



## Original Article

# The impact of colostomy on the patient's life



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### ARTICLE INFO

#### Article history:

Received 14 December 2016

Accepted 27 March 2017

Available online 10 May 2017

#### Keywords:

Colostomy

Quality of life

Digestive system surgical  
procedures

### ABSTRACT

**Purpose:** To evaluate the emotional, psychological, sexual, social, and professional impact, before and after surgery, on individuals submitted to a colostomy.

**Methods:** The study was carried out in two stages, with the participation of 15 individuals. First, we evaluated the emotional, psychic, sexual, social, and professional aspects of their lives, in the preoperative period of colostomy surgery. After that, the same aspects were evaluated six months after the surgery. This evaluation was based on the application of a questionnaire with 16 objective questions.

**Results:** Of the interviewees, 53.64% decreased their willingness to go out and do activities outside their homes, with a statistical significance of  $p=0.001$ . Regarding the environment, 53.85% of the interviewees showed a perception of worsening of the environment. About physical activity, 66.65% showed a difference in the performance of physical activity after colostomy, being statistically significant, with  $p=0.001$ . The sports environment did not change in 50% of the participants. Patient sexuality showed a significant decline with statistical significance ( $p=0.008$ ).

**Conclusion:** The impact that the colostomy generated on the patients' lives, regarding the evaluated aspects, was perceptible, being of great importance the careful indication of this procedure to the patient.

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### O impacto da colostomia na vida de seus portadores

#### R E S U M O

**Objetivos:** Avaliar o impacto emocional, psíquico, sexual, social e profissional, pré e pós colostomia, em indivíduos que passaram por cirurgia de colostomia.

**Método:** Foi realizado em duas etapas com participação de 15 indivíduos. Na primeira houve avaliação sobre os aspectos emocional, psíquico, sexual, social e profissional de suas vidas, no momento pré-operatório à cirurgia de colostomia. Na segunda avaliaram-se os mesmos

#### Palavras-chave:

Colostomia

Qualidade de vida

Procedimentos cirúrgicos do  
sistema digestório

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<http://dx.doi.org/10.1016/j.jcol.2017.03.004>

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aspectos seis meses após a cirurgia. Esta avaliação foi a partir da aplicação de um questionário com 16 questões objetivas.

**Resultados:** Dos entrevistados, 53,64% diminuíram a vontade de sair e fazer atividades fora do lar, com significância estatística de  $p=0,001$ . Quanto ao ambiente instalado, em 53,85% dos entrevistados apresentaram percepção de piora do ambiente. Em relação à atividade física, 66,65% dos participantes apresentaram diferença no desempenho da atividade física pós-colostomia, sendo este dado estatisticamente significativo com  $p=0,001$ . O ambiente esportivo não mudou para 50% dos participantes. A sexualidade do paciente evidenciou grande decaimento com significância estatística ( $p=0,008$ ).

**Conclusão:** Foi perceptível o impacto que a colostomia gerou na vida de seus portadores nos aspectos avaliados, sendo de grande importância a indicação criteriosa desse procedimento ao paciente.

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## Introduction

Colostomy is a surgical procedure that aims to divert intestinal transit when it is anatomically impossible for fecal excretion to occur through the anal canal. The surgical technique used to perform this procedure consists in the incision of the colon wall and its posterior exteriorization in the abdominal wall, allowing the excretion of feces and gases.<sup>1</sup>

Many pathologies affecting the lower gastrointestinal tract can culminate in a colostomy, such as diverticulitis, colorectal tumors, colon and rectum trauma, inflammatory diseases, and congenital anomalies.<sup>2</sup> Depending on the etiology that led to the need for a colostomy, it may be permanent or temporary.<sup>3</sup>

Regarding the number of ostomized individuals, there are 33,864 people with this condition in Brazil, and in the State of São Paulo alone there are 9200 individuals.<sup>4</sup>

It is important to mention that the colostomized individuals do not go through a physical transformation only, but also through a psychosocial one, making them face anxieties, fears and adaptations to their body's self-image<sup>3,5–10</sup> and such issues should be addressed by health professionals, including the physician.

