


ORIGINAL ARTICLE

Quality of life in postostomy surgery patients: A cross-sectional survey

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Key words

colorectal cancer, colostomy, ileostomy, inflammatory bowel disease, stoma.

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Abstract

Background and Aim: Ostomy is a radical treatment that is sometimes required due to severe inflammatory bowel disease (IBD), colorectal cancer (CRC), and so on. Around 8000 people in New Zealand live with stoma bags. We studied factors associated with poor quality of life (QoL) in ostomy patients to improve patient care.

Methods: Eligible adult patients identified through the Southern District Health Board database were invited to participate. The survey consisted of the general stoma QoL, IBD, CRC QoL, and dietary and lifestyle questionnaires.

Results: Response rate was 54.5% ($n = 241/448$). Study participants were a mean (SD) 70.9 (14.2) years old, 60.6% were male, and 89.5% were New Zealand European; 52.5% of the study participants had a colostomy, and 56.4 and 22.4% received their stoma due to CRC and IBD, respectively. Median (first–third interquartile range) duration since ostomy for overall study sample was 6.9 (3.3–15.1) years. Mean (SD) Stoma-QoL score for all the patients was 60.3 (10.8) points (scale 20–80). Stoma-underlying disease ($P = 0.28$) and type of stoma ($P = 0.60$) were not associated with Stoma-QoL scores. Older adults had higher Stoma-QoL, IBD questionnaire and QLQ-C30 quality-of-life scores; 73.1% received dietary recommendations for the stoma, and 56.4% changed their diet, 51.4% found it easy to adhere to dietary recommendations, and 9.2% found it quite/very difficult.

Conclusion: This study found high-quality life scores in postostomy patients and no significant association between the underlying disease, time since ostomy, level of comorbidities, and how the appliance worked, which highlight the multifactorial nature of the quality of life concept and difficulties measuring it.

Introduction

Ostomy is a surgical procedure to treat conditions affecting the digestive or urinary systems, such as severe inflammatory bowel disease (IBD) and colorectal cancers (CRCs).¹ IBD is a chronic disease with recurrent inflammation of the gut, often requiring increasingly more aggressive treatments to induce and maintain disease remission.^{2,3} About 23–45% of the ulcerative colitis (UC) and up to 75% of Crohn's disease patients will require surgery, and for some of them, this will result in an ostomy due to medically resistant disease, medication intolerances, or severe acute IBD.^{3,4} Despite progress in the detection and treatment of CRC, an estimated one in three CRC patients will require removal of the affected tissue section and the subsequent formation of an ostomy.⁵ The need for a stoma can be temporary or permanent. It is estimated that 7000–8000 people in New Zealand (NZ) lived with stomas at the time of the study (2017–2018), with approximately 530 patients in the Otago region (Stoma Nurses' Database).

While an ostomy serves as a treatment for serious underlying diseases, prolonging life and/or ending suffering, the aggressive nature and body-altering effects of the ostomy, along with complications, are often associated with decreased quality of life (QoL) and increased health burden in these patients.^{6,7} Ostomy-associated changes result in altered body image, social isolation, embarrassment, psychological distress, and perceived loss of control that result in decreased QoL.^{7–10} Stoma patients have reported a higher prevalence and higher levels of psychological distress than non-stoma patients,^{8,11} while other studies found no difference.^{12,13}

Ostomy-associated complications and their occurrence rates are dependent on the part of the intestine affected; the type of stoma appliance and its care; and patient characteristics, such as body mass index, individual anatomy, and lifestyle factors. Around 21–70% of ostomy patients will experience complications¹ such as peristomal skin irritation,¹⁴ parastomal hernias (0–48.1% depending on the type of the stoma),¹⁵ stoma prolapse (2–3%),¹⁶ and stoma strictures and retractions.

Furthermore, depending on the area affected, the removal of large segments of the bowel and the formation of an ostomy can affect the absorption of nutrients and electrolytes and reabsorption of fluids, leading to nutritional challenges¹⁷; for instance, some patients with end ileostomies have limited capacity to absorb vitamin B12 due to partial or complete loss of their terminal ileum. Consequently, postostomy patients usually receive specific dietary advice to minimize complications associated with the stoma.^{18,19} While a number of institutes have published dietary recommendations, currently, there is lack of consensus dietary guidelines for postostomy patients,^{17,20} posing a challenge for patients, hospital foodservices, and treating clinicians.

Overall, the main factors that have been associated with changes in QoL in stoma patients include how well the appliance works (fit and leakage), therapeutic outcomes of the intervention, any associated changes in lifestyle, and any associated complications.^{6,9,21} Other factors such as lack of skills and knowledge about stoma, presence of other chronic illness,⁹ receiving emergency ostomy surgery, and being female^{22,23} predicted worse stoma function.

