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Which EORTC QLQ-C30 and -CR29 scores are relevant for clinicians for therapy planning and decisions?

Results of an online survey

Nora Tabea Sibert¹ · Clara Breidenbach¹ · Simone Wesselmann¹ · Sarah Schult¹ · Stefan Rolf Benz² · Stefan Post³ · Thomas Seufferlein⁴ · Patrick Schloss⁵ · Christoph Kowalski¹

¹ Deutsche Krebsgesellschaft e. V., Berlin, Germany

² Department for Abdominal and Pediatric Surgery, Klinkverbund-Suedwest, Klinken Böblingen, Böblingen, Germany

³ Department of Surgery, Universitätsmedizin Mannheim, Medical Faculty Mannheim, University Heidelberg, Mannheim, Germany

⁴ Department of Internal Medicine I, University of Ulm, Ulm, Germany

⁵ Deutsche ilco e. V., Bonn, Germany

Abstract

Background: Colorectal cancer is associated with considerable impairment of quality of life as well as disease-specific symptoms and functional limitations. These can be assessed using standardized patient-reported outcome (PRO) instruments such as the EORTC QLQ-C30 and CR29 questionnaires. To date, no systematic investigation exists regarding which of the total 35 symptoms and functional limitations captured by the EORTC questionnaires are relevant to clinicians. This study aimed to identify the dimensions of the EORTC questionnaires most relevant to clinicians in the pretherapeutic assessment of colorectal cancer patients.

Methods: An online survey was conducted (February–March 2021) in which clinicians from certified colorectal cancer centers were asked to rate the five most relevant scales (for colon and rectal cancer, respectively). The contacted cancer centers all participated in the EDIUM study, in which the PRO instruments were already used. The survey results were analyzed descriptively.

Result: Of 203 respondents, 96 took part in the survey (83 surgeons, 9 internists, 4 not specified/others). For colon, the scales “quality of life” ($n = 80$), “pain” (40), “physical function” (36), “constipation” (33), and “abdominal pain” (31) were most frequently reported; for rectum, these were the scales “quality of life” (74), “fecal incontinence” (62), “pain” (27), “physical function” (25), and “constipation” (25).

Conclusion: The results show that in the pretherapeutic assessment of colorectal patients, the clinicians’ interest mainly focuses on the self-reported quality of life. However, in addition, colorectal cancer-specific symptoms are perceived as important, such as fecal incontinence (for rectum). The results can be used to select specific scales of PROs that are relevant in practice and for further development of these instruments.

Keywords

Patient-reported outcome measures · Colorectal neoplasms · Quality of life · Cancer care facilities · Questionnaires

Supplementary Information

The online version of this article (<https://doi.org/10.1007/s00053-021-00560-2>) contains the results of the online survey as supplementary material, which is available to authorized users.

Availability of data and material

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.



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Specialty	n	%
Surgeon	83	86
Internal medicine	9	9
Others	3	3
Not specified	1	1

Colon cancer is the third most common cancer worldwide [2]. Diagnosis and subsequent treatment decisions are usually dependent on “hard” clinical factors such as tumor stage or comorbidities of the patient [3]. There is an increasing demand to include self-reported symptoms and functional limitations not only as an outcome after treatment, but also before and during therapy [10]. The tools of choice to measure such symptoms and functional limitations are patient-reported outcomes (PRO). These are standardized questionnaires that patients answer themselves and thus provide information about patients’ own assessment of their health status and the symptoms and functional limitations they encounter. In oncology, the European Organisation for Research and Treatment of Cancer Core Quality of Life Questionnaire (EORTC QLQ-C30) is widely used [1], which can be combined with a disease-specific module; for colorectal cancer, this is EORTC QLQ-CR29 [12]. Pioneering work by Bash et al. was able to show that early inclusion of PROs into treatment planning and monitoring leads to a statistically significant increase in life expectancy [4]. Nevertheless, patient-reported outcomes are still very rarely used in colorectal oncologic care [9]. This seems to partly be due to the fact that the questionnaires are very long and thus perceived as impractical for clinical routine (taking the generic module together with the colorectal cancer-specific form, a total of 35 different symptoms and functional scores are captured by the EORTC QLQ questionnaires) [5]. Therefore, it seems to be of high clinical relevance to select those scores that are particularly important from the point of view of the treating clinicians in the pretherapeutic assessment of colorectal cancer patients.

