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## ORIGINAL ARTICLE

### COLOSTOMY AND SELF-CARE: MEANINGS FOR OSTOMIZED PATIENTS

### COLOSTOMIA E AUTOCUIDADO: SIGNIFICADOS POR PACIENTES ESTOMIZADOS

### COLOSTOMÍA Y AUTOCUIDADO: SIGNIFICADOS POR PACIENTES ESTOMIZADOS

Franciele Aparecida Saraiva de Aguiar<sup>1</sup>, Bianca Pinheiro de Jesus<sup>2</sup>, Fernanda Cardoso Rocha<sup>3</sup>, Isabela Barbosa Cruz<sup>4</sup>, Gregório Ribeiro de Andrade Neto<sup>5</sup>, Bruna Roberta Meira Rios<sup>6</sup>, Álvaro Parrela Piris<sup>7</sup>, Dina Luciana Batista Andrade<sup>8</sup>

#### ABSTRACT

**Objective:** to understand the meanings of ostomized patients regarding stoma, as well as the factors involved in self-care based on the assumptions of the Orem Theory. **Method:** it is a qualitative, descriptive study, with phenomenological analysis. The collection was done through the semi-structured interview, with the participation of five people who have a colostomy bag. **Results:** it is revealed that, from the analysis of the interviews, the following categories emerged: Embarrassment/Social Isolation; Faith and Resignification. It is observed that the stoma carriers present difficulties even though they have adapted, mainly in the aesthetic aspects and the insecurity caused in some by the fear of leaks, flatulence and of causing annoyances in the people around them. It was found that most of the ostomized patients did not meet three of Orem's assumptions: human functioning, the dangers of life and well-being, and potential developments. **Conclusion:** participants demonstrated a still repressed demand for information, listening and individualized and holistic care. **Descriptors:** Colostomy; StomataSurgical; Self-Care; Nursing; Quality of Life; Health Services.

#### RESUMO

**Objetivo:** compreender os significados por pacientes estomizados quanto ao estoma, bem como os fatores intervenientes ao autocuidado a partir dos pressupostos da Teoria de Orem. **Método:** trata-se de estudo qualitativo, descritivo, com análise fenomenológica. Deu-se a coleta por meio da entrevista semiestruturada, com a participação de cinco pessoas que utilizam a bolsa de colostomia. **Resultados:** revela-se que, da análise das entrevistas, emergiram as categorias: Constrangimento/Isolamento Social; Fé e Ressignificação. Observa-se que os portadores de estoma apresentam dificuldades mesmo adaptados, principalmente nos aspectos estéticos e pela insegurança provocada em alguns pelo medo de vazamentos, flatulências e de causar incômodos nas pessoas ao seu redor. Constatou-se que a maioria dos estomizados não alcançou três dos pressupostos de Orem: o funcionamento humano, os perigos da vida e o bem-estar e desenvolvimentos potenciais. **Conclusão:** demonstrou-se, pelos participantes, uma demanda ainda reprimida de informação, escuta e assistência individualizada e holística. **Descritores:** Colostomia; Estomas Cirúrgicos; Autocuidado; Enfermagem; Qualidade de Vida; Serviços de Saúde.

#### RESUMEN

**Objetivo:** comprender los significados por pacientes ostomizados en cuanto al estoma, así como los factores intervenientes al autocuidado a partir de los presupuestos de la Teoría de Orem. **Método:** se trata de un estudio cualitativo, descriptivo, con análisis fenomenológico. Se dio la recolección por medio de la entrevista semiestructurada, con la participación de cinco personas que utilizan la bolsa de colostomía. **Resultados:** se revela que, del análisis de las entrevistas, emergieron las categorías: Constrañimiento / Aislamiento Social; Fe y Resignificación. Se observa que los portadores de estoma presentan dificultades incluso adaptadas, principalmente en los aspectos estéticos y la inseguridad provocada en algunos por el temor de fugas, flatulencias y de causar incómodas en las personas a su alrededor. Se constató que la mayoría de los ostomizados no alcanzó tres de los presupuestos de Orem: el funcionamiento humano, los peligros de la vida y el bienestar y desarrollos potenciales. **Conclusión:** se demostró, por los participantes, una demanda aún reprimida de información, escucha y asistencia individualizada y holística. **Descriptores:** Colostomía; Stomata Surgical; Enfermería; Calidad de Vida; Servicios de Salud.

