



## SELF-CARE PRACTICE OF OSTOMY PATIENTS: CONTRIBUTIONS OF THE OREM'S THEORY \*

*PRÁTICA DE AUTOUIDADO DE ESTOMIZADOS: CONTRIBUIÇÕES DA TEORIA DE OREM*

*PRÁCTICA DE AUTOUIDADO DE ESTOMIZADOS: CONTRIBUCIONES DE LA TEORÍA DE OREM*

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This study aimed to identify the conditioning factors to self-care practice of ostomy patients, and verify knowledge and practices on stoma care. Descriptive and qualitative study, referencing the Orem's Self-Care Theory, carried out at the Ostomy Association of Fortaleza-CE, Brazil, in June and July 2007. We identified as the main conditioning factors for self-care: male, aged over 51 years, low education, from the capital city/metropolitan area, married, and with low family income. From the participants' statements, emerged three categories: Learning to take care of stoma: education-support system; Stoma Care: knowledge and practices; and Difficulties found in the practice of self-care. It was concluded that ostomy patients require a multidimensional and individualized nursing care, which enables them to perform self-care effectively.

**Descriptors:** Nursing; Ostomy; Nursing Care; Self Care.

Objetivou-se identificar os fatores condicionantes para o autocuidado em pacientes estomizados, verificar saberes e práticas sobre os cuidados com a estomia. Estudo descritivo e qualitativo, tendo como referencial a Teoria do Autocuidado de Orem, realizado na Associação de Estomizados de Fortaleza-CE em junho e julho de 2007. Destacaram-se, como fatores condicionantes para o autocuidado: sexo masculino, idade superior a 51 anos, baixa escolaridade, procedência da capital/região metropolitana, estado civil casado e baixa renda familiar. Dos discursos emergiram três categorias: Aprendendo a cuidar do estoma: sistema de apoio-educação; Cuidar do estoma: saberes e práticas; e Dificuldades encontradas para a prática do autocuidado. Concluiu-se que pessoas estomizadas necessitam de uma assistência de enfermagem multidimensional, individualizada e que os capacite a realizar o autocuidado de forma eficaz.

**Descritores:** Enfermagem; Estomia; Cuidados de Enfermagem; Autocuidado.

El objetivo fue identificar los factores que influyen en el autocuidado a pacientes con ostomía, verificar el conocimiento y las prácticas en la atención a la ostomía. Estudio descriptivo y cualitativo, basado en la Teoría de autocuidado de Orem, desarrollada en la Asociación de Ostomía de Fortaleza-CE, Brasil, en junio y julio de 2007. Se destacaron como factores condicionantes de autocuidado: sexo masculino, mayores de 51 años, bajo nivel de educación, origen de las ciudades capitales o área metropolitana, estado matrimonial y baja renta familiar. De los discursos sugirieron tres categorías: Aprendiendo a cuidar del estoma: sistema apoyo-educación; Cuidado del estoma: conocimiento y prácticas; Dificultades encontradas en la práctica de autocuidado. Los estomizados precisan de atención de enfermería multidimensional, individualizada que les permita realizar el autocuidado eficaz.

**Descritores:** Enfermería; Estomía; Atención de Enfermería; Autocuidado.

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## INTRODUCTION

Chronic degenerative diseases, especially cancer, contribute to negatively affect the quality of life of the population. The discovery of a cancer diagnosis, even with the possibility of cure, has a devastating effect on the lives of these patients. This brings anguish and suffering, whether by the fear of death, mutilation, disfigurement, or painful treatments<sup>(1)</sup>. According to estimates of the National Cancer Institute (INCA) for 2010, colorectal cancer represents the fourth most common cause of cancer in males and the third most common in females<sup>(2)</sup>. Depending on the etiology and the severity of the disease, the surgeon will indicate the construction of stomas, for the exteriorization of a segment of the intestine through the body, which may be temporary or permanent. Regardless of being temporary or permanent, these stomas cause changes in gastrointestinal physiology, self-esteem, body image, and working, family, social and affective lives of ostomy patients<sup>(3)</sup>. And when the stoma is associated with cancer diagnosis, it doubles the impact, and the changes in patients' lives are more devastating. Cancer is a disease associated with suffering, pain, deterioration, uncertainty about the future, myths related to it, fear of rejection, among others. These transformations are caused by the meanings attributed to the stoma and the disease itself. Feelings of uselessness, because the stoma changed the family or professional role; dependent behaviors; delegating self-care to a family member; intimacy preservation; the need for an appropriate place to change the appliance; psychosocial isolation due to restriction of meetings and travels; among others<sup>(4)</sup>.

