Objective: to analyze the national and international scientific production on the physical, psychosocial changes and the feelings generated by the intestinal ostomy for the patients.

Method: this is an integrative review in the period of 2002 to 2015 with the question “What is the scientific evidence on the physical, psychosocial changes and feelings generated by the intestinal stomas to patients?”. There were searches on the LILACS, MEDLINE, BDBNF and IBECS databases, and in the virtual library SciELO, with the descriptors “ostomy”; Disease impact profile; Psychosocial impact; Emotions and life-changing events and impact, feelings and meaning keywords.

Results: the analysis of the 18 articles was synthesized in themes. Ostomy generated uncertainty and changes in family dynamics and social roles in the patient/family life. Conclusion: knowledge about these changes and feelings can improve the planning of perioperative care and specialized multi-professional support with individualization of needs and use of appropriate strategies. Descriptors: Ostomy; Perioperative Nursing; Psychosocial Impact and Change Lives Events.

ABSTRACT

Physical, psychosocial changes and feelings generated by intestinal ostomy for the patient: integrative review

Mudanças físicas, psicossociais e os sentimentos gerados pela estomia intestinal para o paciente: revisão integrativa

CAMBIOS FÍSICOS, PSICOSOCIALES Y LOS SENTIMIENTOS GENERADOS POR LA ESTOMA INTESTINAL PARA EL PACIENTE: REVISIÓN INTEGRADORA

André Aparecido da Silva Teles, Caroline Francisca Eltink, Livia Mâdolo Martins, Nariman de Felício Bortucanenza, Vanessa Damiana Menis Sasaki, Helena Megumi Sonobe

RESUMO

Objetivo: analisar a produção científica nacional e internacional sobre as mudanças físicas, psicossociais e os sentimentos gerados pela estomia intestinal para os pacientes. Método: revisão integrativa no período de 2002 a 2015 com a questão << Quais as evidências científicas sobre as mudanças físicas, psicossociais e os sentimentos gerados pela estomia intestinal aos pacientes? >>. Realizou-se buscas nas bases de dados LILACS, MEDLINE, BDBNF e IBECS, e na biblioteca virtual SciELO, com os descritores estomia; perfil de impacto da doença; impacto psicossocial; emoções; e acontecimentos que mudam a vida, e as palavras-chaves impacto, sentimentos; e significado. Resultados: a análise dos 18 artigos foi sintetizada em temas. A estomização gerou incerteza e mudanças na dinâmica familiar e nos papéis sociais na vida do paciente/família. Conclusão: o conhecimento sobre estas mudanças e os sentimentos pode melhorar o planejamento da assistência perioperatoria e do suporte especializado multiprofissional com individualização das necessidades e utilização de estratégias adequadas. Descriptors: Estomia; Enfermagem Perioperatoria; Impacto Psicossocial e Acontecimentos que Mudam a Vida.

RESUMEN

Objetivo: analizar la producción científica nacional e internacional sobre los cambios físicos, psicosociales y los sentimientos generados por la estomía intestinal para los pacientes. Método: revisión integradora en el periodo de 2002 a 2015 con la pregunta << ¿Cuáles son las evidencias científicas sobre los cambios físicos, psicosociales y los sentimientos generados por la estomía intestinal a los pacientes? >>. Se realizaron búsquedas en las bases de datos LILACS, MEDLINE, BDBNFe IBECS, y en la biblioteca virtual SciELO, con los descriptores estomía; perfil de impacto de la enfermedad; impacto psicossocial; emociones y acontecimientos que mudan la vida y las palabras-claves impacto; sentimientos y significado. Resultados: el análisis de los 18 artículos fue sintetizado en temas. La estomía generó incertidumbre y cambios en la dinámica familiar y en los papeles sociales en la vida del paciente/familia. Conclusión: el conocimiento sobre estos cambios y los sentimientos puede mejorar el planeamiento de la asistencia perioperatoria y del soporte especializado multi-profesional con individualización de las necesidades y utilización de estrategias adecuadas. Descriptors: Estomía; Enfermería Perioperatoria; Impacto Psicosocial; Acontecimientos que Cambian la Vida.

