ORIGINAL ARTICLE

European Journal of Cancer Care　WILEY

Follow-up practice and healthcare utilisation of colorectal cancer survivors

Seyed M. Qaderi[1] ⓘ　|　Nicole P.M. Ezendam[2,3]　|　Rob H.A. Verhoeven[1,2]　|
Jose A.E. Custers[4]　|　Johannes H.W. de Wilt[1]　|　Floortje Mols[2,3] ⓘ

[1]Department of Surgical Oncology, Radboud university medical center, Nijmegen, The Netherlands

[2]Department of Research & Development, Netherlands Comprehensive Cancer Organisation, Utrecht, the Netherlands

[3]Department of Medical and Clinical Psychology, CoRPS-Center of Research on Psychological and Somatic disorders, Tilburg University, Tilburg, The Netherlands

[4]Department of Medical Psychology, Radboud University Medical Center, Nijmegen, The Netherlands

Correspondence
Seyed M. Qaderi, Department of Surgery, Radboud University Medical Center, Geert Grooteplein Zuid 10, 6525 GA Nijmegen, The Netherlands.
Email: seyed.qaderi@radboudumc.nl

Abstract

Objective: To examine healthcare utilisation and adherence to colorectal cancer (CRC) follow-up guidelines.

Methods: A total of 2450 out of 3025 stage I-III CRC survivors diagnosed between 2000 and 2009 completed the Hospital Anxiety and Depression Scale, SF-12, EORTC QLQ-CR38 and Fatigue Assessment Score questionnaires, in December 2010. Multivariable regression analyses were performed to identify predictors for increased follow-up care (>1 visit than recommended by guidelines).

Results: In the first follow-up year, the average number of cancer-related visits to the general practitioner and medical specialist was 1.7 and 4.2, respectively. More than 80% of the CRC survivors was comfortable with their follow-up schedule, and 49–72% of them received follow-up according to the guidelines. Around 29–47% was followed more than recommended. Simultaneously, around 4–14% of the CRC survivors received less follow-up care than recommended. Survivors of stage III disease treated with chemotherapy received the most follow-up care. In addition, lower socio-economic status stoma and fatigue were associated with increased follow-up care.

Conclusion: CRC survivors were predominantly followed according to national guidelines. Increased follow-up care is driven by advanced disease stage, chemotherapy, SES, stoma and fatigue. Future studies should investigate how increased follow-up care use can be reduced, while still addressing patients' needs.

KEYWORDS
cancer survivorship, colorectal cancer, Follow-up studies, general practitioner, healthcare use

1 | INTRODUCTION

Colorectal cancer (CRC) is the third most common cancer in both men and women. (Siegel et al., 2020) Survival has improved significantly in patients with CRC due to several improvements in early diagnosis and treatment of the primary tumour and of metastatic disease. (Brouwer et al., 2018; Qaderi et al., 2020; Stok et al., 2017) Nowadays, more than two-third of the patients can be treated with curative intent, with or without (neo)adjuvant therapies such as chemotherapy and/or radiation therapy (Jeffery et al., 2016; Stok et al., 2017).

After treatment, patients are followed to detect and treat early disease recurrence or metastases. Surveillance also assesses patients

for complications, adverse effects and long-term consequences, and provides outcome data. (Jeffery et al., 2016) In the Netherlands, follow-up care for CRC survivors is provided according to national guidelines and usually consists of at least biannual clinical visits and laboratory and imaging tests. (Netherlands Comprehensive Cancer Network, 2014) [Supplementary file 1] Currently, there is a lively debate in the literature about intensity and content of follow-up. Previous studies have shown variations in follow-up intensity between countries. (Bastiaenen et al., 2018; Grossmann et al., 2007; Qaderi et al., 2020) Randomised controlled trials showed that intensive follow-up does not necessarily lead to better survival, or at least fails to produce significantly improved outcome. (Primrose et al., 2014; Wille-Jorgensen et al., 2018) Inevitably, intensive surveillance results in higher costs, radiation exposure and discomfort and puts a heavy burden on outpatient services (Davies & Batehup, 2011; Mant et al., 2017; Siddika et al., 2015).

The diagnosis and treatment of CRC impact patients' well-being. (Mols et al., 2007, 2018) Hence, CRC survivors often seek help for physical and psychosocial complaints. (Holla et al., 2016) Besides their medical specialist, patients seek help from the general practitioner (GP) and supportive care professionals. Three studies found that the individual healthcare use is dependent on several factors, including treatment-related factors (e.g. physical and psychological symptoms), clinical factors (e.g. comorbidity) and sociodemographic factors (e.g. age, sex, marital status and educational level). (Ezendam et al., 2013; Holla et al., 2016; Mols et al., 2007) However, these studies investigated the healthcare use of cancer survivors in general, but not specifically that of CRC survivors. Investigation of care use is important since it can provide information about access to health care and will possibly identify points for improvement.

This study aimed to investigate when and which healthcare professionals (i.e. medical specialist or GP) are consulted during CRC follow-up and what percentage of patients reports general and cancer-related care. Also, of importance was to define adherence to national CRC follow-up guidelines since previous studies showed that there is large variation in adherence. (Grossmann et al., 2007; Soreide et al., 2012) Furthermore, factors correlated with increased (cancer-related) care use of CRC survivors were identified.

2 | METHODS

2.1 | Study design and data collection

For this study, data from a prospective population-based survey among CRC survivors, between 1 and 11 years after their diagnosis, were available. The survey was conducted in December 2010, and the data were used in 2020 for this current cross-sectional analysis study. Details of the data collection have been published previously. (Mols et al., 2013) In short, the data collection was performed within PROFILES (Patient Reported Outcomes Following Initial Treatment and Long-Term Evaluation of Survivorship). (Poll-Franse et al., 2011) Those diagnosed with CRC between 2000 and 2009 in the south of

the Netherlands and registered in the Netherlands Cancer Registry (NCR) were eligible for participation. The NCR records register all newly diagnosed cancer patients in the Netherlands.

Survivors were informed of the study via a letter from their attending surgeon. Non-respondents were sent a reminder within 2 months. Ethical approval for the study was obtained from the Medical Ethics Committee of the Maxima Medical Centre Veldhoven, the Netherlands (approval number 0822). All participants gave written informed consent.

2.2 | Patient selection and measures

For this study, the researchers selected those patients with stage I-III CRC that had undergone endoscopic or surgical treatment with curative intent between 2000 and 2009 and completed a questionnaire in December 2010. Patients with unverifiable addresses, with cognitive impairment, those who died prior to the start of this study or were terminally ill, those with stage 0/carcinoma in situ and those included in other studies were excluded. All eligible patients were invited. Individuals were contacted at various points in their survivorship period ranging from 1 to 11 years after initial treatment.

