




# Quality of Life and Financial Impacts of Permanent Colostomy for Rectal Cancer

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## Abstract

**Introduction** Returning to work is an important cancer recovery milestone. Permanent colostomy can be required for rectal cancer treatment and can significantly impact well-being. We aimed to evaluate the impact of permanent colostomy on health-related quality of life and return to work in patients with rectal cancer.

**Methods** This was a retrospective cohort study on 23 employed patients receiving curative surgery for rectal cancer requiring permanent colostomy. Demographic and health-related quality-of-life questionnaires (the Colostomy Impact Score (CIS), the EORTC Quality of Life Questionnaire (QLQ)-C30, and the EORTC QLQ-CR29) were posted to eligible patients.

**Results** On average, patients (10 female, 13 male, mean age 61.8 years) were  $5.0 \pm 3.5$  years post-surgery. At the time of questioning, 73.9% had returned to work (21.7% changed their type of work), while 17.4% never returned to work. Of those that returned to work, 11.8% returned within 1 month of surgery, while 23.5% had not returned after 12 months. Comparison of CIS between patients that returned to the same work ( $14.6 \pm 0.93$ ), changed their work ( $13.0 \pm 0.74$ ), and did not return to work ( $14.3 \pm 2.3$ ) revealed no significant differences ( $p = 0.36$ ). CIS did not correlate with days worked on return, or time to return to work ( $p > 0.05$ ).

**Conclusion** Returning to work following rectal cancer treatment with permanent colostomy is challenging, with 17.4% never returning to work. Of those who returned to work, 23.5% required more than 12 months. This was not associated with CIS in our study.

## Keywords

- rectal cancer
- colostomy
- quality of life
- employment

## Introduction

Globally, colorectal cancer is the third most common cancer diagnosis and the fourth most common cancer cause of death.<sup>1</sup> Treatment can be grueling, with curative options including major surgery, chemotherapy, and radiotherapy. Of surgical treatments for colorectal cancer, the rate of permanent stoma

formation varies considerably. The permanent colostomy rate in Australia was 21.3% in 2021,<sup>2</sup> but the rate has been reported to be up to 63% in some tertiary centers treating complex rectal cancer patients.<sup>3</sup>

The impact of a colostomy on a patient's physiological, functional, and psychosocial well-being can be profound. Poor body image, depression, sexual dysfunction, and financial hardship have been linked to colostomies. However, a 2012 systematic review could conclude whether colostomy

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formation in patients with rectal cancer impaired their quality of life compared with those without colostomy.<sup>4</sup>

Returning to work is an important milestone in recovering from cancer. It is economically important to patients and society for patients to be able to return to work as early as possible. Working can provide patients with a sense of purpose, dignity, and financial independence. With more colorectal cancer diagnoses in younger patients, combined with an increasing age of retirement, it stands to reason that more patients with colorectal cancer will be diagnosed while still engaged in the workforce. Despite this, little research has been conducted examining the impact of colostomy on patient's financial status, including their ability to return to work following surgery.

This study aimed to evaluate the impact of permanent colostomy on health-related quality of life and return to work, specifically in patients with rectal cancer.

### Methods

Ethical approval was gained from the Metro South Human Research Ethics Committee (HREC/18/QPAH/144). This study was performed in conjunction with the Translation and International Validation of the Colostomy Impact Score.<sup>5</sup>

Patients were included if they were operated on electively with curative intent for rectal cancer requiring the formation of a permanent colostomy (abdominoperineal resection, Hartmann's, or pelvic exenteration), and were employed at the time of diagnosis. Patients were excluded if they were <18 years of age, had known disseminated or recurrent disease, had an ileostomy formed, were not employed at diagnosis, or were unable to complete questionnaires.

Basic demographic and health-related quality of life questionnaires (the Colostomy Impact Score (CIS),<sup>6</sup> the EORTC quality of life questionnaire (QLQ)-C30,<sup>7</sup> and the stoma section of the EORTC QLQ-CR29<sup>8</sup> were mailed to 105 prospective participants in a reply-paid envelope with reminder text messages sent to participants on days 7 and 14 after sending to maximize return rate. No financial incentives were offered for the completion of questionnaires. The CIS is a new scoring measure of stoma dysfunction impacting health-related quality of life, only recently validated internationally.<sup>5,6</sup> A CIS of 0–9 points is categorized as minor colostomy impact, while a score of 10–38 points is categorized as major colostomy impact.