In this context, the nursing care to ostomy patients, with emphasis on self-care, has been an important alternative to stimulate the patients to actively participate in their treatment, besides increasing their responsibility for their own care. It is essential that

nurses develop and implement care models that approach a systemic and multidimensional perspective of care, and thus can meet the patients' demands<sup>(5)</sup>.

The model of the Self-care Theory (SCT) proposed by Orem consists of three interrelated theoretical bases: (1) theory of nursing systems; (2) self-care theory and; (3) self-care deficit theory<sup>(6)</sup>. The first describes and explains how people are helped through nursing interventions. The second outlines and explains the care practice performed by any person with some special need to maintain good health and wellbeing. And finally, the self-care deficit theory constitutes the essence of SCT, for designing the need for nursing care.

The self-care deficit theory provides a comprehensive basis for nursing practice, including continuing education as part of the professional component of health education<sup>(7)</sup>, representing an effective way to promote nursing care to chronic patients. Thus, the treatment is directed towards the real needs of these patients, in addition to approaching the holistic aspects of care. In plain words, self-care can be considered the practice of activities that people perform on their own behalf, in order to maintain their wellbeing, which is based on the patient's ability of learning, awareness and decision making about their new life style<sup>(7)</sup>.

Orem also presents the basic conditioning factors for self-care, which may be internal or external to the individual and that affect their ability to engage in self-care, such as: age, sex, development stage, health status, socioeconomic, family and cultural factors, and aspects related to the health care system<sup>(5)</sup>.

There are continuous reports that ostomy patients present difficulties related to self-care, mainly due to lack of guidance in the preoperative period. Therefore, it is important to use Orem's theoretical framework for the

development of this study, in order to help ostomy patients to solve their deficits in self-care, by providing them with useful information, emotional and psychological support.

Furthermore, we hope to make ostomy patients able to meet the needs related to the ostomy management, so they can cope better with the limitations imposed by this problem and improve their quality of life.

Therefore, this study aimed to identify the factors that influence self-care for ostomy patients, and verify knowledge and practices about ostomy care.

## METHODS

This is a descriptive research with qualitative approach, using as theoretical framework the Dorothea Orem's Self-Care Theory.

The study was carried out at the Ceará Ostomy Association, in the city of Fortaleza, Ceará, Brazil. This association is considered a civil institution, of both public and philanthropic character and nonprofit institution that develops activities such as: prescription of ostomy bags, consultations and assistance by stomal therapy nurses, social reintegration activities, and meetings with patients and families.

The number of patients registered in the association is growing, due to the increase in the incidence of diseases that lead to the construction of stomas. 30 patients registered in this association participated in the study, with the following inclusion criteria: people who sought care during the data collection period and that underwent ostomy surgery for at least three months, long enough to acquire skills in ostomy care.

For data collection we used a semi-structured

interview route designed based on the literature seeking to achieve the goals, being divided into two parts: (1) data related to conditioning factors for self-care, and (2) issues related to needs and/or deficits in the self-care management according to Orem's Theory.

To deepen the discussions we used thematic analysis, consisting of discovering cores of meaning, referred to the frequency count of units that have defining meaning of speech character. After thorough readings, data were organized determining the main cutouts before material exploration. Thematic analysis was performed in categories that emerged from the interviewees' statements with common characteristics and that were related to each other, enriching the discussion and facilitating their understanding. The categories created were: Learning to take care of stoma: education-support system; Stoma Care: knowledge and practices; and Difficulties found in the practice of self-care.

In accordance with Resolution No. 196/96 of the National Health Council – Ministry of Health, we respected the ethical-legal aspects required for researches involving human subjects. The project was approved by the Research Ethics Committee of the Universidade Estadual do Ceará (UECE) under protocol No. 05041862-9. To ensure anonymity, participants were identified with the letter O, of ostomy, followed by Arabic numerals according to the order they were interviewed.

## RESULTS AND DISCUSSION

The determining factors for self-care deserve to be studied, since these data are important for assessing the learning conditions of the ostomy patient/family to perform the self-care actions, being arranged in table 1.