2.2.1 | Sociodemographic and clinical characteristics

Survivors' sociodemographic and clinical information (age, sex, disease stage, tumour localisation, treatment and (neo)adjuvant therapies) was available from the NCR. Comorbidity at time of the study was assessed with the adapted Self-administered Comorbidity Questionnaire. (Sangha et al., 2003) Socio-economic status (SES) was determined by an indicator developed by Statistics Netherlands. Questions on marital status, educational level, current occupation, height and weight (to calculate body mass index (BMI)), and stoma information were added to the questionnaire.

2.2.2 | Patient-reported outcomes

The SF-12 was used to assess general health/QoL. (Ware et al., 1995) Scores were linearly transformed to a 0–100 scale; a higher score indicated better functioning.

Patients' disease-specific health status was assessed by using the EORTC QLQ-CR38 Questionnaire (Sprangers et al., 1999). It consists of two multi-item scales, two single-item scales, seven symptom scales and an item on weight loss. All scales were linearly converted into a 0–100 scale. Higher scores indicated higher symptom burden.

The Hospital Anxiety and Depression Scale (HADS) was used to assess anxiety and depressive symptoms. (Zigmond & Snaith, 1983) This questionnaire is comprised of 14 items on a four-point Likert scale: 7 for depression and 7 for anxiety. Total scores were calculated, and a score of ≥8 was used as cut-off for clinically significant

TABLE 1 Differences in baseline characteristics between respondents and non-respondents

N (%) or mean (SD)	Respondents (N = 2450)	Non-respondents (N = 575)	p Value
Age (at time of diagnosis)	64.3 (9.7)	67.4 (9.7)	<0.001[a]
Sex			<0.001[a]
Male	1337 (55)	275 (48)	
Female	1113 (45)	300 (52)	
Localisation			<0.001[a]
Colon	1508 (62)	389 (68)	
Rectum	942 (38)	186 (32)	
Pathological stage			0.02[a]
I	780 (32)	156 (27)	
II	948 (39)	258 (45)	
III	722 (29)	161 (28)	
Resection			0.050
Yes	2448 (99.9)	572 (99.5)	
No	2 (0.1)	3 (0.5)	
Type of treatment			
Surgery only	1215 (50)	342 (60)	
Surgery and radiotherapy	566 (23)	95 (16)	
Surgery and chemotherapy	496 (20)	96 (17)	
Surgery and chemoradiation therapy	171 (7)	39 (7)	
Miscellaneous*	1 (0.04)	3 (0.5)	
Histologic grade			0.78
Well differentiated	205 (8)	43 (8)	
Moderately differentiated	1508 (62)	363 (63)	
Poorly differentiated	291 (12)	71 (12)	
Unknown	446 (18)	98 (17)	
Radiotherapy (rectum only)			<0.001[a]
Yes	712 (76)	132 (71)	
No	230 (24)	54 (29)	
Chemotherapy			0.10
Colon			
Yes	462 (31)	90 (23)	
No	1046 (69)	299 (77)	
Rectum			
Yes	205 (22)	47 (25)	
No	737 (78)	139 (75)	
Stoma			0.16
No	2133 (87)	513 (89)	
Yes	317 (13)	62 (11)	

(Continues)

TABLE 1 (Continued)

N (%) or mean (SD)	Respondents (N = 2450)	Non-respondents (N = 575)	p Value
Socio-economic status			<0.001[a]
High	488 (20)	140 (24)	
Moderate	988 (40)	242 (42)	
Intermediate	879 (36)	162 (28)	
Low	36 (2)	17 (3)	
Unknown	59 (2)	14 (2)	

Note: *miscellaneous: chemotherapy, radiotherapy alone or together without surgical resection. Total number (N) = 3.025.
[a]Statistically significant according to Student t test and chi-square tests.

anxiety or depressive symptoms. (Olsson et al., 2005; Zigmond & Snaith, 1983).

The 10-item Fatigue Assessment Scale (FAS) was used to assess how patients usually feel about their fatigue. It has good psychometric properties (Michielsen et al., 2003) and was previously used with cancer patients. (Michielsen et al., 2007) Responses are scored on a 5-point scale (1: never to 5: always).

Items concerning healthcare use included questions on the number of visits to a GP and medical specialist in the past 12 months. Patients were asked to answer whether and how many outpatient visits they had. Answer categories were 'Every 3 months', 'Every 4 months', 'Every 6 months', 'Every year', 'Every 2 years' or 'No, there are no appointments'. In addition, self-reported patient satisfaction and preference regarding follow-up schedule were assessed.

2.3 | Definitions

Tumour localisation was categorised using the International Classification of Disease for Oncology (ICD-O) into colon (C18.0–18.9) and rectum (C19.9–20.9). Disease stage was based on the pathological tumour lymph node metastasis (TNM) classification according to the edition used at time of diagnosis (5th edition for 1999–2002, 6th edition for 2003–2009). To assess adherence to national guidelines recommendations, a comparison was made between self-reported follow-up schedule and guideline recommendations, with an upper and lower margin of 1 visit (allowing for 1 visit more or less than the guidelines). [Supplementary file 1] Since guidelines do not mark follow-up recommendations after 5 years, for those 6–10 years after diagnosis zero visits with an upper margin of 1 visit were used. Follow-up use was categorised as the percentage that was followed less than, according to, or more than the guideline recommendations.

2.4 | Statistical analysis

Baseline characteristics were presented using descriptive statistics. Baseline patient, tumour and treatment characteristics between respondents and non-respondents were analysed. Continuous

TABLE 2 Sociodemographic and patient-related outcome measures of participants according to each follow-up (FU) year (N = 2.450)

