

# THE TEACHING OF SELF-CARE TO OSTOMY PATIENTS AND THEIR FAMILIES: AN INTEGRATIVE REVIEW

*O ensino do autocuidado aos pacientes estomizados e seus familiares: uma revisão integrativa*

*La enseñanza de auto cuidado para los pacientes ostomizados y sus familias: una revisión integradora*

Systematic Review

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## ABSTRACT

**Objectives:** To characterize the national and international literature on the teaching of self-care to bowel ostomates and their relatives. **Methods:** It is an integrative review, in LILACS and MEDLINE electronic databases, in the period from 1996 to 2006, with the keywords 'teaching', 'ostomates' and 'nursing'. **Results:** The sample was composed of eight articles, which reported the importance of teaching strategies applied with patients and their families regarding self-care and management of the stoma and collectors, however, no study has brought specific and systematized teaching strategies. **Conclusion:** The analyzed literature has demonstrated the importance of teaching strategies addressing the issue of self-care for the ostomates, but expressed the lack of researches and publications on the implementation of contextualized actions and with appropriate language for these patients and their families.

**Descriptors:** Teaching; Surgical Stomas; Nursing.

## RESUMO

**Objetivos:** Caracterizar a literatura nacional e internacional sobre o ensino do autocuidado a pacientes estomizados intestinais e seus familiares. **Métodos:** Trata-se de uma revisão integrativa nas bases de dados eletrônicas LILACS e MEDLINE, no período de 1996 a 2006, com as palavras-chave "ensino", "ostomizados" e "enfermagem". **Resultados:** A amostra foi composta por oito artigos, os quais relataram a importância de estratégias de ensino aos pacientes e familiares sobre o autocuidado com o estoma e equipamentos coletores, porém, nenhum estudo trouxe estratégias de ensino específicas e sistematizadas. **Conclusão:** A literatura analisada demonstrou a importância das estratégias de ensino sobre o autocuidado do paciente estomizado, entretanto, expressou a escassez de pesquisas e publicações sobre a implementação de ações contextualizadas e com linguagem adequada aos pacientes e seus familiares.

**Descritores:** Ensino; Estomas Cirúrgicos; Enfermagem.

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## RESUMEN

**Objetivos:** Caracterizar la literatura nacional e internacional sobre la enseñanza de autocuidado para pacientes ostomizados intestinales y a sus familias. **Métodos:** Se trata de una revisión integradora en las bases de datos electrónicas MEDLINE y LILACS en el periodo 1996-2006, utilizando las palabras clave “escuela”, “ostomizados” y “enfermería”. **Resultados:** La muestra estuvo compuesta por ocho artículos, los cuales mostraron la importancia de las estrategias de enseñanza a los pacientes y familiares sobre el autocuidado con el orificio y el equipo de recolección, sin embargo, ningún estudio ha mostrado estrategias de enseñanza específicas y sistematizadas. **Conclusión:** La revisión de la literatura demostró la importancia de la enseñanza de estrategias de autocuidado en los pacientes ostomizados, sin embargo, mostró la falta de investigaciones y publicaciones sobre la implementación de acciones en el contexto y con un lenguaje apropiado para los pacientes y sus familias.

**Descriptor:** Enseñanza; Estomas Quirúrgicos; Enfermería.

## INTRODUCTION

Among the malignancies, colorectal cancer is the second most prevalent type of cancer in Brazil, with approximately 30,000 new cases for the 2012 year. People diagnosed with cancer need treatments such as cancer chemotherapy, radiotherapy and surgery. It is the second leading cause of death by cancer in developed countries and the fifth in Brazil. It mainly affects people over 50 years of age<sup>(1)</sup>.

The social and economic changes brought about by rapid urbanization, new patterns of consumption, globalization of knowledge, scientific and technological advances have promoted a large health impact nationally, with declining birth rates and increasing population life expectancy, which led to the increase in chronic diseases, especially cancer<sup>(2)</sup>. Once the Brazilians' life expectancy increases, it also grows the importance of neoplasms in the morbidity profile of the population, among them, colon and rectum cancer, which may indicate the need for the creation of an intestinal stoma as part of its treatments<sup>(1,3)</sup>.

