

BMJ Open Readiness for cancer rehabilitation in Denmark: protocol for a cross-sectional mixed methods study

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ABSTRACT

Introduction: Rehabilitation is a key element in most cancer care policies in recognition of the often unmet physical, psychological and social needs among the rising numbers of patients with cancer. A systematic assessment of patients' needs and available rehabilitation services constitute the foundation for timely, comprehensive and coordinated cancer rehabilitation. This study aims to provide insight into the current organisation and practice of cancer rehabilitation in Denmark with special emphasis placed on the assessment of patients' needs and availability of services across the cancer treatment trajectory.

Methods and analysis: A cross-sectional design using a mixed methods approach will be used in order to analyse the readiness for cancer rehabilitation in different sectors and from differing perspectives. Substudy 1 consists of an electronic survey among the 98 Danish municipalities and focuses on the availability and use of cancer rehabilitation services for patients with all types of cancers. In substudy 2, a survey among the 19 surgical and 12 oncological departments involved in colorectal cancer treatment in Denmark is conducted in order to describe the current clinical practice regarding the assessment of rehabilitation needs and referral to services. Substudy 3 involves a retrospective clinical audit and semistructured interviews at four randomly selected surgical and oncological departments treating colorectal patients with cancer in order to elucidate current needs assessment practices.

Ethics and dissemination: The study was approved by the Danish Data Protection Agency and will be conducted in accordance with the principles of the Helsinki Declaration. Representatives from municipalities and clinical practice are engaged in the design and execution of the study in order to ensure the usefulness of survey instruments, reflexive interpretation of data and transfer of implications into practice.

Results: Published in international peer-reviewed scientific journals and presented at conferences, seminars and as short reports.

INTRODUCTION

Increasing attention focuses on how to adapt healthcare systems to meet the complex

Strengths and limitations of this study

- The study provides insight into current practices regarding assessment of patients' rehabilitation needs and referral to rehabilitation services in a cross-sectional perspective, thereby encompassing large parts of the care pathway from the onset of treatment in hospitals and into the community.
- The study will enable the identification of gaps between policies and practice, and point to strategies of overcoming these gaps. The findings from this study thus hold great potential in informing future policy-making within the field of cancer rehabilitation and in enabling better implementation of these policies across different sectors of healthcare systems.
- The findings of this study are context-dependent as the organisation of cancer rehabilitation (eg, delineation of care responsibilities across sectors, out-of-pocket payments, and referral routes) vary between countries with impact on rehabilitation practices. Therefore, findings need to be properly contextualised and caution must be taken in transferring implications for practice to healthcare systems characterised by different funding, governance and provision compared with the Danish publicly funded healthcare system.

physical, psychological and social needs among the growing number of patients with cancer.^{1–3} Rehabilitation needs are complex and shaped by disease severity, the complexity of surgical and oncological treatments, as well as patient characteristics such as age, comorbid conditions, health behaviour and socioeconomic position.^{4 5} Principles underpinning cancer rehabilitation programmes are a biopsychosocial understanding of illness, focus on early assessment of needs and an emphasis on securing a continuous and tailored rehabilitation plan encompassing needs and resources for the individual patients and their relatives.^{2 3 6} Timely, comprehensive and coordinated cancer rehabilitation entails systematic screening of those



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patients in need of rehabilitation services and it necessitates available and accessible high-quality services for the subgroup of patients who need organised cancer rehabilitation during and following cancer treatment. Throughout the cancer treatment trajectory, patients' physical, psychological and social needs may change and different service providers situated in primary care, at hospitals and in the communities where patients live are therefore relevant key persons in the cancer rehabilitation. Correspondingly, a multitude of interventions targeting rehabilitation needs should be made available for those who need help in managing the consequences of cancer. Cancer rehabilitation therefore comprises a wide range of activities such as physical training, psychological counselling, information on economic and work-related issues and support groups.

In the research literature, unmet rehabilitation needs have been documented among a substantial proportion of current and former patients with cancer with negative effect on quality of life, ability to return to work and morbidity.^{5 7-12} Reasons for this suboptimal situation are complex and rooted in an interplay of patient, provider and organisational factors influencing access to and use of appropriate services.^{13 14} Communication barriers in the patient-provider encounter and between providers, insufficient support for providers in screening for rehabilitation needs, suboptimal care coordination, lack of clear delineation of responsibility among providers and a mismatch between available services and patient preferences are just some of these explanatory factors.¹⁵⁻¹⁷ Calls have been made for more comprehensive cancer care plans that address the multitude of rehabilitation needs experienced by patients with cancer and contextualise these needs in the immediate and wider social circumstances of each patient.^{1 13 18} Several countries have developed policies seeking to integrate rehabilitation into the cancer treatment trajectory.^{2 3 19 20} Implementing these policies into practice may be challenging, particularly as comprehensive cancer treatment trajectories involve a range of health and social care providers from primary and secondary care, and increasingly also community-based organisations including municipalities and patient organisations.

