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## RESEARCH ARTICLE

# Patient perspectives on consequences of resection for colorectal cancer: A qualitative study

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## Abstract

**Background:** Colorectal cancer is diagnosed in approximately 500,000 patients each year in Europe, leading to a high number of patients having to cope with the consequences of resection for colorectal cancer. As treatment options tend to grow, more information on the effects of these treatments is needed to engage in shared decision-making. This study aims to explore the impact of resection for colorectal cancer on patients' daily life.

**Methods:** Patients ( $\geq 18$  years of age) who underwent an oncological colorectal resection between 2018 and 2021 were selected. Purposeful sampling was used to include patients who differed in age, comorbidity conditions, types of (neo)adjuvant therapy, postoperative complications and the presence/absence of a stoma. Semi-structured interviews were conducted, guided by a topic guide. Interviews were fully transcribed and subsequently thematically analysed using the framework approach. Analyses were carried out using the following predefined themes: (1) daily life and activities; (2) psychological functioning; (3) social functioning; (4) sexual functioning; and (5) healthcare experiences.

**Results:** Sixteen patients with a follow-up period of between 0.6 and 4.4 years after surgery were included in this study. Participants reported several challenges experienced because of poor bowel function, a stoma, chemotherapy-induced neuropathy, fear of recurrence and sexual dysfunction. However, they reported these as not interfering much with daily life.

**Conclusion:** Colorectal cancer treatment leads to several challenges and treatment-related health deficits. This is often not recognized by generic patient-reported outcome measures, but the findings on treatment-related health deficits presented in this study contain valuable insights which might contribute to improving colorectal cancer care, shared decision making and value-based health care.

## KEYWORDS

cancer survivorship, colorectal cancer, qualitative study, quality of life, value based health care

Rob A. E. M. Tollenaar and Michel W. J. M. Wouters are Senior authors, contributed equally to this work.

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## INTRODUCTION

In Europe, colorectal cancer is diagnosed in approximately 500,000 patients each year, leading to a high number of patients living with the consequences of colorectal cancer treatment [1]. The cornerstone of this treatment is surgical resection, which encompasses invasive and high-risk procedures with an overall complication rate of up to 30% and a 30-day mortality of about 2% [2–4]. Currently, apart from oncological outcomes, psychological and functional outcomes after resection for colorectal cancer are gaining more interest because of increased overall survival, improved oncological care and more awareness of the sequelae of cancer survivorship [5, 6]. Together with an increasing trend towards shared decision-making, the anticipated quality of life after treatment has emerged as an important factor, in addition to (recurrence-free) survival, that should be considered during treatment planning and patient counselling [7]. As this post-treatment quality of life should also be part of the decision-making process regarding treatment options, treatment decisions may be impacted. Therefore, treatment options, for example, “watch and wait” after a clinical complete response to neoadjuvant therapy may be preferred over surgical resection [8]. To provide adequate information to patients in shared decision-making, information on how surgical treatment of colorectal cancer affects daily life and quality of life after colorectal cancer surgery is essential. Previous qualitative research has shown that patients with colorectal cancer find dealing with the disease overwhelming, unpredictable and exhausting [9]. Surgery for colorectal cancer may lead to a decreased quality of life, as well as decreased daily and physical functioning [10]. However, a previous study by our group showed that, 1 year after surgery, quality of life had returned to a level similar to that reported preoperatively, which seems paradoxical given that various treatment-related health deficits may arise post-surgery [11].

Earlier studies have shown that coping mechanisms in patients with malignant diseases might be leading to a relative underestimation of the effect of treatment-related health deficits on patient-reported quality of life [12, 13]. Insight into the long-term consequences of colorectal cancer treatment on daily life and understanding of treatment decisions by patients might positively influence the long-term quality of life and lead to a higher acceptance of possible consequences. Additionally, rehabilitation programmes might be more focused on these consequences [14].

This study aimed to explore the effect of resection for colorectal cancer on patients' daily life. With use of a qualitative approach, more in-depth information on patients' perspectives might be obtained. The major themes from the cancer-specific European Organization for Research and Treatment of Cancer (EORTC) qlq-C30 questionnaire were studied [15]. These themes are often affected by colorectal cancer treatment. Furthermore, the findings of this explorative study could expose outcomes with a high burden on patients' daily life. Ultimately, this information could be used for patient information, shared decision-making and treatment planning. Also, the knowledge gained by this study may provide leads for the

optimization of long-term postoperative care and rehabilitation programmes in colorectal cancer patients.