Each year approximately 1 million and 400 thousand surgical procedures of stoma are performed, which corresponds to a transfer of R\$ 153 million. From January to August 2009, there was an investment of about R\$ 18 million in purchase of collectors equipment, both safety and security, such as collection bags, protective barriers of synthetic skin and urinary collectors<sup>(4)</sup>.

There are physiological and psychosocial consequences associated to surgical treatment that can influence the quality of life of these people and their family. The intestinal ostomy has been identified as the main of these changes,

because it jeopardizes interpersonal, social, labor, sex and leisure aspects<sup>(5-7)</sup>.

The condition of ostomy implies changes in lifestyle not only of the person with a stoma, but of his family. It is evident that the rehabilitation process should be implemented with the patient and his family already in the diagnostic phase, aiming to allow him the activities of social life and improve his quality of life before the impact of the acquisition of the stoma<sup>(8)</sup>. The family of ostomy patients knows their habits and preferences, that is, it has important information that can be useful in planning the rehabilitation<sup>(3)</sup>. The caregiver, in most cases, is a close relative, a friend or someone special whom the ostomate feels safe to express their concerns to and ask for help.

Therefore, the nursing care provided to patients with intestinal ostomy should consider the gastrointestinal physiological changes caused by treatment, as well as their body image and decreased self-esteem, resulting from the surgical mutilation<sup>(6)</sup>. This professional responsibility is reinforced by the participation of nurses at all stages of the care process, but begins in the preoperative phase, when he uses the teaching-learning process. At that moment, there is a need to establish linkages with the patient and their family/caregiver, in order to promote understanding about the real situation and the search for situational adjustments. In the post-operative period, the worries and cares are directed to the stoma, peristomal skin, the exchange of devices, hygiene and food adequacy to reduce gas formation. After discharge, the learning continues at home with the applicability of the strategies, private adaptations and participation in support groups, where the exchange of experiences of living with intestinal stoma take place<sup>(9)</sup>.

Health promotion is the process of enabling people to work in education/health education aiming the improvement in health and quality of life. Its main activities include teaching strategies such as lectures, classes, distribution of educational material, behavioral activities (self-help groups, counseling), health assessments and facilitating access to treatment of existing pathologies<sup>(10)</sup>. To educate on health, it is necessary to understand the worldview, life history, functions or roles in the daily lives and ideas of the learner, since it is needed to understand how their learning is performed, to promote conditions suitable for teaching. In use of written materials, there is a need to verify the compatibility of the information with the culture of the individual, his level of education and any special educational needs<sup>(11)</sup>.

Thus, teaching strategies used by nurses working in this area were searched in literature, in order to: achieve success in teaching; optimize the time spent in each counseling, diminish complications regarding the stomata, reduce

public spending on outpatient care and readmissions, as well as providing better quality of life for patients and their families.

It is noteworthy that, for the ostomate patient to have at least the bare minimum quality of life, there is a need for detailed information and specialized education for the self-care actions to succeed. The nurse who works with this type of patient, besides requiring specific knowledge and theoretical background on stomas and teaching strategies, should show empathy, know how to look, listen, feel, watch, work with various social levels and deal with different situations, whether of revolt, resentment, rejection, among others, always with the purpose of providing comfort and safety to customers<sup>(12)</sup>.

Due to the complexity of teaching ostomate patients and their families/caregivers, it is important to implement and systematize teaching strategies used by nurses working in the area.

For the teaching of the ostomate patient, it is necessary to explore the means, ways, and forms of evidencing thoughts, respecting the favorable conditions to perform the procedure and the characteristics of each patient: their mode of acting, being, thinking and their personal characteristics. To this end, there is a need for teaching techniques appropriate for each one or each context.

Strategy comes from the Greek word *strategia*, the art of applying or explore the means and the available and favorable conditions, in order to achieve specific objectives. Therefore, there is the interest in assessing the teaching strategies used by nurses to teach ostomate patients and their families<sup>(13)</sup>. The teaching strategies (individual or collective) should be selected within the context where patients and their families are included, and the language used must be appropriate to the target audience, so that the objectives are achieved.

