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USERS WITH A STOMA: THE SELF-CARE EXPERIENCE

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ABSTRACT
The objective of the study was to know the experience of patients when performing self-care with the stoma. Qualitative research in which eight interviews were conducted with patients of the Ostomy Outpatient Clinic of the Vila dos Comerciários Unit, in the city of Porto Alegre/RS. Data were submitted to content analysis, and the following two themes emerged: 'Influence of the stoma in social life'; 'Dependence and bonding in self-care with the stoma'. The ostomy causes dependency for the change of the collecting device, and this task is delegated to a trained family member or a specialized professional. The bonding created by the patient through the feeling of security of a 'high quality care' creates dependency for care. Self-care involves the fear of making mistakes when adapting the bag to the skin, since a mistake can result in reduced time of permanence of the bag and generate waste in the number of bags.

Keywords: Ostomy. Self-care. Personal autonomy. Nursing care.

INTRODUCTION

Ostomy is a surgical procedure that forms an artificial opening to the external environment in the exteriorization of a hollow organ. Ostomies are classified according to their location, namely: colostomy, ileostomy, gastrostomy, urostomy and tracheostomy.

The stoma may be temporary or permanent. Temporary stomas protect an organ by preserving it until its reconstitution. Permanent stomas are formed when there is no possibility of future reconstruction, have palliative character and improve users' quality of life. These remain for the rest of life(1).

Ostomies can bring several changes in the daily life of people with a stoma that can reach their personal projects and add new social, economic, emotional and physiological priorities interfering with their daily lives, self-image and interpersonal relationships(2).

In this dynamic relationship between self-care and social interaction, people with a stoma are often taken for the feeling of being different, a feeling that translates into fear, anguish and guilt in their way of being and relating to others. These feelings end up affecting interpersonal relationships and may also affect their identity as a person. Because of the ostomy, these people require more specific health care to their bodies, especially regarding physiological eliminations such as feces and urine, and their management in a new configuration(3).

Thus, the construction of the stoma begins to mark users' lives in a particular way. The acceptance of the stoma or not is an individual transition with several changes of particular proportion. Life and personal experiences of people with a stoma can determine their ability to adapt to the new health condition and face adversities in a less painful way(4).

People with a stoma also need to get used to the different bags in the market, because there are several models and brands commercially available. They have to identify the different specificities in these products, such as accurate hole-cutting and the way of placing on the skin, besides eventual complications occurring if the collection bag remains in contact with the skin. Thus, different problems can lead to difficulties in adapting to stoma support and maintenance devices, leading to insecurity caused by lack of knowledge or lack of care information.

The establishment of self-care and development of never-experienced health-related skills is not easy. It is an important transition faced by many people

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with a stoma. Adaptation to the collecting bag is difficult and involves subjectivities and different problems. Interactions with family, friends and health service professionals can assist people with a stoma in the possible performance of care with autonomy(5).

The social support to individuals around people with a stoma can potentiate the care organization and help these patients to recapture their life management. In this context, nursing professionals have an important role in the development of health promotion and education by directing the knowledge related to interfaces constituted by the stoma and the bag.

For nursing, the self-care and autonomy relationship should influence the work process organization by developing care for people with a stoma through the look, in addition to the physiological and anatomical changes generated by the surgery and stoma preparation. There must be concern with the co-responsibility and empowerment of people with a stoma aiming at their self-care(6).

The changes caused by the stoma and the use of support and maintenance devices require patients' knowledge to manage the available materials hence self-care is an important aspect for autonomy. Many stoma-related difficulties experienced by people bring demands for nursing professionals' practice. In the context of people with a stoma, these professionals can recognize the problems and potentialities to contribute to the management of a full life.

Regarding the health condition of people with a stoma, the Presidential Decree No. 5296, of December 2, 2004 was an important landmark by considering them as disabled individuals. This fact was a social gain for people with a stoma by guaranteeing several rights and promoting the creation of clinics with specialized professionals for the care and regulation of care, and free supply of stoma-related devices(7).