## METHODS

### Setting

A purposive sample was retrieved from a cohort of patients who underwent surgery for colorectal cancer between 2018 and 2021 at the Leiden University Medical Center (LUMC), a tertiary teaching hospital in the Netherlands. Purposeful sampling was used to include patients who differed in age, comorbidity conditions, types of (neo)adjuvant therapy, postoperative complications and the presence/absence of a stoma.

### Participants

Patients ( $\geq 18$  years of age) who had undergone intended curative resection for primary colorectal carcinoma were considered for inclusion in the study; such patients were approached by a physician during follow-up appointments. To be eligible, participants had to understand and speak Dutch. Patients were included until no further pertinent information and themes were forthcoming from at least three interviews, suggesting that data saturation was reached [16, 17].

### Ethics approval

The Medical Ethics Committee Leiden Den Haag Delft assessed the study protocol for this study (ref. no. N21.168) and concluded that no formal review was needed, as this study was not conducted under the Medical Research Involving Human Subjects Act (WMO). All study participants were given verbal and written information about the study and signed an informed consent form.

### Semi-structured interviews

To learn more about the perspectives of patients regarding the effects of oncological colorectal treatment on their daily functioning, a qualitative approach was used [18–20]. For the semi-structured interviews, a topic guide was developed (Appendix 1). The topics, based on the cancer-specific EORTC qlq-C30 questionnaire and the expert opinion of senior oncological surgeons (R.A.E.M.T., F.A.H., K.C.M.J.P. and M.W.J.M.W.), were as follows: (1) daily life and activities; (2) psychological functioning; (3) social functioning; (4) sexual functioning; and (5) healthcare experiences [15]. However, when new codes or themes were identified during analysis, these were then incorporated into the coding scheme to allow an open view of new information. Semi-structured interviews were selected as a

method because these offer flexibility to gather in-depth perspectives and lead to rich, thematically structured narratives with participants [19]. The interviews were conducted online via Zoom by one investigator, a medical doctor involved in surgical oncology (R.T.K.).

## Analysis

The interviews were fully audiotaped and manually transcribed. A theoretical thematic deductive analysis of the transcripts was performed by two researchers (R.T.K. and B.A.M.S.) to identify patterns in the data [18]. The analysis was carried out using the framework approach and followed five sequential steps:

- (1) Both researchers became familiar with the data.
- (2) R.T.K. developed an initial coding scheme, based on the aforementioned themes, using ATLAS.ti 9.
- (3) Both researchers coded the transcripts using the coding scheme and redefined the scheme when new codes were inductively identified. This was carried out independently by each researcher, and the results were then discussed until agreement was reached.
- (4) After the final coding scheme was determined, themes were identified by the two researchers and discussed with the research team.
- (5) Data were summarized by R.T.K. for data interpretation [20].

The researchers met regularly and discussed the coding scheme as it developed during data analysis.

## RESULTS

### Participants

In total, 23 patients met the inclusion criteria and were approached for participation; 16 signed informed consent and were included in this study. Of these participants, nine were male, and the age range of the patients was 54–79 years (Table 1). Patients were interviewed between 0.6 and 4.4 years after surgery. Six had undergone surgery for a primary tumour located in the colon and 10 had undergone surgery for rectal tumours. Six participants had received neoadjuvant therapy and three had received adjuvant chemotherapy. A stoma had been constructed in seven participants; at the time of the interview, three of these participants reported that their stoma was closed. Major complications, requiring reoperation, occurred in six participants; three of these participants experienced an anastomotic leakage. The duration of the interviews ranged from 18 to 47 min.

### Daily life and activities

Multiple participants reported having poor bowel function with increased stool frequency: *"I pass stool at least 10 times a day"* (P16). This influenced their daily life, for example, their work and their

mobility: *"I visit other companies for work and prefer not to go to the toilet there, but I often have to"* (P16) and *"When I'm on the road, I always think 'Am I nearby or can I be at a toilet within ten minutes?'"* (P4) and *"Two hours is really the maximum that I can walk, because then I have to go to the toilet"*. (P2) To avoid these unwanted situations, some participants reported that they paid extra attention to their diet: *"When I eat a lot of legumes and herbs, then it goes wrong"*. (P4) and *"I have to be careful with oil"* (P14).