Moreover, it is necessary that both parties are involved in a joint action, so that there is assimilation of the knowledge needed to carry out procedural content and the teaching process achieves its goals: gathering, assimilation and reporting of information received; client/family's ability to perform the technique with manual ability to care for the stoma and the exchange of devices; demonstration of the procedure of trading the collecting device; demonstration of independence in self-care with the stoma; identification of actions to be taken in the appearance of skin lesions in peristomal region; and how to prevent the onset of these lesions.

A study<sup>(12)</sup> stands out, by seeking to know the experience of ostomate women to perform the planning of nursing care, it has demonstrated that the nurse is the professional who performs most of the teaching-learning practices to patients, thus emphasizing the importance of professional

competence in choosing the appropriate strategy for the education of patients, with a view to the expected results.

Aiming to contribute to this issue and support the multidisciplinary care to people with intestinal stomas and their families, the objective of this study is to characterize the national and international literature on teaching the intestinal ostomate patients and their families.

## METHODS

For this study, it was used the integrative review, for being a broad method, which seeks to obtain a deep understanding of a particular subject, aiming to encourage improvements in the assistance provided to patients, based in evidences and supported by previous studies<sup>(14)</sup>.

Consultations were performed in electronic databases MEDLINE and LILACS, with international indexing (Bireme - the Latin American and Caribbean Center on Health Sciences Information) in the period from 1990 to 2006, using the keywords 'education', 'ostomates' and 'nursing'. Inclusion criteria were the Portuguese-Brazilian, English and Spanish idioms and addressing the subject of the study. The search yielded 10 articles, 02 of which were excluded and 08 constituted the study sample.

For the selection of these articles, three stages were adopted: exploratory reading; selective reading and analytical reading<sup>(14)</sup>. Later, a summary of the data was performed according to the objectives of the study and the interpretation of these led to the construction of two main themes for discussion: 'Learning self-care' and 'Preparing to perform self-care at home'. Next, there was the formulation of conclusions and the establishment of implications for nursing.

## RESULTS

The analysis of the eight articles of the sample revealed that their publication occurred mainly within the period from 1996 to 2006, being four (50%) from the LILACS database and the other four (50%) from the MEDLINE database. Of these, two (25%) are national literature and six (75%) are international papers; four (50%) publications were authored by nurses and four (50%), by stomatherapy nurse specialists. The articles have are academic, laboratory and hospital origins.

After analytical reading of the articles that fulfilled the search requirements, it was found that all of them emphasized the importance of teaching the ostomy patient by the nurse. However, two (25%) of them did not bring a systematic and specific teaching technique employed for this type of patient, despite describing pedagogic resources used for teaching, and six (75%) presented a teaching

strategy, although none has been systematically explained and only some steps were cited by the authors.

## DISCUSSION

All the selected articles<sup>(12,15-21)</sup> emphasized the importance of orientation for the ostomy patient and his family/caregiver, to perform self-care safely at their homes.

Teaching self-care should be started soon after the decision on the therapeutic procedure to be performed. In the preoperative period, immediately upon admission to hospital, the patient should receive the main guidance about his future living conditions and the precautions that, henceforth, will be needed. In the immediate post-operative period (in hospital) and in the later, the patient should have his doubts clarified, demonstrate his skills and show himself capable of performing home care; if a caregiver is needed, he will be the one to make the demonstration. Right upon discharge, the patient will be referred to the Ostomate Program, receiving specialized care and provision of the necessary equipment to his new condition<sup>(12,16,18,20)</sup>.

The discussion is initiated by the theme: 'Learning self-care'<sup>(12,16,18-20)</sup>. Some authors<sup>(12,16,18,20)</sup> emphasized the importance of preoperative teaching, since, at that time, the patient absorbs information better and this may contribute to his physical and psychological adjustment after surgery, better recovery, adaptation and success in self-care. It is also noted that all preoperative information contribute to post-operative teaching, which must be continuous and focused on the difficulties of patients and their families/caregivers.

The hospitalization or preoperative stage is highlighted<sup>(16,18,20)</sup> due to its importance for teaching the patient and family/caregivers. In it, the primary purpose of education is to clarify the patient and caregiver's doubts about the stoma, explaining how it is to have an intestinal stoma, what will change in daily life, which precautions should be taken regarding the intestinal ostomy, that is, overall guidelines and preparing for adaptation to the new clinic condition and rehabilitation.

