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Dekkers, N.; Dang, H.; Graaf, M. de; Nobbenhuis, K.; Verhoeven, D.A.; Kraan, J. van der; … ; Boonstra, J.J.

Citation

Dekkers, N., Dang, H., Graaf, M. de, Nobbenhuis, K., Verhoeven, D. A., Kraan, J. van der, … Boonstra, J. J. (2024). T1 colorectal cancer patients' perspective on information provision and therapeutic decision-making after local resection. *United European Gastroenterology Journal*. doi:10.1002/ueg2.12628

Received: 18 April 2024 | Accepted: 17 June 2024

DOI: 10.1002/ueg2.12628

ORIGINAL ARTICLE

UNITED EUROPEAN GASTROENTEROLOGY ueg journal WILEY

T1 colorectal cancer patients' perspective on information provision and therapeutic decision-making after local resection

Nik Dekkers[1] | Hao Dang[1] | Manon de Graaf[1] | Kate Nobbenhuis[1] | Daan A. Verhoeven[1] | Jolein van der Kraan[1] | Wouter H. de Vos tot Nederveen Cappel[2] | Alaa Alkhalaf[2] | Henderik L. van Westreenen[3] | Kirill Basiliya[1] | Koen C. M. J. Peeters[4] | Marinke Westerterp[5] | Pascal G. Doornebosch[6] | James C. H. Hardwick[1] | Alexandra M. J. Langers[1] | Jurjen J. Boonstra[1]

[1]Department of Gastroenterology and Hepatology, Leiden University Medical Center, Leiden, The Netherlands

[2]Department of Gastroenterology and Hepatology, Isala Hospital, Zwolle, The Netherlands

[3]Department of Surgery, Isala Hospital, Zwolle, The Netherlands

[4]Department of Surgery, Leiden University Medical Center, Leiden, The Netherlands

[5]Department of Surgery, Haaglanden Medical Center, The Hague, The Netherlands

[6]Department of Surgery, IJsselland Hospital, Capelle aan den IJssel, The Netherlands

Correspondence

Nik Dekkers, Department of Gastroenterology and Hepatology, Leiden University Medical Center, PO-Box 9600, Post zone C4-P, Leiden 2300 RC, The Netherlands.
Email: n.dekkers@lumc.nl

Abstract

Background: Decision-making after local resection of T1 colorectal cancer (T1CRC) is often complex and calls for optimal information provision as well as active patient involvement.

Objective: The aim was to evaluate the perceptions of patients with T1CRC on information provision and therapeutic decision-making.

Methods: This multicenter cross-sectional study included patients who underwent endoscopic or local surgical resection as initial treatment. Information provision was assessed using the EORTC QLQ-INFO25 questionnaire. In patients with high-risk T1CRC, we evaluated decisional involvement and satisfaction regarding the choice as to whether to undergo additional treatment after local resection, and the level of decisional conflict using the Decisional Conflict Scale.

Results: Ninety-eight patients with T1CRC were included (72% response rate; 79/98 endoscopic and 19/98 local surgical resection; 45/98 high-risk T1CRC). Median time since local resection was 28 months (IQR 18); none had developed recurrence. Unmet information needs were reported by 29 patients (30%; 18 low-risk, 11 high-risk), mostly on post-treatment related topics (follow-up visits, recovery time, recurrence prevention). After local resection, 24 of the 45 high-risk patients (53%) underwent additional treatment, while others were subjected to surveillance. Higher-educated patients were more often actively involved in decision-making (93% vs. 43%, $p = 0.002$) and more frequently underwent additional treatment (79% vs. 40%, $p = 0.02$). Decisional conflict ($p = 0.19$) and satisfaction ($p = 0.78$) were comparable between higher- and lower-educated high-risk patients.

Conclusion: Greater attention should be given to the post-treatment course during consultations following local T1CRC resection. The differences in decisional involvement and selected management strategies between higher- and lower-educated high-risk patients warrant further investigation.

KEYWORDS
colorectal cancer, endoscopic resection, endoscopic submucosal dissection, local resection

INTRODUCTION

In recent years, local organ-sparing tumor resection has emerged as the first-line treatment for early invasive colorectal cancer (T1CRC).[1] Subsequent management typically involves either additional oncological surgery or surveillance, with the choice depending on balancing the estimated risk of residual or recurrent disease against the potential harms associated with further treatment.[2] The decision-making process can be intricate when a clearly superior option is lacking, a scenario frequently encountered in T1CRC cases with ≥1 histological high-risk features. Patients with high-risk T1CRC face a relatively increased risk of lymph node metastasis, albeit modest in absolute terms (~15%).[2] In these cases, active patient involvement in the decisional process can be important to determine the most suitable treatment choice for that individual patient.[3]

A prerequisite for making an informed decision is providing patients with comprehensive and understandable information about the disease and its clinical management. However, particularly in the context of cancer care, adequate information provision can be difficult for several reasons. Firstly, medical information may be emotionally charged, especially regarding aspects such as the risk of disease recurrence and survival.[4] Secondly, the information provided by physicians may not always align with patients' preferences, potentially leaving out certain topics that patients wish to have more information about.[5,6] Thirdly, medical information often contains numerous considerations and nuances that may be complex for non-experts to understand and interpret. As previously emphasized, this challenge is notably apparent in the management of T1CRCs.

Currently, it remains unclear how patients with T1CRC perceive the provided information and its comprehensiveness. In addition, empirical data on the views of patients with T1CRC regarding decisional involvement and satisfaction are lacking. Therefore, this study aimed to explore the patient's perspective on information provision and the decision-making process following local resection of T1CRC.

MATERIALS AND METHODS

Population

We conducted a cross-sectional multicenter study in patients selected according to the following inclusion criteria.

Key summary

Summarize the established knowledge on this subject

- Local organ-sparing resection techniques have emerged as first-line treatment for T1 colorectal cancer
- Therapeutic decision-making after local resection of T1 colorectal cancer is often complex (i.e. additional treatment vs. surveillance)
- T1 colorectal cancer patients' perspective on information provision and decision-making has never been studied

What are the significant and/or new findings of this study?

- Post-treatment care was identified as the area with the most unmet information needs among locally treated T1 colorectal cancer patients.
- The importance for clinicians to take the educational background of patients into account during consultations and decision-making.
- Satisfaction with decision-making remained consistent regardless of whether patients opted for additional treatment or surveillance.

1. Diagnosed with T1CRC (defined as histologically proven tumor invasion through the muscularis mucosae and into, but not beyond, the submucosa)
2. Initial endoscopic or local surgical resection was performed at the Leiden University Medical Center (tertiary hospital) or Isala Hospital (community hospital) between January 2018 and December 2021.
3. Provided written informed consent.

