



Establishment of a nurse-led clinic for late complications after colorectal and anal cancer surgery: a descriptive study

Jacob Rosenberg¹ · Birthe Thing Oggesen¹ · Marie Louise Sjødin Hamberg¹ · Anne Kjaergaard Danielsen¹

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Abstract

Purpose Survival rates after colorectal and anal cancer are increasing and more patients have late complications to treatment. This represents a clinical field under development, and we have established a specialized clinic for late complications after colorectal and anal cancer. With this paper, we want to give our experiences and present the organizational setup with a nurse as the primary contact person.

Methods We have established a multidisciplinary clinic for the treatment of late complications and the clinic is organized with specialized nurses as the front persons. The structure includes a stepwise increase in expertise level when needed, and the patient has one common entry regardless of symptoms. Initial screening is performed by an electronic questionnaire which is followed up by a consultation with the nurse. The nurse can provide primary treatment according to local algorithms developed in the clinic and refer the patient to more specialized care if needed.

Results Experiences from the first year of service show that more than half of the patients needs this and wants consultation in the late complication clinic. We also found that most of the consultations were performed successfully by phone instead of by physical visits, and the most common clinical problem was bowel symptoms including diarrhea and urge.

Conclusion We have established a nurse-led clinic for late complications after colorectal and anal cancer. There seems to be a high need for this function in a department taking care of colorectal and anal cancer.

Keywords Late complications · Colorectal cancer · Anal cancer · Survivorship · Outpatient clinic

Introduction

Worldwide, colorectal cancers have 1.8 million incident cases annually and hold the second-largest mortality rate [1], and cancer of the bowel was one of the three most prevalent cancers worldwide [2, 3]. More patients survive for a longer time after diagnosis and thereby more patients are living with cancer as cancer survivors [4, 5]. However, there is growing evidence of risk for late complications after surgical and oncological treatment of the diseases [6–9]. Thus, late complications and symptoms after treatment for colorectal and anal cancers are common and they include bowel

symptoms [10–13], urinary problems [14–17], sexual dysfunction [8, 18], depressive symptoms [19, 20], fatigue [21, 22], sleep problems and alterations in social and physical activities [23, 24], chronic pain [25], nutritional issues, and resulting late return to work [26].

Identification of late complications and relevant treatment options are either not available or are not implemented or standardized in health care [8, 9]. Therefore, we set up a multidisciplinary clinic treating patients with a need for survivorship-treatment after colorectal and anal cancer surgery, and patients were invited to the clinic after screening for late complications. Patients are systematically screened for any signs of late complications after cancer treatment and with a planned follow-up of 3 years. Late complications are defined as any new symptoms the patient experience after cancer treatment, but to exclude self-limiting conditions after the cancer treatment we wait 3 months before we screen for late complications. Researchers and clinicians in Denmark and internationally have reported on the need to focus on late complications in a research-based setting [27]. However, it

Jacob Rosenberg and Birthe Thing Oggesen share the first authorship.

✉ Jacob Rosenberg
jacob.rosenberg@regionh.dk

¹ Department of Surgery, Herlev Hospital, University of Copenhagen, 2730 Herlev, Denmark

is not only important to present research results but also to present how and why clinics may be set up.

The aim of our study was to present the establishment of a clinic for the treatment and care of patients with late complications after colorectal and anal cancer surgery with a focus on staffing and the structure of the clinic. Secondly, we will report the preliminary results covering the first year on the characteristics of patients with late complications and details on the clinical contacts.

Patients and methods

This was a descriptive study reporting results of the implementation of the multidisciplinary clinic and the screening process for identifying late complications, and the study is reported according to Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines [28]. All patients undergoing surgery for colorectal or anal cancer, who can participate in either an electronic or paper-based survey, receive an invitation for long-term follow-up in the clinic for late complications. Patients are invited regardless of tumor stage or type of surgery. The clinic opened October 1, 2020, and we here report our experiences from the first year.