N (%) or mean (SD)	FU 1–2 years N = 789	FU 3–4 years N = 488	FU 5–11 years N = 1173	p Value
Sex				0.15
Males	445 (56)	276 (57)	616 (53)	
Females	344 (44)	212 (43)	557 (47)	
Age (at time of survey)				0.09
Males	68.7 (9.8)	69.5 (8.6)	69.9 (9.2)	
Females	69.5 (9.9)	69.4 (9.6)	70.2 (9.5)	
Marital status				0.10
Married/cohabiting	620 (80)	369 (77)	858 (73)	
Divorced/separated	39 (5)	24 (5)	70 (6)	
Widowed	95 (12)	74 (15)	197 (17)	
Never married/never cohabitated	25 (3)	15 (3)	42 (4)	
Comorbidity				<0.001[a]
None	196 (26)	125 (28)	251 (23)	
1	222 (30)	131 (30)	305 (27)	
2 or more	325 (44)	185 (42)	551 (50)	
General health/QoL (SF–12)	76 (19)	77 (19)	78 (19)	0.06
Symptoms (EORTC QLQ-CR38)				
Gastrointestinal	15.4 (14.5)	14.8 (13.7)	14.6 (14.4)	0.53
Chemotherapy-related	11.4 (17.0)	11.0 (15.4)	11.0 (16.1)	0.88
Stoma-related	25.7 (22.7)	24.8 (20.8)	23.8 (22.4)	0.69
HADS				
Anxiety (mean)	4.6 (3.9)	4.7 (3.7)	4.5 (3.7)	0.63
Clinically significant anxiety				
No	610 (80)	362 (78)	898 (80)	
Yes	156 (20)	101 (22)	226 (20)	
Depression (mean)	4.4 (3.8)	4.6 (3.9)	4.2 (3.5)	0.13
Clinically significant depression				
No	624 (81)	366 (79)	942 (83)	
Yes	150 (19)	98 (21)	195 (17)	
FAS (mean)				
Physical	11.6 (4.1)	11.6 (4.1)	11.3 (3.9)	0.11
Mental	9.2 (3.7)	9.2 (3.4)	8.9 (3.4)	0.08
Total	20.9 (7.1)	20.9 (6.8)	20.2 (6.6)	0.06
Clinically significant fatigue				
No	480 (62)	279 (60)	731 (65)	
Yes	294 (38)	185 (40)	401 (35)	

Abbreviations: FAS, Fatigue Assessment Scale; HADS, Hospital Anxiety and Depression Scale.

[a]p values report comparison between follow-up groups, according to ANOVA and chi-square tests. p < 0.05.

A higher score represents a higher quality of life or a higher burden of symptoms or problems.

variables are depicted as means and standard deviations, and categorical variables as frequencies and percentages. Differences in characteristics and utilisation of care between short-term (≤2y), mid-term (3-4y) and long-term (≥5y) survivors were examined using chi-square (categorical), t test (nominal) or ANOVA tests (continuous). Above follow-up categories are commonly used categorisations in cancer research. Univariable logistic regression was used to identify possible associative factors. Hereafter, a multivariable logistic regression model was formed using the identified factors to analyse the association between healthcare use and overuse and age, sex, marital status, BMI, educational level, SES, comorbidity, stoma and (neo)adjuvant therapies (e.g. radiation and chemotherapy). Also, the relation between patient-reported outcomes (anxiety, depression, fatigue) and healthcare utilisation was analysed using multivariable

logistic regression analysis. Analyses were performed using Stata software (*Stata Statistical Software*: *Release 15*. College Station, TX: StataCorp LLC). Two-sided analysis with $p < 0.05$ considered

TABLE 3 General and cancer-related visits to the medical specialist and GP according to follow-up year

N (%)	FU 1–2 years	FU 3–4 years	FU > 5 years	p Value
Number of visits to medical specialist in the past 12 months				<0.001[a]
0 times	36 (5)	34 (7)	239 (21)	
1–2 times	261 (33)	219 (45)	495 (42)	
3–5 times	273 (35)	144 (30)	260 (22)	
>5 times	216 (27)	88 (18)	174 (15)	
Number of cancer-related visits to medical specialist in the past 12 months				<0.001[a]
0 times	65 (8)	71 (15)	436 (40)	
1–2 times	347 (45)	260 (55)	470 (43)	
3–5 times	237 (31)	95 (20)	121 (11)	
>5 times	128 (16)	49 (10)	70 (6)	
Currently in follow-up				<0.001[a]
Yes	726 (93)	433 (90)	715 (62)	
No	54 (7)	49 (10)	434 (38)	
Follow-up care schedule				<0.001[a]
Every 3 months	135 (18)	57 (13)	58 (7)	
Every 4 months	43 (6)	17 (4)	21 (3)	
Every 6 months	386 (53)	222 (51)	173 (22)	
Every year	93 (13)	89 (21)	238 (30)	
Every 2 years	11 (2)	21 (5)	131 (17)	
Less than 2 year	61 (8)	28 (6)	170 (21)	
Comfortable with schedule				<0.001[a]
Yes	709 (92)	428 (91)	899 (81)	
No, I would like more follow-up	39 (5)	29 (6)	99 (9)	
No, I would like less follow-up	11 (1)	8 (2)	19 (2)	
No, I do not want any follow-up	14 (2)	5 (1)	87 (8)	
Currently receiving cancer-related care from GP				0.78
Yes	128 (64)	68 (62)	136 (66)	
No	73 (36)	42 (38)	71 (34)	
Number of visits to GP in the past 12 months				0.47
0 times	100 (13)	68 (14)	182 (15)	
1–2 times	252 (32)	177 (36)	371 (32)	
3–5 times	261 (33)	153 (32)	397 (34)	
>5 times	172 (22)	88 (18)	219 (19)	

(Continues)

TABLE 3 (Continued)

N (%)	FU 1–2 years	FU 3–4 years	FU > 5 years	p Value
Number of cancer-related visits to GP in the past 12 months				<0.001[a]
0 times	440 (59)	336 (72)	855 (79)	
1–2 times	184 (25)	85 (18)	148 (13)	
3–5 times	69 (9)	31 (7)	58 (5)	
>5 times	51 (7)	17 (3)	28 (3)	

Note: N = 2.438 (medical specialist) and N = 2440 (GP).
[a]p values report comparison between follow-up groups, according to ANOVA and chi-square tests.

significant was used. We adhered to the STROBE checklist for observational cohort studies (Elm et al., 2007).

3 | RESULTS

3.1 | Respondents and non-respondents

A total of 2450 out of 3025 curatively treated patients with stage I-III CRC completed the survey, yielding a response rate of 81%. At time of completion of the survey, 789 patients (32%) were 1–2 years in follow-up. Another 488 patients (20%) were 3–4 years in follow-up, and the remaining 1173 (48%) were 5 years or longer in follow-up. More than half of the participants were male (55%). Mean age at time of diagnosis was 64.3 years (SD: 9.7). Non-respondents were more likely to be older, to have a higher SES and been diagnosed with colon cancer. [Table 1].

