RESEARCH

SELF-IMAGE AND SELF-CARE IN THE EXPERIENCE OF OSTOMY PATIENTS: THE NURSING LOOK AUTOIMAGEM E AUTOCUIDADO NA VIVÊNCIA DE PACIENTES ESTOMIZADOS: O OLHAR DA ENFERMAGEM AUTOIMAGEN Y AUTOCUIDADO EN LA EXPERIENCIA DE PACIENTES OSTOMIZADOS: LA MIRADA DE ENFERMERÍA

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ABSTRACT

The objective of this study was to analyze the perception of ostomy patients about their self-image and self-care. This is an exploratory-descriptive and qualitative study conducted in a public hospital in the city of Recife, Pernambuco, with the participation of eleven people with digestive stomata of elimination. A semi-structured interview was used, whose data were submitted to content analysis. Of the 11 patients, seven were female, ranging in age from 19 to 93 years. Through the interviews, three thematic categories emerged: Insufficient knowledge for self-care; Living with the colostomy and its difficulties; The coping related to living with the colostomy bag. Thus, it was possible to perceive that the self-image and self-care of the customized patients are linked to feelings of shame, fear, insecurity, invasion, and suffering, which reflects directly on social, loving and work life, being identified still difficulties about adaptation and colostomy acceptance, reflecting social isolation. It is recommended that nurses deepen their knowledge about colostomy, especially regarding self-care and patient acceptance, that they have a different look, helping individuals to face this experience, and that they can work in support networks, contributing to a better adaptation and a better quality of life for ostomy.

Keywords: Estomach; Self Concept; Self Care; Nursing Care.

RESUMO

O objetivo deste estudo foi analisar a percepção de pacientes estomizados sobre a sua autoimagem e autocuidado. Trata-se de estudo exploratóriodescritivo e qualitativo realizado em um hospital público da cidade do Recife, Pernambuco, com a participação de 11 pessoas com estomas digestivos de
eliminação. Utilizou-se entrevista semiestruturada, cujos dados foram submetidos à análise de conteúdo. Dos 11 pacientes, sete eram do sexo feminino,
com idade variando de 19 a 93 anos. Por meio das entrevistas emergiram três categorias temáticas: conhecimento insuficiente para o autocuidado;
viver com a colostomia e suas dificuldades; o enfrentamento relacionado ao viver com a bolsa de colostomia. Sendo assim, foi possível perceber que
a autoimagem e o autocuidado dos pacientes colostomizados estão ligados a sentimentos de vergonha, medo, insegurança, invasão e sofrimento, os
quais refletem diretamente na vida social, amorosa e laboral, sendo identificadas ainda dificuldades acerca da adaptação e aceitação da colostomia,
refletindo no isolamento social. Recomenda-se que a enfermagem se aprofunde nos conhecimentos sobre estomas, principalmente em relação ao
autocuidado e aceitação do paciente com um olhar diferenciado, auxiliando as pessoas estomizadas a encarar essa experiência e que possam trabalhar
em redes de apoios, contribuindo para melhor adaptação e melhor qualidade de vida dos estomizados.

Palavras-chave: Estomia; Autoimagem; Autocuidado; Cuidados de Enfermagem.

RESUMEN

El objetivo de este estudio fue analizar la percepción de los pacientes ostomizados acerca de su autoimagen y autocuidado. Estudio exploratoriodescriptivo y cualitativo realizado en un hospital público de Recife, Pernambuco, con la participación de once personas con estoma digestivo de
eliminación. Los datos recogidos en entrevistas semiestructuradas fueron sometidos a análisis de contenido. De los 11 pacientes, siete eran mujeres,
entre 19 y 93 años. A partir de las entrevistas se establecieron tres categorías temáticas: conocimiento insuficiente para el cuidado personal; vivir
con la colostomía y sus dificultades; hacer frente al tener que vivir con la bolsa de colostomía. Se observo que la autoimagen y el autocuidado de
los pacientes colostomizados está vinculada a sentimientos de vergüenza, miedo, inseguridad, invasión y sufrimiento, que repercuten en la vida
social, amorosa y laboral. Se constató, asimismo, que hay dificultades para aceptar y adaptarse a la colostomía, lo cual refleja el aislamiento social.
Se recomienda que enfermería profundice sus conocimientos sobre los estomas, especialmente en relación con el autocuidado y la aceptación del
paciente, con una mirada distinta, con el propósito de ayudar a las personas a encarar esta experiencia y que puedan trabajar en redes de apoyo,
lo cual contribuye a una mejor adaptación y calidad de vida de las personas ostomizadas.

