

SOCIAL AND FAMILY DYNAMIC WITH PATIENTS WITH DEFINITIVE INTESTINAL OSTOMY

Dinâmica sócio-familiar com pacientes portadores de ostomia intestinal definitiva

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ABSTRACT – Rational: The person who undergoes a definitive intestinal ostomy experience significant changes in social and family dynamics. Most of the time the patients are fragile by risk due to the new situation. **Aim:** To analyze the social dynamics of people with permanent intestinal stoma. **Method:** Qualitative research on the basis of information collected at the time of the monthly withdrawal of collecting handbags and accessories provided by the unified Health System. Were part of the study 12 users of São Miguel do Oeste, SC, Brazil who agreed to participate in the research. **Results:** Eight women and four men were included. Eleven were elderly and all were retired. Users lived with few people. The largest family interviewed had four people, the other only with the spouse or lived alone. All users indicated that they had someone to help them after the ostomy. Four users have reported that they needed aid routinely and eight were blaming himself alone by the exchange of necessary hygiene and care. Seven said that they had some kind of difficulty or negative feeling because of using the collection bag. Fear and embarrassment were the most mentioned feelings. On the other hand, five users have stated that did not have difficulties or negative feelings due to the ostomy, and that these feelings had been overcome. **Conclusions:** Coexistence with the ostomy is highlighted as causing fears, constraints, discomfort and doubts. The family and social support can promote a new identity to the person, enabling the return of lost self-esteem and social reintegration.

HEADINGS - Public health. Family practice. Ostomy. Unified health system.

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RESUMO – Racional: A pessoa que se submete a realização de uma ostomia intestinal definitiva, vivencia significativas alterações na dinâmica sócio-familiar. Na maioria das vezes percebe-se que elas apresentam-se fragilizadas devido à nova situação que se encontram. **Objetivo:** Analisar a dinâmica sócio-familiar de pessoas com ostomia intestinal definitiva. **Método** - Pesquisa qualitativa com base em informações coletadas na ocasião da retirada mensal das bolsas coletoras e acessórios fornecidos pelo Sistema Único de Saúde. Fizeram parte do estudo 12 usuários do município de São Miguel do Oeste no estado de Santa Catarina, que aceitaram participar da pesquisa. **Resultados** - Foram oito mulheres e quatro homens; 11 eram idosos e todos estavam aposentados. Os usuários residiam com poucas pessoas. A maior família entrevistada possuía quatro pessoas, os demais residiam apenas com o cônjuge ou relataram residirem sozinhos. Todos os usuários informaram que contavam com alguém para auxiliá-los após a ostomia. Quatro usuários relataram que precisavam de auxílio rotineiramente e oito responsabilizavam-se sozinhos pela troca das bolsas, cuidado e higiene necessários. Sete relataram que possuíam algum tipo de dificuldade ou sentimento negativo pelo fato de utilizarem a bolsa coletora. Medo e constrangimento foram os sentimentos mais mencionados. Por outro lado, cinco usuários afirmaram que não possuíam dificuldades ou sentimentos negativos por serem ostomizados, e que estes sentimentos já tinham sido superados. **Conclusões** - A convivência com a ostomia é destacada como causadora de medos, constrangimentos, desconfortos e dúvidas. O suporte familiar e social pode promover uma nova identidade à pessoa portadora, possibilitando retorno da autoestima perdida e a reinserção social.

INTRODUCTION

*Ostomy is not a disease,
It's just living in a different way!*
(FLORIANO, 2008)

Usually, family members of the individual undergoing surgery are responsible for making the first contact with the market supplier of ostomy pouching systems, obtaining information regarding the procedures that are required to manage the stoma, and collecting the pouch and accessories while the patient is still in hospital.

Understandably, people may feel overwhelmed when dealing with their ostomized family member, particularly due to the changes in the individual's day-to-day social life after the procedure.

There are different types of stoma; colostomy, ileostomy, and urostomy are some of the major ones.

All of these require the use of an ostomy pouch by the patient to collect waste drainage. These bags have been improved over time and, nowadays, provide an improved quality of life to patients. The bags are freely available to patients through the Unified Health System (SUS).