**Table 1** - Distribution of conditioning factors for the care of ostomy patients. Fortaleza-CE, Brazil. (N=30)

Conditioning factors	F	%
Gender		
Male	20	66,7
Female	10	33,3
Age group		
31 to 40 years	6	20,0
41 to 50 years	4	13,3
≥ 51 years	20	66,7
Education		
Illiterate	3	10,0
Incomplete basic education	6	20,0
Complete basic education	12	40,0
Complete high-school	6	20,0
Higher education	3	10,0
Origin		
Capital city and metropolitan area	20	66,7
Interior of the State	10	33,3
Marital status		
Single	6	20,0
Married	17	57,0
Divorced	4	13,0
Widowed	3	10,0
Household income		
< 1 minimum wage	8	26,7
1  - 3 minimum wages	15	50,0
3  - 6 minimum wages	3	10,0
> 6 minimum wages	4	13,3
Disease that led to ostomy		
Colorectal cancer	13	43,4
Traumas	7	23,3
Inflammatory diseases	6	20,0
Familial polyposis	4	13,3

As presented in Table 1, the study involved the participation of patients mostly male (66.7%), aged older than 51 years (66.7%), with complete elementary education (40.0%), from the Capital city/metropolitan area (66.7%), married (57%) and with low income (76.7%).

These results agree with the estimate of the

National Cancer Institute (2008), which shows a higher prevalence of colon cancer among people older than 55 years, predominantly among males, behind only of stomach, lung and prostate cancer. Added to this, there is an increasing elderly population around the world; at the same time that there is a decrease in the rate of younger groups in society, and the life expectancy of

Brazilians is 73 years<sup>(8)</sup>. However, there is a growing number of ostomy patients in the younger age, leading to the construction of stomas by trauma due to greater susceptibility and exposure to urban violence<sup>(9)</sup>.

Regarding education, the majority (70%) had good education level, representing a favorable condition to learning, which does not guarantee that the information received by patients is understood. In this context, the authors<sup>(10)</sup> emphasize that the education level is considered a worrying factor due to the information on the disease and treatment, relating to patient adherence to self-care. The low education may reflect in the way they assimilate the guidelines on stoma care; however, it does not interfere with the professional's performance with these people, since the interaction between users, service, and professionals has made it possible to overcome these difficulties.

The fact that the most patients (66.7%) come from the capital and the metropolitan area can be explained by a higher incidence of colorectal cancer in areas of socio-economic development<sup>(11)</sup>. Another important aspect to be considered is that the registration of patients is done using the address of their relatives living in the capital, thus facilitating to receive the benefit.

Another contributing factor for self-care was related to the marital status (57%) of the participants. On this aspect, the authors affirm that the spouse struggles to achieve a balance with the partner, and the relationship can be strengthened through dialogue, which allied to respect and mutual affection represented a fundamental way to seek for balance in their loved one's disease, being extremely careful and protective with their partner. Furthermore, the patient receives significant emotional support and is encouraged by their partner to obey the changes that are imposed on their lifestyle<sup>(12)</sup>.

Family income ranged from one to three minimum

wages (50.0%), with especial reference for those earning less than one minimum wage (26.7%). Therefore, we can conclude that the study population has a low purchasing power, and consequently may have difficulties in acquiring the necessary equipment for effluent drainage essential to the rehabilitation process.

It was verified that the main cause of the stoma, in most patients (43.4%), was colorectal cancer, confirming the INCA estimate that this is the third most common type of cancer worldwide, in both sexes, and the second leading cause in developed countries<sup>(8)</sup>. Other authors also identified colorectal cancer as the main causal factor for construction of stomas, besides inflammatory diseases and abdominal trauma<sup>(12)</sup>.

Based on the patients' statements regarding the interview questions, the following categories emerged:

### **Learning to take care of stoma: education-support system**

The guidelines on stoma care should be performed as early as possible, especially during hospitalization. However, the hospital is an unfamiliar environment, and patients are physically and psychologically debilitated to assimilate new information. Thus, the subjects reported that the Association is the place where their doubts were properly explained and where they felt welcomed, as we can verify in the following statements: *...at the association I learned to change the bag... (O18) ...I learned that it is important not to carry weight, because it can cause hernia, prolapse, and that hygiene is important to prevent skin irritation (O24) ...I learned to wash the belly with warm water, then I dry it well and put the bag (O15).*

For Orem, the nursing system planned by the professional is based on self-care needs and on patients' ability to perform self-care activities. Thus, she identified three nursing systems to meet the requirements of the patient self-care: the full compensation system, the partial compensation system, and the education-support

system.