A multidisciplinary out-patient clinic was implemented with the aim of nurses being the primary providers of the initial treatment in the clinic [29–31]. The clinic for late complications is part of a large out-patient-clinic treating patients with medical as well as surgical gastroenterological symptoms or diseases. The clinic is led by specialized nurses on a day-to-day basis with close supervision by a dedicated surgeon (BTO). The clinic can draw on specialists

from other areas such as, but not limited to, gastroenterologists, urologists, gynecologists, dieticians, sexologists, and psychiatrists.

The clinic uses a stepwise increase in expertise level provided to patients when needed (Fig. 1). The clinic is organized with one common entry for patients with late complications regardless of the type of complication and type of cancer. After initial screening and invitation to the clinic, patients are interviewed by one of the specialized colorectal nurses in the clinic. Based on a dialogue with the patient about their own assessment of symptom severity, the nurse will prescribe the relevant treatment within delegated rights provided by the surgical specialist specifically to the named clinic nurses. This typically comprises initial treatments for bowel symptoms, sexual dysfunction, depressive symptoms and fatigue, and referral to other clinical specialties such as gastroenterology, urology, gynecology, and psychiatry. Nurses in the clinic for late complications use treatment algorithms developed in the clinic and may always confer problems with the surgeon (BTO) on a day-to-day basis. If the problem cannot be handled locally, then various surgeons and physicians get involved depending on the clinical problem. The nurses recruited to the clinic were highly experienced colorectal nurses and received special training and are continuously supervised by the responsible surgeon (BTO).

When attending the regular out-patient clinic for the first time after leaving from the hospital, patients will be informed about the clinic for late complications and offered participation in the survey at 3, 6, 12, 24, and 36 months after surgery. Questionnaires (Table 1) will be sent out either electronically (via Research Electronic Data Capture (REDCap) [32] to e-box [33]) or in a paper version depending on the patients' wishes. Prior to sending out

Fig. 1 Stepwise increase in expertise level provided to patients when needed. LC, late complications; MDT, multidisciplinary team

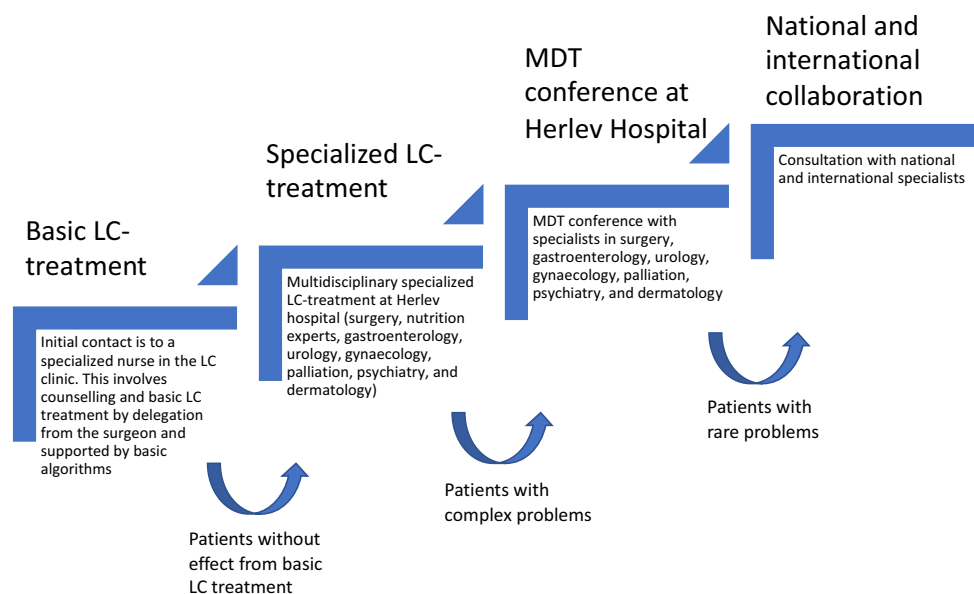


Table 1 List of questionnaires in the electronic survey. Patients will answer the first compound questionnaires before the first consultation in the clinic**Bowel symptoms**

The LARS-score [41] is a five-item validated questionnaire evaluating bowel function after rectal surgery and including issues related to incontinence (flatus and stool), frequency of bowel movements, clustering, and urgency of stool