3.2 | Differences between CRC survivors during follow-up

Patients received a survey 1.4–11.4 year after diagnosis (mean: 5.3 years). Mean age at time of survey for both men and women was between 69 and 70 years (SD: 9–10). [Table 2] The majority were married (74–80%). Around 44–50% of the respondents had 2 or more comorbidities. Comorbidity number was higher in patients longer in follow-up. Around 17–22% (depending on follow-up year) experienced clinically significant anxiety or depressive symptoms. More than one-third experienced clinically significant fatigue symptoms (35–40%). General health/QoL of the respondents was 76–78 on a scale of 0–100 (SD: 19). General health/QoL, anxiety, depressive symptoms and fatigue scores did not differ between patients in short-term (1-2y), mid-term (3-4y) or long-term (≥5y) follow-up.

3.3 | Follow-up visits to the GP and medical specialist

On average, the number of cancer-related visits to the GP was 1.7 during the first post-operative year. [Table 3] The number of cancer-related visits to the GP was lower in patients longer in follow-up ($p < 0.001$).
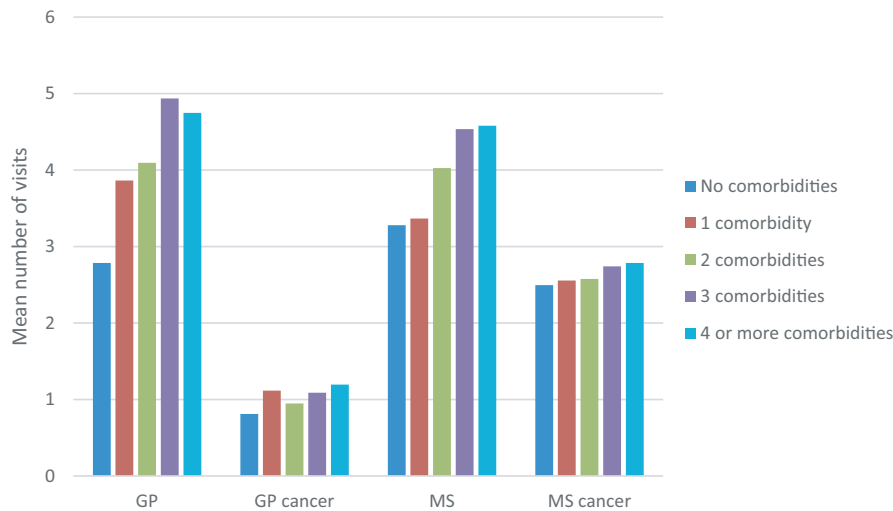
FIGURE 1 General and cancer-related visits to the general practitioner (GP) and medical specialist (MS) by comorbidity number. Note: Number of visits expressed as mean. Comorbidity number was associated with number of GP/medical specialist visits (both $p < 0.001$)
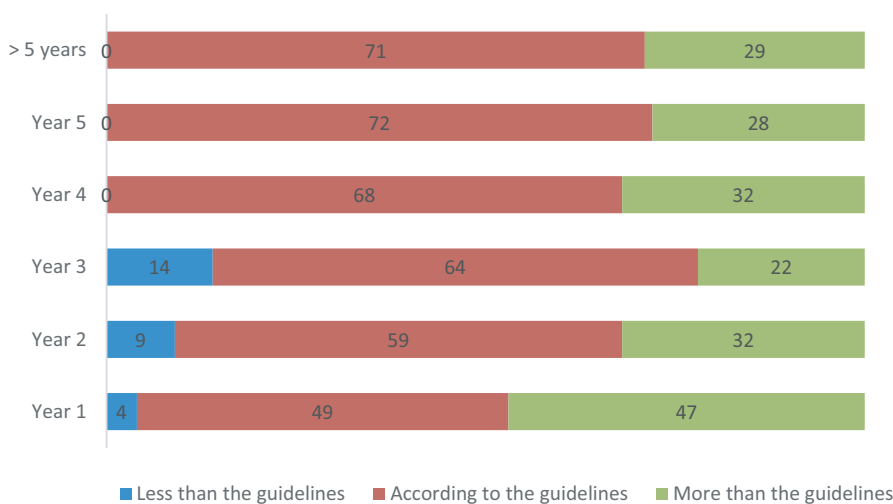

FIGURE 2 Follow-up care adherence to the Dutch CRC guidelines (%). Notes: According to guidelines: 2–3 times a year during follow-up years 1 and 2, and 1–2 times a year during years 3–5. For this comparison, an upper and lower margin of 1 visit was used, meaning 1 visit more than the guidelines was allowed

The average number of cancer-related visits to the medical specialist during the first year postoperatively was 4.2. The majority received follow-up care (62–93%). The number of cancer-related follow-ups was different for patients enrolled at different follow-up intervals. Patients longer in follow-up had less cancer-related visits to the medical specialist. Comorbidity number was positively associated with the number of general visits to the medical specialist and GP. [Figure 1, $p < 0.001$].

3.4 | Guideline adherence and associations with overuse of follow-up care

The vast majority were comfortable with their current follow-up schedule. A small percentage of patients in long-term follow-up preferred to receive less follow-up (7.9%), while 9% preferred to receive more follow-up. Figure 2 shows the percentage of survivors that received less than, according to, or more care than recommended, according to follow-up year. Around 29–47% received more follow-up than recommended by the guidelines. In the first three years, around 4–14% of the CRC survivors received less follow-up care than recommended.

3.5 | Associations

Logistic regression analysis demonstrated no statistically significant association between sex, follow-up year, number of comorbidities, marital status, educational level, BMI, and cancer-related GP and cancer-related medical specialist visits. Multivariable logistic regression analysis showed that survivors with stage III disease treated with or without chemotherapy were more likely to receive more (cancer-related) follow-up care by the medical specialist than recommended by the guidelines. In addition, survivors with lower SES, the presence of a stoma and having clinically significant fatigue symptoms were more likely to receive more follow-up care. [Table 4].

4 | DISCUSSION

In the current Dutch study, most CRC survivors received (self-reported) follow-up care. Patients visited their GP throughout follow-up, most often for reasons that were not cancer-related. The medical specialist was consulted primarily for cancer care. Patients longer in follow-up sought less general and cancer-related medical

specialist care. The vast majority of patients received follow-up care according to the guidelines or even more than recommended. Despite that, there was substantial variation in follow-up practice existed, with both underuse and overuse of care. Around one-third received (or sought) follow-up care more often than recommended, even >5 years after diagnosis. Only a smaller percentage, especially in the first three years, received less follow-up visits than recommended. Nonetheless, more than 80% of survivors were comfortable with their follow-up schedule. Advanced disease stage, receipt of chemotherapy, low socio-economic status, the presence of a stoma and fatigue were factors associated with follow-up care overuse.