The challenges postostomy patients experience are well known; however, relatively few studies attempted to quantify the extent of the problem and identify patients' and stoma characteristics associated with worse QoL outcomes. Identifying specific factors associated with worse psychological outcomes will help to improve stoma management by identifying more problematic groups, addressing specific challenges, and informing future interventions.

We hypothesize that the underlying type and duration of the disease that led to the stoma influence the QoL of postostomy patients. To our knowledge, no such data are available for the NZ population; this knowledge would be highly beneficial in NZ as it has one of the highest rates of IBD and CRC in the world.^{24,25}

Methods

Ethics. This study received ethics approval from the University of Otago Ethics committee (HD15/014). All study participants signed written informed consent forms.

Table 1 Demographics of the respondents who completed the survey, categorized by underlying disease

Characteristic	Total, % (n = 241)	CRC, % (n = 136)	IBD, % (n = 54)
Age (years), mean (SD); range	70.9 (14.2); 22–94	75.1 (11.6)	62.6 (17.1)
Gender: male	60.6% (146/241)	67.6% (92/136)	48.1% (26/54)
Ethnicity			
New Zealand European	89.7% (209/233)	83.8% (114/136)	98% (53/54)
Other European	7.3% (17/233)	10.3% (14/136)	1.9% (1/54)
New Zealand Māori	2.1% (5/233)	1.5% (2/136)	—
Asian	0.9% (2/233)	0.74% (1/136)	—
Stoma type			
Ileostomy	49.6% (117/236)	31.6% (43/136)	96.3% (52/54)
Colostomy	52.5% (124/236)	68.4% (93/136)	3.7% (2/54)
Underlying disease for stoma			
CRC	56.4% (136/241)	—	—
Total IBD	22.4% (54/241)	—	—
Crohn's disease	25.9% (14/54)	—	—
Ulcerative colitis	70.4% (38/54)	—	—
Indeterminate colitis	3.7% (2/54)	—	—
Other disease	15.8% (38/241)	—	—
Undetermined	5.4% (13/241)	—	—
Second stoma, yes	2.9% (7/241)	5.1% (7/136)	0.0% (0/54)
Years since ostomy, median (IQR); range	6.9 (3.3–15.1); 0.27–48.1	5.3 (2.1–10.8); 0.27–41.1	15.6 (6.1–26.1); 0.45–46.1
<1 year	6.6% (16/241)	8.8% (12/136)	3.8% (2/52)
1–5 years	31.5% (76/241)	37.5% (51/136)	19.2% (10/52)
5–10 years	22.4% (54/241)	27.2% (37/136)	7.7% (4/52)
>10 years	36.9% (89/241)	26.5% (36/136)	69.2% (36/52)
Stoma-associated problems [†]			
None reported	44.1% (41/93)	49.0% (25/51)	40.9% (9/22)
Minor	28.0% (26/93)	19.6% (10/51)	31.8% (7/22)
Major	28.0% (26/93)	31.4% (16/51)	27.3% (6/22)
Burden of comorbidities [†]			
None reported	16.0% (15/94)	11.5% (6/52)	28.5% (6/21)
Low (1–3)	45.7% (43/94)	51.9% (27/52)	52.4% (11/21)
High (>3)	38.3% (36/94)	36.5% (19/52)	19.0% (4/21)

[†]Complete clinical notes were available only for a subset of the points at the time of the study.

CRC, colorectal cancer; IBD, inflammatory bowel disease; IQR, interquartile range.

Bold values indicate the most common response for the variable.

Table 2 Quality of life scores' summary by questionnaire and gender; presented as median (1st-3rd IQR)