<sup>1,2,4</sup>Nurses, Unidas do Norte Colleges/ FUNORTE. Montes Claros (MG), Brazil. E-mail: [fran-aguiar2014@live.com](mailto:fran-aguiar2014@live.com) ORCID iD: <https://orcid.org/0000-0001-5418-8190>; E-mail: [byankahot@hotmail.com](mailto:byankahot@hotmail.com) ORCID iD: <https://orcid.org/0000-0003-3910-5347>; E-mail: [isabel\\_belinha00@hotmail.com](mailto:isabel_belinha00@hotmail.com) ORCID iD: <https://orcid.org/0000-0002-7516-2915>; <sup>3,5,6,8</sup>Specialists, Unidas do Norte Colleges/ FUNORTE. Montes Claros (MG), Brazil. E-mail: [nandac.rocha@hotmail.com](mailto:nandac.rocha@hotmail.com) ORCID iD: <https://orcid.org/0000-0001-6381-2063>; E-mail: [gregtec@hotmail.com](mailto:gregtec@hotmail.com) ORCID iD: <http://orcid.org/0000-0002-1417-5237>; [brunameirarios@gmail.com](mailto:brunameirarios@gmail.com) ORCID iD: <http://orcid.org/0000-0002-7715-2921>; E-mail: [dinalucianab@yahoo.com](mailto:dinalucianab@yahoo.com) ORCID iD: <http://orcid.org/0000-0002-7540-3184>; <sup>7</sup>Master, Unidas do Norte Colleges/ FUNORTE. Montes Claros (MG), Brazil. E-mail: [alvaroparrela@yahoo.com.br](mailto:alvaroparrela@yahoo.com.br) ORCID iD: <http://orcid.org/0000-0002-7151-5015>

## INTRODUCTION

It is explained that the stoma is an artificial communication between organs or viscera to the external environment for drainage, elimination or nutrition.<sup>1</sup> A number of difficulties associated with the loss of control of the anal sphincter and the presence of an intestinal portion in the abdomen through which stool and gas elimination occur, are experienced by people who undergo surgery and become ostomized. It is added that, after surgery, the person resumes, in an effective way, the physiological functions that their body, until then, performed automatically.<sup>2</sup>

The colostomy is a simple surgery, performed worldwide due to an obstruction, which consists of the construction of an orifice (stoma), in any segment of the colon,<sup>3-4</sup> being indicated for treatments of various pathologies.<sup>5</sup> Patients undergoing this procedure break their habitual pattern of elimination with privacy, they face psychological difficulties and end up developing a sense of withdrawal from themselves.<sup>6</sup> Therefore, social coexistence can be disrupted and the person may think that they are not normal and feel different because they do not present the characteristics and attributes considered normal by society due to their imperfect body.<sup>2</sup>

It is included, in the set of forms of coping that these people adopt, to deal with their new situation, a varied number of responses centered as much on the problem, as on the emotions, as on other aspects such as the humor, the recognition of positive changes, repression, denial, normalization, resignation or concealment.<sup>2</sup> It is believed that self-care is a process that the patient undergoes in their lives after surgery, and are voluntary actions that the individual is able to perform, having the responsibility to take care of themselves and maintain their health and self-esteem.<sup>7</sup> It has been demonstrated in studies that living with a colostomy negatively influences the general quality of life.<sup>8</sup>

It is noted, however, that people with a temporary colostomy carry with them the hope of reversing this colostomy and need to readjust their lives even if it is only for a period. By this possibility anxiety can be generated, influencing them in a negative way. People with temporary stomas present an average anxiety state that is greater than those with permanent stomies, and it is incumbent on Nursing to intervene in the care of patients for the recovery and the

realization of effective self-care, since several are the factors that influence the self-care of the patient, as well as the adherence and motivation for the treatment and the proposed interventions.<sup>9</sup>

## OBJECTIVE

- To understand the meanings of ostomized patients regarding the stoma, as well as the factors involved in self-care based on the assumptions of the Orem Theory.

## METHOD

It is a qualitative, descriptive study, supported by descriptive phenomenology, in which people with digestive stomas (colostomy or stoma) were included as a consequence of different diseases.<sup>10</sup> These users, as a reference center, are the Physical Rehabilitation Center of the North of Minas Gerais, which is a reference in the delivery of colostomy bags to all the cities in the macro-north of that State. The sampling procedure followed the guidelines of intentional sampling, reaching information saturation and being fixed onto five participants.

The data was collected through semi-structured interviews with guiding questions, and the interviews occurred in September 2016 and lasted from 12 to 25 minutes. Interviews with open-ended questions such as "How did it feel to get this news?" Were used to help them talk about their feelings towards the stoma, leaving questions or central issues for later, such as: "When did you find out that you were going to use a colostomy bag?"; "After the bag was placed, did you get any information about how to deal with it?", Etc. In the transcription of interviews, not only were the verbal expressions sought out, but also what was inbetween the lines, such as facial expressions, pauses, among others.