All data was collated by a separate team member than that who performed the analysis and was de-identified. The data was manually reviewed and corrected for apparent errors in responses. IBM SPSS Statistics 22.0 (IBM Centre, NSW, Australia) was used for data analysis.  $p < 0.05$  was considered statistically significant. Graphs were created with GraphPad Prism 8.0 (GraphPad Software, Inc).

Simple descriptive statistics for baseline demographic information were presented in table format. For continuous variables, the Shapiro-Wilk statistic was used to determine the normality of distribution. The McNemar-Bowker test was used to compare responses regarding employment before

and after permanent colostomy for nominal variables, and the paired  $t$ -test was used to compare continuous variables. The EORTC data was presented as mean (SD), as is conventional. One-way ANOVA was used to compare the CIS and EORTC results between patients who did return to work, changed their type of work, and did not return to work.

### Results

Of 105 surveys distributed, 41 patients responded (response rate 39%), and 23 (56.1%, 13 males, 10 female) were employed at the time of diagnosis and thus met inclusion criteria. Patients that were employed at the time of diagnosis were on average  $61.8 \pm 10.7$  years of age, and younger than the rest of the cohort ( $68.4 \pm 12.6$  years). ►Table 1 shows demographics for those patients who were employed at the time of diagnosis.

**Table 1** Demographic of patients that have undergone curative treatment including surgery with a permanent colostomy for rectal cancer, who were employed at the time of diagnosis ( $n = 23$ )

Demographic	Result
Age (years) at time of questionnaire completion	$61.8 \pm 10.7$
Gender	Female: 10 (43.5%) Male: 13 (56.5%)
BMI	$26.5 \pm 1.3$
Original surgery	Abdominoperineal resection: 17 (73.9%) Hartmanns procedure: 1 (4.3%) Pelvic exenteration: 5 (21.7%)
Post-operative length of stay (days)	11 [10]
Cancer staging	Stage I: 7 (30.4%) Stage II: 8 (34.8%) Stage III: 6 (26.1%) Stage IV: 0 (0.0%)
Neoadjuvant chemoradiotherapy	None: 4 (17.4%) Chemotherapy alone: 1 (4.3%) Chemoradiotherapy: 17 (73.9%)
Adjuvant chemotherapy	None: 12 (52.2%) Chemotherapy: 10 (43.5%)
ASA classification	ASA 1: 3 (13.0%) ASA 2: 17 (73.9%) ASA 3: 2 (8.7%)
Smoking status	Never smoked: 9 (39.1%) Ex-smoker: 12 (52.2%) Current smoker: 2 (8.7%)
Relationship status	Married: 17 (73.9%) Single: 4 (17.4%) Widowed: 1 (4.3%) Other: 1 (4.3%)
Highest education achieved	Secondary school: 7 (30.4%) Training skill / trade: 8 (34.8%) College / higher education: 7 (34.7%)

**Table 1** (Continued)

Demographic	Result
Religion	Christian: 13 (56.5%) Not religious: 6 (26.1%) Other: 4 (17.4%) * No patients identified as Buddhist, Hindu, Jewish or Muslim
Number of people at home relying upon income	1: 10 (43.5%) 2 - 3: 9 (39.1%) 4-5: 1 (4.3%) 5-6: 1 (4.3%)
Income	< \$15,999: 1 (4.3%) \$15-33,799: 2 (8.7%) \$33,800-77,999: 11 (47.8%) \$78,000-103,999: 3 (13.0%) \$104,000-155,999: 4, (17.4%) > \$156,000: 0, (0%)
Level of independence	Manages independently: 21 (91.3%) Needs help with some things: 2 (8.7%)
EORTC QLQ - C30 scores	<b>Global health status / QoL:</b> Global QoL: $73.6 \pm 22.0$ <b>Functional scales:</b> Physical function: $91.8 \pm 13.3$ Role function: $81.2 \pm 29.4$ Emotional function: $81.9 \pm 25.2$ Social function: $73.2 \pm 36.5$ Cognitive function: $88.4 \pm 19.7$ <b>Symptom scales / items:</b> Fatigue: $20.8 \pm 24.2$ Nausea and vomiting: $6.5 \pm 14.9$ Pain: $22.5 \pm 25.9$ Dyspnoea: $8.7 \pm 20.6$ Insomnia: $21.7 \pm 31.2$ Appetite loss: $10.1 \pm 23.4$ Constipation: $10.1 \pm 18.6$ Diarrhea: $17.4 \pm 24.3$ Financial difficulties: $24.6 \pm 39.2$

Abbreviations: ASA, American Society of Anaesthesiology; BMI, body mass index; EORTC QLQ-C30, European Organization for the Research and Treatment of Cancer (EORTC) quality of life 30-item core questionnaire; QoL, quality of life.