Patients were excluded if they could not read Dutch. The study was approved by the Medical Ethical Committees of Leiden University Medical Center (N21.083) and Isala Hospital (20210910).

Clinical variables

Demographic patient characteristics (age, sex, comorbidity) and clinical data (morphology and location of T1CRC; type and timing of local resection; histology parameters: high-risk features, completeness of the resection) were collected from the hospital electronic medical records. In the high-risk subgroup, we also assessed whether patients were referred to a surgeon.

Patients' educational level was collected through a self-reported questionnaire. Higher educational level was defined as completion of at least a bachelor's degree. Physical status was determined using the American Society of Anesthesiologists (ASA) physical status classification system and the Charlson Comorbidity Index (CCI). Completeness of the local resection was classified as either R1 (microscopic positive resection margins), Rx (uncertain resection margins), or R0 (complete resection), the latter being defined as histologically proven cancer-free (≥0.1 mm margin) deep and lateral resection margins. T1CRCs were classified as high-risk if ≥1 histological high-risk feature for lymph node metastasis was present. At the time this study was conducted, the high-risk features were grade three differentiation, lymphovascular-invasion, high-grade tumor budding (≥Bd2), R1 or Rx resection margins of the invasive component, and deep submucosal invasion (Haggitt 4, ≥Sm1 or ≥1000 μm invasion depth).[7] Patients who underwent oncological surgery or chemoradiotherapy[8] after local resection were categorized as ‘additional treatment’, while patients who did not undergo these treatments were categorized as ‘close monitoring’. Secondary local scar resection was not regarded as ‘additional treatment’ since its purpose is mainly to enhance local control rather than addressing potential lymph node metastases.

Questionnaires

Patients' perception on information provision, satisfaction and needs

Information provision, satisfaction and needs were assessed in all patients using the validated Dutch version of the EORTC QLQ-INFO25 (INFO25).[9] The INFO25 consists of 25 items, and the items regarding provided information are organized in four multi-item scales: Information about the disease (four items), medical tests (three items), treatment (six items), other services (four items) and two single items (lifestyle and nutritional advice, things you can do to help yourself get better). Six additional items assess information needs and satisfaction. The response format for most questions is a four-point Likert scale (1—Not at all, 2—A little, 3—Quite a bit, 4—Very much), except for four items (20, 21, 23, and 24), which have a dichotomous (yes/no) scale. All scores were linearly transformed into a score from 0 to 100.[10] A higher score on a certain item indicates a higher level of information received, greater desire for more information, or greater satisfaction. The questionnaire was slightly modified to make it more applicable to the situation of patients with T1CRC. The modifications are described in detail in the Supplementary Methods.

Patients' perception on decision-making

Patients with a high-risk T1CRC were asked to answer several additional questions. The patient's experience on how the decision to either opt for or opt out of additional treatment was assessed in two pre-questions. The first question assessed the level of decisional involvement: “Did you feel like you had a choice regarding whether or not to undergo additional treatment?”. If patients answered affirmatively, they were asked to choose between the following two statements: a. “I had a choice, and I made the decision myself” or b. “I had a choice, but I let the physician make the decision”. The second question assessed the level of decisional satisfaction: “Are you satisfied with the way in which the treatment policy was determined?”. The response format for the second question was a four-point Likert scale (1-Not at all, 2-A little, 3-Quite a bit, 4-Very much), which was linearly transformed to a 0–100 scale for analyses. In line with a previous study,[11] patient involvement in decision-making was classified as ‘active’ if patients reported making the decision themselves. It was classified as ‘passive’ if patients reported allowing their physician to decide or if they indicated they had never experienced having a choice.

Perceptions on the extent of decisional conflict were assessed in patients who indicated that they had experienced a moment of choice (either active or passive) using the Dutch version of the validated Decision Conflict Scale (DCS).[12] The DCS is a 16-item questionnaire that measures five dimensions of decision-making: Informed subscale (three items), values clarity subscale (three items), support subscale (3 items), uncertainty subscale (three items) and effective decision subscale (four items). The response format for all questions is a five-point Likert scale (0—Strongly agree, 1—Agree, 2—Neither agree nor disagree, 3—Disagree, 4-Strongly disagree). All scores were linearly transformed into a score from 0 to 100, with lower scores indicating a lower level of decisional conflict.

Procedures

The consultation procedure in the outpatient clinic was not standardized; instead, the standard of care was assessed. Generally, the consultation procedure was similar in both hospitals. Initially, patients underwent a primary consultation where a healthcare professional briefed the patient on the upcoming colonoscopy or on local treatment directly, depending on the available information. If a colonoscopy was performed and revealed the need for a more extensive local resection (e.g. endoscopic submucosal dissection), a second consultation took place to obtain informed consent. Following local resection and pathological examination, patients returned to the outpatient clinic for the results within ± two weeks. For low-risk T1 CRC cases follow-up was discussed. High-risk cases were usually discussed in a multidisciplinary team before different treatment strategies were discussed with the patient in the outpatient clinic (additional treatment vs. monitoring). Additionally, high-risk patients were often referred for surgical consultation prior to decision-making. The healthcare professionals involved in abovementioned consultations were mostly (i.e. $>95\%$) gastroenterologists or surgeons, and in some cases, a resident or a physician assistant.

Follow-up in both hospitals was generally conducted in a similar manner, in accordance with the national colorectal cancer guideline.[13] The follow-up protocol was most stringent for the high-risk group that opted for close surveillance.

The questionnaires were sent to the patients' home addresses along with a consent form and a stamped return envelope. Patients who did not return the questionnaire within a month were contacted by telephone to confirm the receipt of the study documents and to determine their willingness to participate.

Statistical analyses

Nominal and ordinal variables were expressed as frequencies and percentages and continuous variables as medians and interquartile ranges (IQR). Continuous variables were compared using the Mann–Whitney *U* test. Categorical data were compared using the chi-squared test or Fisher's exact test, as appropriate. Linear or logistic regression were used to evaluate associations between variables.

Based on the results of the validation study, subgroup analyses of the INFO25 scores were performed based on sex, age and educational level.[9] Additionally, we stratified the INFO25 analyses based on histological risk status. Regarding the decision-making process, we explored the association between decisional involvement/satisfaction and adopted treatment policy, sex, age, comorbidity index, tumor location, and total INFO25 score. For the DCS scores, subgroup analyses were performed based on patients' perceived degree of decisional involvement and the treatment decision that was made. Sensitivity analyses were performed to evaluate the impact of the time interval between local resection and questionnaire completion on the results. The median time interval was used as a cut-off to form two groups with similar numbers of participants, thereby minimizing the power reduction of these analyses. SPSS version 24.0 was used for all statistical analyses. A *p*-value <0.05 was considered statistically significant.