The descriptive analysis was based on Minayo's proposal<sup>10</sup>, through phenomenology. To that end, a sequential scheme was followed, based on the steps of: data preparation, organization of data into categories and codes, and interpretation of data. By this proposal, it is required that the analysis phases take place one after the other.

Written consent of the participants was requested, as well as the permission to record the interviews, through the Free and Informed Consent Term (FICT). Ethical precautions were based on Resolution 466/12 regarding these aspects for human research. The research project was approved by the Research Ethics Committee of the Brazilian Educational Association (SOEBRAS), under the opinion

number 1.666.142, of August, 2016. The anonymity of the participants and their speeches was ensured through codification with the letter "E" followed by the interview number.

## RESULTS

It is revealed that five interviewees participated in the interviews, aged between 31 and 65 years, one man and four women, and all had more than three months of temporary or permanent ostomization. Colostomy-type stomata (five people) were present, and were ostomized due to rectal cancer (four) and one due to perforated diverticulitis. Their grades of schooling varied between incomplete elementary school and completed high school. In the analysis of the interviews, using the phenomenological approach, the following categories emerged: 1) Embarrassment/Social Isolation and 2) Faith and Ressignification, considering the principle concepts of Minayo's descriptive phenomenology.<sup>10</sup>

## DISCUSSION

In each category, the assumptions of Orem's theory and the statements that led to the categories formed were observed, which are presented below.

1. Embarrassment and Social Isolation - [...] *the bag stops me going out [...]*.

It is observed, through the interviews, that the ostomized patients strive to continue to attend the same places. It is noticed that one of the major their preoccupations is the fact that the colostomy bag comes off of the abdominal wall and, with that, they undergo some situation of embarrassment. It is added that the fear of making the condition of being ostomized public and being rejected by society due to the production of noises and odors leads it to restrict or eliminate contact with members of the community and even members of the family, resulting in social isolation.<sup>11</sup>

It is presented, by the changes of the body, in the ostomized people, impairment in the corporal aesthetics and, consequently, in the self-esteem. It is necessary for the ostomized persons, due to the stoma and the use of a collecting bag, to modify the way of dressing, above all, by wearing loose clothing, whose purpose is to conceal the collecting device.<sup>12</sup>

It is believed, at first, by the ostomized patients that people would not understand or tolerate their situation; in this way, they tend to become more isolated, establishing a more intimate social relationship with the person who helps them, sometimes with the husband and children.<sup>13</sup>

[...]No, that's it, I'd rather stay home because I'm not in one, one is why the bag empathizes leaving, you can go wherever you want, but it's because I do not like leaving cause the time that makes us go through some shame that got stuck there in the middle of people there, because of this business that I was talking about [...]. (E02)  
[...]That's why I like to stay more at home, but in one she does not walk, she can walk wherever she wants, take a bus, plane, car, anything and anything, but it's because I myself I like to go out [...]. (E02)  
[...]no, the question that is bad even that I told you is when you go to the event that there are people you do not know [...] (E05)  
[...]for me to receive, for me to get the bag, I stayed a long time, I was very sad, so I was a person who went out a lot, you know; after I gave to use the bag, I do not go out, I'm ashamed of people so listening to me, it stinks, so it was very difficult for me, you know, but now I'm controlling more, I'm not going anywhere either none [...]. (Embarrassed Face) (E04)  
[...]Oh, no, I'm already in the mood to be in the middle of people, I prefer to stay like this, that I, for me, the person is listening to me, it keeps on hearing like this, so I like it no, I prefer to stay like this more like this at home [...] (Sad Face) (E04)

1. Faith - [...]I have faith in God so let's go [...]

It is a great tool to confront the stomized spirituality since, in difficult situations, individuals tend to approach values and beliefs in order to cope with unforeseen situations. Faith can be a form of confrontation strategy of each individual before his diagnosis, where he can attribute meaning to his process of accepting his new condition of life, clinging to faith, to alleviate suffering. Faith is thus established as a resource for the multidimensional understanding of the human being, making it essential for understanding the process of health recovery.