The Patient Assessment of Constipation Symptoms (PAC-SYM) questionnaire is a 12-item tool aimed at assessing patients' experiences with constipation over time [42]

The Bristol Stool Chart was developed to evaluate the effectiveness of treatments for various diseases of the bowel with the use of a clinical marker for bowel transit time [43]

The St. Mark's incontinence score is widely used to evaluate the severity of fecal incontinence [44] and is appropriate for the assessment of fecal incontinence and of a treatment outcome [45]

The colostomy impact Scale [46] is a scoring system quantifying the negative impact on patients when living with an end-colostomy

Urinary symptoms

International Consultation on Incontinence Questionnaire Female Lower Urinary Tract Symptoms Module (ICIQ-FLUTS) is a patient completed questionnaire for assessing female lower urinary tract symptoms and impact on patients [47]

International Consultation on Incontinence Questionnaire Male Lower Urinary Tract Symptoms Module (ICIQ-MLUTS) is an instrument aimed at evaluating male lower urinary tract symptoms [48]

Sexual dysfunction

The Female Sexual Function Index (FSFI) is a brief questionnaire with 19 questions used for self-reporting of female sexual function in women across a wide age range, including post-menopausal women [49]

International Index of Erectile Function Scale (IIEF) is a 15-item self-administered questionnaire that assesses five domains of male sexual function, including EF, orgasmic function, sexual desire, intercourse satisfaction, and overall satisfaction [50, 51]

Pain

The rectal cancer pain score is an instrument assessing patients' sensation of pain after pelvic surgery for rectal cancer [25]

Depressive symptoms

The Major Depression Inventory (MDI) [52] was developed to identify depressive symptoms as well as to diagnose levels of depression in mild, moderate, and severe depression

Fatigue

The EORTC Quality of Life Module measuring cancer-related fatigue (EORTC QLQ-FA12) [53] is a 12-item validated instrument assessing fatigue from the patient's perspective covering feelings of cognitive, emotional, and physical fatigue

Health-related quality of life

The EuroQol 5D(imensions)-5L(evels) (EQ-5D) [54] measures health status and is a generic measure of health. It comprises five dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression), and each dimension is rated on five levels

General questions on nutrition, physical activity, social contacts, and symptoms not covered by the questionnaires

Questions on nutrition focus on any adverse symptoms related to eating and drinking. Physical activity and social contacts are based on validated questions used in a rapport on the health profile of the Danish Population [55]

a questionnaire, patients are informed about the survey and consent to participate will be obtained, and if needed patients will be given the opportunity of direct telephone contact with the nurse or doctor to clarify any questions. Apart from this, patients will be asked to consent to the retrieval of data from the medical charts. After consent to participate has been confirmed, the patient will receive the questionnaire and will be invited to reply within 2–4 weeks of receiving it. Apart from the questionnaires sent to patients (see Table 1), the following variables will be registered from the medical charts: Diagnosis (ICD-codes), TNM-stage, type of surgery, acute or planned surgery, date of surgery, stoma (yes/no), type of stoma and expected duration of stoma, chemotherapy and radiation therapy (yes/no), ASA-status, COVID-19-status (yes/no, if yes, positive/negative), BMI, comorbidity, and possible treatment. Based on patients' wishes, they are offered a consultation in the

outpatient clinic for late complications either by phone or as a physical visit. This offer is placed at the end of each questionnaire, where the patient can indicate if they want the late complication clinic to contact them or not.

The study is descriptive, and no statistical testing of data was therefore performed. The study was approved by the Danish Data Protection Agency (P-2020–134). Study data were collected and managed using REDCap hosted in the Capital Region of Denmark. REDCap is a secure, web-based application designed to support data capture for research studies [32]. The Regional Committee on Health Research Ethics was contacted and has documented that the project was exempt from formal ethics committee approval (Journal-nr.: 20,033,634). Patients were informed about the survey and consent was obtained either by digital signing or in paper and complied with all principles of the Helsinki Declaration [34].