Even during that stage, the family/caregiver should be instructed on how to receive the patient at home, the general care required; precautions with food and equipment required at home to facilitate patient's adaptation and rehabilitation. It is important that the healthcare team know how the residence is and what resources and family supports are available, in order to tailor teaching to his reality.

Professionals also need to adapt to his language, communicating and using teaching strategies appropriate for the patient and family/caregiver to understand what is being taught. At that stage, there is a predominance of individual teaching, due to the peculiarities of each patient and family/caregiver, being used the resources of speech,

pictures and mannequins demonstration as strategies for teaching<sup>(16-18,20)</sup>.

It is emphasized<sup>(12,18,20)</sup> that the pre-operative teaching performed by nurses seeks to make the patient feel confident and prepared for the surgery and to perform self-care at home after discharge. However, in many hospitals, this step is not followed since the patient is admitted for surgery and does not receive the necessary information about how his condition will be after the procedure, his body image and how he should perform self-care with the stoma. This lack of guidance derives from the insufficient number of employees working in health institutions; unpreparedness of the health care team regarding resources and teaching strategies; and the lack of theoretical basis, enhancement, training and skills, especially on the part of the nursing team.

On the theme 'Preparing to perform self-care at home', the authors<sup>(12,15,17,21)</sup> highlight that post-operative teaching should be systematic, so that the patient feels safe to be discharged from hospital. In this phase, the patient is already with intestinal stoma, much fragile, sensitized and weakened by surgery and with many doubts concerning the care of the stoma and the necessary adjustments to his new living conditions. Teaching must then be resumed or held focusing on the care of the surgical wound, the intestinal stoma, peristomal skin, its hygiene, and the procedures for emptying and changing the collecting bag.

After discharge, the patient should be referred to the Ostomate Program of the municipality. In this program, funded by *Sistema Único de Saúde - SUS* (Health Unified System), patients shall receive specialized assistance, with training and development of their ability to perform the changing of the ostomy bag (reinforcing the orientation received in hospital or initiating it, if not done yet), receive all the information necessary for their adaptation and rehabilitation, and get in contact with others who are experiencing the same situation, through group meetings<sup>(22)</sup>.

During the teaching process, an evaluation of the peristomal area must be performed, with observation of the presence or absence of lesions in order to decide which bag design is most suitable to that patient, according to his daily activities. This kind of teaching requires a professional with enough time available to educate, aiming to reduce the risk of peristomal lesions in the patient, rendering him confident to change the appliance and thus making him quickly adapted to his new condition, at a lower cost to the local health system<sup>(15)</sup>.

The teaching strategy with step-by-step guidance and supervision by the nurse is the most cited in the literature analyzed<sup>(15-17)</sup>. Among the most widely used teaching resources, stood out delivering leaflets and the use of manuals and guides<sup>(17,18)</sup>.

Prior knowledge on the part of nurses about health education and the teaching-learning process is important to identify the difficulties in learning among the ostomy patients and select proper methods, techniques and strategies in order to facilitate the development of self-care, since nurses in charge of training the staff to care for these patients. It is emphasized that the education of the ostomy patient and his family/caregiver should be gradual, so that they can assimilate the data and information received, meet expectations, solve doubts and decrease the individual's anxiety regarding the surgery<sup>(12)</sup>.

It is also worth noting that the preparation of children and adolescents to deal with intestinal stoma and the relative problems can be accomplished through resources and strategies specific to age, such as flyers, brochures, toys, dolls, demonstrative games (groups) and games with appliances. As an example, the child is encouraged to use an ostomy bag attached to the abdomen, filled with solid material simulating the 'full bag' feeling, thus allowing the feeling of having an ostomy bag for a period. This strategy is used so that the patient knows and feels how it is to have a stoma and decreases his anxiety, giving him more confidence to face surgery. The strategy of demonstration with photographs album is also used, showing how is a child who has undergone the procedure<sup>(18)</sup>.

A study<sup>(21)</sup> that explored the literature production on patient education in the care of the stoma, in order to understand the true meaning/value of education to patients performing practices and skills in the care of stoma, demonstrated that learning involves skills (psychomotor), knowledge (cognitive) and attitude (affective). It stressed the importance of nurses in teaching the practices of care for patients with stomas, since nursing interventions facilitate the patient's adaptation and implementation of practical skills, but there is no citation of specific teaching strategies for the teaching of ostomy patients.