Having a stoma was also reported to present certain challenges in daily life. It took a while for most participants to get used to it. In the beginning, they felt insecure and had several problems, such as uncontrollable flatus and stoma bag leakages. Fortunately, at the time of the interviews, most patients reported almost no stoma-related faecal leakage but still had the fear of this happening. Participants reported that they did not want to be dependent on nurses or family: *"You can tell me how to do it because I want to do it myself; I have to accept it and I have to deal with it"* (P3). Participants reported that they learned to cope with a stoma: *"I always say, 'It never makes you happy, that you have it, but I can deal with it quite well'"* (P6) and *"Sometimes I even forget that I have a stoma"* (P1).

Some participants complained about chemotherapy-induced neuropathy in their feet, which greatly influenced their ability to walk: *"It's mainly my right foot. Because of that I will probably walk slightly differently, which causes problems in my knees and my back"* (P2). Furthermore, chemotherapy-induced neuropathy of the hands was reported not only to cause pain but also to affect daily activities: *"Before I get my hands on small objects, I sometimes have to make multiple attempts, because I don't feel them well"* (P7).

Most participants reported that it took a while before they fully recovered from surgery: *"The surgery itself was not such a problem for me, because I thought, 'That's part of it', but in the end, it took quite a while before I was fully recovered"* (P10). After full recovery, most participants reported that not much had changed in their daily life. Although almost all of the patients faced some negative influences of their treatment on their daily lives, in some cases it did positively change their general perspective on life: *"I look at what I can do, there is a solution for everything"* (P4) and *"I can still live and be a happy person"* (P5).

### Psychological functioning

The interviews showed that colorectal cancer treatment may have an impact on a patient's psychological functioning. Multiple participants reported that, after colorectal cancer treatment, the fear of cancer recurrence played a major role in their daily lives, *"Once you are diagnosed with rectal cancer, the fear of recurrence is always at the back of your mind"* (P12). Consequently, as a result of this fear, participants were more aware of anything different they felt within their bodies: *"You are more aware of things you feel, this makes you worry more"* (P8). Also, their confidence in their own body and physical health was sometimes decreased *"When I feel something in my body I keep wondering if this is normal or if I should visit the doctor"* (P2). Not only did participants experience fear about their bodies, but the follow-up

**TABLE 1** Study participant characteristics.

ID	Age <sup>a</sup> (years)	Gender	Comorbidities	Tumour stage	Time since surgery <sup>b</sup> (years)	Type of surgery	Stoma	Postoperative complications	Reoperation	(Neo-) adjuvant therapy
P1	69	Male	Hypertension Obesity Hypercholesteremia	cT3bN0/ypT2N1M0	2.1	Laparoscopic abdominoperineal resection	Colostoma	Urinary retention	No	Neoadjuvant chemotherapy and radiotherapy
P2	56	Female	Abdominal surgery	pT4aN2b	3.5	Laparoscopic sigmoid resection	-	-	No	Adjuvant chemotherapy
P3	54	Female	Orofacial surgery	pT3N0	1.1	Laparoscopic low anterior resection	Colostoma	Anastomotic leakage Pulmonary embolism	Yes	-
P4	68	Female	-	cT2N1M0/ypT0N0	3.9	Laparoscopic low anterior resection	-	-	No	Neoadjuvant brachytherapy
P5	75	Male	Diabetes mellitus type II Hypertension Hypercholesterolemia	pT3N1b	2.5	Laparoscopic sigmoid resection	-	-	No	Adjuvant chemotherapy
P6	69	Female	Cataract surgery	pT3N0	3.0	Laparoscopic low anterior resection	Colostoma	Anastomotic leakage, abdominal abscess, SIADH	Yes	-
P7	57	Male	-	pT2N1M0	0.7	Laparoscopic hemicolectomy left	-	-	No	Adjuvant chemotherapy
P8	62	Female	COPD Hypertension	pT3N0	4.2	Open transverse colectomy	Colostoma (reversed after 1 year)	Haemorrhage	Yes	-
P9	77	Male	Urolithiasis	pT2N0	4.4	Laparoscopic right hemicolectomy	-	-	No	-
P10	67	Female	Appendectomy	pT1N0	3.2	Laparoscopic low anterior resection	-	-	No	-
P11	79	Male	Nephrectomy, multinodular goitre	pT2N0	0.6	Laparoscopic sigmoid resection	-	-	No	-
P12	74	Male	Cystoprostatectomy	pT2N1b	0.6	Open abdominoperineal resection	Colostoma	Small bowel perforation	Yes	-
P13	54	Male	-	cT3N1/ypT1N0	3.2	Laparoscopic low anterior resection	-	-	No	Neoadjuvant chemotherapy and radiotherapy
P14	57	Female	Hypertension	cT3N1/ypT2N0	3.3	Laparoscopic low anterior resection	-	-	No	Neoadjuvant radiotherapy