Results

A total of 457 patients were invited to participate during the first year, and 269 (59%) have agreed to answer the initial questionnaires where only 37 (8%) patients wanted them on paper. From the answers that we have collected until now, 143 of 166 (86%) eligible patients with colon cancer, 57 of 71 (80%) eligible patients with rectum cancer, and 26 of 32 (81%) eligible patients with anal cancer have answered one or more questionnaires.

Details for the contacts are given in Table 2. It shows that the majority of contacts could be handled by phone, the average length for each contact was around half an hour, and most contacts were handled by the nurse. The most common clinical problem was bowel symptoms typically diarrhea and urge. Other problems, but not as common as bowel symptoms, were urological issues, sexual dysfunction, pain, psychiatric issues, psycho-social problems, and stoma problems.

The late complication clinic is organized with a stepwise increase in expertise level (Fig. 1). It is intended as a one-stop shop for the patient regardless of the type of problem and number of problems. The first person that meets the patient (by phone or in person) is a specialized nurse who may counsel and provide initial treatment after a specific delegation from the surgeon according to basic algorithms. This will in many cases be sufficient, and around half of the patients does not need more contacts or further treatment than this. If the clinical problem is not solved, then the specialized nurse can refer the patient directly to a specialized

surgeon or physician depending on the type of problem. In some cases, there may be a need for a multidisciplinary conference including various specialists and this is set up on a need-basis. We further expect that few patients with severe and rare problems may be discussed with our international network, although this has not been necessary until now. Thus, the central professional in our late complication clinic is the specialized nurse who takes care of the initial contact with the patient and may handle primarily treatment according to pre-specified algorithms.

The late complication clinic was initially set up so we could involve to different specialists such as experts in surgery, gastroenterology, urology, dermatology, gynecology, sexology, palliation, anesthesiology, stoma experts, nutrition experts, and psychiatrists if needed. As seen in Table 2, the most common problem has been bowel symptoms that could in most cases be handled by the specialized nurse according to our local algorithms, and in some cases, the nurse has drawn on the expertise of our gastroenterologist and the surgeon in charge of the clinic.

Discussion

We established a clinic for late complications after treatment of colon cancer, rectum cancer, and anal cancer. The clinic is run on a day-to-day basis by specialized nurses using basic algorithms for the treatment of symptoms,

Table 2 Type of contacts from first to fifth contact with the patients. The table also shows the average length of the contact, the clinical problems, and who handled the contact in the clinic for late complications. Numbers are given as contacts except for the length of contact (average, minutes)

	1st contact	2nd contact	3rd contact	4th contact	5th contact
Phone	135	74	35	11	3
Visit	17	7	3	2	0
Total	152	81	38	13	3
Length of consultation (average, minutes)	35	26	26	35	32
Clinical problem					
Palliation	0	1	1	1	0
Urology	11	5	2	1	1
Sexual dysfunction	11	7	5	1	0
Gynecology	4	0	1	0	0
Pain	8	1	0	0	0
Psychiatry	7	2	1	0	0
Gastrointestinal	90	55	25	11	3
Fatigue	4	0	0	0	0
Stoma problems	9	2	1	1	0
Dermatology	4	5	1	0	0
Psycho-social	26	13	5	1	2
Person taking care of the consultation					
Surgeon	35	24	10	3	1
Nurse	115	57	27	10	2

and only, if treatment fails, a qualified doctor is involved. Our initial experience from the first year shows that a vast majority of problems are bowel symptoms with diarrhea and urge. The second-largest category of symptoms is psycho-social. This category is probably large because it ranges widely, including patients with simple questions or worries about the follow-up program, many patients needing to address their experiences of being a cancer survivor, and only a few patients have depressive or anxiety symptoms. Thus, many patients can be handled by a specialized nurse, and if a doctor is needed, then a gastroenterologist or a surgeon will be involved. Initially, we set up close collaboration with specialists from many specialties in the hospital but based on our experiences from the first year it may not be necessary to involve these many specialists from the beginning. Only in complex and rare problems it is needed to contact specialists from other areas, and we have for this organized an MDT (multidisciplinary team) function where we can discuss these rare cases. Initially, the patient fills out an electronic questionnaire that will form the basis and is very helpful for the subsequent consultation. Most patients can handle the electronic questionnaire and only few will require a paper version. It is also interesting that the majority of consultations could be sufficiently handled by phone without the need for a physical meeting at the hospital.

