



Follow-up of colon cancer patients; causes of distress and need for supportive care: Results from the ICARE Cohort Study

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Abstract

Background: Colon cancer survivors experience physical and psychosocial problems that are currently not adequately addressed. This study investigated distress in patients after curative surgery for colon cancer and studied how this corresponds with the need for supportive care. **Methods:** Prospective cohort of patients with stage I–III colon carcinoma, treated with curative intent, currently in follow-up at 6 different hospitals. A survey recorded symptoms, experienced problems, and (un)expressed needs. Satisfaction with supportive care was recorded. **Results:** Two hundred eighty four patients were included; 155 males and 129 females, with a mean age of 68 years (range 33–95), and a median follow-up of 7 months. 227 patients completed the survey.

Patients experienced a median of 23 symptoms in the week before the survey, consisting of a median of 10 physical, 8 psychological and 4 social symptoms. About a third of these symptoms was felt to be a problem. Patients with physical problems seek supportive care in one in three cases, while patients with psychosocial problems only seek help in one in eight cases.

Patients who recently finished treatment, finished adjuvant chemotherapy, or had a stoma, had more symptoms and needed more help in all domains.

Patients most frequently consulted general practitioners (GPs) and surgeons, and were satisfied with the help they received.

Conclusion: Colon cancer survivors experience many symptoms, but significantly fewer patients seek help for a psychosocial problem than for a physical problem. Consultations with supportive care are mainly with GPs or surgeons, and both healthcare providers are assessed as providing satisfying care.

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Keywords: Colon cancer; Follow-up; Patients; Symptoms; Needs; Supportive care

Introduction

Colorectal cancer (CRC) is one of the most common types of cancer, with more than 15,000 new patients in the Netherlands in 2015.^{1,2} Increasing incidence, improved treatment, and a recent national screening programme

involving faecal occult blood tests and colonoscopy to detect CRC at the earliest possible stage will lead to a considerable rise in the number of patients that are treated with curative intent.^{1–5} After curative treatment for colon cancer, patients are monitored for five years in a follow-up programme that includes periodic laboratory and imaging examinations, and regular consultations.² The national guideline does not recommend which healthcare provider should coordinate follow-up, which accounts for different

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healthcare providers being involved at different hospitals. Nevertheless, all current follow-up is carried out in secondary care, and focuses mainly on detection of recurrent disease. Patients after treatment for cancer, however, apart from being older with more comorbid conditions, experience distress by symptoms in several domains, and have unmet needs regarding supportive care.^{6–9} A survey performed by our study group in 2013 concluded that only half of all patients and physicians in the Netherlands currently involved in colon cancer follow-up were satisfied with the identification of psychosocial problems.¹⁰ Accordingly, identifying causes of distress in patients after treatment for colon cancer, and addressing the need for supportive care remains complex.

The complexity of distress and unmet needs in patients after treatment for colon cancer has led the Dutch Health Counsel, the Dutch Cancer Society, the Federation of Cancer Patients, and the College of General Practitioners to advocate incorporating cancer follow-up into primary care due to its more patient-centred orientation.^{3,4,11} Colon cancer appears to be a suitable candidate because of its high prevalence, older population with frequent comorbid conditions (which are already managed in primary care), and relatively straightforward follow-up schedule.¹² To be able to prepare for future high quality care, we need to understand the causes of distress in patients after treatment for colon cancer, how these lead to specific care needs, and to what extent patients express these needs to healthcare professionals.

This study therefore investigates distress in patients after treatment of colon cancer caused by symptoms and problems in the physical, psychological and social domains. Furthermore, we studied patients after treatment of colon cancer for (un)expressed needs and satisfaction with current supportive care to prepare general practitioners for future colon cancer follow-up.

Patients and methods

Patients

We formed a cohort of colon cancer patients after surgery with curative intent. Recruitment was done at the outpatient clinics of the departments of surgery, oncology and gastroenterology of six Dutch hospitals, depending on which department organised follow-up. Patients were eligible with carcinoma located in the colon, defined as a tumour located 15 cm above the anal verge. Patients with stage I, II, or III disease were included, and also eligible if they had a (temporary) stoma or if they received adjuvant chemotherapy. Patients were excluded in case of stage IV disease, hereditary colorectal cancer, cancer in a patient with inflammatory bowel disease, rectal cancer, (sub)total colectomy, proctocolectomy, history of other primary cancer, or if they had complications during or after surgery where specialised care during the follow-up period was needed.

The inclusion period was November 2013 until November 2014. We identified patients by means of hospital databases used for follow-up planning. After inclusion, patients were divided into four groups. Group 1 consisted of patients who had undergone surgery within the previous 6 months and did not receive chemotherapy. Group 2 were patients currently undergoing adjuvant chemotherapy. Group 3 consisted of patients who had recently (up to 3 months prior) completed adjuvant chemotherapy, and Group 4 consisted of all patients who had finished treatment (surgery and/or adjuvant chemotherapy) more than 6 months ago.

Methods

All patients received written study information. After consent was obtained, patients were asked to complete the survey within one week. This provided information on sociodemographic background and comorbid conditions. Information about cancer characteristics and treatment was obtained from patients' hospital records.

Patient-reported outcomes were measured using a survey derived from existing validated questionnaires: EORTC QLQ-C30,¹³ EORTC QLQ-C29,¹⁴ the Impact on Participation and Autonomy Questionnaire,¹⁵ the Short Questionnaire to assess Health-Enhancing Physical Activity,¹⁶ and the Consumer Quality Index.¹⁷ The survey included 67 specific symptom items: 30 questions on physical symptoms, 21 on psychological symptoms, and 16 on social symptoms. For those patients having a stoma, 7 additional questions on stoma-related problems were added. Questions concerned symptoms in the week before the survey. The answers to the questions were given on a four-point Likert scale, ranging from 'not at all' to 'very much'. If subjects reported having a specific symptom (from 'a bit' to 'very much'), additional questions were asked to assess if reported symptoms were experienced as bothersome (further referred to as a 'problem'), whether patients were in need of (professional) help for this problem, and whether they actually did consult a healthcare professional for this issue. If a patient felt in need of help for a problematic symptom, but did not actually seek help, it was labelled as an '*unexpressed* need'. If a patient did seek help for a problematic symptom, it was labelled as an '*expressed* need'.

When a patient reported consulting a healthcare professional, additional questions were asked on which professional was consulted, and how satisfied the patient was with the care they received. Satisfaction with healthcare professionals was reported on a five-point Likert scale ranging from 'very dissatisfied' to 'very satisfied'.

Statistics

The data were collected using an online survey programme (SurveyMonkey) and analysed using SPSS Statistics 23. The independent samples *t*-test and Mann–Whitney *U*

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