In a systematic review of the literature,<sup>11</sup> the analyzed articles mentioned alterations related to the colostomy: sexual problems, depression, constipation, intestinal gases, dissatisfaction with one's physical appearance, difficulties when traveling, changes in the wardrobe, fatigue, and concern with ostomy sounds. Thus, there is a decline in social participation, since individuals often isolate themselves from others, in addition to often feeling that people who used to be close to them have become distant.<sup>12</sup> Changes in the sexual life of the colostomized individual are due to loss of libido, change in one's body self-image and fear of leakage of feces or gases during sexual intercourse.<sup>6</sup>

Considering all the above, this study is necessary, since the physician who will assist these individuals must be aware of the changes that affect them caused by the colostomy.<sup>13</sup>

Therefore, the aim of this study was to evaluate the emotional, psychological, sexual, social and professional impact of the colostomy on individuals submitted to this type of intervention, comparing these aspects before and after the surgery.

## Method

The present study was submitted to the Ethics and Research Committee of Universidade de Mogi das Cruzes (UMC), and approved under number 696,332 and to the Research Ethics Committee of Hospital das Clínicas Luzia de Pinho Melo, of which approval is under N. 003/14. All the study participants signed the Free and Informed Consent form.

Fifteen individuals submitted to a colostomy surgery were invited to participate in the study from August 2014 to November 2014. As there were two deaths at the end of the study, the number of participants comprised 13 individuals. The number of subjects was defined based on the number of individuals who underwent this procedure and met the inclusion criteria used in this study, mentioned later. All subjects answered the questionnaire in the hospital, while they were hospitalized, at the preoperative or postoperative period of the colostomy.

All individuals aged 20 years or older with cognitive integrity and who agreed to voluntarily participate in the study, after signing the Free and Informed Consent form, were included in this study.

Individuals who had significant impairments, such as cognitive function impairment, severe or profound auditory impairment without intervention, or those who had comprehension difficulties were not chosen to participate in the study, as well as those who could not sign their names and who did not have a guardian to do so on their behalf.

The study was divided into two stages. The first one consisted in the assessment of some general aspects of the individuals' life, in the preoperative period of the colostomy surgery. In the second part, the same aspects were assessed, but six months after the surgery, aiming to assess whether there were differences between the preoperative and postoperative responses.

The evaluation was carried out through a questionnaire that included questions regarding the general identification of the individual, including academic, professional questions, as well as questions on the time of surgery.

Aspects of the social, professional, physical, and sexual life of the colostomized patient were also evaluated based on the application of a questionnaire with 12 objective questions,

with scores ranging from 1 to 5 for each question, with the patient being instructed to answer according to the degree of intensity for each assessed item (very bad, bad, regular, good and excellent), so that the relevant statistical analysis could be performed.

It is noteworthy that this questionnaire was created based on two quality of life,<sup>14,15</sup> adapting them to the objectives of the present study.

The same questionnaire was applied to the same individuals assessed in the first part of the study six months after the colostomy surgery, that is, from February 2015 to May 2015 at the place of their choice. Therefore, some answered the questionnaire at home, others in the hospital while waiting for an appointment and others by telephone. In the postoperative period, two questions were asked at the end of the questionnaire, which are specific for this public, as follows: whether the study subject participated or not in a group of colostomized individuals, which could be found in two addresses in the municipality of Mogi das Cruzes; and whether this participation had helped him or her overcome the difficulties resulting from the surgery.

### Statistical analysis

The results were analyzed through the descriptive analysis of each question, in addition to the parametric Student's *t* test to compare the pre- and postoperative questionnaires of the assessed individuals. The level of significance was set at  $p \leq 0.05$ .

