

RESEARCH ARTICLE

The patient perspective on the preoperative colorectal cancer care pathway and preparedness for surgery and postoperative recovery—a qualitative interview study

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Abstract

Background and Objectives: This study aimed to explore colorectal cancer (CRC) patients' perspectives and experiences regarding the preoperative surgical care pathway and their subsequent preparedness for surgery and postoperative recovery.

Methods: CRC patients were recruited using purposive sampling and were interviewed three times (preoperatively, and 6 weeks and 3 months postoperatively) using semistructured telephone interviews. Interviews were audiotaped, transcribed verbatim and analysed independently by two researchers using thematic analysis with open coding.

Results: Data saturation was achieved after including 18 patients. Preoperative factors that contributed to a feeling of preparedness for surgery and recovery were patient-centred- and professional healthcare organization, sincere and personal guidance, and thorough information provision. Postoperatively, patients with complications or physical complaints experienced unmet information needs regarding the impact of complications and what to expect from postoperative recovery.

Conclusions: The preoperative period is a vital period to prepare patients for surgery and recovery in which patients most value personalized information, personal guidance and professionalism. According to CRC patients, the feeling of preparedness for surgery and recovery can be improved by continually providing dosed information. This information should provide the patient with patient-tailored perspectives regarding the impact of (potential) complications and what to expect during recovery.

Abbreviations: COREQ, consolidated criteria for reporting qualitative research; ERAS, early recovery after surgery; HCPs, healthcare providers; MUMC, Maastricht University Medical Centre; SRQR, standards for reporting qualitative research.

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KEYWORDS

colorectal cancer surgery, patient experiences, patient perspective, preparedness for surgery and postoperative recovery, preoperative cancer care

1 | INTRODUCTION

Colorectal cancer (CRC) is one of the most prevalent cancer types in developed countries,^{1,2} with more than 15 000 newly diagnosed patients in the Netherlands every year.³ The primary curative treatment for CRC is surgical resection, which is performed in 95% of all patients.⁴ The preoperative phase is a vital period to prepare patients for surgery and postoperative recovery.⁵ During this period, patients also have to come to terms with their diagnosis and the fact that they have to undergo surgery. Preparation for surgery is comprehensive, and the time between diagnosis and surgery is limited. Therefore, high quality and well-organized patient-centred cancer care is essential.

To ensure quality and success in the diagnostic and treatment process, CRC care is organized in a multidisciplinary surgical care pathway. Care pathways are complex organizations of cooperating surgeons, anaesthesiologists, oncologists, nurse specialists, physical therapists, dieticians, and other members of the multidisciplinary team.⁵ In the preoperative period, patients go through this extensive surgical care pathway by means of multiple preoperative consultations, cancer-related diagnostics and preoperative assessments to estimate the risk of perioperative complications. Furthermore, patients need to become prepared using physical, cognitive and emotional counselling.⁵⁻⁷

High quality of cancer care is considered increasingly important, and alongside other clinical and patient-related outcomes, patient experiences with cancer care are currently important quality indicators.^{8,9} Despite the aim of healthcare providers (HCPs) to deliver patient-centred care, current Dutch cancer care (including the organizational structure and the provided guidance and information) is still mainly organized based on the professional's perspective. Additionally, the majority of the existing literature mainly examined postoperative experiences and survivorship care, showing that patients often experience unmet needs in information provision, emotional guidance, healthcare organization and expectation management.¹⁰⁻¹² Until now, little attention has been paid to the perspective of CRC patients on the current preoperative cancer care counselling, and how patients experience the period from diagnosis to surgery and recovery, both in clinical practice and in literature.^{9,11,13} Knowledge about the patient's preoperative experience, perspectives and needs is of great value for professionals initializing CRC care pathways, as well as for professionals who seek to further optimize their CRC care pathways by offering holistic and patient-centred care which might prevent patient distress and help to cope with the cancer diagnosis and following treatment.^{11,14}

Therefore, the aim of this study was to explore the patient's experiences and perspectives on the preoperative surgical care

pathway and the preoperative preparation for surgery and postoperative recovery, to truly tailor future CRC care to the patient's perioperative needs.

2 | MATERIALS AND METHODS

2.1 | Study design and setting

This was a qualitative study using a pragmatic approach conducted at the Maastricht University Medical Centre (MUMC+). A pragmatic approach has a strong focus on practicality and aims to understand and describe a phenomenon, a process or the perspectives of the people.^{15,16} In this study, semistructured interviews were conducted with CRC patients to gain a holistic understanding of the patient's experiences and perspectives on the preoperative surgical care pathway and the preparation for surgery and recovery. Ethical approval was obtained by the Medical Ethical Committee of the MUMC+/Maastricht University (METC 2020-1460). The standards for reporting qualitative research (SRQR)¹⁷ and consolidated criteria for reporting qualitative research (COREQ) for reporting of qualitative interview studies¹⁸ were used to enhance reporting quality.