Within accelerated clinical care pathways, securing timely and systematic assessment of the rehabilitation needs of patients with cancer and their subsequent referral to appropriate rehabilitation services across sectors and across time is a challenge that needs to overcome if the potential benefits of comprehensive cancer rehabilitation services are to be realised. Insight into the current organisation of cancer rehabilitation is needed in order to analyse gaps between policy recommendations and practice and subsequently devise strategies enabling the realisation of the goal of coordinated, comprehensive cancer rehabilitation for those patients who need this.

Differences in the organisation and management of healthcare systems influence the organisation and

management of cancer rehabilitation.² Geographical distances to services or lack of health insurance coverage may impede access to cancer rehabilitations in, for example, the USA whereas barriers in countries with tax-financed healthcare services covering populations living in smaller geographical areas may be of a different nature. This study explores cancer rehabilitation in Denmark which is a rather small country with a total of 5.6 million inhabitants. Politically and administratively, Denmark is divided into three levels each involved in the planning and delivery of healthcare services: the state, 5 regions and 98 municipalities.²¹ The Danish cancer management programme published in 2012 outlines the overall integrated and coordinated organisation of cancer rehabilitation which has to be implemented by 2013.²² In terms of cancer rehabilitation, municipalities are responsible for organising rehabilitation at a general level whereas hospitals are required to provide highly specialised rehabilitation for those patients who need this. Services are free of charge and time-limited involving a specified number of activities for each patient. Patients are referred to these services either by their general practitioner or by oncologists/medical staff at hospitals. In addition to this national cancer care plan, integrated care plans have been developed for specific cancers including colorectal cancer.²³

Our aim with this cross-sectional, mixed methods study is to provide insight into the organisation and practice of cancer rehabilitation in Denmark with special emphasis placed on assessments of patients' needs and availability of services in different phases of cancer treatment trajectories involving different sections of the healthcare system. We explore this in three substudies. In substudy 1, the availability and use of cancer rehabilitation services targeting all types of cancers are explored in a survey among all Danish municipalities. In substudies 2 and 3, we narrow our focus to colorectal patients with cancer who comprise a large, diverse and understudied group of patients with cancer and in addition often experience multiple and complex rehabilitation needs.²⁴⁻²⁷ In substudy 2, we use survey methodology to describe the current clinical practice regarding assessment of rehabilitation needs and referral to appropriate services in surgical and oncological departments treating patients with colorectal cancer. Finally in substudy 3, we conduct a clinical audit exploring the systematic identification and documentation of rehabilitation needs in patient files among four randomly selected surgical and oncological departments treating colorectal patients with cancer.

By combining different perspectives and different methodologies, this study will enable the identification of gaps between the principles of comprehensive, coordinated rehabilitation as stipulated by the Danish cancer management programme and the current practice in the clinical encounter and after a patient's transition to community-based cancer care. Insight into encountered barriers for cancer rehabilitation and strategies

developed to overcome these barriers, may inform future development and implementation of policies seeking to integrate rehabilitation into the cancer treatment trajectory.

METHODS AND ANALYSIS

This study uses a cross-sectional design based on a mixed methods approach in order to analyse the readiness for rehabilitation in different phases of the cancer treatment trajectory.²⁸ The study is divided into three substudies, each of which will be conducted subsequently. Preliminary results of each substudy will feed into the design of the following substudy. **Table 1** provides an overview of the aim, methodology, data sources/types of respondents and analysis of the three substudies.

In the following sections, each substudy will be described briefly.

Substudy 1: Nationwide survey among Danish municipalities

According to the Danish cancer management programme, all municipalities should offer cancer rehabilitation as of the beginning of 2013.²² In order to capture the baseline situation and to lay the foundation for the following substudies, the data collection for substudy 1 was initiated in January 2013.

An electronic questionnaire consisting of 29 items measuring availability and use of cancer rehabilitation services is developed based on a review of cancer rehabilitation literature and cancer care policies. The review focuses on main factors found to influence the delivery of cancer rehabilitation services. In addition, we extract key recommendations made by the international scientific literature and by national guidelines detailing the provision of cancer rehabilitation services at the municipal level. During this review process, particular attention is paid to dimensions related to content, scope, timing and organisation of cancer rehabilitation services. Identified barriers for cancer rehabilitation are also included and inequality dimensions are incorporated. Main topics are identified, discussed and translated into survey items by a multidisciplinary group consisting of four cancer rehabilitation researchers. A combination of closed-ended and open-ended questions is chosen in order to solicit additional information from respondents.

