BMJ open

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

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-003775
Article Type:	Protocol
Date Submitted by the Author:	10-Aug-2013
Complete List of Authors:	Kristiansen, Maria; University of Copenhagen, Department of Public Health Adamsen, Lis; Copenhagen University Hospital, UCSF Hendriksen, Carsten; Copenhagen University, Faculty of Health, Instute of Public Health
Primary Subject Heading:	Oncology
Secondary Subject Heading:	Health services research
Keywords:	REHABILITATION MEDICINE, Adult oncology < ONCOLOGY, Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Protocols & guidelines < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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

Maria Kristiansen, Lis Adamsen, Carsten Hendriksen

Department of Public Health, University of Copenhagen, Oester Farimagsgade 5A, 1014 Copenhagen K, Denmark.
Maria Kristiansen, associate professor
Lis Adamsen, professor
Carsten Hendriksen, associate professor

Correspondence to: Maria Kristiansen
Email: Makk@sund.ku.dk
Telephone: +45 35326250
Fax: +45 35327629

Keywords: rehabilitation medicine, adult oncology, organisation of health services, quality of health care, protocols & guidelines

ABSTRACT

Introduction: Rehabilitation is a key element in most cancer care policies in recognition of the often unmet physical, psychological and social needs among rising numbers of cancer patients. 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 upon assessments 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 I 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 assessment of rehabilitation needs and referral to services. Substudy 3 involves a retrospective clinical audit and semistructured interviews at 4 randomly selected surgical and oncological departments treating colorectal cancer patients 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 transferral of implications into practice. Results will be published in international peer-reviewed scientific journals and presented at conferences, seminars and as short reports.

ARTICLE SUMMARY

Article focus

- This cross-sectional, mixed methods study explores the organisation and practice of cancer rehabilitation in Denmark with specific emphasis on assessments of patients' needs and availability of services in different phases of the cancer treatment trajectory.

Key messages

- Systematic assessment of cancer patients' rehabilitation needs is a necessity in order to identify patients with unmet needs and refer these patients to appropriate rehabilitation services.
- There is a need for more attention to potential gaps between policies on cancer rehabilitation on the one hand and the emphasis placed on rehabilitation in actual patient-provider encounters in different phases of the cancer treatment trajectory on the other.

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 both 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 organization of cancer rehabilitation (e.g. 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 contextualized and caution must be taken in transferring implications for practice to healthcare systems characterized by different funding, governance and provision compared to the Danish publicly funded healthcare system.

INTRODUCTION

Increasing attention focuses on how to adapt healthcare systems to meet the complex physical, psychological and social needs among the growing number of cancer patients.[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, co-morbid 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 both needs and resources for the individual patients and his/her relatives.[2,3,6] Timely, comprehensive and coordinated cancer rehabilitation entails both systematic screening of those 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 cancer patients 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 cancer patients 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 cancer patients' rehabilitation needs and subsequent referral to appropriate rehabilitation services across sectors and across time is a challenge that needs to be 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 needs 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 e.g. the U.S. 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 upon 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 substudy 2 and 3, we narrow our focus to colorectal cancer patients who comprise a large, divers and understudied group of cancer patients 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 cancer patients.

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 patients' 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.

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

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

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, and discussions within a multidisciplinary group of cancer rehabilitation researchers. A combination of closed and open-ended questions is chosen in order to solicit additional information from respondents.

Items concern available rehabilitation services for cancer patients; 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; 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 (e.g. 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. In addition, a representative from an interest group and member authority for Danish municipalities (Local Government Denmark) are invited to comment on the questionnaire.

The person in charge of cancer rehabilitation services in each of the 98 Danish municipalities are identified and send the questionnaire via SurveyXact in January 2013. Two reminders are sent; one in written 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.

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

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.

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 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 cancer patients. Items are developed based on 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.

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 that they are unable to answer.

The size and management structures of departments treating colorectal cancer patients 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 and are 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.
Data from closed-ended questions will be analysed using descriptive statistics. Answers to open-ended questions will be coded using content analysis.

Substudy 3: retrospective clinical audit among four randomly selected surgical and oncological units for colorectal cancer patients
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 cancer patients. A total of 10 patient files (electronic and/or written dependent upon availability) will be extracted from each department resulting in a total of 40 patient files included. 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. Each surgical department will be asked to retrieve full patient files for the last 10 patients operated for colorectal cancer at the department. Due 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 published by the National Institute for Clinical 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 assessment of patients' rehabilitation needs across the cancer treatment trajectory will be developed. Criteria will encompass direct measures for rehabilitation needs assessments (e.g. functional ability, co-morbid conditions, mental distress, social network structure) and indirect measures (e.g. referral to physiotherapy/dietician/psychologist, information given to the patient regarding municipal rehabilitation services).
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 into improvements of clinical practice.[30] 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. 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 semi-structured interview based on a short topic guide. This guide will include questions regarding reasons for current documentation of patients' rehabilitation needs; conceptualisation of physical, psychological and social rehabilitation needs in clinical encounters; perceived relevance of and evidence-base underpinning cancer rehabilitation; barriers for

identifying and meeting rehabilitation needs; and recommendations for how to integrate cancer rehabilitation into clinical practice. Audit data will be entered into SPSS and analysed using descriptive statistics. Interviews will be audiotaped and transcribed, and analysed using content analysis.[31]

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 upon completion of the study.
No approval from ethical committees is needed for surveys and interview studies according to official Danish research guidelines. The study was approved by the Danish Data Protection Agency (j. No. 2013-41-1478) which is a national agency overseeing data collection and management.