2.2 | Standard CRC care pathway

Patients diagnosed with CRC enter the CRC care pathway which is coordinated by a nurse specialist. After diagnosis, patients undergo several additional examinations including thoracic and abdominal imaging studies. Based on the results, a multidisciplinary team, consisting of surgeons, oncologists, radiotherapists, pathologists and radiologists, formulates a recommended treatment strategy, which is discussed with the patient afterwards. When the decision to operate is made together with the patient, patients undergo a physical fitness screening by a physiotherapist, a nutritional assessment, a frailty assessment, an anaesthesiological risk assessment, and optional consultations with a cardiologist, pulmonologist, geriatrician or dietician when indicated. All additional appointments are scheduled and communicated with the patient by the nurse specialist, as well as the surgery date. The patients are informed in-depth about the surgery, the hospitalization, and the recovery period by the nurse specialist and the surgeon. Patients also receive a detailed information folder containing all information that was given verbally by the nurse specialist and the surgeon. During hospitalization, patients are guided by specialized nurses and surgeons, as well as a physiotherapist. Patients return to the hospital 2 weeks after discharge to follow the recovery process and to discuss the pathology outcomes.

Six weeks after discharge, patients are contacted by the nurse specialist to check for further recovery. Patients may contact the nurse specialist in case of questions, concerns or uncertainties at any time.

2.3 | Study participants and recruitment

Patients aged 18 years or over, diagnosed with CRC and scheduled for surgical resection were eligible for inclusion. Patients who underwent neoadjuvant therapy were also included in the study. Patients not eligible for inclusion were rectal cancer patients who entered a wait and see program after neoadjuvant therapy and therefore did not undergo surgery, patients with metastatic disease and patients with cognitive impairment. Purposive sampling was used to select study participants to obtain a study population with maximum variation in age, sex, tumour location and neo-adjuvant treatment. Patients were recruited by the oncological nurse specialists during the preoperative consultations at the MUMC+ between October 2020 and February 2021. Eligible patients were informed about the study by the nurse specialists, and were given an information leaflet including an informed consent form and a return envelope. After being informed about the study, the researcher contacted the patients by telephone to check for questions and give additional information. In case patients were willing to participate, they returned the informed consent form by post and an appointment for the first interview was scheduled.

2.4 | Data collection

Semistructured interviews were conducted at three time points: (1) before surgery when the preoperative workup was completed, (2) 6 weeks postoperatively, and (3) 3 months postoperatively (Figure 1). Due to restrictions during the COVID-19 pandemic, all interviews were conducted by telephone. An interview guide was developed by the authors before the start of the study (Supporting Information: File 1). The interviews were opened with a general opening question, such as 'Can you tell me how you are doing at the moment?', 'What did you experience after you received the diagnosis?', and 'Can you tell me how you are doing since hospital discharge?'. The interview guide consisted of questions addressing the patient's perspectives and experiences regarding four themes: (1) organization of the preoperative

surgical care pathway, (2) information provision, (3) preoperative guidance, and (4) preparedness for surgery and recovery. The themes were identified based on literature^{10-13,19} and expert opinion by means of four group discussions of the multidisciplinary team in which the preoperative CRC care pathway and the patient journey were outlined in detail using value stream mapping.²⁰ The four themes made it possible for the interviewer to guide the participants to talk about all the aspects of the pathway. Based on the given answers, the researcher asked additional questions to gain more in-depth information. During the two postoperative follow-up interviews, patients were asked about their experiences during and after hospitalization, and to reflect on their preoperative preparation and expectations. The preoperative interviews of the first two patients were used as a pilot to test the interview guide and assess the clarity of the questions. The pilot test suggested that the wording of several questions was not sufficiently clear, and therefore these questions were simplified. The themes remained unchanged. The pilot interviews were included in the study. The interviews were audiotaped and lasted between 30 and 60 min. The interviews were conducted by the first author who is a clinician with training in qualitative interviewing (A. C. M. C.), and was guided by an experienced qualitative researcher (M. L. K.). The researchers conducting the interviews (A. C. M. C.) or performing the data analyses (A. C. M. C., H. A. v. R. and M. L. K.) did not take part in the care of the patients.

2.5 | Data analysis

Data collection and analysis were conducted concurrently to assess data saturation. The interviews were transcribed verbatim and analysed using Atlas.ti 9.0. Transcriptions were anonymized by replacing names with participant numbers. The transcribed interviews were analysed independently by two researchers (A. C. M. C. and H. A. v. R.) using content analysis²¹ with an inductive coding strategy. The first five transcripts were analysed using open coding. Next, codes were compared and discussed in the presence of a third researcher (M. L. K.) and combined to form a codebook. The remaining transcripts were coded using the codebook. Additional codes were added when new topics appeared in the remaining interviews. Afterwards, the codes were discussed by A. C. M. C., H. A. v. R. and M. L. K. to create categories within the predefined themes. If appropriate, new themes were added.