	Total	Females	Males	p-value
ALL PATIENTS				
Stoma-QoL(+)	60(53-66)	60(52-66)	60(54-65)	0.067 ^a
IBD PATIENTS				
IBDQ, median(IQR)				
IBDQ Total(+)	183(146-202)	174(127-200)	186(156-202)	0.39 ^b
IBDQ Bowel symptoms(+)	59(48-64)	60(45-64)	58(53-63)	0.59 ^b
IBDQ Systemic Symptoms(+)	25(22-29)	24(16-29)	26(23-30)	0.29 ^b
IBDQ Emotional Symptoms(+)	70(53-77)	66(48-75)	70(56-77)	0.46 ^b
IBDQ Social Symptoms(+)	28(21-33)	28(20-33)	29(26-33)	0.64 ^b
CRC PATIENTS				
QLQ-C30, median (IQR)				
Global Health score(+)	67(50-83)	42(25-54)	67(50-83)	0.02 ^{b*}
QLQC30SummaryScore(+)	85(75-93)	61(44-75)	84(73-93)	0.10 ^b
<u>functional scales</u>				
physical(+)	87(67-93)	87(73-93)	87(60-93)	0.31 ^b
role(+)	83(67-100)	100(67-100)	83(50-100)	0.11 ^b
cognitive(+)	83(67-100)	83(67-100)	83(67-100)	0.59 ^b
emotional(+)	83(67-100)	92(67-100)	83(67-100)	0.93 ^b
social(+)	83(67-100)	100(83-100)	83(67-100)	0.01 ^{b*}
<u>symptom scales</u>				
fatigue(-)	26(11-44)	22(0-33)	33(11-44)	0.03 ^{b*}
pain(-)	0(0-17)	0.0(0-8)	0(0-33)	0.09 ^b
nausea and vomiting(-)	0(0-0)	0(0-0)	0(0-17)	0.22 ^b
dyspnoea(-)	0(0-33)	0(0-30)	33(0-33)	0.004 ^{b*}
insomnia(-)	33(0-33)	33(0-33)	33(0-33)	0.49 ^b
appetite Loss(-)	0(0-0)	0(0-0)	0(0-0)	0.31 ^b
constipation(-)	0(0-0)	0(0-0)	0(0-0)	0.24 ^b
diarrhoea(-)	0(0-33)	0(0-33)	0(0-33)	0.87 ^b
financial(-)	0(0-0)	0(0-0)	(0-33)	0.01 ^{b*}
QLQ-CR29, median (IQR)				
<u>functional scales</u>				
body image(-)	89(67-100)	89(7-100)	89(67-100)	0.15 ^b
anxiety(-)	67(67-100)	100(67-100)	67(67-100)	0.02 ^{b*}
weight(-)	100(67-100)	100(67-100)	67(67-100)	0.55 ^b

^at-test.^bWilcoxon-Mann-Whitney test.

*Statistically significant.

(+) indicates higher score – better quality of life; (-) indicates higher score – worse quality of life.

Participant recruitment. Adult patients who were known to have an ileostomy or a colostomy in the Otago arm of the Southern District Health Board according to a stoma nurse database were invited to participate in the study (2017). Participants who had a reversal of their stoma were not included in the study. Patients who provided signed consent to participate in the study received three validated stoma care QoL measures: the general stoma QoL measure (Stoma-QoL)²⁶ (for IBD and CRC), an IBD questionnaire (IBDQ)²⁷ (for IBD), and the EORTC CRC QoL measure (QLQ-CR29)²⁸ (for CRC) and core module (QLQ-C30)²⁹ (for CRC). Participants were asked to complete the questionnaires corresponding to their disease (IBD or CRC). Participants also received a dietary and lifestyle questionnaire designed by the research team. A demographic and medical history data audit was performed. Each participant received a paper version of the questionnaire and a link to an electronic version.

Scoring of questionnaires. Paper surveys were read using TeleForm (11.2, HP, Cardiff, UK), and the entries were manually curated. The Research Electronic Data Capture³⁰ web-based tool was used to host and collect electronic versions of the study.

The questionnaires used, the outcome measures, and the scoring system are listed in Table S1, Supporting information and Supplementary Scoring strategy section; each of them were scored as per their references.

Clinical audit. Clinical and demographic data were collected on the study participants from the patients' clinical notes. Data on the type of stoma, underlying disease, time since surgery, stoma-associated complications, and burden of comorbidities were collected (categories assigned as explained in Supplementary Scoring strategy).