Items concern available rehabilitation services for patients with cancer; reasons for not offering these services; target groups in terms of type of cancer, timing, setting and content of services; organisation of services including staffing, economic resources and collaboration with other public or private actors; the number of patients enrolled in cancer rehabilitation; inequality in use across different patient groups in terms of type of cancer, sex, age, socioeconomic position and ethnicity and perceived reasons for observed inequality;

perception of and attitude towards cancer rehabilitation offered by municipalities; and needs and lessons learned in providing cancer rehabilitation. In addition, respondents are invited to send descriptions and evaluations of existing cancer rehabilitation services to the research team.

When appropriate, respondents are able to choose more than one answer to questions, and they are able to skip sections of the questionnaire that do not apply to them (eg, questions on content and use of services which are not applicable to those municipalities reporting that they do not offer cancer rehabilitation services) or questions that they do not know the answer to.

The questionnaire is pilot-tested by representatives from two municipalities; one situated in an urban context, one in a rural area in order to secure usefulness across geographical settings. The person in charge of cancer rehabilitation in these two municipalities is asked to complete the initial version of the questionnaire with emphasis on the content, scope and wording of questions as well as the completeness and appropriateness of response choices. In addition, a representative from an interest group and member authority for Danish municipalities (Local Government Denmark) is invited to comment on the questionnaire. Suggestions from these three sources are compiled and a number of revisions subsequently made.

The person in charge of cancer rehabilitation services in each of the 98 Danish municipalities is identified through the websites of each municipality which details the organisational structure and responsibilities within the health department. In case of uncertainty, municipalities are contacted by telephone and asked to identify the person in charge of cancer rehabilitation services. At the beginning of the questionnaire, respondents are asked to provide background information detailing their professional background, title and length of employment as this may potentially influence the answers given. The questionnaire was sent via SurveyXact in January 2013. Two reminders were sent; one in written form and one by telephone.

Data will be analysed using descriptive statistics. Answers to open-ended questions will be coded using content analysis and statements that are considered illustrative for these data will be selected and used in the following presentation of results. All analyses are initially conducted independently by two researchers followed by comparison and discussion within the research group.

Substudy 2: Nationwide electronic survey among surgical and oncological departments for colorectal patients with cancer

Substudy 2 explores the current clinical practice regarding assessment of rehabilitation needs and referral to appropriate services in the 19 surgical and 12 oncological departments treating patients with colorectal cancer in Denmark. Data collection for this substudy started in July 2013.

Table 1 Overview of aim, methodology, data sources and analysis of each substudy

Substudy	Aim	Methodology	Data sources/respondents	Analysis
1	Explores availability and use of cancer rehabilitation services in community-settings for all cancers	Nationwide survey	Danish municipalities (n=98)	Descriptive statistics and content analysis
2	Explores assessment of rehabilitation needs and referral to services within clinical care for colorectal patients with cancer	Nationwide survey	Danish surgical and oncological departments treating colorectal cancer (n=31)	Descriptive statistics and content analysis
3	Explores the identification and documentation of rehabilitation needs within clinical care for colorectal patients with cancer	Retrospective clinical audit Qualitative interviews	Random sample of patient files (n=40) compiled from Danish surgical (n=2) and oncological (n=2) departments treating colorectal cancer Representatives from each department involved in the audit (n=4)	Descriptive statistics Content analysis

Two electronic questionnaires have been developed; one for each type of department involved in colorectal cancer treatment. Most items (20 in total) are similar for the two types of respondents, however, respondents from surgical departments are asked an additional question regarding the extent of implementation of fast-track programmes at the specific department as such programmes may influence the ways in which cancer rehabilitation is conceptualised and reported in the survey.²⁹ As in substudy 1, we use a combination of closed and open-ended questions. Items measure types of disease-specific and general rehabilitation needs that are systematically assessed and documented; communication and collaboration within and across hospital departments (surgical and oncological departments) and across sectors (general practice and municipalities); referral to rehabilitation services and information provided to patients; and attitudes towards cancer rehabilitation, emphasising on the perceived relevance of and the strength of the evidence-base underlying current rehabilitation services for colorectal patients with cancer. Items are developed based on a review of the scientific literature, as well as the Danish cancer management programme and the Danish integrated care plan for colorectal cancer.^{22 23} Representatives from the Danish Colorectal Cancer Group are engaged in the development of the questionnaire and were invited in as collaborating partners during this substudy in order to secure the usefulness of the questionnaire and improve the likelihood that results will be translated into improvements of clinical practice. Particularly emphasis is placed on the appropriateness of wordings and response choices that must reflect the opportunities available to clinicians working at large as well as small departments across different regions of the country. When appropriate, respondents may choose more than one answer to questions, and based on our experiences from substudy 1, we retain the possibility for respondents to skip sections of

the questionnaire that do not apply to them or sections they are unable to answer.

