

# Quality of life outcomes in patients living with stoma

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**Abstract.** Background: Quality of life (QOL) has become an increasingly important factor in managing colorectal cancer (CRC). Ostomy remains an important treatment option for CRC, but it has a considerable impact on a patient's life afterwards. Therefore, analyzing how patients are adjusting to the stoma is an important part of medical observation. Aim: The aim of this study is to evaluate the QOL in patients with permanent ostomies. There are five criteria being assessed in the study: family support and social functioning, fear of stoma leakage, optimism, peristomal skin irritation and comfort regarding stoma placement. Material and methods: We developed a questionnaire to address QOL issues in ostomy patients by following the most important parameters established by the Nursing Research and Education City of Hope National Medical Center, California, USA. We evaluated 53 patients who had undergone surgery for colorectal cancer and have permanent ostomies. We applied the questionnaire for the first time in the 5th day after surgery and stoma placement and, then, the same questions were asked 9 months after the operation. Results: Family support and care for the patients with stomas was given the highest grades, both 5 days and 9 months-1 year after surgery (median = 4(2.5; 5) and 4(4;4),  $p = 0.006$ ). One of the main problems patients reported as worse at the 9 month-1 year evaluation was skin irritation, initially with the median= 4(3; 4) in the first 5 days, this dropped to 3(2; 3),  $p$  value = 0.017. Another parameter that had lower values 9 months-1 year after the stoma placement was optimism. Starting with a median of 3(2; 4) 5 days after surgery, it dropped to 2 (1; 2),  $p$  value < 0.001. Conclusions: Our stoma-QOL questionnaire demonstrated that patients with a permanent stoma had satisfactory family support, but they struggled with skin irritation, fear of stoma leakage and their optimism level was still significantly impacted in a negative way 9 months- 1 year after surgery.

**Key Words:** quality of life, ostomies, colorectal cancer.

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## Introduction

Colorectal cancer is amongst the most frequent malignancies and it is often associated with a high morbidity and mortality rate and, unfortunately, colostomy continues to be the necessary treatment option in a large number of patients. In recent years, partly due to improved screening programs, but also because of better multidisciplinary treatment, the survival rate of patients with colorectal cancer has risen. As a consequence, with better life expectancy, comes demand for better life quality, so looking into this aspect is an essential part of therapy. (Edwards et al 2014).

Despite recent progress in surgery, particularly the development of restorative surgical techniques, the usage of stomas is still largely spread and often mandatory. The contribution of stoma therapy to health-related quality of life (QOL) and the impact of a stoma on a patient's life is very little discussed and it is definitely underestimated. Studies suggest that patients with a stoma have a poorer QOL compared to those that had undergone non-stoma related surgery and consider life with a permanent colostomy unacceptable. (Wilson et al 2008; Engel et al 2003). These findings should play their part in choosing the best treatment option for certain patients and individualized

stoma impact assessment should always be performed before such radical surgery.

Without a doubt, a stoma impacts a patient's life considerably. In spite of being reluctant to discussing stoma issues at first, when more thoroughly interviewed, patients express a series of problems that range from impact on family and social life to their own state of mind and the struggle to battle depression. These patients have many concerns about living a somewhat normal life as they constantly worry about how well the stoma is functioning, they fear stoma leakage and they also have to deal with a certain stigma that deeply impacts them psychologically. Furthermore, their difficulties also extend to an altered body image and sexual malfunctions.

All the before mentioned issues are expected to impact their quality of life, but with proper support many problems could be significantly diminished. Therefore, poor QOL is partly due to inadequate management and counseling services provided to stoma patients and with the help of proper education and management, standards could be improved considerably (Khan et al 2011, Mumtaz et al 2011).

The very aim of this study is to demonstrate that stoma patients experience many difficulties on both a personal and a social

level and, as a result, their QOL is diminished. With detailed, specific questions, we were able to grasp an overview of their life after stoma surgery and we encountered many problems that have been neglected. Still, identifying the issues these patients struggle with is just the first step in what we hope will become better stoma management. Adequate counseling both before and after stoma placement is a crucial step on the route to better healthcare for this category.

## Materials and methods

The study was conducted on a total number of 56 patients diagnosed with colorectal cancer and hospitalized in the IIIrd Department of Surgery, between January 1st 2014 and December 31st 2015, who had undergone surgery for colorectal cancer and had permanent ostomies. We developed two questionnaires to address quality of life (QOL) issues to be studied in ostomy patients, selecting statements from the Nursing Research and Education City of Hope National Medical Center, in California, USA. All the participants in this study received all the information about the proceedings and expressed their agreement.