(Continues)



TABLE 1 (Continued)

ID	Age <sup>a</sup> (years)	Gender	Comorbidities	Tumour stage	Time since surgery <sup>a</sup> (years)	Type of surgery	Stoma	Postoperative complications	Reoperation	(Neo-) adjuvant therapy
P15	70	Male	Diabetes mellitus type II Hypertension Peripheral venous insufficiency	cT3N1/ypT3N1c	2.6	Laparoscopic low anterior resection	Ileostoma (reversed after 3 months)	Ureter perforation	Yes	Neoadjuvant chemotherapy and radiotherapy
P16	63	Male	Hypertension	cT3aN2M0/ypT2N0	4.2	Laparoscopic low anterior resection	Ileostoma (reversed after 6 months)	Anastomotic leakage Urinary retention	Yes	Neoadjuvant chemotherapy and radiotherapy

<sup>a</sup>At the time of the interview. Abbreviations: COPD, chronic obstructive pulmonary disease; SIADH, syndrome of inappropriate antidiuretic hormone secretion.

hospital visits were also reported as frightening events: “Every time I have a CT scan or blood test, it is still frightening for me” (P8).

Some participants also reported changes in their mindset after the treatment; for instance, participants were more consciously enjoying life, were better at dealing with work-related issues and were more aware of their goals in life: “I do not make a big fuss about some things anymore, for example at work” (P16) and “I have more plans, I want to get more out of life now” (P15). Additionally, participants reported changes in their perspectives towards themselves: “I have learned a lot about myself, you can do more than you think” (P6) and “I am more aware of my own body” (P8).

Postoperative complications, such as haemorrhage and anastomotic leakage, were reported by the participants as influencing their mental health: “Especially with an emergency reoperation, you are upset for a while. That has had quite a big influence, but it is now going great again” (P12) and “I still suffer from flashbacks, for instance when I have to go to the toilet at 2 am I remember that was the moment when the bleeding started” (P8).

It was also reported that some participants cope differently with their disease; for example, some were hesitant to speak about their colorectal cancer treatment: “I do not really like to speak about my colon cancer, because I do not feel the need to discuss this with other people, since they always have an ‘irrelevant’ story about someone else with cancer” (P12). Others said that it helped them to talk about it “I’d like to talk about it because it relieves me” (P13). Participants with a stoma reported that they were usually open about having a stoma: “I’m not ashamed of it at all, but I don’t want to confront people with it” (P1).

## Social functioning

A few participants reported that the diagnoses of colorectal cancer and treatment did not influence their social functioning: “Actually, little has changed in that respect” (P4). Some participants reported that they felt supported: “You discover how many dear friends and people you have around you” (P2) and “I knew he would always be there for me. He did a fantastic job” (P8). Some relationships were enhanced by seeing a different side of each other: “The bond with my children has definitely deepened after treatment” (P6), and some reported that this was even more so with people who had also had to deal with cancer: “They know a bit more about what I went through, than people who have never had to deal with it” (P13).

Stomas led to specific challenges, as participants with a stoma reported that the fear of stoma-related stool leakage or uncontrollable flatulence influenced social functioning: “During social appointments, I am sometimes afraid that the stoma will leak, then you are not relaxed” (P3).

