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). IBD is a chronic disease with recurrent inflammation of the gut, often requiring increasingly more aggressive treatments to induce and maintain disease remission. 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. 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. 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. Ostomy-associated changes result in altered body image, social isolation, embarrassment, psychological distress, and perceived loss of control that result in decreased QoL. Stoma patients have reported a higher prevalence and higher levels of psychological distress than non-stoma patients, while other studies found no difference.

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 complications such as peristomal skin irritation, parastomal hernias (0–48.1% depending on the type of the stoma), stoma prolapse (2–3%), 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 challenges. While a number of institutes have published dietary recommendations, currently, there is lack of consensus dietary guidelines for postostomy patients, 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, therapeutic outcomes of the intervention, any associated changes in lifestyle, and any associated complications. Other factors such as lack of skills and knowledge about stoma, presence of other chronic illness, receiving emergency ostomy surgery, and being female predicted worse stoma function.

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.

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.
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)\textsuperscript{26} (for IBD and CRC), an IBD questionnaire (IBDQ)\textsuperscript{27} (for IBD), and the EORTC CRC QoL measure (QLQ-CR29)\textsuperscript{28} (for CRC) and core module (QLQ-C30)\textsuperscript{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 Capture\textsuperscript{30} 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).

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\textsuperscript{a} |
| **IBD PATIENTS**    |                   |                  |                   |         |
| IBDQ, median(IQR)   |                   |                  |                   |         |
| IBDQ Total (+)      | 183(146-202)      | 174(127-200)     | 186(156-202)      | 0.39\textsuperscript{b} |
| IBDQ Bowel symptoms (+) | 59(48-64)  | 60(45-64)        | 58(53-63)         | 0.59\textsuperscript{b} |
| IBDQ Systemic Symptoms (+) | 25(22-29)        | 24(16-29)        | 26(23-30)         | 0.29\textsuperscript{b} |
| IBDQ Emotional Symptoms (+) | 70(53-77) | 66(48-75)        | 70(56-77)         | 0.46\textsuperscript{b} |
| IBDQ Social Symptoms (+) | 28(21-33) | 28(20-33)        | 29(26-33)         | 0.64\textsuperscript{b} |
| **CRC PATIENTS**    |                   |                  |                   |         |
| QLQ-C30, median (IQR) |                   |                  |                   |         |
| Global Health score (+) | 67(50-83)  | 42(25-54)        | 67(50-83)         | 0.02\textsuperscript{b} |
| QLC30 Summary Score (+) | 85(75-93) | 61(44-75)        | 84(73-93)         | 0.10\textsuperscript{b} |
| **functional scales** |                   |                  |                   |         |
| physical (+)        | 87(67-93)         | 87(73-93)        | 87(60-93)         | 0.31\textsuperscript{b} |
| role (+)            | 83(67-100)        | 100(67-100)      | 83(50-100)        | 0.11\textsuperscript{b} |
| cognitive (+)       | 83(67-100)        | 83(67-100)       | 83(67-100)        | 0.59\textsuperscript{b} |
| emotional (+)       | 83(67-100)        | 92(67-100)       | 83(67-100)        | 0.93\textsuperscript{b} |
| social (+)          | 83(67-100)        | 100(83-100)      | 83(67-100)        | 0.01\textsuperscript{b} |
| **symptom scales**  |                   |                  |                   |         |
| fatigue (−)         | 26(11-44)         | 22(0-33)         | 33(11-44)         | 0.03\textsuperscript{b} |
| pain (−)            | 0(0-17)           | 0.0(0-8)         | 0(0-33)           | 0.09\textsuperscript{b} |
| nausea and vomiting (−) | 0(0-0)  | 0(0-0)           | 0(0-17)           | 0.22\textsuperscript{b} |
| dyspnoea (−)        | 0(0-33)           | 0(0-30)          | 33(0-33)          | 0.004\textsuperscript{b} |
| insomnia (−)        | 33(0-33)          | 33(0-33)         | 33(0-33)          | 0.49\textsuperscript{b} |
| appetite Loss (−)   | 0(0-0)            | 0(0-0)           | 0(0-0)            | 0.31\textsuperscript{b} |
| constipation (−)    | 0(0-0)            | 0(0-0)           | 0(0-0)            | 0.24\textsuperscript{b} |
| diarrhoea (−)       | 0(0-33)           | 0(0-33)          | 0(0-33)           | 0.87\textsuperscript{b} |
| financial (−)       | 0(0-0)            | 0(0-0)           | (0-33)            | 0.01\textsuperscript{b} |
| QLQ-CR29, median (IQR) |                   |                  |                   |         |
| body image (−)      | 89(67-100)        | 89(7-100)        | 89(67-100)        | 0.15\textsuperscript{b} |
| anxiety (−)         | 67(67-100)        | 100(67-100)      | 67(67-100)        | 0.02\textsuperscript{b} |
| weight (−)          | 100(67-100)       | 100(67-100)      | 67(67-100)        | 0.55\textsuperscript{b} |

\textsuperscript{a}t-test.  
\textsuperscript{b}Wilcoxon-Mann-Whitney test.  
\textsuperscript{*}Statistically significant.  
(+) indicates higher score – better quality of life; (−) indicates higher score – worse 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
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 \((\text{first–third interquartile range [IQR]})\) 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

### 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 (133/238)         | 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                        | 42.1 (102/241)         | 55.6 (30/54)       | 42.6 (68/136)    |
| Total                                              |                        |                    |                  |
| Ileostomy                                          | 57.3 (67/117)          | 57.7 (30/52)       | 67.4 (29/93)     |
| 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                       | 20.3 (49/241)          | 22.2 (12/54)       | 22.1 (30/136)    |
| Total                                              |                        |                    |                  |
| 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 (50/221)          | 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 (53/134)    |
| 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.
(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 (β1 = 0.13 [95% confidence interval, CI: 0.06–0.22]), IBDQ Total and all scores except one IBDQ dimension (Total: P = 0.009; 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 QLC30 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 QLC30 global health dimension (P = 0.036). More years since surgery was also associated (trended towards significance) with higher QLC30 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 QLC30 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 post-ostomy 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 dietician; and 19.3% (n = 44/228) would still like to see a dietician. 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 QLC30. 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 QLC30 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. 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 studies 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. 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’ post-surgery (2018—after the study), and healthy eating consultation for CRC patients (since 2012) as a result of a dietary needs assessment. 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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**Supporting information**

Additional supporting information may be found in the online version of this article at the publisher’s website:

**Appendix S1** Supporting Information.