RESULTS

A total of 137 patients fulfilled the selection criteria and were invited to participate. The response rate was 71.5% (98/137) (Figure 1). The median interval between local resection and study participation was 28 months (IQR 18). Of the 98 patients, 45 underwent local resection for a high-risk T1CRC. Patients' demographic and clinical characteristics, stratified on histological risk status, are summarized in Table 1. Ethical approval does not permit publishing data on non-responders. There is no indication for exclusion not at random.

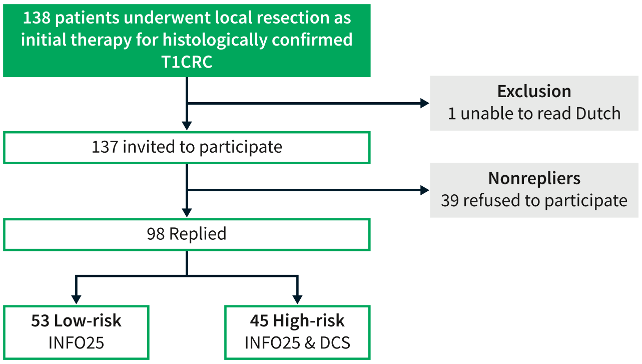

FIGURE 1 Flow-chart of patient selection. CRC, colorectal cancer; DCS, Decision conflict scale; INFO25 EORTC QLQ-INFO25.

Information provision, satisfaction, and needs (EORTC QLQ-INFO25)

The mean scores of all subscales and single INFO25 items are presented in Figure 2 and Table S1. Patients reported having received the most information on the ‘medical test’ subscale, scoring an average of 71 out of 100 points. Patients reported having received the least information on ‘things you can do to help yourself get better’ (mean score 23.5). Of the single items, patients reported having received the most information about the initial local resection (mean score 73.8) and the least about potential avenues for professional psychological support (mean score 11.6).

The mean scores of the overall satisfaction level (item 22) and the perceived helpfulness of the received information (item 25) were 67.0 and 71.1 out of 100 points, respectively. Sixty-nine patients (70.4%) reported no need for additional information. Among the 29 patients expressing a need for more information (15 males and 14 females; 18 low-risk, 11 high-risk T1CRC), 23 specified the specific topics where their information needs were unmet. The most mentioned topics were ‘expected follow-up appointments after local resection’ (10/23) and ‘recovery after local resection’ (8/23) (Figure 3). In addition to the information being provided verbally, 39 patients (39.8%) indicated a preference for receiving additional information on paper and 24 (24.5%) preferred to receive additional information digitally.

In exploratory subgroup analyses, patients with high-risk T1CRC scored higher on multiple INFO25 scales, indicating that high-risk patients experienced receiving more information compared with patients diagnosed with low-risk T1CRC (Figure 2b). Satisfaction with the provided information and reported needs for more information were comparable between high-risk and low-risk patients (Table S3). Moreover, women scored lower than men on multiple INFO25 scales (Figure 2c), including ‘medical tests’ ($p = 0.03$) and ‘things you can do to help yourself get better’ ($p = 0.02$). With regard to information provision, women reported lower satisfaction scores than men (60.2 vs. 71.0, $p = 0.04$) (Table S2). No statistical differences were observed between younger (≤ 65 years) and older patients (>65) or between patients with a higher and lower educational level (Table S3).

TABLE 1 Baseline characteristics.

	All patients (n = 98)	Low-risk (n = 53)	High-risk (n = 45)
Patient characteristics			
Age, years, mean (SD)	64.9 (7.9)	64.1 (8.4)	65.7 (7.3)
Sex, male	62 (63.3)	33 (62.3)	29 (64.4)
Charlson comorbidity index, median (IQR)	2.0 (1)	3.0 (3)	2.0 (1)
Educational level, high	24 (24.7)	10 (18.9)	14 (31.1)[a]
Tumor and treatment characteristics			
Gross polyp morphology			
Pedunculated	33 (33.7)	24 (45.3)	9 (20)
Non-pedunculated	65 (66.3)	29 (54.7)	36 (80)
Tumor location, rectum	42 (46.9)	17 (32.1)	25 (55.6)
Local resection technique			
Snaring	32 (32.7)	23 (43.4)	9 (20)
EMR	11 (11.2)	4 (7.5)	7 (15.6)
ESD	27 (27.6)	12 (22.6)	15 (33.3)[b]
eFTR	9 (9.2)	3 (5.7)[c]	6 (13.3)
TEM/TAMIS	10 (10.2)	5 (9.4)	5 (11.1)
CAL-WR	9 (9.2)	6 (11.3)	3 (6.7)
Timing of local resection			
Direct (during index procedure)	36 (36.7)	24 (45.3)	12 (26.7)
Rescheduled after initial detection	62 (63.3)	29 (54.7)	33 (73.3)
Time interval resection to questionnaire, months, median (IQR)	28 (18.0)	28 (18.0)	28 (18.0)

Note: All values are n (%) unless otherwise defined. Higher educational level was defined as completion of at least a bachelor's degree.

Abbreviations: ASA, American Society of Anesthesiologists; CAL-WR, colonoscopic-assisted laparoscopic wedge resection; eFTR, endoscopic full-thickness resection; EMR, Endoscopic mucosal resection; ESD, Endoscopic submucosal dissection; IQR, interquartile range; TAMIS, transanal minimally invasive surgery; TEM, transanal endoscopic microsurgery; SD, standard deviation.

[a] One patient refused to complete the question regarding educational level.

[b] One patient underwent a hybrid ESD-EMR procedure.

[c] One patient underwent a hybrid eFTR-EMR procedure.

Sensitivity analyses showed that the total INFO25 score was not significantly influenced by the time interval between local resection and questionnaire completion (short vs. long interval: 40.3 and 37.8, $p = 0.43$).

Therapeutic decision-making in patients with a high-risk T1CRC

The decision-making process was evaluated in the 45 patients with locally resected high-risk T1CRC (baseline characteristics and clinical outcomes shown in Table 2). After a median follow-up of 28 months (IQR 18), no recurrences or mortality were observed.

The treatment strategies following local resection included oncological resection (n = 18), chemoradiotherapy in early stage rectal cancer as part of a clinical trial (n = 6), and close monitoring (n = 21; 6 treated with additional local scar resection and 15 no further treatment). In the close monitoring group, 12 patients (57.1%) exclusively consulted a gastroenterologist, and 9 patients (42.9%) were referred for consultation with a surgeon. Nineteen of the 21 patients (90.5%) were discussed in a multidisciplinary team meeting. Higher-educated patients were more likely to undergo additional treatment than lower-educated patients (p = 0.02). There was no significant association between the adopted strategy after local resection and other variables, such as the patient's sex, tumor location, comorbidity index and time interval between local resection and questionnaire completion.