Palabras clave: Estomía; Autoimagen; Autocuidado; Atención de Enfermería.

INTRODUCTION

The colostomy, also known as digestive stoma elimination, is a common procedure in digestive tract surgeries for correction of intestinal alteration caused by obstructions, neoplasms, traumas and inflammatory bowel diseases, through an opening in the wall of the abdomen, for fecal drainage from the large intestine.¹

Precautions should be taken to avoid problems with the difficulty of adherence and possible complications for the placement of the colostomy pouch, avoiding places near bone prominence, waistline, skin folds, navel, and places with scars.² This therapy may be temporary or permanent. The temporary therapy usually results from intestinal traumas or the protection of an anastomosis that is more distant from digestive stomata of elimination, while the permanent therapy, consequent to carcinomas, has more incidence and causes changes in the quality of life of the patient, mainly in relation to his/her self-image.^{2,3}

Patients undergoing digestive stoma surgery lose control of feces and gas elimination being a strong emotional impact factor for them, with altered body perception of self-image and self-esteem. They have their quality of life impaired and come to live with numerous changes, such as insecurity, fear and social rejection, shame and restlessness.^{3,4}

Eliminating digestive stoma brings with it various problems of a psychological and social character to the patient, through the modifications in his habitual physiology, in which he feels invaded and attacked and, with real or symbolic prejudice, such as the incorporation of social stigmas, in which, because of the digestive stoma of elimination, the patient is different from other people and ends up isolated, breaking relationships with friends and family.⁵

The health professional, especially nursing, is required to reflect on the rehabilitation, acceptance and emotional recovery aspects to provide quality care, with a knowledge of their needs that, in addition to being diverse, change constantly.⁶

For nursing, health education is indispensable and of great importance in the care process and this results in a quality care,

because the nurse, besides caregiver, is an educator, not only in relation to the other members of the nursing team but to the patient and his relatives.⁶

Thus, considering the difficulties faced by people with digestive elimination stoma, this study came from the following question: what is the perception of people with digestive elimination stoma on their self-image and self-care?

Therefore, this study aimed to analyze the perception of patients with stoma about their self-image and self-care.

METHOD

This was an exploratory-descriptive study with a qualitative approach, carried out in a public hospital in the city of Recife, Pernambuco, from December 2015 to February 2016. Eleven patients, between 19 and 93 years old, living in the capital and the interior of the state of Pernambuco.

Inclusion criteria were patients older than 18 of both genders, with digestive elimination stomas and who were hospitalized in the surgical clinic. Exclusion criteria were patients without good cognitive conditions and a history of mental illness.

The sample was intentionally constituted by the criterion of sample saturation, in which it is perceived redundancy of information, not presenting some new fact in the testimonials.⁷

The semi-structured individual interview was adopted as an instrument of data collection. The script was composed of questions containing sociodemographic data and the following guiding questions: talk about the nursing guidelines you received at the hospital. How was your day after day after the stoma? How do you see yourself after surgery?

The interviews were conducted in a quiet and calm environment. The recordings obtained were transcribed in full, on the same day of the deposition, avoiding the bias of confusion. The technique of content analysis of Bardin was used, looking for units of signification in the lines of the subjects that gave origin to the thematic categories.

The Bardin method is divided into pre-analysis, treatment of the results obtained and interpretation. The first stage is the organization by using the reading of the material, choosing the documents and, finally, the reference of the indexes and the elaboration of the indicators. The second stage requires more time to perform the encodings when the data are transformed into units that allow descriptions of characteristics related to self-care. At the end, the results obtained are clarified, with the classification of the elements according to their similarities and by differentiation, with regrouping, due to common characteristics.⁷

The research met the requirements of Resolution 466/2012 of the National Health Council. The project was approved by the Research Ethics Committee of Hospital Otávio de Freitas, under the opinion number 1,140,657.

RESULTS AND DISCUSSION

Seven of the 11 patients were female from 19 to 93 years old (mean age 54 years old). Seven patients were married, three were widowed, two were unmarried, and all had at least one child. Most were retired, had a family income of a minimum wage and a half and did not finish elementary school.

Through the interviews, three thematic categories emerged: insufficient knowledge for self-care; living with the colostomy and its difficulties; the coping related to living with the colostomy bag.