The results from the present study suggest that more intensive follow-up practice is common in the Netherlands, despite limited evidence for intensive follow-up schedules. (Jeffery et al., 2016; Wille-Jorgensen et al., 2018) Comparable results regarding variation in follow-up practice and overuse are reported elsewhere. (Arts et al., 2018; Grossmann et al., 2007; Nicolaije et al., 2013) The variation in follow-up care utilisation observed may be explained by the following reasons. First, Dutch national guidelines are not stringent and allow broad interpretations. Second, regional and local protocols derived from the national guidelines can cause differences in practice. Third, survivors might receive care for long-term consequences of CRC treatment such as neuropathy, anxiety, depression, fatigue or stoma-related care. Moreover, approximately 20% of survivors develop recurrent disease during the initial 5 years post-treatment. (Elferink et al., 2015) In that case, patients undergo palliative treatment or curative resection of oligometastatic disease. In case of, for instance, liver surgery for colorectal cancer metastases, follow-up is usually extended with another 5 years. Unfortunately, we did not have information regarding disease recurrence within our cohort. Lastly, endoscopic follow-up extends after surgical follow-up where patients undergo colonoscopies every 3–5 years until at least 75 years of age.

Most patients were comfortable with their current follow-up schedule. A reasonable number of patients more than 5 years in follow-up felt less comfortable in comparison with patients in previous follow-up years, and these patients preferred no follow-up care at all. From clinical experience, it is known that a percentage of patients desires longer follow-up than recommended, even if they are symptom and cancer-free. This group of patients seeks continuing (positive) assurance by the medical specialist or GP. Shared decision-making and tailored counselling are needed to reduce overuse within this group of patients. (Arts et al., 2018) At the same time, a smaller percentage received less than recommended follow-up care. Important patient's perceived needs are support for psychosocial, physical and information and health system-related needs. (Sanson-Fisher et al., 2000) Access to care, time and adequate follow-up care, among other factors, are required for addressing patient care needs and providing supportive care (Qaderi et al., 2020).

General health/QoL, anxiety, depressive symptoms and fatigue scores did not differ between patients in short-term, mid-term to long-term follow-up. Comparable results have been found in other studies wherein quality-of-life levels seem to return to pre-operative levels after one year. (Couwenberg et al., 2019) Previous studies identified these symptoms as major factors impairing cancer patient's lives. (Custers et al., 2016; Heinsbergen et al., 2019; Mols et al., 2018) In our study, fatigue was also associated with overuse of follow-up care. Holla et al. have shown that (supportive) care use was associated with patient-perceived needs such as low physical health, and symptoms such as anxiety, depression and fatigue (Holla et al., 2016).

In our study, deprived patients, patients with advanced disease who received chemotherapy and patients who had a stoma or experienced fatigue were more likely to receive more follow-up care. In an equitable healthcare system, follow-up care use should be mainly explained by patient needs and clinical need factors. (Andersen, 2008) Since lower SES is also associated with more comorbidities and lower survival after CRC surgery (Berg et al., 2020; Syriopoulou et al., 2017), and these patients require more care. Factors such as low education, living alone and advanced disease stage (and therefore more likely to undergo chemotherapy) are associated with persistent low QoL and high psychological distress during follow-up. (Qaderi et al., 2021) Patients undergoing chemotherapy are also more likely to develop fatigue, (Thong et al., 2013) and those with stoma may have a lower QoL (Vonk-Klaassen et al., 2016) and therefore need more follow-up care. Apart from these associations, follow-up care is standardised in the Netherlands with a broad and extensive guideline available, encompassing also various screening methods and treatment of long-term consequences after CRC treatment and provision of supportive care. (Netherlands Comprehensive Cancer Network, 2014) Some of the factors can be modified through early screening, adequate counselling and (supportive) therapy. Also, better and tailored information might relieve (psychological) distress since earlier studies have proven that uncertainty and lack of information lead to distress and dissatisfaction towards follow-up care. (Buunk et al., 2012; Qaderi, Swartjes, et al., 2020; Stiegelis et al., 2004).

Various strategies exist to provide more patient-centred follow-up care. (Qaderi, Swartjes, et al., 2020) At our university medical centre, a remote follow-up plan was introduced for stage I-III CRC survivors. (Qaderi et al., 2019) Within remote follow-up, survivors have access to test results and are empowered by self-management information. Moreover, survivors have access to telemedicine applications such as video consultation, text messaging and telephone services to contact their doctor or nurse practitioner. The results of the current study are informative and can be used in the process and design of such initiatives. The present study has some limitations that should be mentioned. First, although baseline characteristics of non-respondents are known, it remains unclear why non-respondents did not participate. Second, the cross-sectional data used in this paper limit the understanding of course over time of certain variables within patients. Third, recall bias can have led to less accurate answers. Patients were asked to report healthcare use in the past 12 months. Therefore, it is possible that patients who had more recent follow-up remembered their visits more accurately compared with those who had follow-up a longer time ago. Lastly,

TABLE 4 Factors associated with overuse of follow-up care using multivariable logistic regression analysis

N (%)	Overuse (N = 501)	According to guidelines[d] (N = 959)	Odds ratio–95% CI
Age at time of survey			
<60 years	96 (19)	133 (14)	Ref
≥60 years	405 (81)	826 (86)	0.9 (0.6–1.2)
Disease stage			
I	117 (23)	329 (34)	Ref
II	169 (34)	385 (40)	1.2 (0.9–1.6)
III	215 (43)	245 (26)	1.8 (1.2–2.6)[b]
Radiotherapy			
No	327 (65)	695 (72)	Ref
Yes	174 (35)	264 (28)	1.3 (1.0–1.7)
Chemotherapy			
No	299 (60)	733 (76)	Ref
Yes	202 (40)	226 (24)	1.7 (1.3–2.3)[b]
Stoma			
No	367 (73)	776 (91)	Ref
Yes	134 (27)	183 (19)	1.4 (1.1–1.9)[a]
Socio-economic status			
High	85 (17)	212 (22)	Ref
Moderate	213 (43)	369 (38)	1.4 (1.0–1.9)[a]
Intermediate	177 (35)	334 (35)	1.5 (1.0–2.1)[a]
Low	9 (2)	12 (1)	1.6 (0.6–4.3)
Unknown	17 (3)	32 (3)	
HADS anxiety			
No	349 (70)	745 (78)	Ref
Yes	127 (25)	182 (19)	1.1 (0.8–1.6)
Unknown	25 (5)	32 (3)	
HADS depression			
No	363 (72)	771 (81)	Ref
Yes	114 (23)	167 (17)	1.0 (0.7–1.4)
Unknown	24 (5)	21 (2)	
FAS			
No	254 (51)	603 (63)	Ref
Yes	230 (46)	329 (34)	1.3 (1.0–1.8)[a]
Unknown	17 (3)	27 (3)	
Mean (SD)			
General health/QoL[c]	78 (18)	73 (21)	1.0 (1.0–1.0)
Symptoms[c]			
Gastrointestinal	17 (15)	14 (13)	1.0 (1.0–1.0)
Chemotherapy-related	14 (18)	10 (15)	1.0 (1.0–1.0)

Note: Sex, FU year, comorbidity, marital status, educational level and BMI were not statistically significant factors in univariable logistic regression models and therefore excluded from multivariable analysis. N = 1.460. Definitive multivariable model based on 1.367 subjects due to missing values in continuous variables (BMI, general health/QoL and symptoms). The numbers do not always add up to 100 due to rounding off to whole numbers.