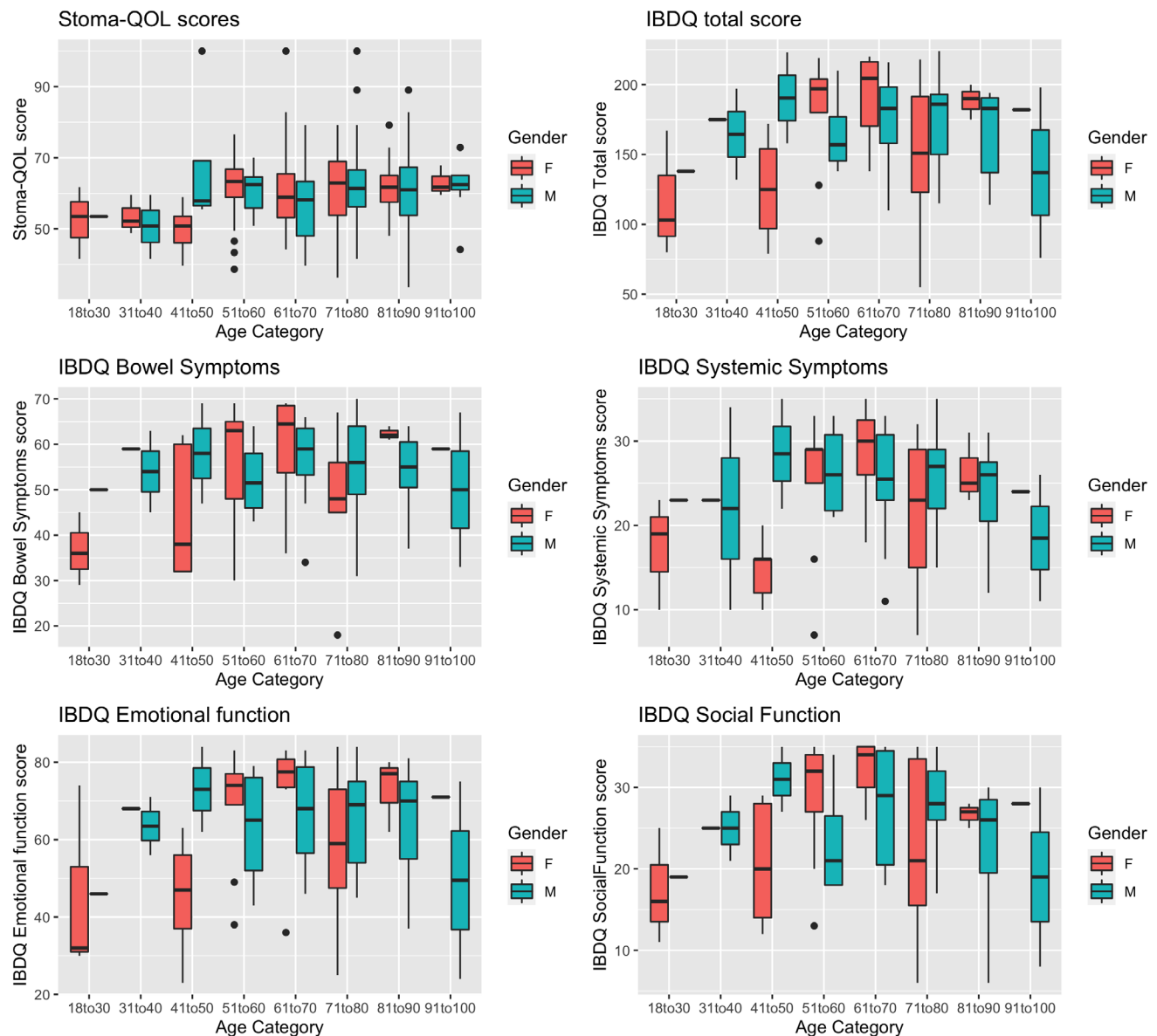


Figure 1 Stoma-quality of life (QoL) scores by age group and gender: Stoma-QoL, inflammatory bowel disease questionnaire (IBDQ) Total, IBDQ Bowel Symptoms, IBDQ Systemic Symptoms, IBDQ Emotional Function, IBDQ Social Function scores. The boxplots show median, 25th, and 75th percentile of scores per age group along with distribution of all the scores for males (blue) and females (red) separately, divided by age categories; higher scores indicate higher quality of life.

Statistical considerations. Summary statistics were derived to describe the study sample. Simple linear regression was used to check explanatory variables of continuous QoL outcomes. Missing responses were excluded from factor analyses. IBDQ Total and QLQ-C30 Summary scores were square-transformed before Pearson’s correlation analysis with Stoma-QoL. *t*-tests and Wilcoxon-Mann-Whitney tests were used to compare QoL scores between males and females. *P*-values lower than 0.05 were considered statistically significant. Analyses were performed using R statistical language.³¹

Results

Study sample. Of the respondents, 54.8% (*n* = 241/448) completed the survey, and 82.6% (*n* = 199/241) of them used the paper version of the questionnaires. Of the remaining patients, 15.6% (*n* = 70) did not want to participate, while 29.9% (*n* = 134) did not respond. The study sample was a mean (SD) 70.9 (14.2) years old, 60.6% (*n* = 146/241) were male, and 89.5% (*n* = 209/233) were NZ European and 2.1% (5/233) Māori. Of the study participants, 52.5% (*n* = 124/236) had a

Table 3 Dietary and stoma management questionnaire response: Total, inflammatory bowel disease (IBD), and colorectal cancer (CRC) study samples