Data reported as mean  $\pm$  standard deviation for continuous normally distributed variables, median [interquartile range] for skewed variables, or n (%) for categorical variables.

Employed patients had their permanent colostomy for a mean of  $5.0 \pm 3.5$  years at the time of questionnaire completion, with 100% ( $n=23$ ) of the patients surveyed caring for their colostomy independently. The patients emptied their colostomy a mean of  $2.4 \pm 1.1$  times daily. Over half of the patients surveyed (56.5%) reported experiencing embarrassment due to their colostomy, and 65.2% believed their colostomy caused a degree of restriction in their everyday activities or chores (►Table 2). The mean CIS was  $13.4 \pm 2.5$ , with 91.4% of patients ( $n=21$ ) having a CIS greater than 10, suggesting a significant impact of the colostomy on quality of life. However, the EORTC-QLQ-C30 global score for our group was  $73.6 \pm 22.0$  which is significantly higher than the published 2008

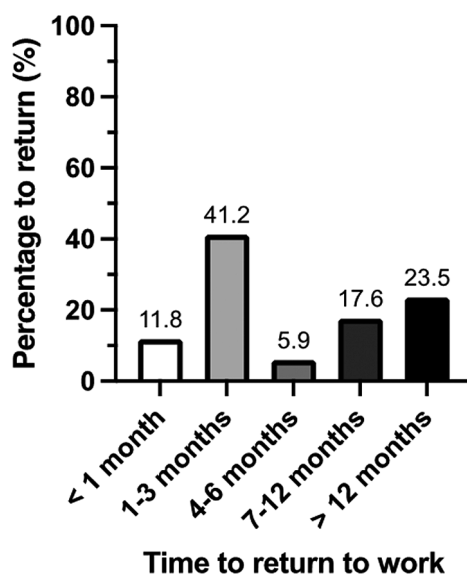
**Table 2** Colostomy impact on perceived quality of life in employed patients ( $n=23$ )

Demographic	Result
Perception of colostomy impact	No impact: 7 (30.4%) A little: 10 (43.5%) Some: 2 (8.7%) A lot: 3 (13.0%)
Embarrassment due to stoma	Not at all: 10 (43.5%) A little: 5 (21.7%) Some: 4 (17.4%) A lot: 4 (17.4%)
Restriction of activities due to stoma	Not at all: 8 (34.8%) A little: 11 (47.8%) Some: 3 (13.0%) A lot: 1 (4.3%)
Colostomy impact score (CIS)	$13.4 \pm 2.5$ Major impact (CIS 10+ points): 21 (91.4%) Minor impact (CIS 0-9 points): 2 (8.6%)
Use of colonic irrigation	No: 17 (73.9%) Regular use: 6 (26.1%)
Funding	Individual: 3 (13.0%) Private health insurance: 1 (4.3%) Public health insurance: 18 (78.3%) Other: 2 (4.3%)
Financial burden of stoma products	Yes, burden: 1 (4.3%) No burden: 21 (91.3%)
Parastomal hernia	Yes: 10 (43.5%) No: 8 (34.8%) Don't know: 5 (21.7%)
EORTC QLQ - CR29 scores	Flatulence: $28.8 \pm 25.8$ Leakage of stools: $20.3 \pm 24.1$ Stomal irritation: $18.8 \pm 29.9$ Bag changes (day): $21.7 \pm 23.8$ Bag changes (night): $19.3 \pm 23.1$ Embarrassment: $19.7 \pm 30.3$ Problems caring for: $7.2 \pm 20.0$

Abbreviations: EORTC QLQ, CR29, EORTC quality of life questionnaire for colorectal cancer; QoL, quality of life.

reference value for patients with colorectal cancer  $60.7 \pm 23.4$  ( $p < 0.005$ ).<sup>9</sup>