## Sexual functioning

Participants, male and female, reported several challenges regarding sexual functioning as a consequence of their colorectal cancer



treatment, while some were not sexually active anymore. Erectile dysfunction and being unable to ejaculate was reported as a major issue: *"I do not get a good erection anymore and ejaculation is not possible at all. I do have medication for this, but it is not the same as it was before surgery"* (P1). As medication for erectile dysfunction might offer some solution, several participants reported that loss of the ability to engage spontaneously in sexual activity was a burden on their sexual function. Furthermore, bowel function might interfere with sexual function: *"I am a bit more hesitant because I am afraid of losing stool"* (P10). Similarly, a stoma also had a negative impact: *"In the beginning, the stoma frightened us"* (P8). Abdominal scars after laparotomy were reported to be of influence on sexual activity. When issues arose, participants stated that talking about this with their partners was very helpful: *"We talk well about sexuality, therefore it has not become a problem"* (P15). By contrast, some other participants did not experience any difficulties or changes regarding sexuality: *"Nothing really changed"* (P7).

## Health care and treatment experiences

Participants reported several factors which they considered as important during colorectal cancer treatment, and which might affect daily life during treatment and follow-up. Good explanation about the surgical treatment and perioperative care was very important: *"The explanations by the doctors about the surgery were good, luckily because I like to know everything"* (P3), *"Whenever I had a question it was answered"* (P7) and *"Before surgery, I knew what was going to happen and the possible consequences"* (P11). Additionally, involvement and openness of medical personnel were reported as important: *"You can call the stoma nurses at any time to solve some issues that might occur"* (P1) and *"The enormous concern and dedication of the surgeon helped me a lot and felt very supportive"* (P6). Others reported finding it difficult to find answers to their questions: *"I would like to know if the symptoms I experience are normal"* (P9).

Conversely, negative experiences regarding doctor–patient communication after complications were reported: *"The surgeon who operated on me the first time never spoke to me after the complication, which I thought was a pity"* (P16). Furthermore, the method of communication affected patient–doctor communication: *"Due to COVID-19 most of the appointments were by phone, therefore you cannot really discuss all your questions"* (P2). Waiting on results was reported as a negative factor for mental health: *"I have been waiting for 3 months on the results of genetic tests, which was quite long and which bothered me"* (P2). Other negative factors that were reported were: *"Usually I can sleep anywhere, but in the hospital, it was very bad"* (P12) and *"I had a pulmonary embolism which was detected quite late, this was a pity because, in hindsight, as I understood, the symptoms were very clear"* (P3).

## DISCUSSION

This study aimed to explore and gain insights into patient perspectives on the consequences of colorectal cancer treatment on their

daily life. Impairments to health, reported as a consequence of colorectal cancer treatment, were poor bowel function, the presence of a stoma, chemotherapy-induced neuropathy of hands and feet, sexual dysfunction and fear of recurrence (Table 2). Poor bowel function impacted daily life and activities, highlighted by patients reporting the need to use the bathroom more frequently and having to pay more attention to their diet. Patients with a stoma reported being afraid of stoma-related faecal leakage and uncontrollable flatus from their stoma in social situations. Patients who suffered from chemotherapy-induced neuropathy in hands and feet reported altered sensory functioning and pain during activities. Sexual dysfunction was reported as a result of erectile dysfunction or loss of ejaculation. Also, the presence of a stoma or abdominal scars affected sexual function. Some patients reported an increased fear of recurrence when their follow-up appointment was due, and some reported that they trusted their body less than before the diagnosis. Social functioning was rarely affected. Coping mechanisms seemed to be different among patients: some patients felt the need to talk about their situation, whereas others preferred not to speak about their colorectal cancer. However, overall, patients reported that daily life remained fairly unaffected by colorectal cancer treatment because they experienced only minor interference with daily life. These findings suggest that various coping mechanisms are in place. This is also supported by the fact that patients with health-care issues adapt to the new situation and reinterpret their lives and social roles [21].

A prior study conducted by our group found that patients reported that, over time, their quality of life seems to return to preoperative levels, suggesting that they face either no treatment-related health deficits or minor challenges only [11]. However, as found in the current study and in other literature, patients who underwent colorectal cancer treatment may still experience various challenges and health deficits. These differ based on the treatment received [9, 22–24]. The findings of this study suggest that the most frequently reported challenges after colorectal surgery are bowel related. The functional bowel complaints that these patients reported were similar to low-anterior resection syndrome (LARS). However, the LARS score was not formally measured in this study [25, 26]. It has been shown

**TABLE 2** Summary of the reported influential factors per theme.

Theme	Reported influential factor
Daily life and activities	Poor bowel function
	Presence of a stoma
	Chemotherapy-induced neuropathy
Psychological functioning	The loss of trust in their own body
	Fear of cancer recurrence
Social functioning	Stoma-related faecal leakage
	Uncontrollable flatus
Sexual functioning	Erectile dysfunction
	Ejaculation loss
	Presence of a stoma
	Surgery-related scars

that quality of life in patients reporting LARS is significantly impaired [27, 28]. Patients with a stoma also reported specific stoma-related challenges, such as worrying about stool leakages and uncontrollable flatulence, which is consistent with previous literature [29].