Question	% Total (n = 234)	% IBD (n = 54)	CRC (n = 136)
Dietary recommendations at the time of stoma formation, yes	73.1 (171/234)	73.1 (38/52)	77.3 (102/132)
Change of diet due to stoma, yes	56.4 (133/236)	55.8 (29/52)	57.0 (77/135)
Important of fluids discussed, yes	76.3 (184/241)	74.1 (40/54)	78.7 (107/136)
Discussed with: [†]			
Surgeons	26.1 (63/241)	25.9 (14/54)	27.2 (37/136)
Stoma nurse	49.8 (120/241)	38.9 (21/54)	55.9 (76/136)
Dietitian	48.1 (116/241)	48.1 (26/54)	52.2 (71/136)
Electrolytes discussed, yes			
Total	42.1 (102/241)	55.6 (30/54)	42.6 (58/136)
Ileostomy	57.3 (67/117)	57.7 (30/52)	67.4 (29/43)
Colostomy	28.2 (35/124)	0.0 (0/2)	31.2 (29/93)
Discussed with: [†]			
Surgeons	14.5 (35/241)	20.4 (11/54)	12.5 (17/136)
Stoma nurse	27.0 (65/241)	29.6 (16/54)	30.1 (41/136)
Dietitian	27.0 (65/241)	29.6 (16/54)	29.4 (40/136)
Intake of B12 discussed, yes			
Total	20.3 (49/241)	22.2 (12/54)	22.1 (30/136)
Ileostomy	22.2 (26/117)	22.2 (12/52)	23.3 (10/43)
Colostomy	18.5 (23/124)	0.0 (0/2)	21.5 (20/93)
Discussed with: [†]			
Surgeons	3.7 (9/241)	7.4 (4/54)	2.2 (3/136)
Stoma nurse	10.0 (24/241)	7.4 (4/54)	12.5 (17/136)
Dietitian	12.9 (31/241)	14.8 (8/54)	14.7 (20/136)
Ease of sticking to dietary recommendations			
Easy	51.4 (112/218)	57.4 (27/47)	56.9 (70/123)
Somewhat difficult	16.5 (36/218)	21.3 (10/47)	14.6 (18/123)
Quite difficult	6.4 (14/218)	2.1 (1/47)	7.3 (9/123)
Very difficult	2.8 (6/218)	0.0 (0/47)	0.8 (1/123)
No dietary recommendations	22.9 (50/218)	19.1 (9/47)	21.1 (26/123)
How long did you follow your dietary recommendations (post-surgery)			
1 month	19.1 (39/204)	15.6 (7/45)	20.5 (24/117)
1–2 months	16.2 (33/204)	17.8 (8/45)	14.5 (17/117)
2 months or more	25.5 (52/204)	31.1 (14/45)	27.4 (32/117)
Still following	39.2 (80/204)	35.6 (16/45)	37.6 (44/117)
Dietary recommendations too restrictive, yes	10.8 (22/203)	4.9 (2/41)	9.3 (11/118)
Do you avoid specific foods, yes	69.8 (164/235)	76.9 (40/52)	65.4 (87/133)
Do you minimise fluid intake to minimise your stoma output, yes	4.8 (11/229)	2.0 (1/51)	5.4 (7/130)
Discussed stoma management diet with dietitian, yes	27.4 (64/234)	3.8 (20/52)	24.6 (33/134)
Would like to see a dietitian, yes	19.3 (44/228)	25.5 (13/51)	19.2 (25/130)
Uses medications to reduce stoma output, yes	18.0 (42/233)	19.2 (10/52)	19.7 (26/132)
Used herbal/naturopathic remedies to reduce stoma output, yes	1.3 (3/233)	0.0 (0/52)	1.5 (2/133)

[†]Multiple selections permitted.

colostomy, and 56.4% ($n = 136/241$) had a stoma due to CRC surgery; 22.4% ($n = 54/241$) of the participants had a stoma due to IBD, of which 70.4% ($n = 38/54$) were due to UC. Of the study participants, 2.9% (7/241) had more than one stoma, all of whom were CRC patients. Median (first–third interquartile range [IQR]) duration since ostomy for the overall study sample was 6.9 (3.3–15.1) years, with 59.3% ($n = 143/241$) receiving their stoma more than 5 years ago. Complete clinical data were available for 94 of 241 patients, of which 28.0% ($n = 26/93$) and

28.0% ($n = 26/93$) of the patients, respectively, experienced minor and major stoma-associated problems; 45.7% ($n = 43/94$) and 38.3% (36/94) had low and high levels of comorbidities, respectively (Table 1).

Quality-of-Life scores. Mean (SD) Stoma-QoL score for all the patients was 60.3 (10.8) points, with 83.4% ($n = 201/241$) of the patients scoring more than median Stoma-QoL score of 50 points. Stoma-underlying disease ($P = 0.28$) or type of stoma

($P = 0.60$) was not significantly associated with Stoma-QoL scores according to linear regression analysis (Table 2).