Abbreviations: FAS, Fatigue Assessment Scale; HADS, Hospital Anxiety and Depression Scale.

[a]$p < 0.05$.

[b]$p < 0.01$.

[c]A higher score represents a higher quality of life or a higher burden of symptoms or problems.

[d]According to guidelines: 2–3 times a year during follow-up years 1 and 2, and 1–2 times a year during years 3–5.

since follow-up utilisation was reported by the patient, it is unclear how much follow-up care was precisely provided to patients.

Regardless of the limitations noted, the results contribute to the current debate about frequency of follow-up care of CRC survivors by demonstrating the state of follow-up care utilisation and identifying the factors associated with follow-up care utilisation. Our results can provide healthcare professionals information to better organise follow-up care. The study was carried out in a population-based setting providing real-world results and representing daily practice. The high response rate, large number of participants and large range in time since diagnosis enhance the generalisation of the results to a broader population of CRC survivors in the Netherlands and to countries with similar healthcare systems.

In conclusion, CRC survivors visited their GP throughout follow-up, often for reasons that were not cancer-related. The medical specialist was consulted primarily for cancer care. Long-term survivors sought less general and cancer-related medical specialist care. CRC survivors were predominantly followed according to national guidelines. However, substantial variation in follow-up practice existed. Follow-up overuse is still practised in one-third of the patients and is driven by advanced disease stage, receipt of chemotherapy, low socio-economic status, the presence of a stoma and fatigue. Proactive screening, adequate counselling and therapy of long-term consequences according to guidelines are important. Future studies should investigate how overuse can be reduced, while still addressing patients' needs.

CONFLICT OF INTEREST

Rob H.A. Verhoeven received research grants from Roche and Bristol Myers-Squib. The other authors have nothing to declare.

CONSENT FOR PUBLICATION

Not applicable.

DATA AVAILABILITY STATEMENT

The data sets used and/or analysed during the current study are available from the corresponding author on reasonable request.

ORCID

Seyed M. Qaderi https://orcid.org/0000-0001-7595-7833
Floortje Mols https://orcid.org/0000-0003-0818-2913

REFERENCES

Andersen, R. M. (2008). National health surveys and the behavioral model of health services use. *Medical Care*, 46(7), 647–653. https://doi.org/10.1097/MLR.0b013e31817a835d.

Arts, L. P. J., Oerlemans, S., Tick, L., Koster, A., Roerdink, H. T. J., & van de Poll-Franse, L. V. (2018). More frequent use of health care services among distressed compared with nondistressed survivors of lymphoma and chronic lymphocytic leukemia: Results from the population-based PROFILES registry. *Cancer*, 124(14), 3016–3024. https://doi.org/10.1002/cncr.31410.

Bastiaenen, V. P., Hovdenak Jakobsen, I., Labianca, R., Martling, A., Morton, D. G., Primrose, J. N., Tanis, P. J., Laurberg, S., & Research Committee and the Guidelines Committee of the European Society of Coloproctology (ESCP) (2018). Consensus and controversies regarding follow-up after curative intent treatment of non-metastatic colorectal cancer: a synopsis of guidelines used in countries represented in ESCP. *Colorectal Disease*, 21(4), 392-416.

Brouwer, N. P. M., Bos, A., Lemmens, V., Tanis, P. J., Hugen, N., Nagtegaal, I. D., de Wilt, J. H. W., & Verhoeven, R. H. A. (2018). An overview of 25 years of incidence, treatment and outcome of colorectal cancer patients. *International Journal of Cancer*, 10, 2758–2766. https://doi.org/10.1002/ijc.31785.

Buunk, A. P., Bennenbroek, F. T., Stiegelis, H. E., van den Bergh, A. C., Sanderman, R., & Hagedoorn, M. (2012). Follow-up effects of social comparison information on the quality of life of cancer patients: the moderating role of social comparison orientation. *Psychology & Health*, 27(6), 641–654.

Couwenberg, A. M., Burbach, J. P. M., Intven, M. P. W., Consten, E. C. J., Schiphorst, A. H. W., Smits, A. B., Wijffels, N. A. T., Heikens, J. T., Koopman, M., van Grevenstein, W. M. U., & Verkooijen, H. M. (2019). Health-related quality of life in rectal cancer patients undergoing neoadjuvant chemoradiation with delayed surgery versus short-course radiotherapy with immediate surgery: a propensity score-matched cohort study. *Acta Oncologica (Stockholm, Sweden)*, 58(4), 407–416. https://doi.org/10.1080/0284186X.2018.1551622.

Custers, J. A. E., Gielissen, M. F. M., Janssen, S. H. V., de Wilt, J. H. W., & Prins, J. B. (2016). Fear of cancer recurrence in colorectal cancer survivors. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, 24(2), 555–562. https://doi.org/10.1007/s00520-015-2808-4.

Davies, N. J., & Batehup, L. (2011). Towards a personalised approach to aftercare: a review of cancer follow-up in the UK. *Journal of Cancer Survivorship*, 5(2), 142–151. https://doi.org/10.1007/s11764-010-0165-3.

Elferink, M. A., de Jong, K. P., Klaase, J. M., Siemerink, E. J., & de Wilt, J. H. (2015). Metachronous metastases from colorectal cancer: a population-based study in North-East Netherlands. *International Journal of Colorectal Disease*, 30(2), 205–212. https://doi.org/10.1007/s00384-014-2085-6.

Ezendam, N. P., Nicolaije, K. A., Boll, D., Lybeert, M. L., Mols, F., Pijnenborg, J. M., & van de Poll-Franse, L. V. (2013). Health care use among endometrial cancer survivors: a study from PROFILES, a population-based survivorship registry. *International Journal of Gynecological Cancer: Official Journal of the International Gynecological Cancer Society*, 23(7), 1258–1265. https://doi.org/10.1097/IGC.0b013e31829dd1e3.