Figure 4 presents a visual depiction of the therapeutic decision-making process and patient involvement, categorized by the adopted treatment policy following local resection. From the patient's perspective, 27 individuals (60.0%) opted for the treatment policy themselves after local resection (an 'active' role). Meanwhile, 9 patients deferred the decision to their physician (a 'passive' role), and an additional 9 patients felt they were not offered a choice (also a

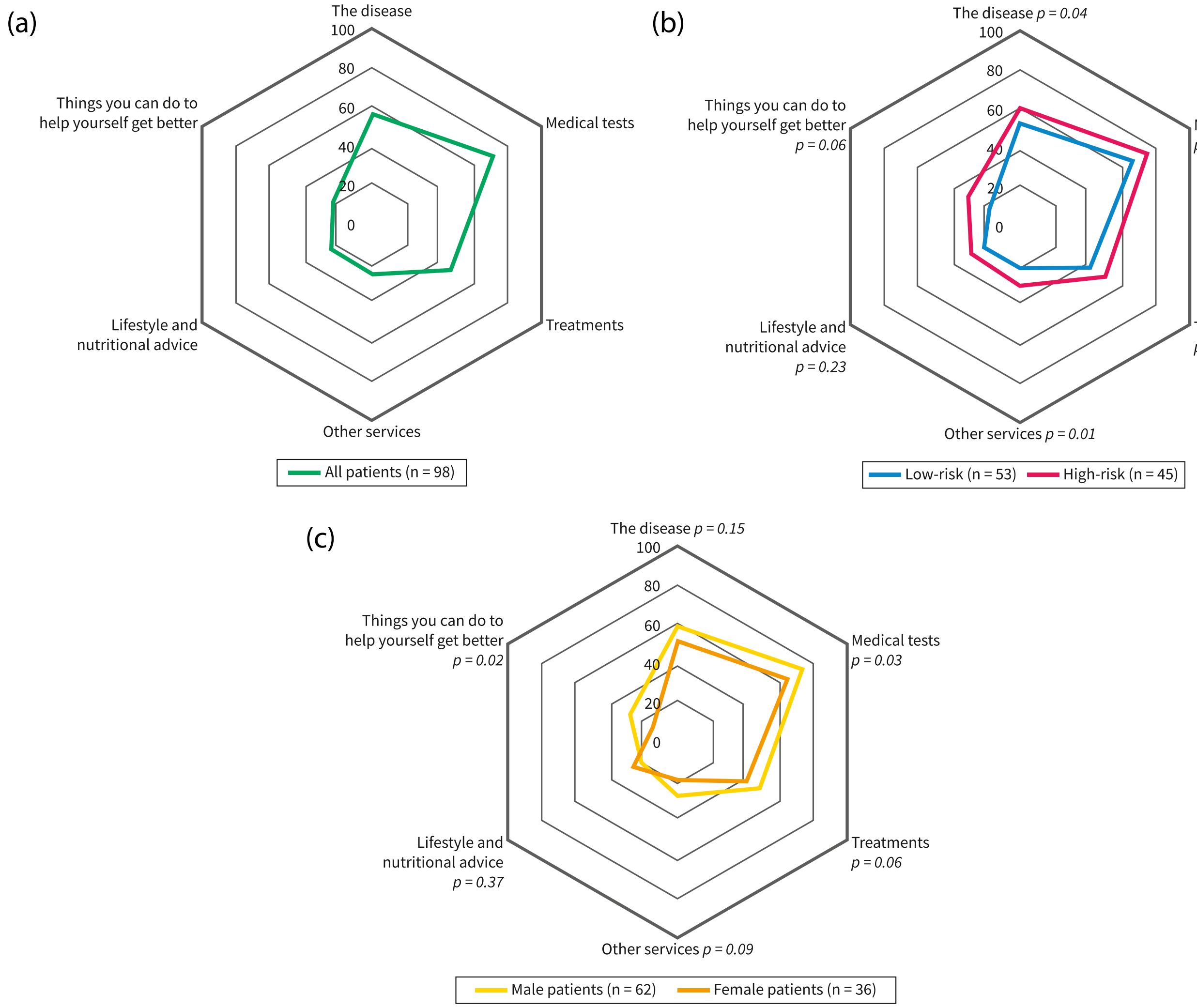

FIGURE 2 Visual representation of the amount of information that was provided on the various disease topics of the INFO25 questionnaire. Comparisons were made by (a) Overall; (b) Grouped by histological risk-status; (c) Grouped by sex. Scale 0–100: ranging from 'not at all' to 'very much'.

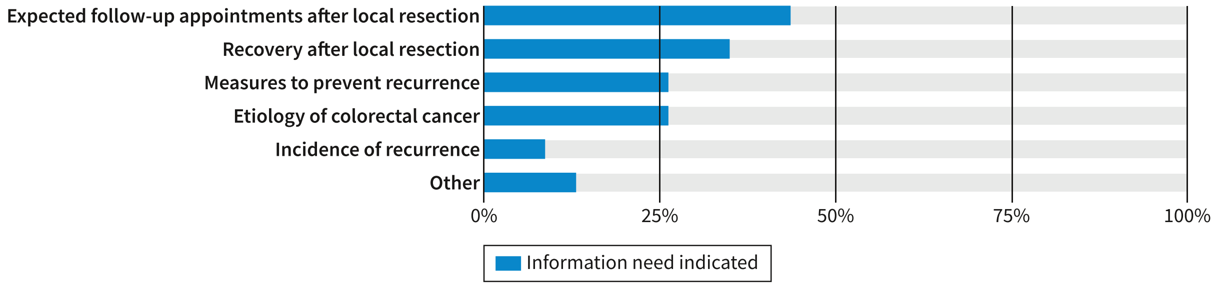

FIGURE 3 Topics with unmet information needs in 23 patients who specified on what topics they wished to have received more information on. The category 'other' was utilized to categorize responses that were provided only once and did not fit into the other predefined categories.

'passive' role). In univariable analyses, higher-educated patients were more likely to experience active involvement in decision-making than lower-educated patients (p = 0.002) (Table 3). No significant association was found between the level of patient's involvement in decision-making and the adopted treatment strategy (additional treatment or close monitoring), sex, age, comorbidity index, tumor location, total INFO25 score, and time interval between local resection and questionnaire completion (Table S4).

Overall, most patients expressed high levels of decisional satisfaction, with 27 (61.4%) reporting being 'very much' satisfied, 14

TABLE 2 Baseline characteristics of patients with a high-risk T1 colorectal cancer.