Materials and methods

The CHERRIES framework for reporting online surveys was used for this study [7].

Design, participants, and recruitment process

Coordinators and directors of certified colorectal cancer centers which participated in a PRO study using the EORTC QLQ-C30 and CR29 questionnaires (EDIUM centers¹) were asked to participate in a closed online survey. The survey was hosted on the platform [sosci-survey.de](https://www.sosci-survey.de) between February and March 2021.

All participants gave their informed consent based on information regarding the time required for the survey (approximately 5 min), contact information to study group, and the pseudonymization process before accessing the online survey.

Directors and coordinators of all EDIUM centers were contacted via mail with information about the survey and study purposes. If they were willing to participate, they could access a personalized link. All eligible directors and coordinators were reminded biweekly three times. There were no additional incentives. The study group set up an internal trust office led by SS for contacting and reminding the eligible directors and coordinators. SS did not take part in any data analysis for pseudonymization purposes.

The survey was part of the evaluation process of the EDIUM study and as such has an ethical approval by the Ethics Committees of the Berlin Chamber of Physicians (Eth-19/18).

Questionnaire

The questionnaire was developed by NTS. A first pre-test was performed by CB and CK, both investigators of the EDIUM study group. The questionnaire was then pre-tested by two clinicians of the independent scientific board of the EDIUM study. Any ambiguities relating to the survey questions were revised afterwards and reworded by NTS, if necessary. The final questionnaire consisted of three main questions followed by two optional fields

¹ EDIUM study: “Ergebnisqualität bei Darmkrebs: Identifikation von Unterschieden und Maßnahmen zur flächendeckenden Qualitätsentwicklung”; <https://www.edium-studie.de>.

for any additional comments on the survey or the EDIUM study in general.

The first two questions were (translated) “Which of the following dimensions (disease-specific symptoms and function) of the EORTC questionnaires QLQ-C30 and CR29 are most relevant regarding clinical assessment, treatment preparation, and discussion before a definitive treatment (e.g., surgery) of COLON carcinoma?”² and “Which of the following dimensions (disease-specific symptoms and function) of the EORTC questionnaires QLQ-C30 and CR29 are most relevant regarding clinical assessment, treatment preparation, and discussion before a definitive treatment (e.g., surgery) of RECTAL carcinoma?”³. Both main questions had 35 response options—the number of EORTC QLQ-C30 and CR29 dimensions—and the participants were asked to choose the five most relevant dimensions for them. Afterwards, the participants were to indicate which specialty (internal medicine, surgery, other) they work in.

The survey offered completeness checks and reminded the participants if any question was not yet answered. However, completeness was not compulsory for submitting the survey. After submitting, the respondents were not able to re-submit the questionnaire or change their responses.

Data analysis

Data were descriptively analyzed using R version 4.0.2 (2020.06.22; R Core Team (2020). R: A language and environment

² Original German question: Welche der folgenden Dimensionen (krankheitsspezifische Symptome und Funktionen) aus den EORTC-Fragebogen QLQ-C30 und -CR29 finden Sie für die Behandlungsvorbereitung und -besprechung sowie zur klinischen Beurteilung vor Beginn einer definitiven Therapie (z.B. Operation) für das KOLONKARZINOM besonders relevant?

³ Original German question: Welche der folgenden Dimensionen (krankheitsspezifische Symptome und Funktionen) aus den EORTC-Fragebogen QLQ-C30 und -CR29 finden Sie für die Behandlungsvorbereitung und -besprechung sowie zur klinischen Beurteilung vor Beginn einer definitiven Therapie (z.B. Operation) für das REKTUMKARZINOM besonders relevant?