FIGURE 1 Interview timeline.

TABLE 1 Patients characteristics (N = 18)

Sex	
Male	9 (50.0%)
Female	9 (50.0%)
Age	70.4 (11.6)
Living status	
Cohabiting	14 (77.8%)
Living alone	4 (22.2%)
Employment status	
Employed	5 (27.8%)
Currently unemployed	1 (5.6%)
Retired	11 (61.1%)
Unknown	1 (5.6%)
Tumour location	
Colon ^a	14 (77.8%)
Rectum ^b	4 (22.2%)
Surgery type	
Laparoscopy/robot	12 (66.7%)
Open	3 (16.7%)
Converted	3 (16.7%)
Ostomy	
No	13 (72.2%)
Temporary	3 (16.7%)
Permanent	2 (11.1%)
Neoadjuvant therapy	3 (16.7%)
Complications	7 (38.9%)

Note: Values presented as mean (SD) or number (percentage).

^aRight hemicolectomy (n = 10), left hemicolectomy (n = 2), and sigmoid resection (n = 2).

^bLow anterior resection (n = 3), abdominoperineal resection (n = 1).

3 | RESULTS

A total of 20 patients were approached to participate in the study. One patient declined participation (P-01) and one patient eventually did not undergo surgery and was therefore excluded (P-20), resulting in 18 patients who participated in the study. Patient characteristics are displayed in Table 1. The second interview, at 6 weeks, was conducted in 16 patients. One patient died in the hospital (P-18) and one patient declined further participation (P-02). The third interview, at 3 months, was conducted in 14 patients. Two patients could not be reached after multiple attempts (P-06 and P-09). One patient experienced severe postoperative complications and was transferred to a rehabilitation centre (P-03). Therefore, he could only be approached once during the postoperative period. During this

postoperative interview, the questions of the two follow-up interviews were combined.

The themes that eventually emerged from the interviews were organization of the preoperative surgical care pathway, information provision, guidance and coping. Information provision was subdivided into two subthemes: information content and information presentation. Table 2 displays the main themes accompanied by identifying quotes.

3.1 | Organization of the preoperative surgical care pathway

Patients appreciated efficient and thorough CRC care organization with noticeable experience of the HCPs and without irrelevant appointments. This contributed to a professional appearance. Patients emphasized the importance of speed in their surgical care. Having CRC was a major source of fear and patients preferred surgical removal as soon as possible. *'I will get surgery next week, but I would rather have surgery tomorrow. Everything was put into action very quickly. That overwhelmed me a bit, but I was also very happy with it. Diagnosis was last week, the next day I had an appointment with the nurse specialist, and next week I will have surgery already (P-16, preoperative).'*

Preoperative hospital visits were usually planned without consulting the patient's private schedules, and were often not scheduled on one day, leading to multiple separate hospital visits. While most patients did not experience this as disturbing, younger and non-retired patients, and patients living further away from the hospital, did express that these multiple appointments were an additional burden. Clustering appointments in one day would be considered an improvement but at the same time patients expressed concerns regarding the amount of information they would need to process in one day. *'I wished that the appointments were concentrated on one or two days. Now I have to come to the hospital separately for every appointment. Try to schedule those things on one or two days and do everything at once (P-06, preoperative).'*

Patients did appreciate short waiting times in-between separate appointments. Some patients experienced last-minute changes in appointments and treatment, which led to confusion and concern. Patients were pleased to get familiar with the team of HCPs and much appreciated the reassurance that the surgeon they consulted in the preoperative period was also the one performing the surgery. Additional explanatory quotes are presented in Supporting Information: File 2.

3.2 | Information provision

3.2.1 | Information content

Information regarding the presence of metastases, the chances of receiving an ostomy and the potential need for adjuvant treatment