	Additional treatment ($n = 24$)	Close monitoring ($n = 21$)	p-value
Baseline characteristics			
Sex, male	15 (62.5)	14 (66.7)	>0.99
Educational level, high	11 (45.8)	3 (14.3)	0.02
Tumor location, rectum	11 (45.8)	14 (66.7)	0.23
Charlson comorbidity index, median (IQR)	2.0 (1)	3.0 (2)	0.16
High-risk features			
Rx	0	3 (14.3)	0.38
R1	5 (20.8)	5 (23.8)	
Other JSCCR high-risk feature(s)	15 (62.5)	10 (47.6)	
Both	4 (16.7)	3 (14.3)	
Time interval since treatment, <28 months	7 (29.2)	12 (57.1)	0.08
Extent of decision involvement, active	17 (70.8)	10 (47.6)	0.14
Outcome of treatment strategy			
TNM-stage[a]			
T1N0M0, without residual tumor rest	16	*NA*	*NA*
T1N1M0, with residual tumor rest	1		
Underwent CRT (i.e. no TNM)	6		
Cancer recurrence, yes	0[a]	0	>0.99

Note: Patients who underwent oncological resection ($n = 18$) or chemoradiotherapy ($n = 6$) after local resection were categorized as ‘additional treatment’, while patients who underwent an additional local scar resection ($n = 6$) or refrained from any additional treatment were grouped together as ‘close monitoring’. All values are n (%) unless otherwise defined.

Abbreviations: CRT, chemoradiotherapy; IQR, interquartile range; JSSCR, Japanese Society of Cancer of the Colon and Rectum; TNM, Tumor, Nodes, and Metastases classification of malignant tumors.

[a] Follow-up data of one patient was missing.

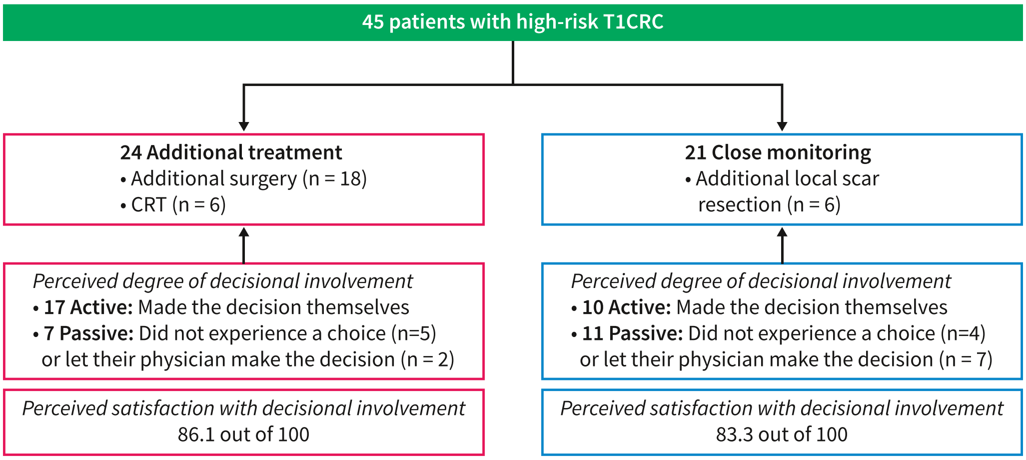

FIGURE 4 Overview of the therapeutic decision-making in patients with high-risk T1 colorectal cancer. CRC, colorectal cancer; CRT, chemoradiotherapy.

(31.8%) being ‘quite a bit’ satisfied and 3 (6.8%) being 'a little' satisfied with the decision-making process. One patient couldn't recall her level of decisional satisfaction. Decisional satisfaction did not differ between higher- and lower-educated patients (83.3 vs. 85.6; $p = 0.78$), as well as between patients with active and passive decisional involvement (86.4 vs. 82.4; $p = 0.43$), patients receiving additional treatment or close monitoring (86.1 vs. 83.3; $p = 0.76$) and patients receiving additional chemoradiotherapy or surgical resection (83.3 vs. 87.0; $p = 0.97$).

TABLE 3 Implemented treatment policy after local resection and extent of patient involvement with regard to this decision, stratified for educational level.

	Additional treatment		Close monitoring		
	Active patient involvement (*n* = 16)	Passive patient involvement (*n* = 7)	Active patient involvement (*n* = 10)	Passive patient involvement (*n* = 11)	*p*-value
Low level of education (*n* = 30)	6 (37.5)	6 (85.7)	7 (70)	11 (100)	*0.004*
High level of education (*n* = 14)	10 (62.5)	1 (14.3)	3 (30)	0 (0)	

Note: Patients who underwent oncological resection (*n* = 18) or chemoradiotherapy (*n* = 6) after local resection were categorized as 'additional treatment', while patients who underwent an additional local scar resection (*n* = 6) or refrained from any additional treatment were grouped together as 'close monitoring'. The extent to which patients were involved in decision-making was categorized as 'active' if patients reported to have made the decision themselves, and 'passive' if patients reported to have let their physician make the decision or if patients reported that they never felt that they were given a choice. Higher educational level was defined as completion of at least a bachelor's degree. One patient who did not provide their educational level was excluded from this subgroup analysis. All values are *n* (%) unless otherwise defined the *p*-value studying the association between educational level - additional treatment (yes/no) and extent of decisional involvement (active/passive).

Decisional conflict (decisional conflict scale)

The assessment of decisional conflict was conducted among the 36 high-risk patients who reported having had a choice in therapeutic decision-making. Overall, the mean total DCS was 16.7 out of 100 (SD 14.9). DCS domain scores and total DCS were comparable between patients with active and passive decisional involvement (Table S5). Likewise, there was no significant association between the total DCS score and the adopted treatment strategy (additional treatment or close monitoring), type of additional treatment (chemoradiotherapy or additional surgical resection), sex, age, comorbidity index, tumor location, total INFO25 score, and time interval between local resection and questionnaire completion (Table S6).

DISCUSSION

Overall, our study indicates that most patients with T1CRC express satisfaction with the information provided after local tumor resection but may require additional details about the post-treatment course. Similarly, satisfaction levels concerning the decision-making process were high among patients with high-risk T1CRC, irrespective of their level of involvement in decision-making or the adopted treatment approach. However, the degree of decisional involvement varied considerably among patients with different educational backgrounds, with higher-educated patients more often actively choosing additional surgery after local resection of a high-risk T1CRC. To our knowledge, this is the first study to present empirical data on the perspectives of patients with T1CRC regarding information provision and the decision-making process following local T1CRC resection.