CATEGORY 1: INSUFFICIENT KNOWLEDGE FOR SELF-CARE

This category is related to the guidelines received by some subjects in the preoperative and postoperative period, representing the knowledge acquired from information and care provided by nursing professionals, demonstrating the importance of the health team in the hospital environment in front of the orientation process for the self-care. However, there will also be a gap in these guidelines due to the lack of information that some patients did not have access.

In the promotion of a new knowledge after the colostomy, individuals experience to accepting themselves as a different being, imposing an adjustment of their image and self-concept, as well as coping with several complications that need to be addressed by the health professional so the patient can perform self-care.⁸ Thus, the nursing professional appears as a figure supporting the transition to new experiences experienced by patients, and nurses are an articulator of this process.

The service, the teaching they give to us was very good [...] they gave assistance every day. That's where I've gotten more comfortable. They helped a lot (E3, F, 56 years old).

The nurse taught only how the cleaning was done (E4, F, 51 years old).

From these reports, it was noticed that the nursing team was advised in relation to care with the bag collector in five interviewees. However, it was insufficient due to the nuance in the other orientations that are due to it.

Two participants demonstrated a lack of information about the guidelines with the colostomy and, four participants did not know about the medical and nursing professionals in the preoperative phase regarding the diagnosis and the possibility of the stoma, but they were informed later.

Here in the hospital, it was not enough, no [...] we had no one who clearly came to explain, no (E10, M, 48 years old).

The doctor did not say I was going to take it. We came to receive guidance here (in this hospital). What they (nursing) passed on to my sister was that they had to be cleaned. Then I listened, but they did not say anything to me. Not for me. They simply took out the liquid and said nothing (E2, F, 22 years old).

I think the nursing should teach a little more, how to cut (the hole of the bag) because my daughter (caregiver) does not know very well. I did not receive nursing guidance. I did not receive anything. Because not everyone knows about the bag [...] it is a life that I will have to adapt I do not know how (E4, F, 51 years old).

The speeches demonstrated the discrepancy in relation to the guidelines passed by the professionals for the patients, mainly for the self-care and adaptation of the new life condition. This could be explained by the lack of quality in the care provided to these patients, professional posture or by the various activities performed with the workload of the nursing team. However, when the guidelines were performed, they provided it safety and well-being of the patient.

Health education is a preponderant factor in avoiding complications and problems related to inadequate colostomy management. Therefore, the nursing team constitutes an important link in health education and in the individual's capacity for self-care.9

In this orientation, the nurse should clarify not only the handling of the bag collection but all the necessities involved that require changes and how to accomplish them, bringing benefits and comfort to the life of the person. To do this, it is necessary to encourage patient autonomy by promoting new knowledge minimizing fears and uncertainties, and making the individual's life healthier.¹⁰

In this way, the image of the nurse emerges as the one who coordinates, receives, cares, supports and advises the patient's care process. The activities of health education are also indispensable for the development of self-acceptance and for better adaptation of these people, helping them to live.¹⁰

It is necessary to have an understanding of patients' perception of living with the colostomy for the professionals involved to work together, whether from a physical, emotional and/or social point of view, reflecting in the self-image and acceptance of this reality. Through the guidelines provided to the patients of the study, it was possible to obtain adequacy in individualized care as answers to the needs presented regarding their social, work, sexual adaptation and, mainly, to the reduction of negative feelings such as fear and rejection, for example.

Thus, the role of health professionals and, especially, the nursing team is important in the sense of teaching and integrating the family into patient care, which is fundamental for the new reality to be faced by the customized.^{11,12}

CATEGORY 2: LIVING WITH THE COLOSTOMY AND ITS DIFFICULTIES

In this category, the main difficulties manifested by the patients in relation to the use of the colostomy bag are listed. Several changes in day-to-day activities due to the limitations arising from the use of the device are observed. Considering the difficulties that patients face, the importance of adequate professional care is seen to minimize the problems arising from the adaptation process.

Faced with the use of the colostomy, changes were observed in the patient's lifestyle caused by physical, psychic and social changes that influence his body image. In addition to the circumstance of diagnosis, this device directly threatens the standards and values socially attributed to physical beauty, to the healthy and hygienic body, to physiological self-control, and inversely proportional to the disabled person.¹³

Some physical and social limitations imposed by the new condition were referenced in the following reports and show the reflections by the nursing on the difficulties of adaptation that they presented:

The question of lying on the side, walking better, sitting down. It keeps marking the clothes [...] a lot of noise, noise, it bothers me. It's very boring. The walking is a strange thing that we did not have (E2, F, 22 years old).