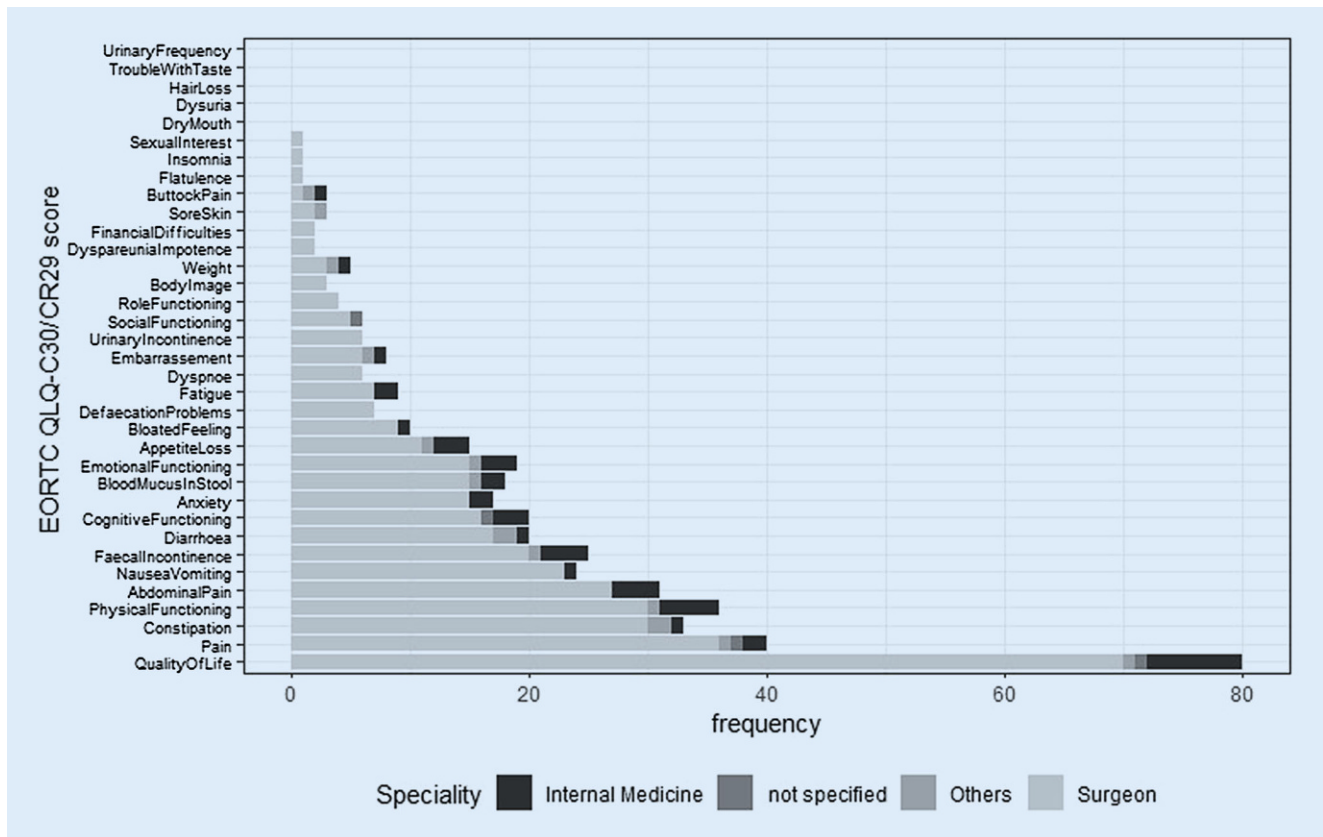


Fig. 1 ▲ Most relevant EORTC QLQ-C30 and CR29 scores for colon cancer (arranged by surgeons' responses)

for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. URL <https://www.R-project.org/>). A summarizing, qualitative analysis of the two "further comments" sections (text fields) was also performed.