A prospective study was conducted on patients with colorectal cancer and permanent ostomies. The data we have used was obtained from the questionnaires patients had filled out and also from hospital records. The first questionnaire contains 15 statements, with 1-5 score points and it was completed 5 days after performing ostomy. The second questionnaire contains 16 statements with score points of 1-5 and it was applied on patients anywhere between 9 months to 1 year after performing ostomy. The interpretation of the score points of the questionnaires is, as follows: unsatisfactory (grades 1-2), medium satisfactory (grade 3), satisfactory (grades 4-5). The 56 patients enrolled in the study, filled out both questionnaires, at 5 days and at 9 months-1 year after surgery.

In the enrolled patients we observed the following objective parameters: gender, age, tumor location, surgery type and approach (classic or laparoscopic) and the stoma type.

Then, using the before mentioned questionnaires, we were able to follow several subjective parameters, which they graded 1 to 5:

- The degree of skin irritation around the stoma.
- The degree of stoma leakage
- Availability of family support and care of the stoma patient.
- Patient's optimism regarding the changes brought by the stoma appliance.
- Patient's comfort regarding the location of the stoma appliance.

The statistical analysis was performed with the help of MedCalc Statistical Software 16.4.3 (MedCalc Software bvba, Ostend, Belgium; <https://www.medcalc.org>; 2016). Quantitative variables were tested for normality using the Kolmogorov-Smirnov test and were expressed using the median and the 25 and 75 percentiles. Qualitative variables were expressed using absolute and relative frequency. The difference of a variable between the initial assessment and the 9-12 months assessment was verified using the Wilcoxon test. P value < 0,05 was considered statistically significant.

## Results

We began data analysis by calculating gender distribution. The majority were male subjects, more precisely 31 patients,

representing 58,5%. There were 22 female subjects, cumulating 41,5% of patients. The average age was  $65,4 \pm 9,3$  years.

Out of the 56 cases, in most patients, we opted for curative treatment. However, in 10 patients, the stoma was merely a palliative intervention due to the advanced tumor stage (T4). Out of these, 3 patients were declared inoperable and we only performed a stoma without any tumor resection.

Preoperative chemotherapy and radiotherapy was recommended for T3N1 or a higher stage patients. In our study, 8 patients out of 56 benefited from it.

There were 11 emergencies, the rest were scheduled interventions. Most emergencies were bowel obstructions, but we also encountered severe cases of hemorrhage. All of these patients were informed about the possibility of the surgery ending with a permanent stoma and expressed their written consent.

The type of surgical intervention was resection (amputation) of the rectum: 34/56 (60.73%), anterior resection of the rectum: 10/56 (17.85%), right hemicolectomy: 3/56 (5.35%), recto-sigmoid resection: 7/56 (12.5%), transversostomy (paleative): 2/56 (3.57%). Although uncommon, the reason why we had to perform a right hemicolectomy on 3 patients is because these cases were emergencies, who arrived with a bowel obstruction by ascending colon cancer.

The location of the tumor was on the ascending colon: 3/56 (5.35%), rectum: 45/56 (80.37%), sigmoid colon: 8/56 (14.28%).

Regarding the ostomy type, we obtained the following: colostomy 48/56 (85.71%), transversostomy 5/56 (8.92%), ileostomy 3/56 (5.35%). All of these were permanent, including the 3 ileostomies. In these cases, 2 out of 3 had severe associated pathologies that prevented a reintervention and the remaining patient had severe loose tissue in the abdominal cavity.

Out of the 56 patients initially included in the study, we had 3 deceased patients. Therefore, we analyzed the scores of 53 patients and compared the 5 parameters we used in the 5 days questionnaire and in the 9 months-1 year questionnaire. The degree of skin irritation around the stoma 5 days after surgery was given a higher grade, with a median of 4 (3;4) than after 9 months-1 year, where the median was 3 (2;3), with p value = 0.017. After 9 months, patients with permanent ostomy still present skin irritation around the stoma, even if they use special ointments for several hours a day.

When assessing the patients' fear regarding the pouch coming off and leakage, we noticed lower grades at 5 days after surgery, the median being 2 (2;4) than after 9 months-1 year, where the median was 3 (2;3), with p value = 0.730.

Availability of family support and care of the stoma patient had similar high grades, both at the 5 days assessment – median = 4 (2.5;5) and at the 9 months-1 year reevaluation – median = 4 (4; 4), with a p value of 0.006. We noticed the implication of family members had risen from the moment of surgery to the 1 year evaluation.