The education-support system allows nurses working at the Ostomy Association to stimulate patients able to perform self-care measures, although they are not able to do it without assistance. At this point, the patient's demands on self-care consist in decision-making, behavior control, and knowledge and skills acquisition. In this system, the nurse is responsible for promoting education, providing better performance in the development of patient self-care activities<sup>(7)</sup>.

One of the help methods identified by Orem is teaching the other. Nurses must use this method in order to teach self-care, favoring a clearer thought and establishing actions that help the patients to be independent<sup>(7)</sup>.

Therefore, we considered that nursing guidelines is one of the strategies that can encourage and develop the potential of patients and families, as well as instrument them to take, as subjects, actions aimed at dealing with problems arising from this treatment<sup>(13)</sup>. The treatment to this need is a basic requirement of nurse-patient interaction, to assist them in understanding their condition of sick person.

Despite previous statements reflect learning, some interviewees reported difficulties in teaching and learning: *...I did not learn anything at the beginning; later I learned everything here with the nurse at the Association...* (O8) *...(I did not learned) nothing! But suffering brings learning.* (O20) *...I left the hospital very quickly. I knew nothing. Then came a girl that was putting the parenteral nutrition, she was an angel, because besides guiding me, she also sent me here* (O10).

Therefore, there is a clear need of establishing a channel of communication, guidance and empathy with the patient still in the hospital environment, from the preoperative, considering the physical and emotional changes consequent to surgery. Perioperative assessment of surgical stoma construction is essential for achieving efficient care-oriented rehabilitation and reducing their rates of complications<sup>(14)</sup>. It is also worth

mentioning the importance of referral to the Association, requiring that nursing strengthen its educational activity, especially at the tertiary level of health care.

The complexity of nursing care provided to ostomy patients refers to the essential understanding of changes that occur in their lives and how they experience this whole process, for further deepening and more coherent planning of interventions in clinical practice. The individual receives support, encouragement and understanding from family and professionals, since the individual mechanisms to meet the human needs will depend on their culture, personality and economic status. This may determine the view on their ostomy condition, influencing them to resume their normal lives. Only then we can perform a human and individual care<sup>(15)</sup>.

Ostomy care requires not only teaching the patients the hygiene care and how to change ostomy bags. There is the need of implementing a care plan with a multidisciplinary approach that includes the participation of stomal therapy nurses, social workers, psychologists, nutritionists, surgeons and physician assistant.

Health education aims to facilitate changes on the way these patients think and act, needed for self-care education. It is an ongoing process and sometimes can take a while. Therefore it is important to begin during hospitalization.

However, at this time, there are many concerns that afflict patients. Thus, the Ostomy Association is a place where patients clarify their doubts, share experiences and receive ongoing guidance, besides emotional support.

### **Stoma care: Knowledge and Practices**

This category gathers the speeches that approached the knowledge acquired and the practice of stoma care, which begin at the time that patients

receive appropriate guidance on handling the bag, until the appearance of conflicting feelings and difficulties to deal with the new situation that lead them to know their limitations and changes in daily life.

One aspect emphasized by patients is related to knowledge about the care for the ostomy bag, as we can see in the following statements: *...I learned to keep it always clean! (O1) ...wash it with asseptol, clean it, dry it well, and properly put the bag... (O3) ...clean it with liquid soap ...if you are wounded, there is a powder or egg white. Cut the bag in the right size... (O6).*

According to the statements, we notice the great concern about cleansing peristomal skin. Stomal therapy nurses have the often concern with the demarcation of the stoma, which if not performed favors the onset of complications, such as skin reactions<sup>(16)</sup>. A well located stoma allows good adhesion of the appliance and the patient has easy visualization to it, avoiding the complications mentioned and encouraging self-care actions<sup>(14)</sup>.

The care experiences mentioned by ostomy patients should be valued by nurses, with regard to the issue of cleansing peristomal skin and necessary care for its integrity. Researchers of the area say that the cleaning of stoma and peristoma skin should be done with neutral soap and water, using soft towel to dry it with light touches<sup>(9)</sup>. These guidelines have been duly explained by the interviewees.