Results

Participants and response rates

A total of 203 directors and coordinators of 103 EDIUM centers were asked to participate in the survey. After three biweekly reminders, 96 of the contacted persons submitted the questionnaire, resulting in a response rate of 45.8%. Most of the respondents were surgeons (83 in total, 86%). The frequencies of the different specialities can be found in [Table 1](#).

On average, respondents needed 3.6 min (standard deviation 1.9 min) to answer the survey.

Relevant EORTC QLQ-C30 and CR29 items

Colon cancer

For colon carcinoma, the "quality of life" score was most often chosen to be one of the five most relevant scores (70 of 83 surgeons, 8 of 9 specialists for internal medicine). The other four most frequently chosen scores were: "pain" (36 surgeons, 2 specialists for internal medicine), "physical function" (30 surgeons, 5 specialists for internal medicine), "constipation" (30 surgeons, 1 specialist for internal medicine), and "abdominal pain" (27 surgeons, 4 specialists for internal medicine). The scores "dry mouth," "dysuria," "hair loss," "trouble with taste," and "urinary frequency" were not chosen by any participants. For the exact frequencies, compare [Fig. 1](#) and the supplementary Appendix.

Rectal cancer

For rectal cancer, the "quality of life" score was most often chosen to be one of the five most relevant scores (65 of 83 surgeons, 7 of 9 specialists for internal medicine).

The other four most frequently chosen scores were: "fecal incontinence" (54 surgeons, 6 specialists for internal medicine), "pain" (23 surgeons, 3 specialists for internal medicine), "constipation" (22 surgeons, 1 specialist for internal medicine), and "physical function" (20 surgeons, 4 specialists for internal medicine). The scores "dry mouth," "hair loss," "insomnia," and "trouble with taste" were not chosen by any of the respondents. For the exact frequencies, compare [Fig. 2](#) or the Appendix.

Additional remarks

The participants had the possibility to fill out a text field if they had any additional remarks. Two participants highlighted the importance of the patients' perception of stomal therapy:

"How stressful do patients find a stoma depending on their age and life situation?" (Specialist for internal medicine)

Another participant doubted that any dimensions of EORTC QLQ-C30 and -CR29 should be regarded on their own, as the