The high INFO25 scores on the disease, medical test and local treatment-related items indicate that current information provision mainly centers around the primary objective of the outpatient consultation following local T1CRC treatment. This goal entails informing the patient about the histological outcomes of the tumor resection and determining the subsequent management strategy. Considering the high satisfaction scores[14,15] and low levels of decisional conflict,[12,16] most of the information provided by physicians seems to align well with the patient's preferences. However, we did identify some subgroups and topics with unmet information needs. First, a substantial proportion of (both low and high-risk) patients required more details on the post-treatment course, and in particular the type and frequency of follow-up visits, the estimated recovery time after local or surgical resection, and possible measures for preventing disease recurrence. Comparable information needs were also found in patients who underwent primary surgery for stage I-III CRC,[17] indicating that the post-treatment course is an aspect of CRC care that is frequently neglected. To enhance patient-provider communication in the future, we propose that greater attention should be given to post-treatment topics in the outpatient clinic. However, the lack of specific scientific evidence on certain topics, such as recovery and prevention, may also contribute to clinicians' limited information provision. Therefore, future research in the field of T1CRC should focus on addressing these aspects of treatment.

Our data also reveal that women with T1CRC reported having received less information on multiple topics than men, as well as being less satisfied with the provided information. Such a difference was also found in multiple other cancer patient populations,[9,18,19] including patients with surgically treated colorectal cancer.[20] Possible explanations for these findings might involve gender bias among clinicians,[21–23] leading to suboptimal information provision to women. Besides, women might also exhibit a greater demand for information in response to a medical diagnosis.[24,25] This coping style is typically referred to as "monitoring"[26] and is associated with lower levels of satisfaction with the received healthcare and information.[24,27–29] To further improve information provision after local T1CRC treatment, clinicians need to be aware of possible gender bias affecting their communication as well as the potentially higher information demands among female patients.

In our study, decisional satisfaction following local tumor resection did not differ according to the degree of decisional involvement and the adopted management strategy. This was not unexpected, considering the wide variability in patient preferences regarding decisional involvement[30,31] and the fact that the vast majority of both surgically and locally treated patients with T1CRC do not experience cancer recurrence or adverse events.[32–34] However, we found striking differences in the decisional process between higher- and lower-educated patients. More highly educated patients were twice as likely to report active decisional involvement and to opt for additional treatment. While the high levels of decisional satisfaction suggest that lower-educated patients do not strongly desire active involvement in the decision-making process, it must be kept in mind that the above-mentioned differences may also arise from possible systemic inequities in health literacy.[35–37] Therefore, clinicians should not presume that lower-educated patients prefer passive decisional involvement. Instead, they should actively explore the reasons behind the patient's choice not to be involved in decision-making, and address possible low literacy levels by tailoring their communication strategy. For example, they could develop tailored educational materials or decisional aids, such as patient educational videos on T1 colorectal cancer.[3]

The explanations for the difference in management strategies between lower- and higher-educated patients with high-risk T1CRC may be two-fold. On the one hand, lower-educated patients with passive decisional involvement might be less likely to undergo additional treatment due to a higher prevalence of comorbidities that render them less suitable for surgical interventions.[38–40] Recent studies have shown that in comorbid patients with locally resected high-risk T1CRC, additional surgery may not result in a long-term survival benefit compared with a close monitoring approach.[34,41–43] In light of these findings, the considerable proportion of lower-educated high-risk patients subjected to close monitoring might actually reflect the recent trend among physicians to refrain from additional surgical resections for comorbid patients more frequently. Unfortunately, the data did not allow us to substantiate this hypothesis with sufficiently powered subgroup analyses. On the other hand, higher-educated patients may be more inclined to actively choose additional treatment because of their higher level of health literacy. As a result, they are more likely to seek out health information themselves,[44–46] and prefer active involvement in the decisional process.[47–49] Given that most guidelines do not (yet) consider the very recently published papers mentioned above[34,41–43] and still recommend surgery in all cases of high-risk T1CRC, it seems reasonable that higher-educated patients more frequently opt for additional treatment. To confirm that decision-making after local T1CRC treatment does not depend on educational level but is confounded by other factors, in-depth interview studies with both patients and clinicians are needed.

Several limitations of this study should be acknowledged. Firstly, the sample size is limited, particularly in the high-risk subgroup, which should be taken into account when interpreting the results. Secondly, both response and recall bias may have influenced the results, although the response rate of our study is quite high (71.5%)[50] and the time interval between local resection and questionnaire completion did not influence the outcomes in sensitivity analyses. Thirdly, various (types of) physicians provided non-standardized information in the outpatient consultations after local resection. Given the importance of information framing in patient understanding and decision-making,[51] this lack of uniformity may have affected the study findings and conclusions to a certain degree. Lastly, the extent of decisional involvement most likely exists on a spectrum broader than the options examined in this study. Future research would benefit from a validated questionnaire to thoroughly investigate this aspect. Unfortunately, such a tool is not yet available.

CONCLUSION

From the patient's perspective, the information provided after local T1CRC resection seems to align well with the primary objective of the consultation, but some patients may require more details on certain items, for example, post-treatment course and follow-up. Although patient satisfaction with the decision-making process following local resection of high-risk T1CRC was high, decisional involvement and management strategies differed considerably between patients of different educational backgrounds. Our results provide valuable insights that can aid physicians in optimizing information provision and shared decision-making in the outpatient clinic.

ACKNOWLEDGMENTS

There were no funding sources.

CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

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.

REPORTING GUIDELINE

STROBE guidelines for cross-sectional studies.[52]

ORCID

Nik Dekkers https://orcid.org/0000-0003-0301-7011
Hao Dang https://orcid.org/0000-0001-5502-4980
Daan A. Verhoeven https://orcid.org/0009-0008-5869-9703
James C. H. Hardwick https://orcid.org/0000-0002-9575-5099

REFERENCES

1. Dekker E, Tanis PJ, Vleugels JLA, Kasi PM, Wallace MB. Colorectal cancer. Lancet. 2019;394(10207):1467–80. https://doi.org/10.1016/s0140-6736(19)32319-0
2. Rex DK, Shaukat A, Wallace MB. Optimal management of malignant polyps, from endoscopic assessment and resection to decisions about surgery. Clin Gastroenterol Hepatol. 2019;17(8):1428–37. https://doi.org/10.1016/j.cgh.2018.09.040
3. Dekkers N, Dang H, van der Kraan J, Hardwick JCH, Langers AMJ, Boonstra JJ. Patient educational videos on T1 colorectal cancer. VideoGIE. 2023;8(12):527–8. https://doi.org/10.1016/j.vgie.2023.08.009
4. Mulcare H, Schofield P, Kashima Y, Milgrom J, Wirth A, Bishop M, et al. Adjustment to cancer and the information needs of people with