Following surgery, 17 (73.9%) of the initially employed patients returned to work, with 5 of these (21.7%) changing their type of work. 4 patients (17.4%) never returned to work, and 2 patients declined to comment. Of those who were initially employed at diagnosis, 11 (47.8%) were prevented from returning to work due to physical factors, 2 (8.7%) for psychosocial factors, and 3 (13.0%) due to a combination of both. 7 patients declined to comment. Many patients that did return to work ( $n=17$ ) took several months after surgery to return to work, with only 11.8% ( $n=2$ ) of patients returning to work within 1 month of surgery. After 12 months, 23.5% ( $n=4$ ) of patients had still not returned to work (see ►Fig. 1). A chi-square test was performed and did not find a significant relationship between adjuvant chemotherapy and return to work ( $p=0.342$ ), or time to return to work ( $p=0.09$ ). Furthermore, there was no significant relationship between the type



**Fig. 1** Time to return to work after formation of permanent colostomy ( $n = 17$ ).

of surgery performed or return to work ( $p = 0.735$ ), or time to return to work ( $p = 0.198$ ). Patients worked significantly fewer days per week following return to work ( $4.7 \pm 0.6$  pre-operatively,  $4.1 \pm 1.2$  post-operatively  $p = 0.007$ ), and fewer hours per week although this was not statistically significant. There also appeared to be a trend where patients who returned to work transitioned to part-time, casual, or self-employed roles rather than full-time positions, although this was not statistically significant.

One-way ANOVA comparing CIS between patients that returned to the same work ( $14.6 \pm 0.93$ ), changed their type of work ( $13.0 \pm 0.74$ ), and did not return to work ( $14.3 \pm 2.3$ ) revealed no significant differences ( $p = 0.36$ ). Similarly, no significant differences were found between the components of the EORTC QLQ-CR29, and the EORTC QLQ-C30 scores in those that returned to work, changed their type of work, and did not return to work ( $p > 0.05$ ), with one exception. The physical function of those who did not return to work on the EORTC QLQ-C30 ( $75.0 \pm 24.0$ ) was significantly less than that of those who returned to work ( $97.3 \pm 3.7$ ) and changed their type of work ( $94.4 \pm 6.7$ ) ( $p = 0.015$ ). One-way ANOVA comparing CIS based on relationship status (married, single, widowed, other), religion (Christian, not religious, other), and employment status (employed, unemployed, retired) also found no significant differences ( $p = 0.77$ ;  $0.30$ ;  $0.44$  respectively). There was no difference in the CIS between different genders ( $p = 0.87$ ). Days worked per week following surgery did not significantly correlate with the CIS ( $r = 0.18$ ,  $n = 17$ ,  $p = 0.49$ ). Furthermore, time to return to work did not significantly correlate with the CIS ( $r = -0.138$ ,  $n = 17$ ,  $p = 0.60$ ).

## Discussion

This study evaluated the health-related quality of life and return to work patterns in patients undergoing surgery with permanent colostomy for rectal cancer. We found that a

significant proportion (17.4%) of our cohort did not return to work following surgery, and of those who did return to work, 23.5% took more than 12 months to do so.

Most previous studies examine return to work behaviors in patients with colorectal cancer group colon cancer patients with rectal cancer patients. However, the treatment for colon cancer is very different from the treatment for rectal cancer, and we believe this impacts a patient's recovery, quality of life, and ultimately return to work. There are several previous studies on return to work in colorectal cancer patients. First, a retrospective study in the Dutch population examined the return to full work duties in colorectal cancer patients, including 164 patients with a colostomy. The median time to return to full work duties was 423 days, and 32.5% of patients had not completely returned to work at the 2-year follow-up.<sup>10</sup> A further study in the Australian population of 239 patients with colorectal cancer found that at 12 months following diagnosis, 46% of patients had decreased or ceased work. These patients were 3.5 times more likely to have stopped work compared with age and gender-matched controls. However, only 13 patients in this cohort (5.4%) had permanent stomas.<sup>11</sup> Metastatic disease, emotional distress, postoperative complications, a larger work company size, trajectory of return to work (direct return versus a gradual return), radiation therapy, chemotherapy, advanced age, and comorbidities have also been identified in studies as negative predictors of returning to work.<sup>10,12</sup>