In line with a previous study, postoperative complications can, in some cases, affect the doctor–patient relationship. This encourages preoperative counselling of patients to provide information about the risks of surgery [30]. A noticeable complaint that was frequently reported by patients in our study who underwent (neo)adjuvant chemotherapy was peripheral neuropathy. In accordance with existing literature, patients reported that the symptoms decreased over time, but a large proportion of patients still experienced the problem [31–33]. These complaints of chemotherapy-induced peripheral neuropathy do not, however, affect global health status, even though they result in impaired ability to perform specific physical tasks [32].

Another domain that is reported in this study, and in accordance with published literature, is sexual function, which may be decreased as a result of colorectal cancer treatment [24]. As previously studied, sexual dysfunction may be caused by both surgery and radiotherapy. Additionally, the presence of a stoma is also described to have a negative effect on sexual activity, in this study as well as in previous research [34–36].

Previous studies have shown that coping strategies, employed to cope with treatment-related health deficits and challenges, differ between patients. This is similar to what was witnessed under the psychological functioning theme in the present study [37]. Previous studies in patients with ovarian carcinoma and colorectal carcinoma showed that patients may have various coping strategies, and that coping might even be enhanced as a result of cancer survivorship [12, 13, 38]. The coping style employed by patients might explain the underestimation of the effect of treatment-related health deficits on quality of life (e.g., poor bowel function, chemotherapy-induced neuropathy) because patients can modify their lifestyle with the use of various strategies and self-management techniques to maintain their quality of life [39]. Additionally, there is considerable individual variation between patients on how these self-management strategies are undertaken [40].

The knowledge acquired by this study on challenges that patients face after treatment could be taken into account when making treatment decisions and by implementation of new treatment strategies [41, 42]. For example, recently, studies have reported complete mesocolic excision as a new surgical technique for right-sided colon cancer, which entails a more extensive procedure to ensure adequate lymphatic resection [43]. An alternative strategy might be to make the colonic resection more precise, and potentially less extensive, by performing a sentinel node procedure instead of a complete mesocolic excision [44]. In theory, a less extensive resection might lead to a lower rate of postoperative complications and better functional bowel outcomes [45]. Additionally, when multiple treatment options exist, information on postoperative consequences of the treatment on quality of life and the associated treatment-related health deficits may provide important information for patients during shared decision-making. Furthermore, as shown in this study, some patients

reported that good preoperative education on the consequences of colorectal cancer treatment is important to them. Explicit patient consideration of their treatment and certain trade-offs are shown to have a positive effect on long-term quality of life, as it leads to increased acceptance of treatment consequences [14, 27]. As shown in this study, after colorectal cancer treatment, patients face several treatment-related health deficits in various domains (e.g., psychological, social, physical) [22]. In addition, these patients have an increased risk of other health issues, such as adverse effects of treatments and psychosocial challenges [46, 47]. The knowledge of treatment-related health deficits (e.g., poor bowel function) and psychosocial deficits (e.g., fear of recurrence) should lead to early recognition of treatment-related issues by healthcare providers. Furthermore, optimizing post-treatment psychological, sexual, nutritional and cognitive function of colorectal cancer survivors could be an integral part of rehabilitation programmes. Some treatment-related health deficits, however, may not be treatable, so reliable outcome data on these sequelae may provide important knowledge for incorporation in preoperative patient education and in shared decision-making.

## Value-based health care

The insights of this study are important in light of the newly introduced management strategy, value-based health care (VBHC). An important element of VBHC is measuring outcomes and costs for every patient [48, 49]. To measure patient outcomes uniformly, a standard set of patient-centred outcomes was developed by The International Consortium for Health Outcomes Measurement (ICHOM), including survival and disease control, the disutility of care, degree of health and quality of death [50], using both generic and disease-specific questionnaires. By trying to streamline implementation of the patient-reported outcome measurements, some have suggested using only generic quality-of-life assessment strategies. However, the present study shows that caution is required in using only these generic patient-reported outcome sets and quality-of-life questionnaires because these might provide a limited picture of the actual quality of life experienced by a patient. As the present study shows, colorectal cancer patients still experience challenges and treatment-induced health deficits [38, 51].