The size and management structures of departments treating colorectal patients with cancer vary across Danish hospitals, and identifying the most relevant recipient poses a challenge. Questionnaires are therefore initially sent to all heads of departments via SurveyXact. These recipients are easily identifiable through the websites of each hospital. Each recipient is asked to forward the questionnaire to the relevant clinician in charge of the departments' colorectal cancer treatment programme. Two written reminders will be sent to non-responders followed by a reminder via telephone.

Data from closed-ended questions will be analysed using descriptive statistics. Answers to open-ended questions will be coded using content analysis. All analysis will be discussed at regular meetings within the research group.

Substudy 3: Retrospective clinical audit among four randomly selected surgical and oncological departments for colorectal patients with cancer

In the final substudy, we conduct a retrospective clinical audit exploring the systematic identification and documentation of rehabilitation needs in patient files compiled from two surgical and two oncological departments treating colorectal patients with cancer. The audit will measure current clinical practice within cancer rehabilitation up against the guidelines presented in the Danish cancer management programme and the Danish integrated care plan for colorectal cancer. The overall aim is to improve the quality of record keeping as well as the integration of rehabilitation into clinical practice. A total of 10 patient files (electronic and/or written dependent on availability) will be extracted from each department resulting in a total of 40 patient files included. This sample size is

chosen as it is assumed to be adequate for creating credible results regarding the current documentation of cancer rehabilitation in Danish clinical practice. Departments will be randomly selected among the 19 surgical and 12 oncological departments enrolled in substudy 2. No selection criteria will be enforced besides geographical spread in order to ensure attention to potential regional differences between eastern and western parts of Denmark. Departments will therefore be divided according to location (east or west Denmark) and type (surgical or oncological department). A lottery method of sampling will be used. Each department will be assigned a unique number; these numbers will be thoroughly mixed; and one number will be drawn from each subgroup of departments. This sampling process will result in the inclusion of one surgical and one oncological department from each of the two geographical regions of Denmark. The remaining departments will be assigned to a prioritised list following the same lottery methodology. Heads of departments will receive a written invitation to participate in the audit and, if needed, researchers will give an oral presentation of the aim, methodology and expected outcome in terms of both research and suggestions for improved clinical practice. If this process does not lead to collaboration, the next department on the prioritised list will be approached.

Each surgical department will be asked to retrieve full patient files for the last 10 patients operated for colorectal cancer at the department. Owing to the more prolonged treatment modules within oncology and to ensure that full care trajectories are covered in the audit, each oncological department will be asked to retrieve patient files for the last 10 patients who have been enrolled in treatment for at least 7 months.

The clinical audit will be carried out in accordance with the Principles for Best Practice in clinical Audit A published by the National Institute for Care Excellence.³⁰ The audit will focus on systematic documentation of patients' rehabilitation needs and referral to rehabilitation services in clinical practice. Explicit, measurable process criteria indicating the assessment of patients' rehabilitation needs across the cancer treatment trajectory will be developed. Criteria will encompass direct measures for rehabilitation needs assessments (eg, functional ability, comorbid conditions, mental distress, social network structure) and indirect measures (eg, referral to physiotherapy/dietician/psychologist, information given to the patient regarding municipal rehabilitation services). The patient files comprise - albeit with varying degrees of completeness - quantitative, standardised data, for example, related to waiting times, referral patterns, comorbidity and functional ability, while data on social network structures, mental distress and information given to the patient often appear in free text. Both quantitative and qualitative data will be retrieved and entered into a computer database. Since the aim of the substudy is to explore the

systematic identification and documentation of rehabilitation needs in patient files, we will consider missing data as an important outcome measure.

Representatives from the involved departments will be engaged as collaborating partners as their active participation will help ensure both access to data from patient files, adequate selection of assessment criteria and measurement of performance, and not least the translation of findings in improvements of clinical practice.³⁰ The patient files will be systematically reviewed by two independent and trained reviewers; one from the research team and one representative from the specific department in order to secure validity and consistency in the measurement of performance. Ratings will be compared and consensus sought between reviewers.