Nursing care requires a close relationship with users that results in a mutual interactive process of interpersonal relationships, in which dialogue and contact are valued, and always based on ethics and respect(8).

Therefore, knowing the difficulties faced by people with a stoma when performing self-care with the stoma and its devices may approximate health professionals' actions and patients' needs. The objective of the study was to know the experience of people with a stoma when performing self-care with the stoma.

METHODOLOGY

This is a qualitative study. This type of research studies people's relationships, representations, and perceptions about how they live, feel, and think(9).

The study was conducted with users of an ostomy outpatient clinic, within the network of specialized services of the Municipal Health Department of the city of Porto Alegre (state of Rio Grande do Sul – RS). The outpatient clinic under study is responsible for an area covering two health districts that includes 22 neighborhoods of Porto Alegre with an estimated population of 340,465 people(10). This clinic provides services that aim to evaluate and perform nursing care with the stoma and peristomal skin, and favor the rehabilitation of patients' self-care activities.

Inclusion criteria for the study were users with a temporary or permanent stoma receiving outpatient care at the Ostomy Outpatient Clinic of the Vila dos Comerciários Unit, and who were lucid and able to answer the questions. The exclusion criteria were users younger than 18 years.

Eight users chosen by the clinic professionals were intentionally selected. According to the professionals' evaluations, these patients did not perform self-care with their stoma and related devices, and care was performed by nursing professionals or their family caregivers.

Firstly, users were informally invited by the outpatient team to participate in the study. After acceptance, was arranged the day and time for interviews that were performed in the households or in a private space in the Ostomy Clinic according to patients' choice.

Information was generated through semi-structured interviews performed in August, 2016 and recorded in MP3. Transcripts were used as a basis for structuring the results and performing analysis. For the organization of speeches, was used a codification by assigning the letter 'E' for patients (E is the first letter of estomizado, person with a stoma) together with a number represented by the transcription order of interviews.

For the analysis of information was used the thematic analysis technique. The exposed themes were translated from nuclei of meanings, frequencies and presence of meanings that composed participants' own discourses. These meanings were transmitted and brought to light the multiplicity of feelings experienced by participants by finding answers on the studied object(9), i.e., in the self-care experience of patients with their stoma.

Considering ethical aspects, the requirements for research with human beings were fulfilled, according to Resolution No. 466/2012(11). The study is part of the project: 'Integrated Research on Work Organization and Integrality in Services: new technologies in care for users with skin injuries in the Health Care Network of the State of Rio Grande do Sul', and was approved by the Research Ethics Committee of the Universidade Federal do Rio Grande do Sul (CEP/UFRGS) under number CAAE: 56382316.2.0000.5347. Before the interview with each participant, were signed two copies of the Informed Consent (IC) form.

RESULTS AND DISCUSSION

The study included eight people with a temporary or permanent stoma, aged between 45 and 85 years, of which five were men and three were women. Their time with the stoma ranged from six months to four years, and the mentioned types of ostomies were colostomies and ileostomies.

Women participating in the study stated the following work activities: domestic, handicraft and street salesperson. In relation to men, two were taxi drivers/drivers, two were teachers and a civil construction worker. The causes that led to the stoma were intestinal cancer (E1, E4, E8), intestinal obstruction (E3, E6), inflammatory process of the intestine (E2, E7) and enterovesical fistula (E5). The educational level ranged from illiterate (1 participant), elementary school (5 participants), and higher education (2 participants).

In the data analysis emerged two thematic categories that composed the corpus of discussion of the study, namely: 'Influence of the stoma on social life' and 'Dependence and bonding in self-care with the stoma'.