The life changes that individuals with an ostomy undergo may have psychological and social consequences. For these people, living with a new device in their body may lead to fear, embarrassment, and self-doubt.

In this context, family is of fundamental importance, given its role as a form of support structure to the ostomate. However, vulnerability among family members has also been observed. Thus, a multi-professional health team could play an important role in informing and improving the quality of life of the ostomates, as well as that of the family unit.

However, each person is unique, with his/her own way of dealing with the situation and adapting to this new life condition that possibly involves suffering, pain, uncertainties, myths, and fears.

Monitoring the ostomates is essential, as they need support to overcome the changes brought about by an ostomy and the partial loss of a bodily system aimed at maintaining their control over defecation and gas leakage.

Each ostomy pouch has distinct features, with individuals further reacting differently to the use thereof. Thus, the frequency with which the pouch is replaced differs from one person to another. On average, most ostomates empty their pouches between five to 10 times a day. The pouch should ideally be replaced one to two times a week¹ and emptied before reaching 1/3 of its filling capacity to avoid the risk of rupture.

It is important for users of the ostomy pouch not to perceive it as an "enemy." Although it requires special care and attention, the pouch offers users the opportunity to lead a normal life.

After overcoming the initial shock, most colostomates/ileostomates can lead a normal life and must, by all means, adhere to several guidelines regarding hygiene, and use of appropriate materials to ensure safety². However, the ability to overcome initial difficulties will be directly dependent on each individual's internal resources, the family, social support, and the health professionals involved in the case, as well as the supporting service structure that is offered to the patient.

The objective of this study is to analyze the dynamics in the social and family lives of individuals who have undergone a permanent intestinal ostomy.

METHODS

Qualitative research was conducted on the basis of the information collected during the monthly removal of stoma-collecting pouches and accessories during the 1st Regional of Health Management of the state of Santa Catarina, São Miguel do Oeste, SC, Brazil. The data was also collected during

home visits to individuals with a permanent intestinal stoma. The study was conducted from July to December 2010.

Twelve users of the pouches agreed to participate in this research and subsequently signed the Free and Informed Consent Term. The project was approved by the Research Ethics Committee for research involving human beings at Santa Catarina West University (UNOESC) (Opinion of No. 094/2010).

Semi-structured interviews consisting of open and closed questions were conducted with the use of a checklist. The interviews tapped into variables such as age, sex, marital status, duration of the colostomy pouch usage, family structure, initial difficulties with pouch usage, and changes in the dynamics of the participants' social and family lives.

RESULTS

Among the 12 pouch users that were interviewed, eight were women, representing 67% of the sample (Table 1).

TABLE 1 - Relationship between patients' demographic information and ostomy data

Patient	Age	Marital Status	Duration of stoma pouch usage
1	76 years	Widow	5 years
2	82 years	Married	4 months
3	80 years	Widow	24 years
4	82 years	Widow	4 years
5	73 years	Married	2 years
6	59 years	Divorced	16 years
7	77 years	Married	41 years
8	73 years	Married	4 months
9	92 years	Widow	20 years
10	60 years	Married	9 years
11	74 years	Widow	8 years
12	74 years	Married	1 year

In relation to family structure, this study revealed that pouch users usually lived with a small number of people. Of those studied, the largest family comprised four individuals; the remainder of the participants either lived with a spouse or alone.

All users reported that they relied on someone for assistance after the ostomy. One reported that his wife helped him in the initial phase, three were assisted by their daughters, one by her daughter-in-law, while another hired someone to support him; half of the users, who constituted the remainder, reported that nurses from the Family Health Strategy team helped them. Four users reported that they needed regular assistance, while the remaining eight were entirely responsible for replacing their own pouches, and undertaking essential health care and hygiene procedures.

The interviews revealed that of the 12 users, seven experienced some difficulties or harbored negative feelings regarding their use of the collection pouch. The most frequently mentioned feelings were fear and embarrassment. However, five users reported no difficulties or negative feelings regarding their condition as ostomates, further adding that they had already overcome those feelings.