It's hard for us to go out and go to church, but God has already spoken to me so I do not worry about it. After that, he has the "pum" and the people listen (E3, F, 56 years old).

Adapting these anatomical changes in the body, individuals alter their lives and begin to wear looser clothes to avoid evidence of the presence of the collecting device, elimination of feces and flatus, which can impair their social relationship. This corporal alteration tends to be perceived as a mutilation, precipitating in emotional alterations, that lead to the embarrassment and the low self-esteem, with distance of its work activities, of leisure and in the affective behavior, taking it to the social isolation.¹⁴

Relevant factors that affect patient reactions are the characteristics of fecal secretions and the lack of ability to control them, which causes the patient to lose self-esteem since he is not able to control intestinal movement, bad odors, overflowing or leaking liquid feces. ¹⁰ These experiences were evidenced by some participants:

My sweaters have been changed to the ones that have to open in the front [...] at the time of the bath. I also feel a little difficulty because I cannot get my bag wet. [...] I sleep on one side only because it is leaking on the side of the bag (E5, F, 93 years old).

I cannot wear any clothes. You have to wear clothes that do not show it. I cannot go anywhere, like before. I stopped taking care of my daughter; I stopped going and stayed home because of that. I stopped going to some places, parties, events (E6, F, 19 years old).

Patients who undergo colostomy surgeries experience a variety of feelings, such as anxiety and concerns related to learning to manipulate their device, which influences self-esteem and body image. They often see the colostomy as invasive and deforming. When well placed, it can be covered up by clothing and does not interfere with the patient's activities. However, they feel different in this experimentation of their new reality of life.¹⁰

Even the placement of the collection bag is to guarantee an adequate quality of life to the patient, negative feelings permeated by the difficulty of adaptation can be perceived, which promote sufferings that until then were non-existent:

I get scared. I know I have a lot of prejudices, but about that, I do not care (E4, F, 51 years old).

Feeling ashamed because I do not imagine myself normal to be with it (E6, F, 19 years old).

The colostomy can cause changes in self-esteem and self-image regarding physical health, psychological status, level of independence, social and personal relationships and beliefs.¹⁵ Regarding the interviewees' daily lives, their interference with quality of life was evidenced in the following statements:

I stopped taking a right shower. I do not know what a bath is right anymore. It's a rather uncomfortable thing (E4, F, 51 years old).

I stopped going to the beach, I have a bikini, but I do not use it. I have a bathing suit, but now he's retired (E1, F, 82 years old).

I stopped going to the beach. I left the job because I cannot work with it and several things I stopped doing in the normal day to day (E6, F, 19 years old).

I am always very sick. I loved the beach and now I'm not going anymore (E10, M, 48 years old).

Living with a colostomy causes distressing feelings because people come to believe that they are unreliable in their routine activities or perhaps because of fear of prejudice tend to become isolated.¹⁵ The dimension of sexuality can be affected by compromising the behavioral expressions of desires, values, and attitudes. Visible not only by the patient but also by the partner, the colostomy can cause disruptions that translate into difficulties in maintaining or initiating an affective relationship.^{10,16} This limitation was remarkable in the outburst of an interviewee:

I stopped relating [...] to feeling embarrassed because I did not imagine myself normal (E6, F, 19 years old).

The decision of this participant to opt for isolation should be better explored by health professionals, especially the nurse, so it is faced with another look and find compensatory and adaptive mechanisms in life, including through the social support network.

The evaluation of self-esteem in people with a colostomy is increasingly important and necessary because when patients undergo this procedure, they have a different experience, in which their pattern and rhythm of life begin to change.¹⁵ Thus, it is essential to the performance of the health team involved and active in the rehabilitation and coping with this reality so this transition is as natural as possible.

There are several alternatives to minimize and even solve complications resulting from colostomy, indicating the need for a multidimensional approach to care, which encompasses physical, psychosocial, cultural and educational well-being. The success of this rehabilitation will be a consequence of a joint and coherent action with the various health professionals related to the treatment, as well as the fundamental participation of the family so they can meet the demands of the patients.¹⁷

CATEGORY 3: THE COPING RELATED TO LIVING WITH THE COLOSTOMY BAG

In this category, it will be approached how patients face the new reality of having to live with the colostomy device, being found negative experiences about the acceptance, as well as hopeful ways, considering that they will have to live with this new health condition for the rest of life.