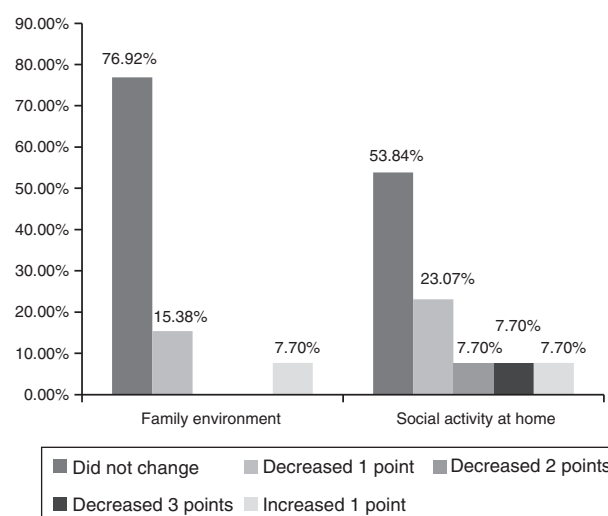
## Results

Data on 15 patients were initially collected in the first questionnaire to evaluate the pre-colostomy life and after 6 months, they were assessed again regarding the post-colostomy evaluation. There were two deaths and, therefore, a total of 13 participants at the end of the collection.

The data of the study participants were collected, showing a mean age of 66.3 years, 65% of the sample consisted of males, and 35%, females. As for the participants' level of schooling, 38.46% of them had not finished Elementary School, 30.76% had finished Elementary School, 15.38% had finished High School and 7.70% were illiterate; 75% of them were married and 40% were retired.

Regarding the work activity, 76.92% of the sample worked at the time of the first interview and only 30% continued to work after the colostomy surgery. Thus, considering only those who returned to their professional activities (evaluation of how much the individual was able to perform work activities at the pre-colostomy and post-colostomy periods), 33.33% of the participants had a 4-point decrease, when comparing both questionnaires; 33.33% decreased 2 points and 33.33% decreased only 1 point. This means that a considerable number of them had a large decline in their professional activity performance. However, this result was not statistically significant ( $p = 0.64$ ).

Regarding the work environment before and after the colostomy, that is, the type of relationship with co-workers, considering only those who returned to work (30% of the



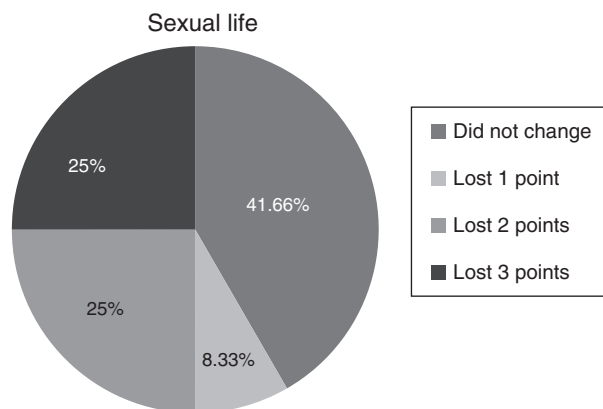
**Fig. 1 – Pre- and post-colostomy comparison regarding the family aspect of the colostomized patient.**

sample working in the first interview), it was shown that 33.33% decreased 3 points when comparing the pre- and post-colostomy questionnaires, that is, the professional environment worsened after the colostomy. On the other hand, 33.33% decreased only one point, being initially 5 points in the pre-colostomy period and decreasing to 4 points after the surgery, whereas the remaining 33.33% did not notice any difference regarding the pre- and post-colostomy environment, without any decrease in the score.

Regarding the individual's willingness to do social activities outside the home, such as going to friends or relatives' houses and going to restaurants, cinemas or religious temples, for instance, it was observed that 38.46% of the participants maintained the same willingness to do activities outside the home even after the colostomy, 23.07% had a decrease of 1 point in the desire to leave the house and the same percentage showed a decrease of 3 points in the willingness to do external activities. It was also observed that 7.70% had a 2-point decrease and the same percentage showed a 4-point decrease in the willingness to leave home to do other activities. These data showed statistical significance, with  $p = 0.001$ .

Regarding the social environment existing between the patient and people present at the site (outside the home), 46.15% said there were no changes in the scores regarding how this environment was in pre- and post-colostomy periods; 15.38% showed a decrease of 2 points, the same percentage showed a decrease of 1 point, and 15.38% of them had a one-point increase after the colostomy. There was also a decrease of 1 point between the pre- and post-colostomy questionnaires in 7.70% of the interviewees. There was no statistical significance for this question, with a value of  $p = 0.051$ .