TABLE 2 Themes and identifying quotes

Theme	Subtheme	Quotes
Organization		<ul style="list-style-type: none"> - You notice that they have a lot of experience. And there is a centre especially for oncology patients. I always pay attention to what happens in the hospital. If one mistake after another had been made, I would have thought "are these people going to perform surgery on me?" But it was all very professional and that gave me confidence in the surgery and the next steps. (P-17 preoperative)
Information provision	Information content	<ul style="list-style-type: none"> - The surgeon has to explain to me what is going to happen. Not only the piece of intestine that will be taken out, but also where the incisions will be and why. And also that there will be a larger incision to remove the intestine. (P-09, preoperative) - I was told what the possible risks could be. If you're not told, and it would happen, it would be a disappointment. When they would have told me the risks afterwards, I would have said "if only you had told me that beforehand". I was told that it was possible that I might have a leak, or maybe get an ostomy. Luckily none of that happened, but I was prepared for it. (P-19, 3 months postoperative, no complications)
	Information presentation	<ul style="list-style-type: none"> - I was told honestly what was going on and what they were going to do (P-12, 3 months postoperative) - The information I received in the hospital is way more important to me than what I can get from the internet. (P-11, preoperative)
Guidance		<ul style="list-style-type: none"> - They see you as an individual. They treat every patient with care and try to do everything they can to make it as comfortable as possible for you. That gives a very nice feeling. That you don't feel like you're the next in line. How they came across to me and my husband: clearly skilled and patient centred, not as a number. (P-14, preoperative and 3 months postoperative)
Coping		<ul style="list-style-type: none"> - It's like a train you can't get out of. You just have to sit through the ride, but that's easier said than done (P-16, preoperative) - I thought, "don't think, just go". I wouldn't know how to deal with it otherwise. I let everything come to me. I'm a fighter I know, and as soon as I can, I will definitely get back to work. But how long that will take, 1 week, 2 weeks, I don't know. So yeah, we'll see. (P-11, preoperative)

caused the most anxiety and were therefore considered the most important information topics by the majority of the patients. The possibility of having metastases was associated with impending death, and reassurance regarding the absence of metastases provided a great matter of relief and resignation towards the upcoming treatment. *'I had two scans and then a conversation with the surgeon. They told me there were no metastases. Until that moment, I was terribly scared. Because otherwise, I wouldn't have much longer to live (P-08, preoperative).'*

When metastases were ruled out and the decision to perform CRC surgery was definite, most patients were predominantly eager to learn about the location of the tumour, details of the surgical procedure, and details regarding length of hospital stay. *'I don't need to know all the details right now. I will experience it piece by piece. I will be admitted next week and then I will have to stay there for about five days. I don't expect much really. I just need to get through surgery and then we'll see. I just hope it all goes well and then I can go home after that week (P-17, preoperative).'*

Preoperatively, the majority of the patients expected an average length of stay of 4–5 days. Patients were also informed about early recovery after surgery (ERAS). Preoperatively, patients found it difficult to oversee postoperative hospitalization, but were generally optimistic. Patients who already experienced previous hospital admissions, surgery, or cancer diagnoses knew better what to expect,

which made them feel more prepared. *'My husband had diverticulitis and he had emergency surgery this summer and was admitted to the same ward I will be admitted to. He has been treated fantastically and it went very well. So I expect that to happen for me too. That's how I imagine it now (P-10, preoperative).'*

Preoperatively, patients focused primarily on surgery, almost without being concerned about postoperative outcome, regardless of the patient's age or sex. Information regarding postoperative morbidity was given to all patients but a minority of the patients considered morbidity risk an important preoperative information topic. Many patients preferred to know as little as possible to avoid further anxiety and because surgery was regarded as inevitable. *'I didn't want to know it in advance. Just tell me when it happens. Otherwise, you start to worry anyway. So only tell me when it's applicable (P-10, 3 months postoperative, no complications).'*

In the postoperative interviews, it became clear that several patients who developed postoperative complications were unpleasantly surprised by the impact of the complication on their postoperative recovery, which led to a feeling of helplessness and uncertainty. Several patients emphasized the importance of mentioning the most prevalent complications including a short explanation about what this would potentially mean for their hospital stay and recovery. *'I did not expect that a complication*

would have such an impact. That was a very unpleasant experience. You just lay there in your bed, helpless. Afterwards, I understood that an ileus is a common complication. They could have told me that in advance. They should really indicate in advance what the consequences of surgery can be and explain what to expect. If you already know, then only a little additional information needs to be given during hospitalisation (P-09, 6 weeks postoperative, suffered from complications)'. Others didn't want to know preoperatively what the consequences of complications might be. 'I didn't want to know it in advance. Just tell me when it happens. Otherwise, you start to worry anyway. So only tell me when it's applicable (P-10, 3 months postoperative, no complications)'.

Comparable perspectives were observed regarding preoperative expectations of recovery during hospitalization and after discharge. Preoperatively, patients had a confident and positive view on their postoperative recovery, which was expected to take 6–12 weeks. Detailed information regarding in-hospital recovery and recovery after discharge was considered unnecessary and most patients felt it was too difficult to predict in the preoperative period. 'I expect to be in the hospital for four days. I haven't heard much about it, but I think you can tell much more precisely after surgery than before. So I'm not really concerned about that. I will experience how it goes. And if it turns out that not everything goes smoothly, I will notice that in those four days and we will take the necessary actions (P-08, preoperative)'. Postoperatively, some patients recovered without any physical complaints and their recovery met their preoperative perspectives. Others, especially patients who experienced postoperative physical complaints, found it difficult to distinguish between harmless and potential harmful postoperative symptoms during the stages of recovery. These patients also found it unclear what and when one was allowed to do certain activities. These experiences led to uncertainty and fear. Patients expressed the wish of a more realistic description of postoperative recovery in the preoperative phase. 'They talk about a recovery period but they should differentiate more between the different weeks. Like, "don't expect to be working in the first weeks". Now they say that your recovery period will take two to three months, but how complaints evolve in time is not mentioned (P-06, 6 weeks postoperative)'.