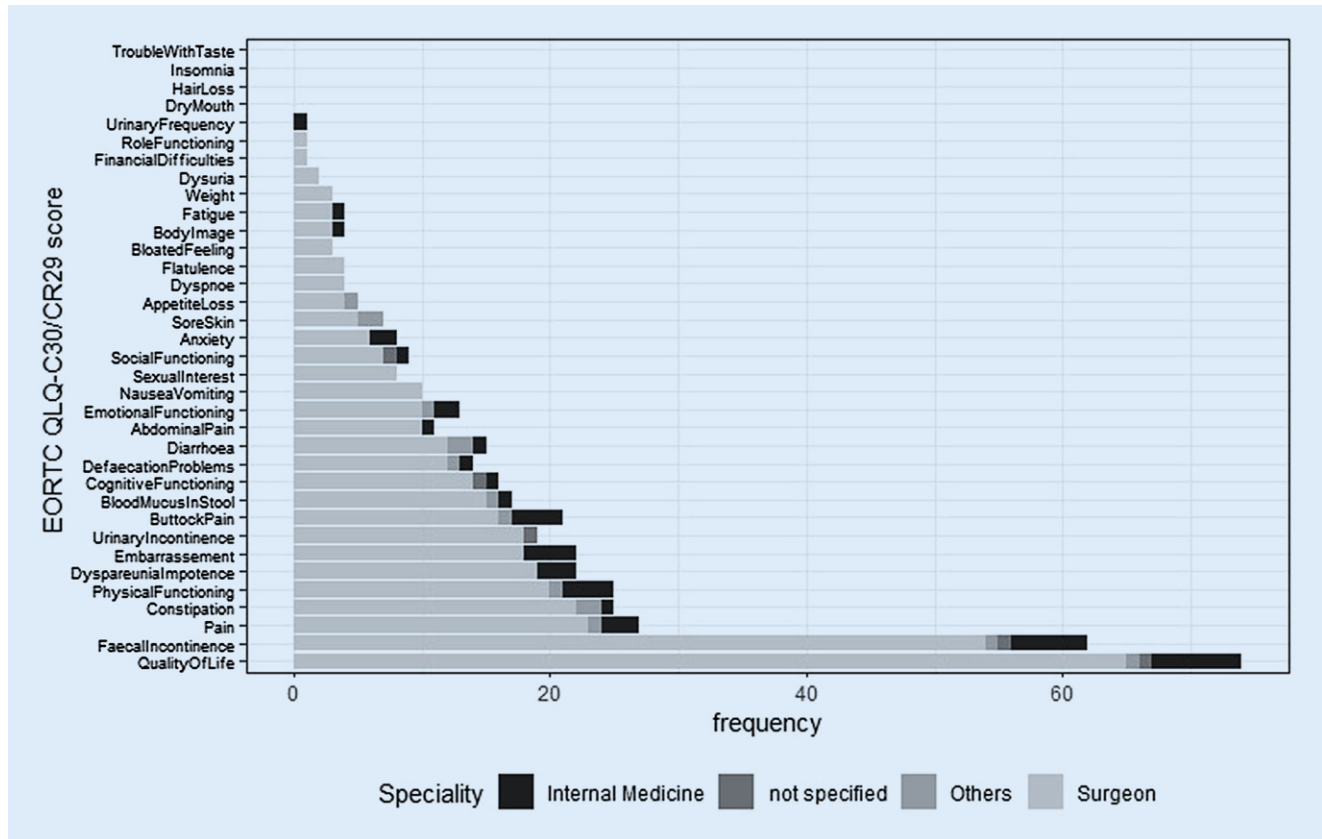


Fig. 2 ▲ Most relevant EORTC QLQ-C30 and CR29 scores for rectal cancer (arranged by surgeons' responses)

overall picture of the patient is most relevant:

"I find the selection problematic. We actually want to have an overall picture. Many of the individual factors listed must be evaluated by the patient and then discussed, whereas others require direct action." (Surgeon)

Moreover, one participant named "sexual life" as an important additional piece of information about the patients, another "psychiatric comorbidities."

Discussion

To the authors' knowledge, this is the first summary and presentation of clinicians' assessment of the relevance of the EORTC QLQ-C30 and -CR29 scores for treatment planning in colorectal cancer patients. First, it should be emphasized that a general summary score such as the quality of life score is most relevant for both rectal and colon cancer from the clinicians' perspective. Differences in the localization of these tumors explain why fecal incontinence is mentioned in second place for

rectal cancer (seventh place for colon cancer). Dyspareunia and impotence, which are frequently mentioned in rectal cancer, can also be explained by the location of the tumor. Symptoms occurring after cancer treatment (e.g., chemotherapy) were not reported at all or rarely (e.g., "trouble with taste" or "hair loss" in both entities).

Our results underline the importance of standardized recording of symptoms and functions in patients with colorectal cancer. However, based on our survey and other findings, it is recommended to make an appropriate selection of EORTC-QLQ scores in order to not overburden patients or clinicians with unnecessary information [8, 11]. The clinicians' particularly strong focus on quality of life also underscores this information's relevance for treatment planning.

Often, however, quality of life is not recorded in a standardized way, but may only be taken into account during the medical history taking. In the interests of equal treatment of all patients and quality assurance in oncologic care, it is advisable to query patients in a structured and thus

binding manner before the start of a therapy rather than to rely on an unstructured anamnesis. If collected in a standardized way, information can only not be lost less easily, but it can also be used by the entire treatment team instead of by a single physician who talked to the patient. Here, too, it seems particularly relevant to restrict oneself to the clinically important scores, in order to promote acceptance among clinicians beforehand—even though one participant strengthened the importance of non-restriction as an additional remark.