Median (first–third IQR) IBDQ total score in IBD patients was 182.5 (145.5–201.8); 83.0% ($n = 44/53$) of patients scored higher than the median questionnaire value of 128. There were no statistically significant differences between the males and females in either IBDQ total score or any functional scores ($P > 0.29$) (Table 2).

CRC patients' QLQ-C30 and QLQ-CR29 questionnaire scores are summarized in Table 2. Females performed significantly better on the social functioning scale ($P = 0.01$) but had significantly higher QLQ-CR29 anxiety scores ($P = 0.02$). Males scored significantly worse in three of nine QLQ-C30 symptom scales, with higher fatigue ($P = 0.03$), dyspnea/shortness of breath ($P = 0.004$), and financial challenges ($P = 0.01$).

Factors associated with quality of life. Simple linear regression results indicate that age significantly predicted the Stoma-QoL scores ($\beta_1 = 0.13$ [95% confidence interval, CI: 0.06–0.223], $P = 0.0075$) and IBDQ Total and all scores except one IBDQ dimension (Total: $P = 0.0098$; Bowel Symptoms: $P < 0.001$; Systemic Symptoms: $P = 0.026$; Emotional Function: $P = 0.034$; Social Function: $P = 0.089$); older age adults had higher QoL scores (Fig. 1).

However, age did not significantly predict either the CRC patients' QLQ-C30 global health/QoL score ($P = 0.16$) or the QLQC30 Summary Score ($P = 0.13$). There was evidence that males scored significantly higher QLQ-C30 global health/QoL scores ($P = 0.012$) and summary scores (*trending towards significance* $P = 0.055$). Those with a second stoma also scored higher in the QLQ-C30 global health dimension ($P = 0.036$). More years since surgery was also associated (*trended towards significance*) with higher QLQ-C30 global health/QoL scores ($P = 0.058$) (Fig. 1).

None of the other studied factors were associated with Stoma-QoL, IBDQ, or QLQ-C30 questionnaire scores.

Stoma-QoL strongly correlated with IBDQ Total (Pearson's $r = 0.80$ [95% CI: 0.71–0.87], $P < 0.001$) and QLQC30 Summary Score (Pearson's $r = 0.47$ [95% CI: 0.33–0.58], $P < 0.001$), indicating interquestionnaire consistency.

Dietary factors in study sample. This study also investigated dietary habits and associated information received by postostomy patients. Of the participants, 73.1% ($n = 171/234$) received dietary recommendations for stoma management when it was formed; 56.4% ($n = 133/236$) changed their diet as a result of having a stoma, and 39.2% ($n = 80/204$) are still following specific dietary recommendations at the time of the survey; 19.1% ($n = 39/204$) followed the recommendations for a month or less; 51.4% ($n = 112/218$) found it easy to adhere to dietary recommendations, and only 9.2% ($n = 20/218$) found it quite or very difficult; 69.8% ($n = 164/235$) avoid certain foods, and only 4.8% ($n = 11/229$) limit their fluid intake to minimize stoma output; 10.8% ($n = 22/203$) found dietary recommendations too restrictive; 27.4% ($n = 64/234$) have discussed their stoma management with a dietitian; and 19.3% ($n = 44/228$) would still like to see a dietitian. Importance of fluids, electrolytes, and B12 intake was discussed with 76.3% ($n = 184/241$), 42.1% ($n = 102/$

241), and 20.3% ($n = 49/241$) of patients, respectively; 57.3% ($n = 67/117$) of ileostomy and 28.2% ($n = 35/124$) of colostomy patients received advice regarding the use of electrolytes; 22.2% ($n = 26/117$) of ileostomy patients and 18.5% ($n = 23/124$) of colostomy patients received advice regarding B12 intake; and 18.0% ($n = 42/233$) used medications to reduce stoma output, and 1.3% ($n = 3/233$) used herbal/naturopathic remedies to reduce stoma output. There were no notable differences between the dietary habits of CRC and IBD patients as presented in Table 3.

Having received dietary recommendations or the perceived ease of adherence to dietary recommendations were not significantly associated with the Stoma QoL, IBDQ, and QLQ-C30. How well the stoma appliance works and existing comorbidities (as captured by clinical notes) were not associated with any of the used QoL measures (Stoma-QoL, IBDQ, and QLQ-C30 global health and summary score).

Discussion

This study investigated stoma-specific QoL scores in postostomy IBD and CRC patients and found a relatively high QoL in the study sample and an association between older age and higher QoL scores.

The majority (83.4%) of the study participants scored more than 50 points in Stoma QoL (middle score), which was higher than other similar studies.²³ This could be due to the older age of our study sample (mean [SD] 70.9 [14.2] years old) and the fact that two thirds of the participants had their stoma bags for a relatively long time. It is likely that our dataset underrepresents the experience of younger patients and those with a more recent stoma formation.