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Keywords: Ostomy; Disease impact profile; Psychosocial impact; Emotions and life-changing events and impact, feelings and meaning.
INTRODUCTION

The term ostomy or stoma, of Greek origin, means artificial opening. It is made surgically in a hollow organ, which enables the communication with the external environment. In the case of the intestinal ostomy, the deviation of the fecal contents to the exterior aims to protect the intestinal surgical anastomosis or favors intestinal emptying/decompression. In cases of obstruction, it is called a protective stomatous, in general, of a temporary nature. In many cases, due to the amplitude of the resection performed, the intestinal reconstruction becomes infeasible, and the stoma becomes definitive.¹

Anatomically, the intestine is a tubular organ, more than seven meters long, covered internally by a richly vascularized mucosa and it is one of the components of the digestive system. It can be divided into three main parts (thin, thick and straight) and its main function is the absorption of nutrients from food ingested. When in proper functioning, everything that is ingested and not absorbed, it is excreted through the intestine through the anus. Among the various causes that may lead to the need for an intestinal stoma, diverticular and inflammatory bowel diseases such as Crohn’s disease and ulcerative colitis, colorectal cancer (CCR), abdominal traumas and colorectal anomalies are prominent.¹

In diverticular disease, there is a sac-like growth in the intestinal lining (diverticulum), whose accumulation of food or bacteria causes inflammation and occasionally intestinal perforation. Partial bowel resection is often necessary with an ointment in the large intestine (colostomy) or small intestine (ileostomy).¹

Inflammatory bowel diseases have unknown etiology and are characterized by chronic inflammation of the mucosa with/without perforation or intestinal obstruction, often leading to colostomy or ileostomy.¹

CCR is the main cause of intestinal stoma formation.¹ According to the National Cancer Institute José Alencar Gomes da Silva (INCA), it is estimated 34,280 new cases in Brazil for 2016, of which 16,660 are men and 17,620 are women. It is considered the second most common cancer among women and the third among men, except for non-melanoma skin cancer, which results in an increasing number of intestinal stomas.²,³

Regardless of the diagnosis, both the patient and the family have to live with the stoma, which arouses several physical and psychological sensations.⁴ In the physical aspect, there is a change in the place of stool elimination and the need to use collecting equipment for stool, adhered to the abdomen. Also, it coexists with the uncomfortable odor, with the concern of detachment of equipment and effluent leakage.⁵

In the psychological aspect, one of the important commitments is the changes of the body image, which generates the sensation of mutilation and self-rejection, by feeling dirty or different. Another important aspect is the sexuality, after a stoma, resulting in erectile dysfunction for men or dyspareunia for women, due to surgical treatment, adverse events of antineoplastic therapies, or psychoemotional impairment. Not infrequently are the cases of patients who, after surgery, cannot return to their work routine, because they feel insecure to reconcile the care of the stoma with the work activity, precipitating the disability retirement.⁵

Besides the evolution of surgical techniques, the intestinal stoma has a wide range of equipment collectors and adjuvants at its disposal, helping in the adaptation and return to daily activities. Despite all this, a stoma can be traumatizing and mutilating, with profound changes in the lives of these people and their families.¹

Because of these changes, the patient should adapt to a new way of living. In this process of adaptation and rehabilitation, nursing is the team that maintains greater contact time during the perioperative period, with the opportunity to identify the feelings and reactions, as well as the significant changes generated by the intestinal stoma for the life of the patient and his family. In this context, it is essential to welcome the patient and the family to meet the main needs, so that they can face the moment they live with more optimism.⁶

Nursing has the role of caring, identifying their needs, their desires and difficulties, respecting and accepting the differences in the planning of a humanized, individualized and quality assistance, and enabling the rehabilitation for this patient.⁶

OBJECTIVE

● To analyze the national and international scientific production on the physical, psychosocial changes and the feelings generated by the intestinal stomas for patients.

METHOD

This is an integrative review (IR), based on the Evidence Based Practice (EBP), which can subsidize the construction of in-depth knowledge with analysis of previous studies on
The research question was: What is the scientific evidence from the national and international literature on the physical, psychosocial changes and feelings generated by the intestinal stomas in patients’ lives?