Despite the presence of a case manager, patients seemed less eager to call the hospital postoperatively. 'You don't know what is normal and what is not. But you also do not want to call the hospital for every concern you have (P-13, 6 weeks postoperative)'.

To improve information provision, patients emphasized the importance of ongoing information provision during hospitalization and after discharge, which is tailored to their individual treatment and course of recovery. 'That you need that gastric tube and that you cannot eat and are therefore dependent on your IV. They should also make this clear during the course of treatment. That it takes a few days and that your stomach needs that tube to drain the fluid. What wasn't said either was how long it would take until the tube could be removed. You have no idea how long it will take. That should have been explained so you know where you are in your recovery (P-09, 6 weeks

postoperative)'. Additional accompanying quotes are presented in Supporting Information: File 3.

3.2.2 | Information presentation

The amount of information was experienced as overwhelming by most patients. 'All the information just hits you in the face. They explained it well, but I think I only heard half of it. They tell something and my mind just explodes. It was all too much. I always bring my daughter-in-law and that helps a lot. You have to remember too much and too much information told (P-16, preoperative and 6 weeks postoperative)'. Patients perceived all-encompassing and honest information provision as positive. Contradictions and outdated information led to a decrease in trust and was considered unprofessional. Hence, patients appreciated information to be accurate. 'We got a brochure from the admission office and the date on the brochure was 2016. That is five years ago. If that folder does not need to be updated, fine, but update those dates then. Then people see that it is recent information. Also the visiting hours. We were reading the brochures and thought: "wait a minute, our nurse specialist said something else". Make sure it's up to date. When a brochure says it was published in 2016, I have my doubts (P-14, preoperative)'.

It appeared that the majority of the information was provided preoperatively, and only little (additional) information was given during hospitalization and after discharge. Patients indicated the need for dosed and ongoing information provision after surgery. Some patients also mentioned that the information was often not personalized, making it difficult to determine whether some of the written information applied to them or not. 'I would have wanted the information to clearly apply for my personal situation. That information is important (P-18, preoperative)'.

Information received in the hospital, especially during preoperative consultations, was rated as the most important source of information. Searching additional information on the internet was done by some but avoided by others. A few patients would have appreciated the possibility to talk to patients who had already experienced the CRC care pathway. Some patients wished to receive information on paper, where others preferred a digital information portal. Regardless of how the information was provided, visualization was very important to patients. Drawings, pictures and videos led to an improved understanding of the disease and treatment. Especially patients who received an ostomy felt more prepared after seeing pictures and ostomy-related material preoperatively. 'The surgeon told me where the tumour was using a drawing. I'm no medical expert so I don't know exactly what it looks like on the inside. I also had a brochure and images from the nurse and she drew it by hand. Also about radiotherapy, with drawings and photos. It was presented in a way you could get familiar with what was going on. Also regarding the ostomy. That was also very visual and made it more understandable and clear (P-17, preoperative and 6 weeks postoperative)'. Additional accompanying quotes are presented in Supporting Information File 4.

3.3 | Preoperative guidance

The most important aspect of preoperative guidance was the way of approaching patients. All patients highly appreciated when HCPs were sincere, empathetic and showed attention for the individual. Attention for concerns of family members was also considered positive. *'The most important thing for me was the personal contact. That you are not sitting opposite a robot that fires questions, but that there is real contact (P-08, preoperative).'*

The presence of a case manager was seen as highly valuable. Patients welcomed the fact that there was one person who coordinated the preoperative care. The case manager was easily accessible for questions and contacted the patients regularly when needed, which was reassuring and brought peace to patients. The way of communicating was rated an important aspect of preoperative guidance and patients appreciated honest and straightforward communication without being overly negative or petrifying. Patients expressed the importance of addressing physical, psychological and social aspects of the disease and that help would be offered in all areas when requested. *'Everything is handed to you and if you want it, it is there. I haven't used any of the additional help yet, but maybe I will someday, I don't know. But you know it's there, and that's reassuring. My case-manager indicated that and it is nice to know that it is there when you need it (P-10, 3 months postoperative).'* Postoperatively, most patients remained satisfied regarding the preoperative guidance. Having the reassurance that family or friends would be around to help postoperatively, gave comfort. However, some patients mentioned the postoperative guidance and follow-up appointments to be too limited. Simultaneously, patients seemed less likely to contact the hospital despite the presence of complaints and concerns. More intensive aftercare and follow-up would have been a welcome improvement for some patients. *'My energy is not quite what it should be. And sometimes I wonder, "you don't see a doctor anymore". I did call the hospital with some questions, but then you don't hear anything back anymore. I find that weird. I haven't seen a surgeon in the months since I got home. If you call, you will get guidance I think. But not just like that. I only have been to my case manager once after my surgery (P-11, 3 months postoperative).'* Additional accompanying quotes are presented in Supporting Information: File 5.