Another study<sup>(20)</sup> demonstrated the need for ostomy patient's evaluation by the nurse and described how a suitable environment should be at the time of evaluation, how to perform the orientation, the importance of recognizing the needs of each patient, and contributed with a descriptive model of the guidelines on how the patient should remove and place an ostomy bag.

The patient education should begin preoperatively, on admission, since in that period, he absorbs information better and this may contribute to his physical and psychological adjustment; guidelines should be provided gradually to avoid saturation. It is suggested the use of an ostomy bag in the abdomen, filled with liquid, so that he becomes familiar with the discomfort. Then follows the directions in the post-operative period, so he can perform safely at home the self-care with the stoma. The exchange of information is very

important and contributes to the education for self-care and rehabilitation<sup>(20)</sup>.

The occluder system technique is also addressed<sup>(15)</sup> as a means of teaching the ostomy patient. It describes how the verbal explanations should be performed, the steps to be followed in the use of the occluder system, and then the patient must be evaluated and corrected when performing the technique, with further guidance and supervision. The study brings the sequential phases that nurses must follow, but does not detail any of them, that is, it exposes a teaching strategy but without systematization<sup>(15)</sup>.

Teaching patients with an ostomy is a complex process, which requires prior assessment, planning and training of caregivers, therefore, learning depends on three domains: cognitive, affective and psychomotor<sup>(17)</sup>. The challenges to effective instruction are: need for limited time for teaching, and reducing costs and the need to teach populations that are increasingly diverse and aging. Nevertheless, the application of well-known teaching and learning principles can make the process efficient, effective and satisfactory to the patient and the nurse<sup>(15)</sup>.

Another study addressed the life with a stoma<sup>(19)</sup> - the strategy of using a guide for professionals to orientate their patients, family members and others about the intestinal stoma. Teaching is done through a booklet, where patient fills information throughout his learning. The booklet brings as much information as possible to the patient's daily self-care, guidance on skin care, precautions on the change of the collecting system and other relevant information. Through this brochure, the professional checks the peculiarities of each patient, promoting the teaching according to the correct sequence for the collector and skin care, bathing, physical exercises, sexual activity etc. At the end, it demonstrates how to empty the bag and wash it. Brochures are used by nurses as a support strategy in the teaching of care to be performed by patients and family members/caregivers.

Another study<sup>(18)</sup> sought to become familiar with the difficulties/facilities that intestinal ostomy patients feel when reading the educational material produced as a teaching strategy<sup>(16)</sup>. For this, we used a readability formula (Printed education materials - PEM) to determine the readability of printed materials with instruction to ostomy patients, used by nurses to inform their patients.

The nurses assessed the readability of the material and, indirectly, the patients' instruction, so that they could combine teaching with the ability and needs of each patient. There is no explicit teaching strategy, but it can be seen that, in the service evaluated, nurses used as a teaching resource for guidance a printed text, which has been used by many health services, regardless the cognitive or psychomotor abilities of each patient, impairing learning.

In recent decades, self-care has been the focus of several discussions in nursing, since, through it, the patient acquires more autonomy, greater capacity to perform activities necessary for health and seeks to maintain, promote, restore and/or live with the effects and limitations of such changes in health, contributing to its integrity, operation and development<sup>(23)</sup>. Analysis of articles revealed: scarcity of research and publications about teaching ostomy patients; range of teaching strategies, due to the fact that there are several contexts for their accomplishment; cultural diversity and patient characteristics, and lack of specialized training for nurses working in this area.

Nurses seek to propose better tools/strategies to suit the profile of each patient and thus, be able to guide him according to his habits, culture and previous knowledge, always focusing on their physical, cognitive and psychological features to facilitate the learning of care, with the expectation that patients put their knowledge into practice and exercise self-care safely. However, there is not a systematized proposal regarding such strategies and there is also a lack of specialized training for the nurses on the teaching to this type of patient.

## CONCLUSION

The literature analyzed demonstrated the importance of the teaching strategies regarding the self-care of the ostomates; however, it pointed out the scarcity of researches and publications about the implementation of contextualized practices with proper communication for the patients and their families.

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