Certain diseases bring profound changes in the daily life of the affected person and compromise their quality of life.¹⁴ When analyzing the individual's perception of their self-image, it was observed that the negative changes are related to self-esteem, which was evidenced in the speeches:

I do not know what to do next, but at the moment I do not think I'm feeling well (E4, F, 51 years old).

I see myself as totally negative. I think if I spend the rest of my life with this bag, I will not live any longer [...] It does not feel good to be with this. It is not that others need to see to be speaking (E6, F, 19 years old).

Besides the changes in self-esteem, there are other factors that are also affected, including biological, psychological, social and spiritual, due to modifications related to anatomy, dependence, compromised sexuality, inferiority, suffering and biopsychosocial imbalance. The well-being of the patient provokes sudden changes in their quality of life and was reported emphatically:

Tired, Tired, Tired! I'm sad, I'm thinking. I have a son and I cannot take him in my arms (E2, F, 22 years old).

I feel useless. I would like to go out, solve my problems, do my things and, with this bag, everything will be difficult (E11, F, 56 years old).

In these testimonies, the negative expectation of the individual experiencing this new reality of life was evident, and the presence of a multidisciplinary team that accompanies them in this very special moment is evident, guiding them and encouraging them on the forms of adaptation.

On the other hand, despite all the negative perception that the device entails, future expectations and projections have been observed in the new reality in a positive way, corroborated by the support of family and friends, as well as faith and religion.

That suddenly you have a life and from one moment to another it changes totally. I'll start all over again, all over again (E4, F, 51 years old).

I'm being looked after by everyone and I'll be fine soon. The important thing is to be well. Life is new now (E7, M, 53 years old).

Oh, I have faith. I started to be Protestant. If I had not been a Protestant, I would have died (E9, M, 66 years old).

Colostomy making changes individuals in their bodies in terms of appearance, function, and sensation. But over time, there is an adjustment for acceptance, through the perception of control over your colostomy, which can decrease awareness of their body change, facilitating adaptation and self-acceptance.¹⁸

The successful transition to life with colostomy comprises an effective acceptance of the new health circumstances, from a reorganization and reorientation of daily living, in which feelings of anguish and destructive behavior are replaced by feelings of well-being and control of the situation.¹³

It is necessary to support the strategies that help the patient in the corporeal domain from the placement of the colostomy to facilitate rehabilitation and promote self-acceptance and balance of the individual, which is a primary factor in coping with their new life condition.¹⁸

It is fundamental that the professionals involved understanding the habits, perceptions, and attitudes, feelings and emotions demonstrated in the most diverse situations that happen to these patients, including those who accompany and support them in this life-changing experience.⁸

The best thing to do is that the health care for these individuals should be approached considering the patient and his/her family, as this is often closely linked to care and favors the patient's confidence, amplified in the synergy of the relationships involved in the tripod professional-patient-family relationship.

With this, it is noticed that besides the health professionals, the patient with a stoma needs a network of relationships such as the family, religious members, friends and support groups that help him in the care and the acceptance of the new reality. It is worth mentioning that the social network becomes important in the adaptation process since it favors links to the individual and provides a better quality of life.¹⁹

These results allow visualizing aspects to be considered, such as the health services and the professionals who are involved in caring. This care goes far beyond the problem since it aims to welcome the patient holistically, allowing healthcare professionals to orient him/her to the needs of adaptation, through a simple and adequate language in order to provide gains, protection, and acceptance of the new condition.

CONCLUSION

It was possible to analyze the experiences and expectations of the patients who underwent colostomy and it was noticed that

the use of colostomy is linked to feelings of shame, fear, insecurity, invasion, and suffering, which are reflected directly in social, loving and work life of these individuals. Difficulties were also identified regarding the adaptation and acceptance of the colostomy, reflecting social isolation, because they feel unstable and fearful of exclusion, causing psychological, emotional and social changes.

Expectations were mainly focused on the need to receive adequate guidelines that fit into reality and prepare patients for the challenges and complications they may encounter on a day-to-day basis, as well as help improve the adaptation of the patient to a new world, rescuing and potentializing their strengths and collaborating to overcome their weaknesses.

The study emphasized the importance of patient-professional relationships to build trust, self-acceptance, and assistance with adequate guidelines for self-care and assent to their new life, highlighting the nurse professional as a facilitator of the process.

It is recommended that nursing study the knowledge about elimination stomas, especially regarding self-care and patient acceptance with a different look, helping individuals to face this experience. Support networks are also recommended, contributing to better adaptation and quality of life of the stomas.

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