One has the faith or the quest for divine help as a way out for the person who launches looking for resources to cope with their daily struggle. They are raised, through the approach of God, forces to endure this situation. Therefore, the ostomized patient, seeks in the religiosity, associated with the support of family members, strength to overcome the obstacles, seeking to face, in a more pleasant way, the situation.<sup>14</sup>

This faith of a religious nature is directed to something supernatural and superior that anything can, if it so desires and desires. Thus, through religion, relief in suffering can be produced by allowing changes in subjective representations, in the face of illness and



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personal growth, by stimulating reflection on the meaning of life, the way it was experienced and its finitude.<sup>15</sup>

*[...]because there are people who get scared, right? I do not, I went normally, I have a lot of faith in God, there's God with me, so there are people who stay with depression, but I do not, I was normal [...]* (Calm Face) (E01)

*[...]The doctor, who was there at the hospital, said that I had cancer, I said: "Let God's will be done, because I have had the first, second, thirteen years, I gave birth, I said cause one more, one less, one, no problem, I have faith in God, so let's go [...]* (Smiling face) (E01)

*[...]I just asked, "Yeah, but you gotta use it?" He said: Yes! I said: Oh, okay, whatever God wants and sends [...]* (E02)

1. Re-signification - [...]I said: I do not want to be disturbed [...]

They become the understanding of a stoma and the action of the person facing the new fundamental challenges in the construction of a sense, in the interpretation of the situation experienced as a result of this stoma and in the understanding as an opportunity for survival that the bag provides to the person. It implies, in the resignification of life, an intangible process, in which the person starts to take ownership of their illness and to operate a new way of facing their life.

In this new situation, it is necessary to adapt to the daily life of ostomized patients, and that the time factor is essential for confronting and accepting the ostomy, which, despite limitations, can carry out its activities and maintain the social interaction. It is necessary to modify the eating habits to avoid excessive flatulence and other complications, such as diarrhea.<sup>16</sup>

The presence of the colostomy causes the patient to have to face his new condition: gastrointestinal physiological changes; care with the colostomy bag; emergence of conflicting feelings; worries and difficulties to deal with this new situation lead ostomized patients to visualize their limitations and to face the changes that have occurred in their daily lives.<sup>17</sup>

*[...]No, I do not have stress, nothing, nothing, nothing, nothing [...]* (E01)

*[...]The time I take, I'm going to have more freedom, but this will not stop me for now, not [...]* (E03)

*[...]I embroider, I, I weave crochet, I don't sew because my machines I took everything to my daughter's house [...]the more I board, the more I spend, if it's the case of washing clothes, ironing clothes, everything, I do everything normal [...]* (E01)

*[...]I said: I do not want to be disturbed because, on November 20, I have to take the course [...]* (E03)

According to Orem's assumptions in this research, the presence of seven of the nine assumptions of this theory, namely: adequate supply of air, water and food, is perceived in the interviews; elimination care; balance between activity and rest, solitude and social interaction; potential well-being and development, and a desire for normality, and all respondents cited at least five of these assumptions during their speeches.

The use of Dorothea Orem's theory of self-care is considered to be a valid instrument, which has helped to promote a more objective communication between the patient and the environment in which he or she lives, adapting to a certain extent in the planning of care. Nursing, after all, Orem sees people as human beings, who differentiate themselves from other living things, by their ability to reflect on themselves and their environment, possessing the capacity for learning and development.

## CONCLUSION

It is concluded that the stoma represents a major impact on the life of the users, which is progressively reduced with the adaptation to the new ostomized condition, which includes the adaptation of the collection bag to the control of intestinal incontinence. It is observed that the stoma carriers present difficulties adapted, especially in the aesthetic aspects and the insecurity that this procedure causes in some, due to the fear of leaks, flatulence and to cause discomfort in the people around them. It is important to emphasize that exclusive interventions in the pre, trans and postoperative periods are the responsibility of the nurse, aiming at the best adaptation to the stomized condition, promoting coping for a better quality of life of the user, requiring continuous and prolonged health care.

After analyzing the data, it was found that most of the stomas did not reach all three of Orem's assumptions, namely: human functioning, life hazards and potential well-being and development, space for further research in this area. It was possible to conclude during the interviews that the quality of life of the ostomized patients is closely related to the strategies adopted by them to cope with these biological, physical and psychological changes, since the older interviewees accepted this situation better, as well as, through their experience of life, they fit in the acceptance or denial in the coping with the stoma.

In view of the above, it is questioned that, if the ostomized patients had a continuing education for more systematized self-care, they would have no more opportunities to fully achieve Orem's assumptions; Would this improve their quality of life and create a new meaning for their lives? This paper presents gaps for not being able to answer these questions, opening more space for research on ostomized patients, which proved to be of great relevance.

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**Corresponding Address**

Fernanda Cardoso Rocha  
Rua São Roberto, 55  
Bairro Todos os Santos  
CEP: 39400-121– Montes Claros (MG), Brazil