lung cancer. Psycho Oncol. 2011;20(5):488–96. https://doi.org/10.1002/pon.1752

5. Mesters I, van den Borne B, De Boer M, Pruyn J. Measuring information needs among cancer patients. Patient Educ Couns. 2001;43(3):253–62.
6. Lowenstein LM, Volk RJ, Cuddy A, Hempstead AP, You YN, Van Loon K, et al. Patients' information needs and attitudes about post-treatment surveillance for colorectal cancer in the United States: a multi-perspective, mixed methods study. BMJ Open. 2019;9(8):e025888. https://doi.org/10.1136/bmjopen-2018-025888
7. Hashiguchi Y, Muro K, Saito Y, Ito Y, Ajioka Y, Hamaguchi T, et al. Japanese society for cancer of the colon and rectum (JSCCR) guidelines 2019 for the treatment of colorectal cancer. Int J Clin Oncol. 2020;25(1):1–42. https://doi.org/10.1007/s10147-019-01485-z
8. Borstlap WA, Tanis PJ, Koedam TW, Marijnen CA, Cunningham C, Dekker E, et al. A multi-centred randomised trial of radical surgery versus adjuvant chemoradiotherapy after local excision for early rectal cancer. BMC Cancer. 2016;16(1):513. https://doi.org/10.1186/s12885-016-2557-x
9. Arraras JI, Greimel E, Sezer O, Chie W.-C, Bergenmar M, Costantini A, et al. An international validation study of the EORTC QLQ-INFO25 questionnaire: an instrument to assess the information given to cancer patients. Eur J Cancer. 2010;46(15):2726–38. https://doi.org/10.1016/j.ejca.2010.06.118
10. McCaughan E, McKenna H. Information-seeking behaviour of men newly diagnosed with cancer: a qualitative study. J Clin Nurs. 2007;16(11):2105–13. https://doi.org/10.1111/j.1365-2702.2006.01785.x
11. Lithner M, Johansson J, Andersson E, Jakobsson U, Palmquist I, Klefsgard R. Perceived information after surgery for colorectal cancer—an explorative study. Colorectal Dis. 2012;14(11):1340–50. https://doi.org/10.1111/j.1463-1318.2012.02982.x
12. Filler T, Dunn S, Grace SL, Straus SE, Stewart DE, Gagliardi AR. Multi-level strategies to tailor patient-centred care for women: qualitative interviews with clinicians. BMC Health Serv Res. 2020;20(1):212. https://doi.org/10.1186/s12913-020-05082-z
13. Gagliardi AR, Green C, Dunn S, Grace SL, Khanlou N, Stewart DE. How do and could clinical guidelines support patient-centred care for women: content analysis of guidelines. PLoS One. 2019;14(11):e0224507. https://doi.org/10.1371/journal.pone.0224507
14. Fayers P, Aaronson NK, Bjordal K, Sullivan M. EORTC QLQ–C30 scoring manual: European organisation for research and treatment of cancer; 1995.
15. Noteboom EA, May AM, van der Wall E, de Wit NJ, Helsper CW. Patients' preferred and perceived level of involvement in decision making for cancer treatment: a systematic review. Psycho Oncol. 2021;30(10):1663–79. https://doi.org/10.1002/pon.5750
16. O'Connor AM. Validation of a decisional conflict scale. Med Decis Making. 1995;15(1):25–30. https://doi.org/10.1177/0272989x9501500105
17. Federatie Medisch Specialisten. Guideline colorectaal carcinoom (CRC). 2019. https://richtlijnendatabase.nl/richtlijn/colorectaal_carcinoom_crc
18. Cuypers M, Lamers RED, de Vries M, Husson O, Kil PJM, van de Poll-Franse LV. Prostate cancer survivors with a passive role preference in treatment decision-making are less satisfied with information received: results from the PROFILES registry. Urol Oncol. 2016;34(11):482e11–8. https://doi.org/10.1016/j.urolonc.2016.06.015
19. Grenot M, Vandenbroucke T, Bucau M, Koskas M. Quality of information and decision regrets during fertility-sparing management for atypical hyperplasia and endometrial cancer in a prospective cohort study. J Gynecol Obstet Hum Reprod. 2024;53(4):102722. https://doi.org/10.1016/j.jogoh.2024.102722
20. Wyatt KD, Branda ME, Inselman JW, Ting HH, Hess EP, Montori VM, et al. Genders of patients and clinicians and their effect on shared decision making: a participant-level meta-analysis. BMC Med Inform Decis Mak. 2014;14(1):81. https://doi.org/10.1186/1472-6947-14-81
21. Wieldraaijer T, Duineveld LAM, Bemelman WA, van Weert H, Wind J. Information needs and information seeking behaviour of patients during follow-up of colorectal cancer in The Netherlands. J Cancer Surviv. 2019;13(4):603–10. https://doi.org/10.1007/s11764-019-00779-5
22. Arraras JI, Manterola A, Hernandez B, Arias de la Vega F, Martinez M, Vila M, et al. The EORTC information questionnaire, EORTC QLQ-INFO25. Validation study for Spanish patients. Clin Transl Oncol. 2011;13(6):401–10. https://doi.org/10.1007/s12094-011-0674-1
23. Alcalde-Rubio L, Hernandez-Aguado I, Parker LA, Bueno-Vergara E, Chilet-Rosell E. Gender disparities in clinical practice: are there any solutions? Scoping review of interventions to overcome or reduce gender bias in clinical practice. Int J Equity Health. 2020;19(1):166. https://doi.org/10.1186/s12939-020-01283-4
24. van de Wal D, van Doorn B, den Hollander D, Desar IME, Gelderblom H, Oosten AW, et al. The association of having a monitoring or blunting coping style with psychological distress, health-related quality of life and satisfaction with healthcare in gastrointestinal stromal tumour (GIST) patients. Acta Oncol. 2023;62(12):1616–24. https://doi.org/10.1080/0284186x.2023.2269302
25. Ek S. Gender differences in health information behaviour: a Finnish population-based survey. Health Promot Int. 2015;30(3):736–45. https://doi.org/10.1093/heapro/dat063
26. Miller SM. Monitoring and blunting: validation of a questionnaire to assess styles of information seeking under threat. J Pers Soc Psychol. 1987;52(2):345–53. https://doi.org/10.1037//0022-3514.52.2.345
27. Rood JA, Van Zuuren FJ, Stam F, van der Ploeg T, Huijgens PC, Verdonck-de Leeuw IM. Cognitive coping style (monitoring and blunting) and the need for information, information satisfaction and shared decision making among patients with haematological malignancies. Psycho Oncol. 2015;24(5):564–71. https://doi.org/10.1002/pon.3699
28. Timmermans LM, van Zuuren FJ, van der Maazen RW, Leer JW, Kraaimaat FW. Monitoring and blunting in palliative and curative radiotherapy consultations. Psycho Oncol. 2007;16(12):1111–20. https://doi.org/10.1002/pon.1177
29. Ong LM, Visser MR, van Zuuren FJ, Rietbroek RC, Lammes FB, de Haes JC. Cancer patients' coping styles and doctor-patient communication. Psycho Oncol. 1999;8(2):155–66. https://doi.org/10.1002/(sici)1099-1611(199903/04)8:2<155::aid-pon350>3.3.co;2-1
30. Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: a narrative review. Patient Educ Couns. 2006;60(2):102–14. https://doi.org/10.1016/j.pec.2005.02.003
31. van Til JA, Pearce A, Ozdemir S, Hollin IL, Peay HL, Wu AW, et al. Role preferences in medical decision making: relevance and implications for health preference research. Patient. 2024;17(1):3–12. https://doi.org/10.1007/s40271-023-00649-4
32. Dang H, Dekkers N, le Cessie S, van Hooft JE, van Leerdam ME, Oldenburg PP, et al. Risk and time pattern of recurrences after local endoscopic resection of T1 colorectal cancer: a meta-analysis. Clin Gastroenterol Hepatol. 2022;20(2):e298–314. https://doi.org/10.1016/j.cgh.2020.11.032
33. Yeh JH, Tseng CH, Huang RY, Lin CW, Lee CT, Hsiao PJ, et al. Long-term outcomes of primary endoscopic resection vs surgery for T1 colorectal cancer: a systematic review and meta-analysis. Clin Gastroenterol Hepatol. 2020;18(12):2813–23. https://doi.org/10.1016/j.cgh.2020.05.060
34. Chen Y, Jing W, Chen M, Wang Z, Wu J, Yang J, et al. Long-term outcomes of local resection versus surgical resection for high-risk T1 colorectal cancer: a systematic review and meta-analysis.