Influence of the stoma in social life

In general, a stoma may bring some difficulties in daily activities and lead to feelings of fear and social limitation. Fear of discrimination, based on health or shame, modifies a person's identity, and may decrease self-esteem and restrict participation in social activities(12). For example, the impossibility of finding a suitable bathroom for cleaning or changing the collection bag can expose users to public embarrassment, and create the need to program their routine in order to have access to a place with minimal structure for emptying, cleaning or changing the bag.

Not only this is related to the care needs, but also signals the lack of adaptation of social environments for the hygiene of the collection bag. When these bags are full, people with a stoma often avoid certain places, making social interaction difficult(4). This reality was mentioned by some participants. They reported to organize their commitments bearing in mind the accessibility of available toilets to clean the bag.

> The stoma is a bit limiting 'cause if I have to go out, I need to organize myself. My fear is precisely of moving around long distances and taking transportation where I cannot clean the bag. I always try to be near a restroom. When I go out, I always organize myself in order to have an available restroom where I go, so I can empty the bag a little. (E7)

> I'm a limited man, that's the thing. I'm no longer the same, I was a guy who used to sing, play the guitar, cheer people up, go to church, participate in groups. I miss all that. When you have to go out, people with a stoma have to make sure there are good toilets available where you are going. (E8)

For respondents, dealing with emptying the collection bag has particularities. It is advised that they empty the bag before it reaches a third of its capacity, therefore, people with a stoma should do it five to ten times a day, on average, to avoid the risk of rupture and its detachment from the abdomen(13).

To this end, there must be a place with minimum conditions of hygiene and physical structure, such as a sink and a toilet located in the same space with privacy, for emptying or changing the bag. Both the cleaning and change of the collection bag may expose people with a stoma to public embarrassments because of their condition.

In some situations, people with a stoma make choices to avoid these possible social embarrassments, such as limiting feeding or choosing foods that slow or modify fecal content production. However, these food choices can harm one's own health, since dietary restrictions result in nutrient reductions and may affect health.

> As I still work, I have to clean the bag in the morning when I wake up and at night when I get home, and I try to control my food at lunch time. I cannot eat much, because the bag will not hold, it'll be full before I get home at night. My diet has to be controlled. (E4)

> I limit my diet, but this limitation causes me problems. After the surgery, I started to have a more differentiated diet, eating a little less and more often, and whenever I eat, I have to empty my pouch, so it's limiting for me. (E7)

> Health professionals say: you can eat everything! Diet is unrestricted! Even a diet written on paper, but not quite, 'cause you'll need to clean the bag all the time, it's impressive, and that's not said. This has to be said to people, the more you eat the more you'll have to clean the bag. (E8)

The search for new healthy eating habits is necessary for the better well-being of people with a stoma, taking care not to ingest or avoid the consumption of certain foods because of their characteristics of producing gases, liquid feces or increased intestinal output. With this concern and care, users are able to work and maintain social relationships(8). Dietary changes occur as a way of adapting to life with the stoma and need the health professionals' understanding within the context of users' fear and insecurity, aggravated by the lack of social inclusion support for people with a stoma, despite the already conquered legal advances.

Lack of public support was brought by study participants because they did not find adapted spaces to their health condition, requiring that they are creative to perform self-care. Physical structure deficiencies of collective spaces have a negative impact on the quality of life, because in many situations, people with a stoma limit their social life and remain at home, often in a process of social isolation.

Dependence and bonding in self-care with the stoma

The difficulties with handling of the stoma related to the change of the bag by people with a stoma, and care with the peristomal skin guided the construction of this theme. Fears came to surface loaded with one's own senses with impact in self-care, as patients reported not having the courage to look at the stoma and touch it. However, the occurrence or non-acceptance of a new life condition is an individual process with several changes and proportions that are particular to each person(4). Positive and/or negative experiences related to daily life give singular meaning to moments experienced by patients. When such experiences are symbolized through fear and anxiety by modification of the body itself as a result of the stoma, these can expose difficulties such as dependency to perform self-care(14).