3.4 | Coping

During the interviews and data analysis, coping emerged as an additional theme. Preoperatively, the majority of the patients developed a sense of resignation. Surgery was described as inevitable. To survive, patients had no choice but to undergo surgery. *'You just have to go through it, you don't have much of a choice. It's not easy, but I have no choice (P-18, preoperative).'* As a result of this mindset, which appeared to be present regardless of the patient's age or sex, postoperative outcome was subordinate to surgery. Accepting the presence of CRC was difficult, however patients tried to stay positive, distract themselves and tried not to worry too much. *'There's*

nothing we can do but to undergo it. Smile, go into surgery and get out again (P-03, preoperative).' Postoperatively, patients who experienced a problem-free recovery quickly moved on. Patients with postoperative complications or a troublesome recovery sometimes had more difficulties coping with what had happened. Having some knowledge about the impact of complications and potential difficulties during recovery after discharge would have made setbacks easier to accept and deal with. *'They did not tell me what I was allowed to do and what not. Neither did they tell me for how long I could not do something. That disappointed me. I really missed that information, especially regarding physical complaints (P-11, 6 weeks post-operative).'* Despite the attitude of resignation of the majority of the patients, some patients expressed preoperative fear and anxiety. *'I want to go into surgery positively, and I have to do that, but I find it very intense (P-10, preoperative).'* Patients were glad that psychological help was offered within the hospital as part of the care pathway, although most patients rather reached out to family members, friends and general practitioners to help in the coping process. *'I have a lot of nice people around me, but when it comes to physical stuff regarding the disease, I contact the hospital. My case manager did offer psychological help, but I didn't need it. I have a very sweet husband and children with whom I share everything. And I also have other people around me who help me (P-10, 3 months postoperative).'* Additional accompanying quotes are presented in Supporting Information: File 6.

3.5 | Preparedness for surgery and recovery

Preparedness for surgery and postoperative recovery was initially seen as a separate theme. However, during the interviews, preparedness for surgery and recovery appeared to be the outcome of the previously identified themes (Figure 2). Due to professional and efficient healthcare organization, emphatic and sincere guidance by the case manager, and personalized and honest information regarding how surgery would be performed and what to expect afterwards, patients felt prepared for surgery. Furthermore, these elements led to confidence and resignation, which appeared to help cope with the disease, thereby further improving the sense of preparedness. Preoperatively, all concerns focus on surgery, and postoperative recovery is seen as something to encounter and accept as it unfolds. Postoperatively, patients sometimes experienced a lack of perspective regarding recovery. To improve preparedness for postoperative recovery, patients requested ongoing guidance and personalized information provision giving them a better perspective of how a normal recovery looks like.

4 | DISCUSSION

This study showed that positive preoperative experiences were shaped by efficient and professional healthcare organization, sincere and personal guidance, and thorough information provision. These factors contributed to a feeling of trust and safety, leading to a