The audit methodology is based on measurable indicators of cancer rehabilitation as identified in electronic or written patient files. However, some aspects of cancer rehabilitation are more likely to be recorded than others and some activities may be indicated as performed in the patient files while they were not fully implemented in actual clinical practice. In order to contextualise findings from the audit and provide a deeper understanding of current practices, the audit will be supplemented with a small-scale qualitative study. One representative from each department included in the audit will be invited to participate in a semistructured interview after the completion of the first part of the audit. Written invitations to participate in a 30–60 min semistructured interview will be sent to all medical doctors and nurses at the participating departments followed by oral presentations of the aim and focus of the interview if needed. Written and oral consent will be retrieved from interviewees and careful attention will be given to protect their anonymity. This is particularly important as qualitative data may reveal discrepancies between recorded data in patient files informed by official clinical guidelines and real life clinical decision-making that may fall short of the standard given in these guidelines. Interviews will be conducted at a time and place chosen by the interviewee. A short topic guide will be used and interviewees will be invited to elaborate on their answers. This guide will include a number of questions and discussion points based on a vignette constructed from the patient files in the first part of the audit. The following themes will be covered:

- A. When in the clinical care pathway would this patient's rehabilitation needs be assessed? By whom? How?
- B. Would this differ between different patient groups, for example, related to degree of disease severity, socioeconomic status, age or comorbidity?
- C. How are rehabilitation needs conceptualised and weighted (physical, psychological, social rehabilitation needs)?
- D. How would the assessment of the needs for rehabilitation be documented in the patient's file? By whom? And to what extent?

- E. What are the perceived responsibilities and competencies in assessing and documenting rehabilitation needs among nurses and medical doctors?
- F. Is the assessment and documentation of needs informed by national policies and guidelines? Why or why not?
- G. What is the perceived relevance of integrating cancer rehabilitation into clinical practice? How strong is the evidence-base?
- H. Are there barriers at the patient, professional and/or organisational level that influence your ability to identify rehabilitation needs?
- I. How can assessment of rehabilitation needs among colorectal patients with cancer be integrated more systematically into clinical practice?

Audit data will be entered into SPSS Version 20 and analysed using descriptive statistics. Interviews will be audiotaped and transcribed, and thereafter analysed using content analysis.³¹ To ensure reflexivity, emergent findings from the analysis of qualitative data will be discussed within the research group.

ETHICS AND DISSEMINATION

Each of the substudies will be conducted in accordance with the ethical principles for medical research as described in the Declaration of Helsinki.³² Securing the anonymity of respondents remains a challenge due to the nationwide design including potentially all municipalities in substudy 1 and all hospital departments involved in colorectal cancer treatment in substudy 2. However, findings will be presented in aggregated form and care will be taken to ensure that no respondents are identifiable. Sensitive data potentially identifying individual patients will be omitted before processing data from patient files in substudy 3, and patient files will be reviewed at the departments. All data will be securely stored and deleted on completion of the study.

During the developmental phase of this study, we have had a strong intention to firmly anchor the study within real-life clinical and community encounters between patients with cancer on the one hand and the professionals and organisations responsible for securing comprehensive, coordinated cancer rehabilitation across different phases and settings in the cancer treatment trajectory on the other. We have taken various measures to secure the usefulness of the survey instruments and to ensure appropriate reflexivity during analysis and dissemination of results, for example, by involving key representatives from municipalities and clinical practice in the design and execution of the study. In addition, the progression of the substudies and analysis of findings will be regularly discussed in a multidisciplinary research group (the Center for Integrated Rehabilitation of Cancer patients research network) and at biannually meetings with a steering committee consisting of experienced researchers from university and clinical departments.

The dissemination strategy of the study is informed by the same ambition to bridge the divide that at times leads to suboptimal communication and implementation of research findings into practice. Results from the three substudies will be published in international peer-reviewed scientific journals separately and in a concluding paper combining findings across perspectives and methodologies. Furthermore, findings will be presented at conferences and seminars, internationally and in Denmark, and through short reports aimed at practitioners and policy-makers in a Danish context in order to secure communication of main findings and implications for practice for relevant stake holders.

Contributors CH, LA and MK conceived the study and are involved in data collection, analysis and dissemination of the entire study. This paper was drafted by MK, and revised and edited by all the authors. CH is the guarantor.

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Competing interests None.

Ethical approval Approval was obtained from the Danish Data Protection Agency (j. No. 2013-41-1478).

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