Some users mentioned they cleaned the collecting bag but did not change it, which makes performing self-care difficult. These cases require a specialized professional or trained family member to do this task. Only the emptying and cleaning of the bag was performed with some autonomy, but the change of the bag, when necessary, was delegated to other people on the pretext that they would feel more secure about maintenance of the bag.

> I still don't change the bag at home. I haven't had the guts to look there, so I change with the nurse at the health unit. The intestine goes out a lot, so I'm afraid. I just empty it, because the bag has an opening underneath, but I still haven't got used to it. I have no difficulty with cleaning it, but I don't have the courage to change it, I'm afraid. (E2)

> It is very easy to clean the bag, it's always very clean, but I don't change it, no one does, only there with the nurses. I'm afraid of someone else doing it and not doing it well. I feel more secure with the nurses. (E3)

Being prepared or not for the experience of a stoma and its modifications can influence the performance of self-care. Patients must feel safe to perform self-care with autonomy, both when cleaning and changing the bag(5). By exercising self-care with property, patients organize their daily life with greater freedom according to their chores by exercising the power of choice with themselves.

Autonomy is a person's capacity to understand him/herself, and the context in which he/she is inserted, with the possibility of acting on him/herself and that context(15). Through autonomy people with a stoma can recapture their life in the fullness of daily work and family and social life by recreating the conditions to move on and face the inherent difficulties with resilience(16).

The interviews also showed the difficulty of performing peristomial care due to fear of making mistakes when adapting the bag to the skin, which would result in a shorter permanence time of the device hence more waste of bags.

> Changing the bag is terrible, how can I do it by myself? I can't. There are people who change it, but then the wife or someone helps, I have no conditions, nor want to. Changing the bag is a problem, I won't do it right, I won't work for a week with the bag if I change it, it won't work, I'm sure. That's why I decided I won't do it at home any more, I waste time and waste my bag if I

> change it badly, I've been going to the health clinic for four years to change it. (E4)

For interviewees, the fear of making mistakes and wasting bags was associated with insecurity regarding self-care with the stoma and its peculiarities. Although nursing professionals offer guidance on handling the stoma and the stoma bag, they were mentioned as a contribution for the development of patients' necessary autonomy to manage their self-care.

Care is expressed in the behaviors and actions involving knowledge, values, skills and attitudes undertaken to favor people's potential to maintain or improve their living conditions(8). Self-care can ensure the independence of people with a stoma regarding the cleaning and change of the bag, the perception of complications related to the stoma and, consequently, to act on them(17).

The presence of the stoma and the necessary care bring important changes in the daily life of people with a stoma. For the most part, are required from patients new and never experienced skills that are specific and full of meanings(4). Not infrequently, care with the body and stoma requires confidence and security to do so, which are found in health professionals, particularly in nursing, who offer the guarantee of safe performance, reported by study participants as 'high quality care'.

The bond established in the care relationship between nursing professionals and people with a stoma created a character of dependence on the change of collection bags that resulted in user embracement. However, the feeling of security generated from this bond highlights the dependence relationship between professional performance and users' well-being.

> I prefer to have the nurse change it, check if there are any injuries. I change it with the nurse because there may be some problems, a skin injury that I cannot see in the stoma folds, that's why I change it with her. (E1)

> I don't change alone, I always go to the health clinic, I find it more practical, they know more, and we cannot change it alone because it has to be in the right place and it's difficult. The position of the bag is not easy. How am I going to look at it and put it in the right place? (E6)

Therefore, the concern with self-care guidelines must begin before the surgical procedure by preparing the person for the new to come, such as the demarcation of the stoma site in order to facilitate later self-care and promote quality of life(18). The social support potential of institutions for people with a stoma, and specialized care sites should be considered as part of care by acting beyond care guidelines and preparing patients with a stoma to cope with diverse aspects of everyday life through health education(19).