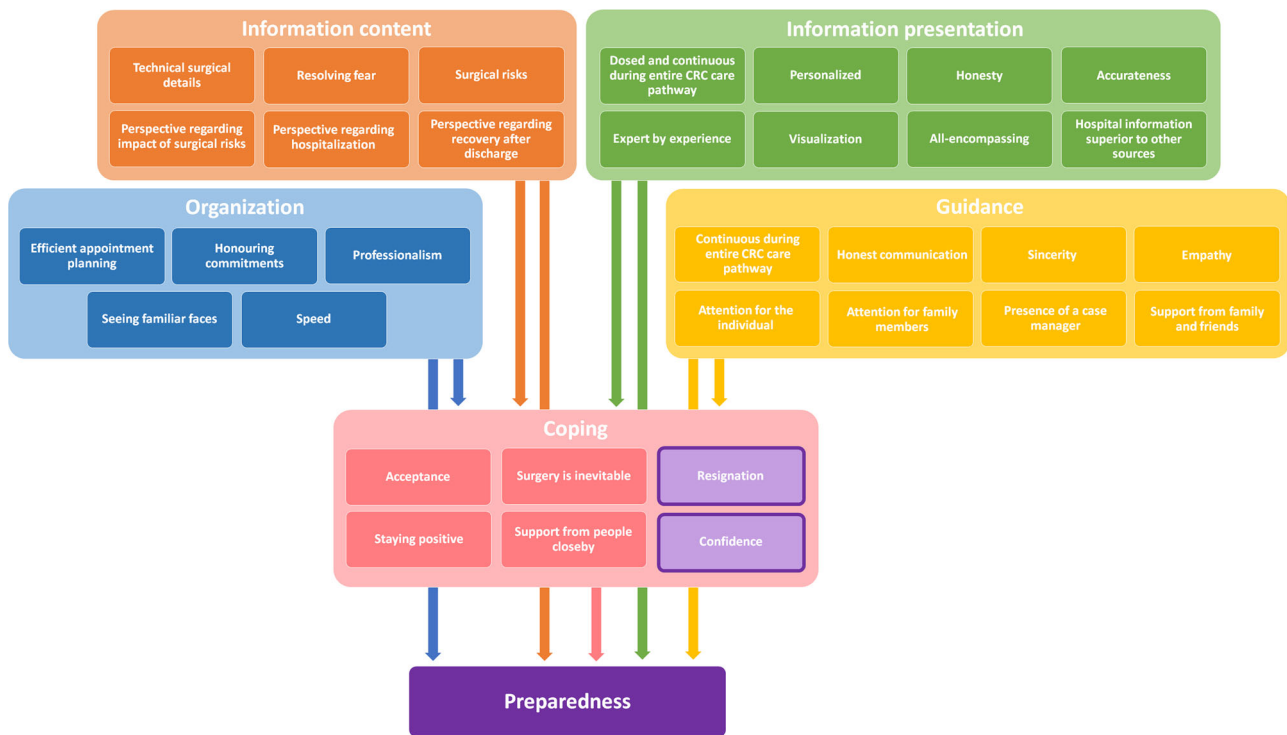


FIGURE 2 Elements of patients' perspective regarding preoperative preparation.

sense of preparedness for surgery and postoperative recovery. Patient-centeredness within preoperative guidance, information provision and CRC healthcare organization contributed most to patient satisfaction. Due to the prospective design of the study, preoperative perspectives could be compared to postoperative experiences, which revealed areas of discordance, especially regarding information provision. In case of postoperative complications and physical complaints after discharge, unmet information and supportive care needs were revealed. These patients experienced a lack of perspective regarding the impact of potential complications and what to expect during the course of postoperative recovery. The unexpectedness of such postoperative adverse events, which led to a sense of insecurity and doubt, displayed the importance of enlightening details regarding postoperative recovery early in the CRC pathway.

Providing information to newly diagnosed patients is one of the most important aspects of supportive cancer care and helps to maintain or regain a sense of control.^{22,23} Not knowing what to expect from treatment, how to deal with symptoms or how to self-contribute to health and recovery might lead to perioperative distress.^{10,13,24,25} While the importance of adequate information provision is widely acknowledged, it is sometimes unclear whether information provision adequately matches patients' information needs,^{12,26,27} and sufficiently prepares patients for what to expect from surgery and recovery.^{11,13} Preoperatively, patients seem to regard surgery as the most important, imminent and inevitable upcoming event. Because the preoperative mindset of the patients in this study population focussed almost entirely on surgery, and

because preoperative information provision by HCPs also mainly focussed on surgery, short-term surgical risks and hospital length of stay, preoperative information provision met the patient's preoperative information needs. Postoperatively, however, information needs changed and became subject to the course of postoperative recovery, as shown by the increased information needs from patients experiencing postoperative complications and physical complaints. These results are in line with previous literature, showing that patients often are satisfied with perioperative guidance, monitoring and communication, but that receiving tailored and dosed information in the postoperative phase remains an unmet need.¹³

For patients to be prepared for what is ahead and to avoid unpleasant or unexpected postoperative experiences, patients need some kind of understanding regarding postoperative outcomes.²⁸ Patients who suffered postoperative adverse events in this study often wished more detailed and dosed preoperative information to be better prepared for what to expect. How to optimally organize preoperative information provision remains challenging as information needs differ among patients and several factors influence a patient's ability to process preoperative information.²² First, the ability to take in information and feel prepared for surgery is affected by aspects of preoperative healthcare organization and guidance, whereas conflicting advice, poor quality relationships with HCPs and poor continuity raise feelings of anxiety and decreased confidence in treatment.^{29,30} Second, patient-related characteristics such as age, sex, cultural background and educational status, as well as a patient's mindset, which predominantly focuses on upcoming surgery, potentially affect their ability to create realistic expectations regarding