Gastrointest Endosc. 2023;97(6):1016–30. https://doi.org/10.1016/j.gie.2023.02.027
35. Clough JD. Functional health illiteracy: what patients don't know can hurt them. Cleve Clin J Med. 2002;69(5):355. https://doi.org/10.3949/ccjm.69.5.355
36. Doak CC, Doak LG, Friedell GH, Meade CD. Improving comprehension for cancer patients with low literacy skills: strategies for clinicians. CA Cancer J Clin. 1998;48(3):151–62. https://doi.org/10.3322/canjclin.48.3.151
37. Williams MV. Recognizing and overcoming inadequate health literacy, a barrier to care. Cleve Clin J Med. 2002;69(5):415–8. https://doi.org/10.3949/ccjm.69.5.415
38. Chen L, Alexanderson KAE. Trajectories of sickness absence and disability pension before and after colorectal cancer: a Swedish longitudinal population-based matched cohort study. PLoS One. 2021;16(1):e0245246. https://doi.org/10.1371/journal.pone.0245246
39. Pincus T, Callahan LF. Associations of low formal education level and poor health status: behavioral, in addition to demographic and medical, explanations? J Clin Epidemiol. 1994;47(4):355–61. https://doi.org/10.1016/0895-4356(94)90156-2
40. Robbins AS, Pavluck AL, Fedewa SA, Chen AY, Ward EM. Insurance status, comorbidity level, and survival among colorectal cancer patients age 18 to 64 years in the national cancer data base from 2003 to 2005. J Clin Oncol. 2009;27(22):3627–33. https://doi.org/10.1200/jco.2008.20.8025
41. Corre F, Albouys J, Tran VT, Lepilliez V, Ratone JP, Coron E, et al. Impact of surgery after endoscopically resected high-risk T1 colorectal cancer: results of an emulated target trial. Gastrointest Endosc. 2024;99(3):408–16.e2. https://doi.org/10.1016/j.gie.2023.09.027
42. Ouchi A, Komori K, Masahiro T, Toriyama K, Kajiwara Y, Oka S, et al. How does omitting additional surgery after local excision affect the prognostic outcome of patients with high-risk T1 colorectal cancer? Ann Surg. 2024;279(2):290–6. https://doi.org/10.1097/sla.0000000000006092
43. Ha RK, Park B, Han KS, Sohn DK, Hong CW, Chang KB, et al. Subpopulation analysis of survival in high-risk T1 colorectal cancer: surgery versus endoscopic resection only. Gastrointest Endosc. 2022;96(6):1036–46.e1. https://doi.org/10.1016/j.gie.2022.07.016
44. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. Ann Intern Med. 2011;155(2):97–107. https://doi.org/10.7326/0003-4819-155-2-201107190-00005
45. van der Heide I, Uiters E, Sørensen K, Röthlin F, Pelikan J, Rademakers J, et al. Health literacy in Europe: the development and validation of health literacy prediction models. Eur J Public Health. 2016;26(6):906–11. https://doi.org/10.1093/eurpub/ckw078
46. van der Heide I, Wang J, Droomers M, Spreeuwenberg P, Rademakers J, Uiters E. The relationship between health, education, and health literacy: results from the dutch adult literacy and life skills survey. J Health Commun. 2013;18(Suppl 1):172–84. https://doi.org/10.1080/10810730.2013.825668
47. Hahlweg P, Kriston L, Scholl I, Brähler E, Faller H, Schulz H, et al. Cancer patients' preferred and perceived level of involvement in treatment decision-making: an epidemiological study. Acta Oncol. 2020;59(8):967–74. https://doi.org/10.1080/0284186x.2020.1762926
48. Smith SK, Dixon A, Trevena L, Nutbeam D, McCaffery KJ. Exploring patient involvement in healthcare decision making across different education and functional health literacy groups. Soc Sci Med. 2009;69(12):1805–12. https://doi.org/10.1016/j.socscimed.2009.09.056
49. Zhu X, Weiser E, Jacobson DJ, Griffin JM, Limburg PJ, Finney Rutten LJ. Patient preferences on general health and colorectal cancer screening decision-making: results from a national survey. Patient Educ Couns. 2022;105(4):1034–40. https://doi.org/10.1016/j.pec.2021.07.033
50. Neve OM, van Benthem PPG, Stiggelbout AM, Hensen EF. Response rate of patient reported outcomes: the delivery method matters. BMC Med Res Methodol. 2021;21(1):220. https://doi.org/10.1186/s12874-021-01419-2
51. Menichetti J, Gulbrandsen P, Landmark AM, Lie HC, Gerwing J. How do physicians frame medical information in talks with their patients? An inductive microanalysis. Qual Health Res. 2024;34(1-2):101–13. https://doi.org/10.1177/10497323231205152
52. Cuschieri S. The STROBE guidelines. Saudi J Anaesth. 2019;13(Suppl 1):S31–S4. https://doi.org/10.4103/sja.sja_543_18

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How to cite this article: Dekkers N, Dang H, de Graaf M, Nobbenhuis K, Verhoeven DA, van der Kraan J, et al. T1 colorectal cancer patients' perspective on information provision and therapeutic decision-making after local resection. United European Gastroenterol J. 2024;1–11. https://doi.org/10.1002/ueg2.12628