When looking at optimism regarding the changes brought by the stoma, the grades given by the patients were higher in the 5 days after surgery questionnaire, with a median of 3 (2;4) than in the 9 months-1 year questionnaire, where the median was 2 (1;2). P value < 0.001.

Patients' comfort regarding the placement of the stoma appliance was initially given a median grade of 3 (2; 4) and after 9 months-1 year, the median was still 3 (3; 4), with a p value = 0.05.

## Discussion

Patients with colorectal cancer that undergo surgery and are subsequently left with a permanent ostomy are a rather unique category. Besides the psychological impact of the malignancy, the stoma itself affects the patient in many ways. Adapting to a new lifestyle, which includes the permanent presence of the stoma appliance is more than challenging and there are many issues to be discussed when assessing the quality of life in these patients. One of the most frequently mentioned concerns of stoma patients is leakage from the stoma bag and the fact that others may learn about its presence (Ponczek *et al* 2005). In our study, we noticed this fear was higher in the first days after surgery and it diminished by the 1 year evaluation, as patients started adapting to their new life and learned to live with the stoma. Having an ostomy brings along the additional effort of having to take proper care of it and it associated with high anxiety levels, as illustrated in several Canadian studies. These problems are more severe in elderly patients (Mastracci *et al* 2006).

Optimism, or its lacking to be more precise, is another very important issue in stoma patients as they have high expectations as far as surgical treatment is concerned and presenting them with the news that stoma formation is necessary is often disappointing. With time, some patients suffering from potentially fatal diseases, realize that saving their life is invaluable and this allows them to reconsider the stoma and to look at life and their daily activities more optimistically (Allal *et al* 2005). However, in the present study, patients' optimism was graded with a very low score and, surprisingly, the score was lower after 9 months-1 year than at the initial evaluation, in the first days after surgery. Low optimism levels were also reported by Anaraki *et al* (2012), who conducted a study that illustrated how permanent stomas impact the overall quality of life. Almost 70 % of patients were dissatisfied and expressed 'depression feelings.' The overall QOL was impacted by several factors, the most important being the illness that caused the need for a stoma, the location of the ostomy and battling depression in regards to both the disease and the permanent stoma. In previous studies, optimism was found to have a significant impact on the quality of life as it is associated with lower psychological distress. In addition, several studies have illustrated that hope and generally a positive attitude towards the outcome of cancer treatment can have a positive impact and it can significantly lower psychological distress in patients with cancer (Lynch *et al* 2008; Rustøen *et al* 2010; Utne *et al* 2010).

Another aspect impacting the quality of life in these patients is skincare in regards to the stoma. Skin irritation, caused by the close contact with stoma effluent and skincare products under the adhesive, was reported in several patients and it was one of the parameters that had worsened from the 5th day evaluation to the 9 months-1 year reassessment. Using a skin-friendly adhesive and changing the stoma appliance often were helpful, but only to some extent. However, if skin irritation is experienced, regular visits at the stoma care clinic could truly ensure optimal stoma skin management and they could prevent the before mentioned problems (Ratliff *et al* 2005; Liao *et al* 2014). Studies focusing on the complications after ostomy surgery have shown rates between 21-70 % and peristomal dermatitis was mentioned in several cases (Shabbir *et al* 2010). Furthermore, Lynch *et al* (2008) conducted a study on ostomy-related problems and

concluded that skin irritation and sensitivity around the stoma, in addition to odor and noise linked to the stoma appliance were amongst the most frequent difficulties encountered by patients. However, in their study, the number of participants reporting these problems decreased over time.

Although the present study illustrated that stoma patients struggle with many difficulties, family support was not one of them. Immediately after surgery, but also after 1 year, family members showed dedication and patients graded family care as satisfactory. Other studies stated that a permanent colostomy or ileostomy impact both social and family relationships in a negative way, alongside travelling, physical activity, sexual function and finances (Dabirian *et al* 2011, McMullen *et al* 2008). Denlinger *et al* (2009) illustrated how a permanent ostomy impacts QOL in more than one way. As a result of the stoma, patients experience body image problems and fear financial difficulties, which also affect family life.

## Conclusion

These findings confirm that colostomy or ileostomy has a profoundly negative impact on the optimism level of these patients 9 months-1 year after surgery, in spite of satisfactory family support. Specialized counseling provided by a dedicated team can definitely improve some of the issues reported, particularly stoma leakage and skin irritation. Ostomy still has a largely negative impact on patients' quality of life as their mindset is the main issue. The idea of having to live with a stoma bag remains a significant problem for this group of patients.

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