The exclusion criteria were: scientific papers related to the topic, published from 2002 to 2015, in Portuguese (Brazil), English and Spanish, available in full by the digital access of the University of São Paulo (USP) Central Library - Campus Ribeirão Preto, whose search was performed with the descriptors stoma; Disease impact profile; Psychosocial impact; Emotions and life-changing events and impact, feelings and meaning keywords. The exclusion criteria were: publications in dissertation formats, thesis or literature review articles.

The search took place from August to December 2015, in the Scientific Electronic Library Online virtual library and the LILACS (Latin American and Caribbean Literature in Health Sciences) databases; MEDLINE (Medical Literature Analysis and Retrieval System Online); Nursing Database (BDENF) and IBECS (Spanish Bibliographic Index of Health Sciences).

The initial search resulted in 100 articles. The ones duplicated in the searches, those that did not approach the subject were discarded, besides the exclusion by the established criteria, resulting in a final sample of 18 scientific articles (Figure 1).
The categorization of the sample, the main aspects addressed by the studies and the levels of evidence are presented in Figure 2.

Regarding the levels of scientific evidence, considering the methods used for the development of the studies, the sample on this subject presented little evidence, that is, one (1) scientific article obtained level of evidence IV (evidence derived from well-delineated, non-experimental cohort and case-control studies), 15 articles were level of evidence VI (evidence derived from a single descriptive or qualitative study) and two (2) articles were level VII (opinion of authorities and/or reports of committees of experts), according to Figure 2.⁸
<table>
<thead>
<tr>
<th>Study</th>
<th>Aspects Addressed and Level of Evidence</th>
<th>Themes</th>
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<tbody>
<tr>
<td>A1⁰⁰</td>
<td>There is a negative emotional impact due to loss of health, lack of information about pathology, surgery and its consequences, limitations in life and the need for learning about care and skills development (VII)</td>
<td>Feelings experienced by the patient with a stoma</td>
</tr>
<tr>
<td>A2¹¹</td>
<td>Spiritual well-being is a source of resilience or stimulus for the adaptation to the altered body with intestinal stoma to cope with deficiency in cancer survival, which influences the quality of life of these patients (VI)</td>
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<tr>
<td>A3¹²</td>
<td>To relieve negative feelings for the patient, stoma care is taken care by the family member and patients with ostomy associations feel safe and accepted (VI)</td>
<td></td>
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<tr>
<td>A4¹³</td>
<td>Statistically significant correlation between social isolation, emotional support, and satisfaction with life; as well as the relationship between social connectivity, satisfaction with life and body image, which can result in social inhibition and anxiety. The results indicate that the interventions of the stoma Specialist and stoma decarication favor postoperative recovery and the perception of body image and self-esteem (IV)</td>
<td></td>
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<tr>
<td>A5¹⁴</td>
<td>Feelings of low self-esteem, social isolation, eating disorders, sleep, rest and sexuality related to stoma, denial of the word cancer, changes in family dynamics, lack of information/preoperative preparation (VI)</td>
<td></td>
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<tr>
<td>A6¹⁵</td>
<td>Professional support and support network favor the confrontation of negative feelings for patients (VI)</td>
<td></td>
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<tr>
<td>A7¹⁶</td>
<td>Changes in the way of life, difficulties in work, leisure, social and family life, sexuality, and food; by the presence of feelings of shame and insecurity (VI)</td>
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<tr>
<td>A8¹⁷</td>
<td>The report on the feelings and experience of stomas can be used as a teaching strategy for undergraduate nursing students in the discussion on humanization of care (VII)</td>
<td></td>
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<tr>
<td>A9¹⁸</td>
<td>Changes in work, family, social and emotional life; Sexual dysfunctions; Phases of acceptance; Feelings resulting from a stoma, increased quality of life according to the time of stoma; Family and professional support are crucial in the adaptation phase to the new condition (VI)</td>
<td>The life of the Post-stoma patient</td>
</tr>
<tr>
<td>A10¹⁹</td>
<td>Family should be inserted throughout the process, as it is a therapeutic resource for the patient in the decision for surgery, in accepting the condition, as emotional support in the performance of care; The support of the spouse are fundamental for the adaptation in the sexual relation (VI)</td>
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<tr>
<td>A11²⁰</td>