## Strengths and limitations

A strength of this study is, differences in complaints were witnessed between subgroups. However, to study significant differences between subgroups, a quantitative study design is more applicable. Despite this, the results of the present study give valuable insights into the quality of life and influential factors on daily life after colorectal cancer treatment. A strength of this study is the qualitative approach used, allowing complementary and more in-depth insights to be gathered that add to the findings of previous



quantitative studies [52]. Another limitation of this study is that it was a single-centre study in an academic teaching hospital with relatively advanced/complex cases, which might affect the generalizability of the results. To overcome this issue, purposeful sampling was used to include patients of different ages, comorbidity conditions and types of (neo)adjuvant therapy, with various postoperative complications and the presence/absence of a stoma. However, patient characteristics and complication rates are not representative of the general population. A third limitation of this study is that interviews were held online and via Zoom, as several interviews were conducted during the COVID-19 pandemic. This might have influenced the quality of the conversations with the participants. However, Shapka et al. showed no differences in quality between interviews conducted face-to-face and online [53]. Therefore, we expect that our method of interviewing did not affect our results significantly. A fourth limitation of this study is small, but data saturation was reached. This means that no more forthcoming information or themes were gained in the last three interviews, as described by Hennink et al. [17].

## CONCLUSION

In conclusion, the findings of this explorative study demonstrate that patients who underwent treatment for resectable colorectal cancer face several challenges and treatment-related health deficits in the long term, but that these challenges and health deficits lead to only minor interference with daily life. The reported minor interference might suggest that coping mechanisms are in place. Frequently reported health deficits after colorectal cancer treatment are the presence of a stoma, poor bowel function, chemotherapy-induced neuropathy, fear of tumour recurrence and sexual dysfunction. The results of this study offer in-depth insights into patient perspectives on the consequences of colorectal cancer treatment. These insights are important in the application of generic quality-of-life questionnaires, in which post-treatment health deficits may be less noticeable and therefore may be underestimated.

## AUTHOR CONTRIBUTIONS

**Robert T. van Kooten:** Conceptualization; methodology; formal analysis; project administration; writing – original draft; data curation. **Bianca A.M. Schutte:** Writing – original draft; formal analysis. **Dorine J. van Staaldunin:** Writing – original draft; formal analysis; methodology. **Jetty H.L. Hoeksema:** Supervision; methodology; conceptualization. **Fabian Holman:** Supervision; data curation. **Chantal van Dorp:** Supervision; data curation. **Koen Peeters:** Conceptualization; supervision; methodology; data curation. **Michel W.J.M. Wouters:** Supervision; conceptualization; methodology.

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## CONFLICT OF INTEREST STATEMENT

Authors declare no conflict of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

## ETHICS STATEMENT

The Medical Ethics Committee Leiden Den Haag Delft assessed the study protocol for this study (ref. no. N21.168) and concluded that no formal review was needed, as this study was not conducted under the Medical Research Involving Human Subjects Act (WMO). All study participants were given verbal and written information about the study and signed an informed consent form.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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## APPENDIX 1

### Topic Guide for Semi-structured Interviews

Ask for brief details about age, occupation, partner, children, etcetera, to frame the interview.

Can you tell me something about your health status before surgery such as comorbidities?

Can you tell me a little bit about yourself and how you came to have this surgery? (*explore important aspects further*).

How has this colorectal cancer treatment impacted your daily life? How did this change between surgery and now?

(*from answer to above question*) What factors (not limited to physical symptoms) have affected you most and why? (*explore important aspects further*).

What effect does the colorectal cancer treatment have on your relationship with your immediate family/partner/friends?

What activities or hobbies are challenging or are not possible anymore after colorectal cancer treatment? (explore the differences between before and after).

What effect does the colorectal cancer treatment have on your psychological wellbeing?

What effect does the colorectal cancer treatment have on your sexual functioning?

How do you feel about the healthcare system during your treatment?

Any other aspects that have not already been discussed or you would like to expand upon?