Thus, the performance of consolidated care must be consistent with patients' self-care. When changing the stoma bag, health professionals' guidelines should be focused beyond technical actions, question professional practice, and reflect a better performance(15). When built together, bonding focused on autonomy can generate motivational impact on patients' self-care, such as the development of skills previously considered impossible, for example, changing the collection bag with security.

FINAL CONSIDERATIONS

The stoma process causes dependence for changing the collecting device by delegating this task to a trained family member or a specialized professional. The bond created by users through the sense of security of a 'high quality care' creates care dependence, and at the same time, embracement of patients with a stoma. Self-care includes fear of making mistakes when adapting the bag to the skin. If it fails, the time of permanence of the bag can be reduced and generate wastage in the number of bags one has available.

The difficulty with performing self-care can affect the daily life of people with a stoma, mark their lives in a singular way and bring problems in the adaptation to stoma bags. Self-care obstacles faced by people with a stoma may lead to dependence when performing stoma care.

Fear, anguish, social limitations and diet modifications are reactions generated by the stoma process. These are difficulties in the social life of people with a stoma, since they need to organize their routine in order to access a place with minimal structure for emptying, cleaning or changing the bag. These needs impact on patients' quality of life by making them choose to stay at home or restrict their frequency only to places with adequate restrooms.

Nurses and the health team can act in peculiarities arising from patients' difficulties with performing stoma care. They can also promote health education to the point of reinforcing the commitment of care by establishing a certain protagonism of patients with their health condition.

Thus, it is important to develop and deepen further research on self-care with the stoma by stimulating intervention studies focused on self-care by people with a stoma in order that nursing can promote the empowerment for self-care of these users and contribute decisively to the strengthening of autonomy.

USUÁRIOS COM ESTOMIA: A VIVÊNCIA DO AUTOCUIDADO

RESUMO

O objetivo do estudo foi conhecer a vivência dos usuários na realização do autocuidado com a estomia. Pesquisa qualitativa, sendo realizadas oito entrevistas com usuários do Ambulatório de Estomias da Unidade Vila dos Comerciários, no município de Porto Alegre/RS. Os dados foram submetidos à análise de conteúdo, emergindo duas temáticas: "Influência da estomia no convívio social"; "Dependência e vínculo no autocuidado com a estomia". A estomia causa dependência para a troca do dispositivo coletor, delegando essa tarefa a um familiar treinado ou um profissional especializado. O vínculo criado pelo usuário através do sentimento de segurança de um "*estar bem feito*" cria uma dependência para o cuidado. A realização do autocuidado esbarra no medo de errar ao adaptar a bolsa à pele, já que o erro pode provocar uma diminuição do tempo de permanência da bolsa e gerar desperdício no número de bolsas.

Palavras-chave: Estomia. Autocuidado. Autonomia Pessoal. Cuidados de enfermagem.

USUARIOS CON ESTOMÍA: LA EXPERIENCIA DEL AUTOCUIDADO

RESUMEN

El objetivo del estudio fue conocer la experiencia de los usuarios en la realización del autocuidado con la estomía. Investigación cualitativa con la realización de ocho entrevistas con usuarios del Ambulatorio de Estomías de la Unidad Vila dos Comerciários en la ciudad de Porto Alegre-RS-Brasil. Los datos fueron sometidos al análisis de contenido, surgiendo dos temáticas: "Influencia de la estomía en el convivio social"; "Dependencia y vínculo en el autocuidado con la estomía". La estomía causa dependencia para el cambio del dispositivo recolector, delegando esta tarea a un familiar entrenado o a un profesional especializado. El vínculo creado por el usuario a través del sentimiento de seguridad de un "estar bien hecho" crea una dependencia para el cuidado. La realización del autocuidado raya el miedo de equivocarse al adaptar la bolsa a la piel, si se equivoca puede provocar una disminución del tiempo de permanencia de la bolsa y generar desperdicio en el número de bolsas.

Palabras clave: Estomía. Autocuidado. Autonomía Personal. Cuidados de enfermería.

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