<td>The ability to adapt is influenced by previous knowledge and experiences, a network of family and social support, and the nurse is fundamental in this process with educational interventions for patient and family, favoring social reintegration, work and overcoming their weaknesses (VI)</td>
<td></td>
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<tr>
<td>A12²¹</td>
<td>How the patient with a stoma is perceived in the world; Feelings revealed in their experiences after hospital discharge; restricted to its world, marked by suffering; Changes in post-stomatal life; Emotional pain; The person with a stoma is singular, feels different and can be perceived by its corporal expression (VI)</td>
<td></td>
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<tr>
<td>A13²²</td>
<td>Adoption of new healthy eating habits after the postoperative guidelines, which improves bowel functioning, with demystification of beliefs (VI)</td>
<td></td>
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<tr>
<td>A14²³</td>
<td>Sexual experience of women with stoma surviving CCR; Sexual changes and adaptations experienced after surgery; A solitary partner can influence the adaptation to their new condition, physical and psychological problems can cause sexual dysfunction, knowing these experiences can help in the sexual health of these women (VI)</td>
<td></td>
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<tr>
<td>A15²⁴</td>
<td>Changes in the life of the patient were related to the learning of self-care, oncological survival; Postoperative follow-up; Negative psychosocial impact (body image changes, overturning of the stoma, sexuality, travel problems, stigma); Need for emotional support and specialized education; And overcoming the difficulties of life with the stoma (VI)</td>
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<tr>
<td>A16²⁵</td>
<td>Emotional Disorganization (surprise, fear, anger, and impotence) and strategies such as repression, denial, substitution, normalization and overturning are used to deal with discrimination, as well as the support of the associations of stomas (VI)</td>
<td></td>
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<tr>
<td>A17²⁶</td>
<td>Being unknowing about health, being single and having stomas resulting in the abandonment of leisure, sports, and work. The family, support network and specialized multi-professional assistance are important for the fulfillment of their needs (VI)</td>
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<tr>
<td>A18²⁷</td>
<td>Changes in the daily life and family dynamics of the stomas; Feelings related to the stoma; Lack of information in the perioperative period; Role of the nurse in the stomas (VI)</td>
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Figure 2: Synthesis of the study sample. (SP), Brazil, 2016.
The publication of the analyzed production occurred in the journal Index of Nursing with five (5) scientific articles and in the Journal of Coloproctology; Psychooncology; Revista Texto e Contexto em Enfermagem; Journal of Wound, Ostomy and Continence Nursing; Revista da Rede de Enfermagem do Nordeste; Revista Enfermagem UERJ; Revista da Escola de Enfermagem da Universidade de São Paulo; Revista Eletrônica de Enfermagem; Women Health; The Journal of Supportive Oncology; Revista Latino-Americana de Enfermagem; Revista Chilena de Cirugía and Revista Brasileira de Enfermagem with an article, respectively.

The sample was categorized into two themes: “Feelings experienced by the intestinal stoma” and “The life of the patient after stoma”, which resulted from the analysis and interpretation of the data.

*Feelings experienced by the intestinal stoma*

In this theme, it was evidenced that eight articles focused on the feelings experienced by the intestinal stoma, which can be subdivided into two moments: before and after the preparation of the stomach. In the first moment, when the patient was informed of the diagnosis and the necessity of the preparation of the stomach, the feelings reported by the patients were of surprise, anxiety, uncertainty, fear of diagnosis and death, anger, despair, anguish, rejection and impotence. We also identified reports of patients who only knew about the need to make a stoma after surgery, and the right to know and to make the decision about their body was not respected. In general, the stoma process is linked to the diagnosis of cancer, which has a devastating effect on patients and their relatives.

This devastating effect is the result of social stigma in cancer as a synonym of suffering and finitude, which often leads to lay understanding as if there was no possibility of cure for these people, even with early diagnosis. In addition, cancer treatment involves mutilatory surgery and other therapies such as antineoplastic chemotherapy and radiation therapy. There is a need for follow-up of control for five years, with a high demand for emotional and time investment, since the risk of relapse, metastases and other complications becomes the focus of their concerns, requiring specialized perioperative care.