Surprisingly, we did not find any significant differences between the types of underlying disease, time since ostomy, burden of comorbidities, or how well the stoma appliance worked. This is unexpected and contrasts with findings from some studies¹² but is in agreement with some others. We may have not captured statistically significant associations due to a small sample size and the limitations associated with studying the multifactorial concept of QoL. In this investigation, the relative burden of comorbidities and appliance-associated complications was assigned based on a retrospective audit of available clinical data, which means that the outcome is subject to reporting and evaluation biases. Clinical records for a large proportion of patients were not available at the point of the study, which may have resulted in omission of some important clinical features of the study sample. Some of these challenges highlight the value of standardized robust health data reporting for health research and identification of patients at risk.

There was a significant association between the age of the participants and the Stoma QoL and IBDQ total and dimension scores, with the younger participants reporting lower QoL. This could be due to lifestyle and social acceptability-associated factors, as well as unknown confounding variables such as clinical severity of the cases and the duration of postoperative stays in the hospital.

Several previous studies found females to have worse QoL scores postostomy.^{23,32} While we found that females had significantly higher anxiety scores, males scored lower in social functioning and several symptom scales (fatigue, shortness of

breath, and experienced financial challenges). We also found a link between having more than one stoma and improved QoL. While we did not have sufficient clinical data to explain this finding, it could be linked with higher therapeutic outcomes dealing with severe disease.

While most of the study participants have received dietary advice, and only a small proportion of them found the recommendations too restrictive, there was an insufficient discussion of the intake of electrolytes and B12 with the ileostomy patients (57.3 and 22.2%, respectively). The variable responses to dietary questionnaires could also be an outcome of changing clinical practice through the years. Study participants would have experienced several postostomy dietary recommendation frameworks, such as the introduction of the Enhanced Recovery After Surgery pathway in 2012, nurse-led patient check to return to a regular diet 6 weeks' postsurgery (2018—after the study), and healthy eating consultation for CRC patients (since 2012) as a result of a dietary needs assessment.²⁰ Furthermore, given the lack of consensus dietary guidelines for postostomy patients and a lack of emphasis on targeted advice, this further highlights the complexity of the issue.

This study had several other additional limitations, with the main one being the self-selection of the study participants. It is possible that only the most motivated patients who were doing well enough to complete and return the study questionnaires participated in the survey. Hence, it is possible that our study overestimated the QoL of postostomy patients. However, the opposite is also possible as patients who may experience most challenges may be the most motivated to share their experiences. Furthermore, the study uses retrospective self-reporting questionnaires that capture subjective experience and are subject to recall bias and misinterpretation of the questions. The study lacks an evaluation of objective challenges experienced by postostomy patients, such as decline in physical activity, loss of employment, and psychological state.

In summary, our postostomy patient sample has a relatively high QoL compared to similar previous studies; however, the rates of targeted dietary advice is not sufficient for the needs of this patient population.