As for the question regarding the family environment before and after the colostomy, that is, the environment between the patient and his/her family members, as well as the patient's willingness to engage in social activities at home such as meetings, dinners and having visitors over (also pre- and post-colostomy) the house, the results are shown in Fig. 1.



**Fig. 2 – Changes in the sexual life of the participants before and after the colostomy;  $p$  value = 0.008.**

As for the environment with physical activity and sports before and after the colostomy, only 6 of the participants were able to respond. Regarding physical activity, about how much the study subject was able to do of the proposed exercises, 33.33% had a 4-point decrease when comparing the pre- and the post-colostomy questionnaires. For 16.66% of respondents, there was a 3-point decrease in performance when comparing the pre- and post-questionnaires and the same percentage of subjects had a 5-point decrease for this comparison. There was no change in performance before and after the colostomy for 16.66% of the analyzed cases. Still related to the performance of physical activities, there was one individual who did not perform any activity before the colostomy and who started doing them after the surgery and the score given by that individual was 4 points, that is, there was a gain of 4 points between the pre- and post-colostomy periods. This question showed statistical significance, with a  $p$  value = 0.001.

As for the sports environment between the study participant and the other sports colleagues, 50% said there were no changes in the quality of the pre- and post-colostomy environment; 16, 66% said there was a 4-point decrease after the colostomy; and 16.66% said there was a decrease of 5 points, since the participant performed physical activities before the surgery, but stopped after the colostomy. There was also a gain of 4 points in the comparison of the pre- and post-colostomy periods for one subject (16.66%). This question showed statistical significance, with  $p = 0.04$ .

Regarding how the participants assessed their overall health, before and after the colostomy surgery: 7.70% had a 4-point decrease when comparing overall health before and after the colostomy; 23.07% had a 2-point decrease between the pre- and post-colostomy periods and the same percentage had a 1-point decrease in the same comparison. For 23.07% of the interviewees, there was no change in the overall health status. For 15.38%, there was a gain of 1 point, referring to an improvement in the overall health status after the colostomy when compared to the pre-colostomy period. For 7.70%, there was a gain of 2 points when comparing the questionnaires related to this question. This question showed statistical significance, with a  $p$  value = 0.04.

Regarding the changes in the participants' sexual life, Fig. 2 shows the results.

As for the last two questions asked in the second stage of this research, that is, if the participant participated in a colostomy support group, 100% of them reported never attending a specialized group. When asked about the reason they did not seek to participate in these groups, the reasons given were related to being hospitalized with no prediction of discharge, lack of knowledge that existed, great distance between the group location and the patient's home, being well adapted to the colostomy, and extra expenses related to transportation from home to where the group was located.

## Discussion

With the need for a surgical intervention to receive a colostomy pouch, patients must go through changes regarding several aspects of their lives,<sup>16</sup> in order to adapt to their new condition and have the best possible quality of life.

This study, which comprised 13 individuals who, for different reasons, were submitted to a colostomy, showed there were several changes in their daily lives, when comparing life before and after the colostomy. Such changes, in general, are demonstrated by the literature, which mentions that during a disease process, there is a high emotional load and that it eventually interferes with the individual's life process.<sup>17</sup>

As for the specificities of each aspect evaluated in this study, regarding the social scope, there was a change in performance, which was reduced in all cases, albeit at different levels, in the functions performed before the colostomy. The working environment did not change for 33.33% of the sample. Although not statistically significant, such data discloses the difficulties experienced by these individuals regarding their occupational activity and their social role. This finding is in line with what is demonstrated in the literature, that is, the adaptation process is influenced by the acceptance of these individuals in face of their new condition and the existing social stigma.<sup>18</sup> Moreover, the perception that the individuals with colostomy themselves have of the decrease or loss of their productive capacity also influences this process.<sup>5</sup>

As for these patients' willingness to do social activities outside the home and the local environment after the colostomy, 53.64% of the interviewees decreased their willingness to go out and do activities outside the home, due to discomfort regarding possible odors and sounds from the colostomy pouch, according to their reports. This result was statistically significant, with  $p = 0.001$ . Regarding the established environment, 53.85% of the interviewees showed, in their responses, some degree of environmental deterioration perception. Such difficulties are described in the literature, which shows that many ostomized individuals become isolated after the colostomy.<sup>5</sup> There was one participant who declared, for instance, that he did not go to church anymore, because he was afraid of the sounds coming from the colostomy pouch and also because of the bad smell that can occur. Another participant also mentioned that he did not take buses anymore, because he felt humiliated once, when he needed public transportation and a passenger complained about the sudden bad smell in the bus. These qualitative statements corroborate the aforementioned literature.