It is as the lives of these people and their families remain in suspension, with interruption of future projects and life becomes the here and now. On the other hand, the patient with stoma is more dependent on his family for the care of the stomas, collecting equipment and for outpatient follow-up, as well as on the emotional aspect. There is a change in family dynamics and organization.

After the preparation of the stoma, the different feelings experienced by the patients were focused. These felt their self-esteem diminished due to the alteration of the corporal image, having to adapt to a new body and a new form of elimination of the feces. Feelings such as uselessness, depression, anguish, revolt, insecurity, disgust, hatred, anger, revulsion, aggression, non-acceptance, self-rejection, mourning, loss of identity and self-concept have also been reported.

By having a stoma in the intestine, the patients presented loss of confidence, dignity and autonomy, with feelings of sadness, fear of the unknown, agony, embarrassment, nonconformity and restlessness, because they feel different from others, which can lead to a social isolation. They reported feelings of discredit before society, a feeling of loss of productive capacity and also fear of eating in public due to the uncontrollable elimination of gases and feces.

Also, feelings of disgust were reported in the studies, contempt and shame at the time of cleaning the bag collection, and not liking to live or feel uncomfortable using an omen. On the other hand, there was a fear of having to adapt to the use of equipment, hygienic care and the management of daily difficulties. They reported concern about the mutilation caused by the surgery and the dependency of the health team and other family members to perform self-care activities, resulting in feelings of loss of control and autonomy over their lives, a great concern to have adhered to their abdomen equipment, in addition to the fear and shame of unpleasant odor, which could be exhaled by the collecting bag. These feelings raise the fear of having their stoma condition denounced.

The definitive intestinal stomas understand the need for adaptation to the stoma, but for those with a temporary stoma it becomes impossible to live with it. Acceptance also appears as a major problem to be faced by them, as they present difficulties in adapting to their new living conditions, which directly interfere with the performance of self-care.

After the stoma, the patients, without choice, go on to a new stage, where they have to live with the stoma and with all the difficulties imposed by it. In this context,
The dietary pattern of these patients has also been changed due to the fear of eliminating gases and feces in public spaces, uncontrollably. On the one hand, some patients reported an improvement in the quality of food after surgery. However, usually the patient adopted drier foods, eliminated those who cause flatulence as an attempt to control the increase in the frequency of intestinal functioning, can lead to deficiency of nutrients. It is necessary for the patient to maintain a balanced diet, including healthier foods and avoiding those that previously caused intestinal problems. It is also necessary for health professionals to be attentive, to identify and to act in situations of risk for serious nutritional deficits by the adoption of a new dietary pattern by the patients after the making of the stoma.22,25

Even with all these changes, over time, some patients understood the stoma as an alternative to their survival, solving their problem, improving health, a new opportunity, a “second chance.” For these patients, stoma represented a prospect of prolonging life and a relief to their suffering. They understood the need to continue life and reported that an adaptation to their new condition was possible, mobilizing their strength to resume their routine before the stoma. Gradually they resume their role in family and society. They reported that, with the support of their family, religiosity, health teams, support network and associations of stomas, it was possible, even with restrictions, to resume most of their daily activities.18,21,24,7

**DISCUSSION**

In the sample, the physical, psychosocial changes and significant feelings generated by the intestinal stoma were evident, besides the repercussions in the daily life of these patients.