Moreover, if patients are actively involved during treatment planning and treatment decision-making by contributing information about their disease burden themselves, and thus by being able to control what is particularly important to them for treatment, the communication between clinicians and patients is strengthened. This contributes to an improvement of colorectal cancer treatment [6].

These results may help to select relevant scores to be queried in one's own care unit. Due to the low level of par-

ticipating specialists in internal medicine, conclusions can be drawn from the current survey mainly for surgical departments. However, since colorectal cancer patients often first encounter surgeons, it seems reasonable to set a main focus on surgically important PROs. Since the EORTC-QLQ instruments were only introduced in many participating centers during the EDIUM study, it is possible that responders are comparably inexperienced in the use of PROs. Further research may investigate whether responses differ in samples with more PRO experience. Moreover, the authors strongly encourage further research in patient-relevant symptoms and functions, which might be others than those important to clinicians. Nevertheless, this is the first listing and survey of the most relevant symptoms and functions—which can be self-reported by the patient—for the treatment decision in colorectal cancer and, as such, should also be included in the clinical oncology daily routine.

Corresponding address

Nora Tabea Sibert

Deutsche Krebsgesellschaft e.V.
Kuno-Fischer-Straße 8, 14057 Berlin, Germany
sibert@krebsgesellschaft.de

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Author Contribution. NTS planned the online survey and analyzed and interpreted the data. The online questionnaire was developed with the aid of NTS, CB and CK. CK and SW lead the EDIUM study. CB, NTS and CK coordinate the EDIUM study. SS led the internal trust office for this online survey. NTS wrote the first draft of the manuscript. All authors read and approved the final manuscript.

Declarations

Conflict of interest. N.T. Sibert, C. Breidenbach, S. Wesselmann, C. Kowalski, and S. Schult are employees of the German Cancer Society, the institution in charge of the EDIUM study. T. Seufferlein is honorary president of the German Cancer Society. S.R. Benz, S. Post, and P. Schloss declare that they have no competing interests.

Welche EORTC QLQ-C30 und -CR29 sind für Kliniker*innen bei der Therapieplanung und -entscheidung relevant? Ergebnisse einer Onlineumfrage

Hintergrund: Darmkrebs ist mit einer erheblichen Beeinträchtigung der Lebensqualität sowie mit krankheitsspezifischen Symptomen und Funktionseinschränkungen verbunden. Diese lassen sich gut mit standardisierten patient-reported-outcomes(PRO)-Instrumenten, wie den EORTC QLQ-C30- und -CR29-Fragebogen, erfassen. Bislang wurde nicht systematisch untersucht, welche der insgesamt 35 Symptome und Funktionseinschränkungen, die mit den EORTC-Fragebogen erfasst werden, für Kliniker*innen relevant sind. Ziel dieser Studie war es zu untersuchen, welche der in den EORTC-Fragebogen erfassten Dimensionen für Kliniker*innen bei der prätherapeutischen Beurteilung der Darmkrebspatienten am relevantesten sind.

Methoden: Eine Onlineumfrage wurde durchgeführt (Februar/März 2021), bei der Kliniker aus zertifizierten Darmkrebszentren gebeten wurden, die fünf relevantesten Skalen (für das Kolon- bzw. Rektumkarzinom) anzugeben. Alle kontaktierten Darmkrebszentren nahmen an der EDIUM-Studie teil, in der die PRO-Instrumente bereits verwendet wurden. Die Umfrageergebnisse wurden deskriptiv ausgewertet.

Ergebnis: 96 von 203 Befragten nahmen an der Umfrage teil (83 Chirurg*innen, 9 Internist*innen, 4 nicht angegeben/sonstige). Für Kolon wurden die Skalen „Lebensqualität“ (n = 80), „Schmerzen“ (40), „Verstopfung“ (33) und „Bauchschmerzen“ (31) am häufigsten genannt; für Rektum die Skalen „Lebensqualität“ (74), „Stuhlinkontinenz“ (62), „Schmerzen“ (27), „körperliche Funktion“ (25) und „Verstopfung“ (25).

