

Support groups focus on physical and psychosocial rehabilitation, by creating a place that promotes social support, expansion of skills, education, information and the discussion of existential issues. Health professionals encourage the independence of people with a stoma, by empowering and encouraging them to adopt new attitudes.

## CONCLUSION

We sought to understand the importance of the SS for people with a stoma. The study data shows that the ostomy creates deep changes in the lives of its sufferers, causing them to require the support of health professionals / nurses working in the SS.

Regarding the relevance of the SS to the person with a stoma, the data showed that patients participate in the service to care for their

stoma, to purchase materials and equipment, to update themselves about the possibilities of improvement in care, to make contact with others in a similar life situation, to establish relationships of mutual support and exchange experiences and to learn to live with the stoma. The SS represents a safe place, where health professionals are available to help them overcome their difficulties.

We observed that in the SS, patients with ostomy acquire knowledge about the disease that resulted in the stoma, the necessary care measures concerning the stoma and how to get a better quality of life through self-care. They gradually build skills for their self-care and develop specific strategies to their needs.

Contact with people who are in similar situations helps the stomized individuals realize they are not alone living with this situation. At the SS, they seek encouragement, they acquire knowledge about self-care, renew their hope, find group cohesion through altruism and universality, and gradually they rediscover their social life.

We concluded that the changes caused by living with an ostomy require time to be assimilated. Thus, searching for a space to express their fears, their doubts, their repressed feelings and receive the support they need to face the ostomy and everything that surrounds this new condition, people with a stoma seek the SS because they know they will find the professionals and the support group that will understand their difficulties and anxieties.

The knowledge generated in this study may help to build more effective care for the patient, presenting the SS as an essential source of support and care skills acquisition and development. Nurses working in this type of service need to be able to help people and their families in coping with their illness and recovery process after surgery. It is possible for people with a

stoma to live well. They need to reframe their life, rebuild their self-image and regain self-esteem, building a social support network able to provide them support. The SS is a place for the construction and maintenance of this link.

This study presents, as a limitation, the fact it was performed in only one SS. Thus, further studies on how the different SS units are acting and qualifying the lives of patients with a stoma should be conducted.

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