In our study, 74% of the patients eventually returned to work, which is a higher rate than in the previous studies on colorectal cancer patients. This may be due to the retrospective nature of our evaluation and the longer follow-up time (5 years) allowing capture of patients with a prolonged time to return to work (23.5% of those returning to work took over 12 months to do so). Our patient cohort also had a significantly higher global quality of life score (EORTC QLQ-C30) compared with the reference value for patients with colorectal cancer and were mostly healthy or suffered from only mild systemic disease (American Society of Anaesthesiology [ASA] 1 or ASA 2, 86.9%). This may have increased their interest and ability to return to work despite their new diagnosis. Furthermore, our patient cohort trended toward decreasing working days and hours on return to work, with some transitioning to part-time positions as they adapted to their new stoma, which may have made them more likely to return to some form of employment with reduced hours. Interestingly, the average age of the employed patients completing the questionnaire was 61.8 years, which is only a few years shy of the age pension eligibility age in Australia and above the age at which superannuation can be accessed.

There have also been a few recently published studies examining return-to-work behaviors in rectal cancer patients specifically. A sub-analysis of a prospective Australian study on 120 rectal cancer patients found that 78% of their patient cohort returned to work within 12 months, which is consistent with our rate of return. Those undergoing laparoscopic-assisted surgery, having a successful curative resection, or those with dependent children were more likely

to return to work at 12 months.<sup>13</sup> Another study in a Dutch cohort of 292 patients with rectal cancer (approximately one-third receiving a permanent ostomy) found that 30% of patients had not resumed work 24 months post-treatment.<sup>14</sup> Those with ostomies, older age, requirement for neoadjuvant or adjuvant treatment, more advanced malignancy, lower educational background, and lower baseline income have been reported to be less likely to re-engage with the workforce after diagnosis with rectal cancer.<sup>15,16</sup> To the best of our knowledge, our paper is the first to specifically target those receiving a permanent colostomy, and identified impaired physical function (EORTC QLQ-C30) in those who were unable to return to work.

Cancer patients' clinical follow-up generally does not routinely assess return to the workforce, and patients are rarely spontaneously provided with work-related advice by their clinicians. It is well documented that a diagnosis of cancer increases the risk of unemployment in both the short and long term.<sup>17</sup> Unemployment, in addition to the direct and indirect financial costs of treatment, can distress patients. In our cohort, 91.3% of patients did not report any financial burden related to the purchase of their stoma products, reflecting the success of the Australian stoma appliance scheme. However, despite stomal appliances themselves not being financially burdensome, the stoma itself does impact aspects of quality of life in our group, with over half of patients reporting being embarrassed by their stoma, and 65.2% of patients believing their colostomy restricted their activities. Our cohort had a mean CIS of 13.4, suggesting a major impact of their colostomy on quality of life. Interestingly, the CIS and the EORTC QLQ-CR29 were not statistically significantly different in groups of patients that returned to work or did not return to work, suggesting that stomal concerns did not necessarily relate to return to work in this group.

The strengths of this study include its focus on return to work in rectal cancer patients with colostomy, which is a unique group not usually researched separately from colon and rectal cancer patients without permanent colostomy. The study utilizes the newly validated CIS, and the validated EORTC QLQ-C30 and EORTC QLQ-CR29 scoring systems. There are also limitations. These include the advanced age of the cohort, which impacted the employed sample size and response rate to the questionnaire (the majority of patients were already retired) but may have also influenced the work outcome following surgery (i.e., patients choosing to retire early rather than return to work). We note that some patients were reluctant to answer all questions on the survey regarding their income and time to return to work. Return of functionality and financial questions can be sensitive topics for patients, and this information could potentially be better furnished prospectively during routine cancer follow-up. Further, concerning the study design, questionnaires regarding the utilization of alternative income sources (i.e., superannuation, income protection insurance, sick leave) following diagnosis would also clarify the financial impact of the diagnosis and treatment on the patient.

In conclusion, returning to work following surgical treatment of rectal cancer with a permanent colostomy can be lengthy and challenging, with 17.4% of patients never returning to work following surgery. Of those who returned to work, 23.5% took greater than 12 months to do so. However, 74% of patients did eventually return to work, despite the advanced age of this cohort. Return to work following diagnosis and treatment of rectal cancer is complex and numerous potential factors could affect this. Interestingly, return to work was not associated with the CIS and EORTC QLQ-CR29 in our study. Further larger-scale studies will be required to investigate this further.

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#### Conflicts of Interest

The authors declare that they have no conflicts of interest relevant to the manuscript.

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