Schlussfolgerung: Die Ergebnisse zeigen, dass sich das Interesse der Kliniker*innen bei der prätherapeutischen Beurteilung von Darmkrebspatient*innen v.a. auf die selbstberichtete Lebensqualität konzentriert. Darüber hinaus werden auch krankheitsspezifische Symptome als wichtig empfunden, wie z. B. Stuhlinkontinenz (für Rektum). Die Ergebnisse können für die Auswahl spezifischer Skalen von PROs, die für die klinische Praxis relevant sind, und für die Weiterentwicklung dieser Instrumente genutzt werden.

Schlüsselwörter

Patient-reported-outcome-Instrumente · Kolorektale Karzinome · Lebensqualität · Krebsversorgungseinrichtungen · Fragebögen

As part of the EDIUM study evaluation, this online survey was approved by the Ethics Committees of the Berlin Chamber of Physicians (Eth-19/18). Informed consent was given by the participants.

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Stefan R. Benz, Robert Grützmann, Benno Stinner (Hrsg.)

Chirurgie des Kolonkarzinoms

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Trotz langsam sinkender Inzidenz stellt unverändert die Resektion eines Kolonkarzinoms den häufigsten onkologischen Eingriff in der Viszeralchirurgie dar. Methodisch, publikatorisch und hinsichtlich Prognoseverbesserung war es lange ein Stiefkind gegenüber dem Rektumkarzinom und den Tumoren des Oberbauchs. Hinzu kommt, dass kein anderer viszeralchirurgischer Tumor an so vielen verschiedenen Kliniken von ein so großen Zahl Chirurgen und Chirurginnen operiert wird.

Alles dies spricht – zusammen mit der Entwicklung und Verbreitung neuerer Techniken – dafür, dass gerade für dieses Krankheitsbild ein großer Fort- und Weiterbildungsbedarf besteht. Dieser Bedarf wird vom vorliegenden Werk in hervorragender Weise befriedigt.

Auf über 500 Seiten in 36 Kapiteln wird von 60 renommierten Autoren aus dem deutschsprachigen Raum das Krankheitsbild in allen seinen Aspekten beleuchtet. Der Bogen ist weit gespannt von der Historie und Anatomie über Bildgebung, Endoskopie, Pathologie bis hin zu Chemotherapie, Palliation und Strukturvoraussetzungen. Wesentlicher und entscheidender Kern des Buchs sind aber die Kapitel zur operativen Therapie, insbesondere der Technik und intraoperativen Taktik bei der kompletten mesokolischen Exzision, die extensiv und detailliert in Wort und Bild für alle Tumor-Lokalisationen, -Stadien und Zugangstechniken erläutert wird. Optisch herausgehobene Praxistipps, „CAVE!“-Warnungen, gute Abbildungen, Tabellen, Zusammenfassungen und adäquate Literaturverzeichnisse erhöhen die Lesbarkeit und Anschaulichkeit und runden das Ganze didaktisch exzellent ab.

Kleinere Inkonsistenzen in der verwendeten Nomenklatur, bei Angaben zu Varianten-Häufigkeiten und kleineren operativen Details sind der einzige mögliche Kritikpunkt, können aber den Gesamtwert des Werkes nicht im Geringsten schmälern und sind bei der Vielzahl der Autoren wenig verwunderlich.

Zusammenfassend ist dieses Werk uneingeschränkt allen onkologisch tätigen Viszeralchirurgen zu empfehlen. Es stellt eine große und in hohem Maße praxisrelevante Bereicherung der (nicht nur deutschsprachigen) Literatur dar. Seine Lektüre sollte zur Voraussetzung gemacht werden, bevor angehende Viszeralchirurgen Kolonkarzinome reseziieren dürfen. Auch Erfahrene können manches Neue lernen. Selten hatte der Rezensent so wie hier den Eindruck, dass die weite Verbreitung eines einzelnen Buchs das Potenzial hat, die Prognose der betroffenen Patienten flächendeckend zu verbessern.

S. Post (Mannheim)