In this way, stoma represents the loss of a person’s capacity to respond to personal, family, professional and, above all, social expectations, as if they lost their previous identity and this happens through everyday situations involving prejudice and stigma.29

The loss of sphincter control may lead the patient with a stoma to have feelings of infantilization and inability to maintain social and professional activities as if they prevented them from resuming daily life before illness and stoma. In this way, the stoma specialist, in general, avoids situations that may denounce his new condition. Thus, if they have to go to an outpatient clinic, sometimes they stop feeding the day properly before, so they do not have to empty the
collection bag, or when they go to parties, they restrict everything they eat or drink, which decreases the opportunity to enjoy social life and leisure.12, 6, 18, 24, 26, 29

During the analysis of the articles, the importance reported by the patients on nursing care and the role of nursing and health teams in the process of adaptation to the intestinal stoma was evidenced. The patients emphasized that nursing is the team that is present, from the moment of diagnosis and in the perioperative period, and that their emotional support and their educational intervention for self-care, mainly for their family ensure the return to the home.10, 13, 15, 6, 20, 24

Nursing needs technical and scientific knowledge about the pathophysiology that has determined the making of the stomas for the specialized care planning to be coherent and adequate to the reality and necessity of this patient, as well as the subjective experience after the stoma (reactions and problems). For this, it is necessary investment in the permanent education of the team, fomenting the acquisition of new knowledge of these professionals to offer specialized assistance.14, 16-7, 25, 6

Stoma is procedural, and in the preoperative period, this patient and his family need educational interventions on the disease, surgery with the possibility of making the intestinal stomas, the routine of the surgical center and the post-anesthetic recovery and referral to the Program of Patients with a Stoma and teaching of self-care.10, 13, 5, 25, 27, 30

Another important aspect is the demarcation of the stoma site linked to the preoperative education, performed by the stoma specialist nurse or trained nurse, which will reduce the occurrence of complications of stoma and peristomal skin in the postoperative period, which is concomitantly performed with preoperative teaching, aiming to reduce anxiety and fear, favoring the recovery process and postoperative rehabilitation of this patient.13, 27, 30

The nurse with the multidisciplinary team should plan to discharge the patient as early as possible. Specifically, for the stoma specialist and his/her family/caregiver, educational interventions on self-care with the stoma, collecting equipment and adjuvants should be offered, as well as an indication appropriate to the individual needs of each person. Also, this patient should be referred to a Stoma Program at the secondary level of the Unified Health System (SUS).10, 14, 16, 24, 28

The enrollment in this health program allows specialized multi-professional assistance composed of doctors, nurses, social worker, nutritionist and psychologist in addition to the free acquisition of collecting equipment and adjuvants. In this team, each one within his/her training area will provide the patient and family with the professional support needed to cope with the stoma process to rehabilitation.28-9

The stoma must also be analyzed under the prism of patient’s rights, ensured by legislation with public health policies, which brings together the National Cancer Care Policy, the Cancer Patient’s Rights, the Disability Assistance Program, Patients with a Stoma Program and Ordinance 400 with the National Guidelines for the Health Care of the Stoma People in SUS. Despite the rightful registration of this patients in this Program, it is not yet extended to all throughout the national territory due to difficulties in implementation and other challenges such as the quantitative and qualitative maintenance of collecting equipment, as well as specialized assistance that meets the specific demands of this clientele.28

The stoma represents the process of illness, which goes beyond the new condition, encompassing physiological, clinical, social, financial and family changes, which for the recovery of daily life, the stomas need to seek adaptations and strategies to deal with these changes.14, 16, 18, 24-5

It is important to emphasize that the physical and psychosocial rehabilitation of these patients depends not only on the acquisition of equipment collectors and adjuvants but also on the multi-professional support that assures the recovery of daily life with maximum autonomy and independence, respecting internal and external capacities and resources Available to these people. To this end, it is necessary to articulate the specialized assistance with the teaching of self-care, use of strategies appropriate to the demands of needs, with the insertion of the family caregivers and follow-up of clinical control, which defined the need for intestinal stoma preparation.10, 12-4, 18-20, 24-5, 27-8

CONCLUSION

Stoma entails innumerable physical, psychosocial and emotional changes that affect the patient’s daily life, but, with the support of the family, the health team and religious support, the adaptation and conviviality with their new condition can be favored for the partial or total recovery of their activities, before to surgery.
Nursing can contribute to specialized assistance to the intestinal stoma and its family, especially with educational interventions on self-care and the management of situations or changes required during the perioperative period. The multi-professional team should provide professional support to the individual needs of each patient.

There is a need for future studies with better methodological design to subsidize specialized clinical practice with stronger scientific evidence.

REFERENCES