Grossmann, I., de Bock, G. H., van de Velde, C. J., Kievit, J., & Wiggers, T. (2007). Results of a national survey among Dutch surgeons treating patients with colorectal carcinoma. Current opinion about follow-up, treatment of metastasis, and reasons to revise follow-up practice. *Colorectal Disease*, 9(9), 787–792. https://doi.org/10.1111/j.1463-1318.2007.01303.x.

Holla, J. F., van de Poll-Franse, L. V., Huijgens, P. C., Mols, F., & Dekker, J. (2016). Utilization of supportive care by survivors of colorectal cancer: results from the PROFILES registry. *Supportive Care in*

Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer, 24(7), 2883–2892. https://doi.org/10.1007/s00520-016-3109-2.

Jeffery, M., Hickey, B. E., Hider, P. N., & See, A. M. (2016). Follow-up strategies for patients treated for non-metastatic colorectal cancer. *Cochrane Database of Systematic Reviews*, 11, CD002200. https://doi.org/10.1002/14651858.CD002200.pub3.

Mant, D., Gray, A., Pugh, S., Campbell, H., George, S., Fuller, A., Shinkins, B., Corkhill, A., Mellor, J., Dixon, E., Little, L., Perera-Salazar, R., & Primrose, J. (2017). A randomised controlled trial to assess the cost-effectiveness of intensive versus no scheduled follow-up in patients who have undergone resection for colorectal cancer with curative intent. *Health Technology Assessment*, 21(32), 1–86. https://doi.org/10.3310/hta21320.

Michielsen, H. J., De Vries, J., & Van Heck, G. L. (2003). Psychometric qualities of a brief self-rated fatigue measure: The Fatigue Assessment Scale. *Journal of Psychosomatic Research*, 54(4), 345–352. https://doi.org/10.1016/S0022-3999(02)00392-6.

Michielsen, H. J., Van der Steg, A. F., Roukema, J. A., & De Vries, J. (2007). Personality and fatigue in patients with benign or malignant breast disease. *Supportive Care in Cancer*, 15(9), 1067–1073. https://doi.org/10.1007/s00520-007-0222-2.

Mols, F., Beijers, T., Lemmens, V., van den Hurk, C. J., Vreugdenhil, G., & van de Poll-Franse, L. V. (2013). Chemotherapy-induced neuropathy and its association with quality of life among 2- to 11-year colorectal cancer survivors: results from the population-based PROFILES registry. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 31(21), 2699–2707. https://doi.org/10.1200/JCO.2013.49.1514.

Mols, F., Coebergh, J. W., & van de Poll-Franse, L. V. (2007). Health-related quality of life and health care utilisation among older long-term cancer survivors: A population-based study. *European Journal of Cancer*, 43(15), 2211–2221. https://doi.org/10.1016/j.ejca.2007.06.022.

Mols, F., Helfenrath, K. A., Vingerhoets, A. J., Coebergh, J. W., & van de Poll-Franse, L. V. (2007). Increased health care utilization among long-term cancer survivors compared to the average Dutch population: a population-based study. *International Journal of Cancer*, 121(4), 871–877. https://doi.org/10.1002/ijc.22739.

Mols, F., Schoormans, D., de Hingh, I., Oerlemans, S., & Husson, O. (2018). Symptoms of anxiety and depression among colorectal cancer survivors from the population-based, longitudinal PROFILES Registry: Prevalence, predictors, and impact on quality of life. *Cancer*, 124(12), 2621–2628. https://doi.org/10.1002/cncr.31369.

Netherlands Comprehensive Cancer Network (2014). *National guideline Colorectal Carcinoma, version 3.0.* https://www.nhg.org/sites/default/files/content/nhg_org/uploads/colorectaalcarcinoom.pdf

Nicolaije, K. A., Ezendam, N. P., Vos, M. C., Boll, D., Pijnenborg, J. M., Kruitwagen, R. F., Lybeert, M. L. M., & van de Poll-Franse, L. V. (2013). Follow-up practice in endometrial cancer and the association with patient and hospital characteristics: a study from the population-based PROFILES registry. *Gynecologic Oncology*, 129(2), 324–331. https://doi.org/10.1016/j.ygyno.2013.02.018.

Olsson, I., Mykletun, A., & Dahl, A. A. (2005). The hospital anxiety and depression rating scale: a cross-sectional study of psychometrics and case finding abilities in general practice. *BMC Psychiatry*, 5, 46. https://doi.org/10.1186/1471-244X-5-46.

Primrose, J. N., Perera, R., Gray, A., Rose, P., Fuller, A., Corkhill, A., George, S., & Mant, D. (2014). Effect of 3 to 5 years of scheduled CEA and CT follow-up to detect recurrence of colorectal cancer: the FACS randomized clinical trial. *JAMA*, 311(3), 263–270. https://doi.org/10.1001/jama.2013.285718.

Qaderi, S. M., Dickman, P. W., de Wilt, J. H. W., & Verhoeven, R. H. A. (2020). Conditional survival and cure of patients with colon or rectal cancer: A population-based study. *Journal of the National Comprehensive Cancer Network*, 18(9), 1230–1237. https://doi.org/10.6004/jnccn.2020.7568.

Qaderi, S. M., Swartjes, H., Custers, J. A. E., & de Wilt, J. H. W. (2020). Health care provider and patient preparedness for alternative colorectal cancer follow-up; a review. *European Journal of Surgical Oncology*, 46(10), 1779–1788. https://doi.org/10.1016/j.ejso.2020.06.017.

Qaderi, S. M. V. D. H. J., Verhoeven, R. H. A., de Wilt, J. H. W., & Custer, J. A. E. (2021). *Trajectories of quality of life and psychological distress in patients with colorectal cancer; a Population-Based Study.* Submitted.

Qaderi, S. M., Vromen, H., Dekker, H. M., Stommel, M. W. J., Bremers, A. J. A., & de Wilt, J. H. W. (2019). Development and implementation of a remote follow-up plan for colorectal cancer patients. *European Journal of Surgical Oncology: The Journal of the European Society of Surgical Oncology and the British Association of Surgical Oncology*, 46(3), 429-432. pii: S0748-7983(19)30895-9.

Qaderi, S. M., Wijffels, N. A. T., Bremers, A. J. A., & de Wilt, J. H. W. (2020). Major differences in follow-up practice of patients with colorectal cancer; results of a national survey in the Netherlands. *BMC Cancer*, 20(1), 22. https://doi.org/10.1186/s12885-019-6509-0.