A cross-sectional survey in a late complication clinic should focus on patient-reported outcomes [7, 35–37]. The patient-centered approach at the initial contact guided the exploration of symptoms, so questions would not only focus on well-known symptoms but also on symptoms that were more seldom. Furthermore, participants were prompted to identify any other symptoms that they might have experienced after cancer treatment. Where possible, validated questionnaires were used in full, and furthermore, we added questions from questionnaires aimed at social interaction and physical activity. We researched the following symptoms: bowel symptoms, stoma problems, urinary tract symptoms, sexual dysfunction, pain, social interaction, physical activity, changes in educational or professional life, fatigue, depressive symptoms, changes related to the intake of fatty nutrition, and health-related quality of life. Moreover, patients were given a list of late complications where they could tick off any symptoms that they deemed relevant.

Treatment algorithms for late complications after colorectal and anal cancer are scarce [9, 38], and we have therefore with help from specialists collaborating with the clinic developed a set of basic treatment algorithms for treating symptoms and to guide nurses in the clinic. Important elements of the organization of our late complication clinic are that we have put a nurse in front and delegated prescription rights to this person. If treatment failure or complex

problems occur, the nurse can refer the patient to a relevant specialist. This also enables a one-stop shop for the patient so it will not be necessary to consult many different specialties/clinics, and instead, the patient can go to one place that will handle all the problems. Thus, interprofessional collaboration within the clinic and care coordination is not left for the patient to deal with, as they need coordination of care [39]. Our model also involves multidisciplinary conferences for complex and rare cases if needed.

In the electronic questionnaire, we have used patient-reported outcomes, and thereby it enables health professionals to be more attentive to problems that are not traditionally studied as complications of treatment and disease, thereby having the chance to alleviate symptoms that may not traditionally focus on the traditional health professionals [40]. Our organization may also have limitations. We do not know if we screen for all the relevant symptoms, but we have chosen a broad battery of patient-reported outcomes in our questionnaires, and hopefully, we cover the most relevant symptoms. We will, however, continuously gather experience from our integrated patient care and thereby pick up areas needing attention. We also chose a broad battery of symptom questionnaires to facilitate a research-based approach, and maybe some of the questionnaires can be left out in the future. Since we ask the questions in our native language, Danish, there is a risk that we exclude some patients that do not fully master the Danish language.

We have made a concept for detecting and treating late complications after colorectal and anal cancer treatment. Since this setup is replicable, we have invited other hospitals to copy our model and this work is ongoing. We want to explore more about this clinical setup and hopefully improve the concept, and therefore, we have planned both qualitative and quantitative research in this field.

In conclusion, we have established a clinic for late complications after colorectal and anal cancer and we have chosen to put a specialized nurse in front taking care of the initial contact and treatment algorithms with the patient. Thus, the surgeon has delegated limited prescribing rights to the specialized nurse. If necessary, the nurse will contact surgeons or physicians of relevance to the patient's needs. Most consultations have been performed by phone and the most common problems have been bowel symptoms including diarrhea and urge.

Author contribution All authors contributed to the study conception and design, material preparation, data collection, and analyses. The first draft of the manuscript was jointly written by J. R., B. T. O., and A. K. D., and all authors revised it critically. All authors have read and approved the final version for publication.

Data, material, and/or code availability Data are in general not available because of barriers in Danish law, but with a reasonable request to the corresponding author, specific aggregated data may be shared.

Declarations

Ethics approval The study was approved by the Danish Data Protection Agency (P-2020–134). Study data were collected and managed using Research Electronic Data Capture (REDCap) tools hosted in the Capital Region of Denmark. The Regional Committee on Health Research Ethics has been contacted and has documented that the project is exempt from approval (Journal-no.: 20033634). The study complied with all principles of the Helsinki Declaration.

Informed consent Patients were informed about the survey and consent was obtained either by digital signing or on paper.

Conflict of interests The authors declare no competing interests.

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