DISCUSSION

According to data from the State Secretary of Health, in 2010 approximately 2000 people were registered as ostomates in the Specialized Service of Santa Catarina state.

In Brazil, it is estimated that in 2010, there were 13,310 new cases of colorectal cancer among men, and 14,800 among women. These figures correspond to an estimated risk of 14 new cases in every 100 000 men and 15 in every 100 000 women.

Before 2004, the rights of ostomized people were limited to obtaining collection bags, as stipulated in Ordinances 116/93 and 146/93 of the Ministry of Health (MS). On December 20, 1999, Decree No. 3.298 initiated the supply of collection pouches as a form of technical support to people with ostomy³. However, Decree No. 5.296⁴, as of December 2, 2004, encompassed major advances in this respect, as it classified individuals with ostomy as physically disabled. Thus, ostomates were safe-guarded by laws that regulate the rights of disabled people. An example of this is the right to Continued Provision Benefit, which is financial support in the form of a monthly minimum wage paid to individuals with a disability or elderly persons (65 years old or older) who cannot support themselves financially or receive financial support from those closest to him/her. In this regard, it is essential that income per capita be below ¼ of the minimum wage.

Furthermore, as of November 16, 2009, on the National Day of Ostomates, Ordinance SAS/MS No. 400⁵ introduced National Guidelines to support the health of ostomized people under the scope of the SUS. According to this Ordinance, healthcare units were required to establish multi-professional and specialized teams, as well as create an appropriate physical structure for the support of these patients, who must be provided with collection pouches and monitored by a doctor, nurse, social assistant, psychologist, and a nutritionist. The minimum constituents of each of these teams for the Support to Ostomized People I service should include a doctor, a nurse, and a social assistant. Further, the Support to Ostomized People II service is aimed at patients with complications or those requiring stoma reversal surgery, and support by a psychologist, nutritionist, and specialized doctors in proctology, urology, surgery, gastroenterology, and oncology.

The importance held by the Family Health Strategy team to these patients should not be understated. Ostomates rely on the support provided by these professionals to obtain help for whatever they need to maintain a good quality of life, despite their condition. Patients have reported that, in most cases, this type of assistance occurs when health professionals conduct home visits.

Typically, several stoma care treatments are needed. In the initial phase, the ostomized person may find it difficult to adjust as the body has an additional, sensitive device that requires considerable care.

After surgery, difficulties in adjusting are quite common among ostomates. This process differs from one person to another, but family plays a fundamental role, as does the support/ orientation that is provided by the professionals involved.

Users have reported numerous changes in their day-to-day social and family lives. It was evident, based on the

narratives that significant changes had occurred in the patients' daily lives, particularly regarding their participation in the community, working, and family environments. Patients specified shame, fear, insecurity, and embarrassment as the prevailing feelings associated with their condition.

Therefore, adequate family and social support could lead to a major transformation within the individual, leading to higher self-esteem and the possibility of social reintegration.

In this regard, Family Health Strategy teams, together with the social and family support networks, must meet the expectations of the ostomized person.

It is necessary, above all, for family members to acknowledge the feelings of hurt, resentment, revolt, and loss of the ostomate in order to facilitate acceptance of the individual's new lifestyle after an ostomy.

Learning how to live with a stoma could present challenges in anyone's life. There have recently been important developments in surgical techniques and the technology used by ostomized individuals, particularly regarding pouches, which contribute to a significant increase in the individuals' quality of life. Despite these advances, these individuals still contend with many changes in their lifestyles due to the surgery. Nevertheless, such changes should be regarded as similar to any other changes that could occur in a person's life and necessitate adjustment; examples of these are a new job, city, or language. People who undergo surgical intervention resulting in stoma formation will have to adjust to daily activities brought about by their new body form. Therefore, after surgery, a period of adaptation is expected to occur in order to allow the individual to re-establish himself/herself, and learn how to deal with the physical changes and adjust mentally to these.

CONCLUSIONS

Coexistence with the ostomy is highlighted as causing fears, constraints, discomfort and doubts. The family and social support can promote a new identity to the person, enabling the return of lost self-esteem and social reintegration.

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