postoperative outcome and to understand the potential impact of postoperative recovery.²⁸ Preoperative anxiety and stress about surgery as well as fear of the unknown might further impair the patients' ability to receive and absorb information.³¹ This also highlights the association between coping and information provision. The ability to cope largely depends on a patient's preoperative mindset and on seeking and receiving the desired information.³² Next to providing preoperative baseline information, HCPs should inventory patients' individual preoperative information preferences and adjust the degree of further information provision accordingly.¹⁹ Where some patients only want information about the immediate next step to prevent being overwhelmed by information and becoming afraid, others prefer to know all possible details.³³ Meanwhile, HCPs should anticipate to a patient's mindset and make patients aware that the treatment process encompasses not only surgery but also the recovery process in the hospital and at home. Attention should be paid to the patient's potential inability to understand the impact of surgery and its risks due to anxiety and being overwhelmed by the amount of the provided information. Based on current results and previous literature, patient-tailored information provision and guidance appear crucial to lower the likelihood that patients experience unmet information needs and to improve preparedness for both surgery and postoperative recovery. A preoperative consultation with a social worker or mental health professional might be a valuable addition to the standard preoperative workup to explore a patient's underlying ability to cope. This might help to identify fears and potentially incorrect expectations, and to provide patients with additional information and support in a timely manner to feel fully prepared for surgery and postoperative recovery.³²

Postoperatively, HCPs should keep in mind that information and supportive care needs change during the course of treatment and are subject to contextual factors, such as complications and postoperative complaints.^{34,35} Furthermore, HCPs should realize that postoperative adverse events affect every patient differently, and that the impact of complications as experienced by patients does not necessarily match the clinical grading of complications severity. Minor complications, which are often not mentioned before surgery, might affect a patient's experience equally or more severely than major complications.³⁶ This highlights the importance of continuing patient expectation management during the recovery phase. Attention to the mental state of a patient, by HCPs and by the help of social workers or mental health professionals, is also of great importance postoperatively. By staying in touch with patients and exploring experiences and thoughts, HCPs can identify individual needs and offer information and supportive care adjusted to the individual situation of the patient. Information and support can be offered by multiple sources including hospital consultations, calling a case manager, written information, internet and mobile applications, or support groups, so patients can control the information seeking according to their own needs.³⁷ To prevent information overload in patients, separate information modules could be made per complication and per potential postoperative complaint. These modules could

be offered either on paper or digital, when necessary. Future research should focus on how to individualize continuous patient-centeredness of information provision and perioperative guidance by focussing more on individual personalities, coping strategies and needs.

4.1 | Strengths and limitations

A strength of this study was the longitudinal design. Patients were interviewed three times during their CRC pathway. This enabled an in-depth insight into preoperative expectations and perspectives and a possible mismatch with postoperative experiences without hindsight bias due to any perioperative complications and setbacks. Methodological accuracy was strengthened by performing the analysis by two independent researchers who subsequently compared and discussed their findings with a third independent experienced researcher. This study also has some limitations. This was a single centre study in an academic hospital in the South of the Netherlands, limiting the generalizability of the results towards the entire Dutch population of patients with CRC. Specific experiences might not be generalizable as they are subject to the CRC pathway organization within the study hospital. However, it is expected that the Dutch CRC care is organized largely the same in all hospitals in accordance with the national guidelines. Furthermore, themes and subthemes are likely to be transferable to other health care organizations due to purposive sampling. Member checking was not feasible. Therefore, study participants were not able to agree or disagree with the interpretation of their perspectives and experiences and the formulated themes and categories. Furthermore, some element of subjectivity can never be completely ruled out due to background knowledge of the researchers. However, the impact and subjective interpretation of the researchers was expected to be limited due to the use of a semistructured interview guide with predefined themes.

5 | CONCLUSION

Positive preoperative experiences were shaped by patient-centeredness and professional healthcare organization, sincere and personal guidance, and thorough information provision. These factors contributed to a feeling of preparedness for surgery and postoperative recovery. Improving preparedness for surgery and especially postoperative recovery can be achieved by ongoing and tailored information provision which starts preoperatively and continues during postoperative recovery. In this way, perspective can be given to patients regarding the impact of potential complications and what to expect during the course of postoperative recovery. HCPs should anticipate the patient's preoperative mindset and make them aware that the treatment process encompasses not only surgery but also an entire recovery process. Furthermore, attention should be paid to the

patient's potential inability to understand the impact of surgery and its risks.

AUTHOR CONTRIBUTIONS

Anne C.M. Cuijpers contributed to conceptualization, investigation, methodology, data curation, formal analysis, writing original draft and visualization. Tim Lubbers and Laurents PS Stassen contributed to conceptualization, methodology, supervision, and writing review and editing. Heleen A. van Rens contributed to formal analysis, and writing review and editing. Valerie Smit-Fun contributed to conceptualization, methodology, and writing review and editing. Christel Gielen and Kim Reynders contributed to data acquisition, and writing review and editing. Merel L. Kimman contributed to methodology, data curation, formal analysis, supervision and writing review and editing. All authors read and approved the final manuscript.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

Ethical approval was obtained by the Medical Ethical Committee of the MUMC+/Maastricht University (METC 2020-1460). Therefore, the study has been performed in accordance with the ethical standards as laid down in the Declaration of Helsinki and its later amendments. All patients signed informed consent for participation and use of their (interview) data for research purposes.

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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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