Patients also reported their practices related to emptying the ostomy bag. On this aspect, it is common for patients to react fearfully in front of other people in their social life, by presenting a different appearance than usual, thinking that they will bother, which can be found through the following statements: *...I never let the bag overfilling, always by half, so that it lasts more and nobody senses the bad smell... (O8) ...attention to hygiene, changing period, because if you stay a long time with the bag, people can feel the stench! (O9).*

Scholars<sup>(17)</sup> confirm the concern of interviewees, considering that the change of the appliances should be

performed whenever the skin barrier is saturated, because when there is no good adherence occurs effluent leakage. As the patients handle their stoma, they establish the time of change. The appliance must be emptied whenever the contents reach a third or up to half its capacity to increase its durability.

We highlight the major concern of these patients in feeling uncomfortable with the elimination of odors. This undermines the personal relationship, leading, in some cases, to distance from the family and social isolation, which indicates an important factor to be addressed by the nurse. A study showed that the loss of control of the disposal of feces and gases may cause psychological and social isolation, based on negative feelings that permeate interpersonal relationships<sup>(18)</sup>.

Another important factor to be considered by ostomy patients concerns the eating, since some foods produce foul-smelling stools, reiterating the concern of the interviewees in above mentioned statements. The dietary guidance should be given to the patient still in the hospital environment, by offering a balanced diet, already correcting eating habits and decreasing gas-forming foods, such as beans, cabbage, onions, among others<sup>(19)</sup>.

### **Difficulties Found in the Practice of Self-care**

In this category we discuss the statements related to the difficulties pointed out by interviewees, highlighting the care for ostomy bag, including placement and adaptation of appropriate appliance, according to the following reports: *...having to bend over to put the bag right into the hole (O1) ...the adaptation of the ostomy bag, because my stoma is irregular and I could not put it into the bag. Another annoying thing is when the stool fall out at the changing of the bags (O18).*

Another concern was related to the cost of the bag and the fear of running out of it, because most patients were treated at the public hospital and depended on the free supply of this material, the

absence of which leads to insecurity. The low income of these patients also represented difficulty to acquire quality material, since the appliances purchased in the Association are tested and have their attribute previously proven. One respondent pointed out such difficulty: *...at the beginning it was very tough, because I had no proper bag. Then with the new bags I was adapting, but I was afraid of running out of bags, because it must be expensive and I cannot afford it* (O11).

It is worth mentioning the importance of demarcation performed preoperatively to confirm the location of the stoma to reduce future complications, considered one of the main actions of the nurse in ostomy care<sup>(15)</sup>. Not performing this procedure leads to poorly located stomas that hinder the adherence of appliances, as reinforced in the following speeches: *...to cut, to clean, to have sex, because it is constantly detaching* (O2) *...pain, due to the lack of adherence of the bag to the body hair, and irritations, because I'm afraid that it falls when I least expect it!* (O12) *...when I went to sleep, sometimes it comes loose, because I move too much asleep. Then I wake up all wet* (O14).

The difficulties mentioned have been followed by the development of appliances in the market, all of which contribute to alleviate this suffering and readjust ostomy patients to their social life, free from prejudice and more confident to perform their daily activities.

## FINAL CONSIDERATIONS

Ostomy patients need constant monitoring and motivation to better adapt and thus promote effective self-care. At the end of this study, we obtained important clinical findings for the development of an individual, comprehensive and systematic nursing care for ostomy patients.

As the main conditioning factors for self-care, we identified: gender, age, education, household income, among others; and as major difficulties: placement and adaptation of appropriate appliance,

prejudice and fear of bothering, high costs of collection bag, among others. The greatest concern pointed out by the subjects was related to the management of the stoma, especially to its cleansing and the skin around it, besides changing appliances.

Knowledge of the factors related to self-care of ostomy patients enabled to obtain data that contribute to effective strategies and interventions in their rehabilitation process. These data may also contribute to the improvement of nursing care to ostomy patients, besides strengthening the nursing educational practice.

Therefore, we suggest the development of perioperative care educational technologies grounded on nursing theories, aiming the health promotion of ostomy patient as a strategy to be used by nurses in helping to change habits and decrease complications. It adds up to the need to clarify the doubts and minimize fears of patients, systematically contemplating a comprehensive and quality care.

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