Sangha, O., Stucki, G., Liang, M. H., Fossel, A. H., & Katz, J. N. (2003). The self-administered comorbidity questionnaire: a new method to assess comorbidity for clinical and health services research. *Arthritis & Rheumatism*, 49(2), 156–163. https://doi.org/10.1002/art.10993.

Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., & Cook, P. (2000). The unmet supportive care needs of patients with cancer. *Cancer*, 88(1), 226–237. https://doi.org/10.1002/(SICI)1097-0142(20000101)88:1<226:AID-CNCR30>3.0.CO;2-P.

Siddika, A., Tolia-Shah, D., Pearson, T. E., Richardson, N. G., & Ross, A. H. (2015). Remote surveillance after colorectal cancer surgery: an effective alternative to standard clinic-based follow-up. *Colorectal Disease: The Official Journal of the Association of Coloproctology of Great Britain and Ireland*, 17(10), 870–875. https://doi.org/10.1111/codi.12970.

Siegel, R. L., Miller, K. D., Goding Sauer, A., Fedewa, S. A., Butterly, L. F., Anderson, J. C., Cercek, A., Smith, R. A., & Jemal, A. (2020). Colorectal cancer statistics, 2020. *CA: A Cancer Journal for Clinicians*, 70(3), 145–164. https://doi.org/10.3322/caac.21601.

Soreide, K., Traeland, J. H., Stokkeland, P. J., Glomsaker, T., Soreide, J. A., & Korner, H. (2012). Adherence to national guidelines for surveillance after curative resection of nonmetastatic colon and rectum cancer: a survey among Norwegian gastrointestinal surgeons. *Colorectal Disease: The Official Journal of the Association of Coloproctology of Great Britain and Ireland*, 14(3), 320–324. https://doi.org/10.1111/j.1463-1318.2011.02631.x.

Sprangers, M. A., te Velde, A., & Aaronson, N. K. (1999). The construction and testing of the EORTC colorectal cancer-specific quality of life questionnaire module (QLQ-CR38). European Organization for Research and Treatment of Cancer Study Group on Quality of Life. *European Journal of Cancer*, 35(2), 238–247. https://doi.org/10.1016/S0959-8049(98)00357-8.

Stiegelis, H. E., Hagedoorn, M., Sanderman, R., Bennenbroek, F. T., Buunk, B. P., van den Bergh, A. C., Botke, G., & Ranchor, A. V. (2004). The impact of an informational self-management intervention on the association between control and illness uncertainty before and psychological distress after radiotherapy. *Psycho-Oncology*, 13(4), 248–259. https://doi.org/10.1002/pon.738.

Syriopoulou, E., Bower, H., Andersson, T. M., Lambert, P. C., & Rutherford, M. J. (2017). Estimating the impact of a cancer diagnosis on life expectancy by socio-economic group for a range of cancer types in England. *British Journal of Cancer*, 117(9), 1419–1426. https://doi.org/10.1038/bjc.2017.300.

Thong, M. S. Y., Mols, F., Wang, X. S., Lemmens, V. E. P. P., Smilde, T. J., & van de Poll-Franse, L. V. (2013). Quantifying fatigue in (long-term) colorectal cancer survivors: A study from the population-based

Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship registry. *European Journal of Cancer*, *49*(8), 1957–1966. https://doi.org/10.1016/j.ejca.2013.01.012.

van de Poll-Franse, L. V., Horevoorts, N., van Eenbergen, M., Denollet, J., Roukema, J. A., Aaronson, N. K., Vingerhoets, A. D., Coebergh, J. W., de Vries, J., Essink-Bot, M. L., & Mols, F. (2011). The patient reported outcomes following initial treatment and long term evaluation of survivorship registry: Scope, rationale and design of an infrastructure for the study of physical and psychosocial outcomes in cancer survivorship cohorts. *European Journal of Cancer*, *47*(14), 2188–2194. https://doi.org/10.1016/j.ejca.2011.04.034.

van den Berg, I., Buettner, S., van den Braak, R. R. J. C., Ultee, K. H. J., Lingsma, H. F., van Vugt, J. L. A., & Ijzermans, J. N. M. (2020). Low socioeconomic status is associated with worse outcomes after curative surgery for colorectal cancer: Results from a large, multi-center study. *Journal of Gastrointestinal Surgery*, *24*(11), 2628–2636. https://doi.org/10.1007/s11605-019-04435-2.

van der Stok, E. P., Spaander, M. C. W., Grunhagen, D. J., Verhoef, C., & Kuipers, E. J. (2017). Surveillance after curative treatment for colorectal cancer. *Nature Reviews Clinical Oncology*, *14*(5), 297–315. https://doi.org/10.1038/nrclinonc.2016.199.

van Heinsbergen, M., Maas, H., Bessems, S., Vogelaar, J., Nijhuis, P., Keijzer-Bors, L., van Liempd, A., & Janssen-Heijnen, M. (2019). Follow-up after surgical treatment in older patients with colorectal cancer: The evaluation of emerging health problems and quality of life after implementation of a standardized shared-care model. *Journal of Geriatric Oncology*, *10*(1), 126–131. https://doi.org/10.1016/j.jgo.2018.07.014.

von Elm, E., Altman, D. G., Egger, M., Pocock, S. J., Gotzsche, P. C., & Vandenbroucke, J. P. (2007). The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *The Lancet*, *370*(9596), 1453–1457. https://doi.org/10.1016/S0140-6736(07)61602-X.

Vonk-Klaassen, S. M., de Vocht, H. M., den Ouden, M. E., Eddes, E. H., & Schuurmans, M. J. (2016). Ostomy-related problems and their impact on quality of life of colorectal cancer ostomates: a systematic review. *Quality of Life Research*, *25*(1), 125–133. https://doi.org/10.1007/s11136-015-1050-3.

Ware, J., Kosinski, M., & Keller, S. (1995). *How to score the SF-12 physical and mental health summary scales*. 2nd Ed. Boston, MA: The Health Institute, New England Medical Center.

Wille-Jorgensen, P., Syk, I., Smedh, K., Laurberg, S., Nielsen, D. T., Petersen, S. H., Renehan, A. G., Horváth-Puhó, E., Påhlman, L., & Sørensen, H. T. (2018). Effect of more vs less frequent follow-up testing on overall and colorectal cancer-specific mortality in patients with stage ii or iii colorectal cancer: The colofol randomized clinical trial. *JAMA*, *319*(20), 2095–2103. https://doi.org/10.1001/jama.2018.5623.

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, *67*(6), 361–370. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.