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References

- Shabbir J, Britton DC. Stoma complications: a literature overview. *Colorectal Dis.* 2010; **12**: 958–64.
- Harbord M, Eliakim R, Bettenworth D *et al.* Third European Evidence-based Consensus on diagnosis and management of ulcerative colitis. Part 2: current management. *J. Crohns Colitis.* 2017; **11**: 769–84.
- Gionchetti P, Dignass A, Danese S *et al.* 3rd European Evidence-based Consensus on the Diagnosis and Management of Crohn's Disease 2016: part 2: surgical management and special situations. *J. Crohns Colitis.* 2016; **11**: 135–49.
- Windsor A, D'Hoore A, de Buck van Overstraeten A *et al.* European evidence based consensus on surgery for ulcerative colitis. *J. Crohns Colitis.* 2014; **9**: 4–25.
- Gastinger I, Marusch F, Steinert R, Wolff S, Koeckerling F, Lippert H. Protective defunctioning stoma in low anterior resection for rectal carcinoma. *Br. J. Surg.* 2005; **92**: 1137–42.
- de Miguel VM, Jimenez Escovar F, Parajo CA. Current status of the prevention and treatment of stoma complications. A narrative review. *Cir. Esp.* 2014; **92**: 149–56.
- Ross L, Abild-Nielsen AG, Thomsen BL, Karlsen RV, Boesen EH, Johansen C. Quality of life of Danish colorectal cancer patients with and without a stoma. *Support. Care Cancer.* 2007; **15**: 505–13.
- Sprangers MA, Taal BG, Aaronson NK, te Velde A. Quality of life in colorectal cancer. Stoma vs. nonstoma patients. *Dis. Colon Rectum.* 1995; **38**: 361–9.
- Liao C, Qin Y. Factors associated with stoma quality of life among stoma patients. *Int. J. Nurs. Sci.* 2014; **1**: 196–201.
- Sarabi N, Navipour H, Mohammadi E. Relative tranquility in ostomy patients' social life: a qualitative content analysis. *World J. Surg.* 2017; **41**: 2136–42.
- Mahjoubi B, Mohammadsadeghi H, Mohammadipour M, Mirzaei R, Moini R. Evaluation of psychiatric illness in Iranian stoma patients. *J. Psychosom. Res.* 2009; **66**: 249–53.
- Bekkers MJ, van Knippenberg FC, van Dulmen AM, van den Borne HW, van Berge Henegouwen GP. Survival and psychosocial adjustment to stoma surgery and nonstoma bowel resection: a 4-year follow-up. *J. Psychosom. Res.* 1997; **42**: 235–44.
- Grumann MM, Noack EM, Hoffmann IA, Schlag PM. Comparison of quality of life in patients undergoing abdominoperineal extirpation or anterior resection for rectal cancer. *Ann. Surg.* 2001; **233**: 149–56.
- Nybaek H, Jemec GB. Skin problems in stoma patients. *J. Eur. Acad. Dermatol. Venereol.* 2010; **24**: 249–57.
- Carne PW, Robertson GM, Frizelle FA. Parastomal hernia. *Br. J. Surg.* 2003; **90**: 784–93.
- Fleshman JW, Lewis MG. Complications and quality of life after stoma surgery: a review of 16,470 patients in the UOA data registry. *Semin. Colon Rectal Surg.* 2007; **18**: 19–24.
- Willcutts K, Touger-Decker R. Nutritional management for ostomates. *Top. Clin. Nutr.* 2013; **28**: 373–83.
- Floruta CV. Dietary choices of people with ostomies. *J. Wound Ostomy Continence Nurs.* 2001; **28**: 28–31.
- Mitchell A, Perry R, England C, Searle A, Atkinson C. Dietary management in people with an ileostomy: a scoping review protocol. *JBI Database System Rev. Implement. Rep.* 2019; **17**: 129–36.
- Pullar JM, Chisholm A, Jackson C. Dietary information for colorectal cancer survivors: an unmet need. *N. Z. Med. J.* 2012; **125**: 27–37.
- Makela JT, Turku PH, Laitinen ST. Analysis of late stomal complications following ostomy surgery. *Ann. Chir. Gynaecol.* 1997; **86**: 305–10.
- Braumann C, Muller V, Knies M, Aufmesser B, Schwenk W, Koplín G. Quality of life and need for care in patients with an ostomy: a survey of 2647 patients of the Berlin Ostomy-Study (BOSS). *Langenbecks Arch. Surg.* 2016; **401**: 1191–201.
- Jayarajah U, Samarasekera DN. A cross-sectional study of quality of life in a cohort of enteral ostomy patients presenting to a tertiary care hospital in a developing country in South Asia. *BMC. Res. Notes.* 2017; **10**: 75.
- Global Cancer Facts & Figures*, 2nd edn. Atlanta, GA, USA: American Cancer Society, 2011.
- Coppell KJ, Galts CP, Huizinga FY *et al.* Annual incidence and phenotypic presentation of IBD in Southern New Zealand: an 18-year epidemiological analysis. *Inflamm. Intest. Dis.* 2018; **3**: 32–9.

- 26 Prieto L, Thorsen H, Juul K. Development and validation of a quality of life questionnaire for patients with colostomy or ileostomy. *Health Qual. Life Outcomes*. 2005; **3**: 62.
- 27 Guyatt G, Mitchell A, Irvine EJ *et al.* A new measure of health status for clinical trials in inflammatory bowel disease. *Gastroenterology*. 1989; **96**: 804–10.
- 28 Whistance RN, Conroy T, Chie W *et al.* Clinical and psychometric validation of the EORTC QLQ-CR29 questionnaire module to assess health-related quality of life in patients with colorectal cancer. *Eur. J. Cancer*. 2009; **45**: 3017–26.
- 29 Aaronson NK, Ahmedzai S, Bergman B *et al.* The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J. Natl. Cancer Inst.* 1993; **85**: 365–76.
- 30 Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J. Biomed. Inform.* 2009; **42**: 377–81.
- 31 *R: A Language and Environment for Statistical Computing*. R Foundation for Statistical Computing. Vienna: R Core Team, 2018 . Available from URL: <https://www.R-project.org/>.
- 32 Grant M, Ferrell B, Dean G, Uman G, Chu D, Krouse R. Revision and psychometric testing of the City of Hope Quality of Life-Ostomy Questionnaire. *Qual. Life Res.* 2004; **13**: 1445–57.

Supporting information

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Appendix S1 Supporting Information.