However, the literature also shows that many individuals restart their lives and maintain their interpersonal relationships, which is in line with what was shown in the present study, with 46.15% of respondents showing no difference regarding the stimulus to leave home and meet other people, or the established environment, i.e., the same in the pre-colostomy situation.<sup>5</sup>

Regarding the social activity at home and the family environment, there was no change for 76.92% and 53.84% of the participants, respectively. According to the reports of some participants, “the family is the safe haven” and if it were not for the family, they would not know how to go through the process of the disease and the colostomy. This aspect is highlighted in the literature related to the area, which reports how much the support of the family and significant people is important for the rehabilitation and reintegration of the colostomized individual.<sup>5</sup>

As for the physical activity and the established environment, regarding the first aspect analyzed there was a total of 66.65% of participants who showed a difference in physical activity performance before and after the colostomy, with a decrease of 3–5 points in this performance, which was statistically significant with  $p = 0.001$  (considering that six subjects were involved in these questions related to physical activity). The sports environment did not change for 50% of the participants, who felt as welcome as they did before, whereas the other half showed varying degrees of deterioration regarding how they felt welcomed and at ease in that environment. The literature showed similar data, where colostomized patients do not usually return or only return partially to “active” leisure activities such as sports, due to the concerns about the colostomy pouch, fear of needing to clean the pouch during the physical activity and physical and/or health problems.<sup>5,6</sup>

As for the overall health quality, 54.84% of the participants showed a decrease, to some degree, after the colostomy, whereas 23.07% had no pre- and post-colostomy changes and 23.08% had a gain in the overall post-colostomy health. This self-perception about overall health in our study is in contrast with the literature, which mentions that the individual can associate the use of the colostomy pouch to disease resolution, which leads to greater positivity regarding recovery and adaptation to the condition, as well as contributing to the reduction of their suffering.<sup>19</sup>

There were great changes regarding the patient’s sexuality aspect, with a statistically significant decrease ( $p = 0.008$ ) in this function. Although 41.66% of the participants did not report any changes between the pre- and post-colostomy questionnaires, 50% of the sample showed a decrease of 2 or 3 points in the post-test when compared to the pre-test, showing that the sexual life deteriorated after the colostomy. These data are corroborated by the literature, which shows that the colostomized individual may feel ashamed in the presence of his/her partner, embarrassment with the new body image and insecurity regarding the colostomy pouch.<sup>5,20–23</sup> Some participants mentioned that they were embarrassed regarding their partners, whereas others said the partner was afraid of complications during the sexual act that would embarrass the patient, such as colostomy pouch leakage. Others also reported the partner’s fear of hurting the colostomy pouch site.

It was observed that none of the present study participants had sought any Ostomy Support Groups (OSG), and several reasons were given, with the most often mentioned one being the lack of knowledge about the existence of these groups. During the interview, it was observed that some difficulties presented by the participants could be attenuated with the participation of these individuals in the OSGs, requiring a period of guidance provided by appropriate professionals, whenever the individual needs, to elucidate the family and the colostomized patient about the changes that will occur, attenuating the difficulties related to self-image and social, leisure and work activities.<sup>24</sup>

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## Conclusions

Considering the abovementioned facts, the complexity of the changes that occurred in the life of the colostomized individual has been demonstrated.

Of the aspects that were evaluated, there was a statistically significant decrease in the willingness to perform social activities outside the home, physical activities, as well as an important decline in the sexual area. Such changes demonstrate the importance of a holistic approach, and a careful indication of this procedure to the patient by the physician.

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## Funding

CNPq/PIBIC.

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## Conflicts of interest

The authors declare no conflicts of interest.

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## Acknowledgements

To Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq), which provided funding support through a PIBIC scientific initiation grant.

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