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 cancer patients 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 e.g. 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 CIRE research network) and at biannually meetings with a steering committee consisting of experienced researchers from both 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 both 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.

Funding: The research is supported by grants from 'The Center for Integrated Rehabilitation of Cancer patients' (CIRE), a center established and supported by The Danish Cancer Society and The Novo Nordisk Foundation.

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

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 authors. CH is guarantor.

Competing interests: None.

REFERENCES

1 Hewitt M, Greenfield S, Stovall E. From Cancer Patient to Cancer Survivor: Lost in Transition. Institute of Medicine, National Academies of Sciences; 2005.

2 Stubblefield MD, Hubbard G, Cheville A, et al. Current perspectives and emerging issues on cancer rehabilitation. Cancer 2013;**119**:2170-2178.

3 Hellbom M, Bergelt C, Bergenmar M, et al. Cancer rehabilitation: A Nordic and European Perspective. Acta Oncol 2011;**50**:179-186.

4 von Heymann-Horan AB, Dalton SO, Dziekanska A, et al. Unmet needs of women with breast cancer during and after primary treatment: A prospective study in Denmark. Acta Oncol 2013;**52**:382-390.

5 Veloso AG, Sperling C, Holm LV, et al. Unmet needs in cancer rehabilitation during the early cancer trajectory - a nationwide patient survey. Acta Oncol 2013;**52**:372-381.

6 Dalton SO, Johansen C. New paradigms in planning cancer rehabilitation and survivorship. Acta Oncol 2013;**52**:194.

7 Hansen DG, Larsen PV, Holm LV, et al. Association between unmet needs and quality of life of cancer patients: a population-based study. Acta Oncol 2013;**52**:391-399.

8 Ross L, Petersen MA, Johnsen AT, et al. Are different groups of cancer patients offered rehabilitation to the same extent? A report from the population-based study "The Cancer Patient's World". Support Care Cancer 2012;**20**:1089-1100.

9 Holm LV, Hansen DG, Johansen C, et al. Participation in cancer rehabilitation and unmet needs: a population-based cohort study. Support Care Cancer 2012;**20**:2913-2924.

10 Gjerset GM. Rehabilitation in cancer survivors - with focus on physical activity. Faculty of Medicine, University of Oslo, Norway; 2012.

11 Thorsen L, Gjerset GM, Loge JH, et al. Cancer patients' needs for rehabilitation services. Acta Oncol 2011;**50**:212-222.

12 Holm LV, Hansen DG, Larsen PV, et al. Social inequality in cancer rehabilitation: a population-based cohort study. Acta Oncol 2013;**52**:422.

13 Parry C, Kent EE, Forsythe LP, et al. Can't see the forest for the care plan: a call to revisit the context of care planning. J Clin Oncol 2013;**31**:2651-2653.

14 Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? J Health Soc Behav 1995;**36**:1-10.

15 Carlson LE, Waller A, Mitchell AJ. Screening for distress and unmet needs in patients with cancer: review and recommendations. J Clin Oncol 2012;**30**:1160-1177.

16 Chubak J, Tuzzio L, Hsu C, et al. Providing care for cancer survivors in integrated health care delivery systems: practices, challenges, and research opportunities. Health Policy 2012;**8**:184-189.

17 Forsythe LP, Alfano CM, Leach CR, et al. Who provides psychosocial follow-up care for post-treatment cancer survivors? A survey of medical oncologists and primary care physicians. J Clin Oncol 2012;**30**:2897-2905.

18 Alfano CM, Ganz PA, Rowland JH, et al. Cancer survivorship and cancer rehabilitation: revitalizing the link. J Clin Oncol 2012;**30**:904-906.

19 Richards M, Corner J, Maher J. The National Cancer Survivorship Initiative: new and emerging evidence on the ongoing needs of cancer survivors. Br J Cancer 2011;**105**:1-4.

20 National Institute for Clinical Excellence. Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. The Manual. NHS: National Institute for Clinical Excellence; 2004.

21 Rudkjøbing A, Olejaz M, Birk HO, et al. Integrated care: a Danish perspective. BMJ 2012;**345**(e4451).

22 National Board of Health. Forløbsprogram for rehabilitering og palliation i forbindelse med kræft - del af samlet forløbsprogram for kræft 2012. [Care programme for rehabilitation and palliation in cancer - part of the total care programme for cancer 2012]. Copenhagen: 2012.

23 National Board of Health. Pakkeforløb for kræft i tyk- og endetarm. [Integrated care plan for colorectal cancer]. Copenhagen: 2012.

24 de Vries E, Soerjomataram I, Lemmens VEPP, et al. Lifestyle changes and reduction of colon cancer incidence in Europe: A scenario study of physical activity promotion and weight reduction. Eur J Cancer 2010;**46**:2605-2616.

25 Van Mossel C, Leitz L, Scott S, et al. Information needs across the colorectal cancer care continuum: scoping the literature. Eur J Cancer Care (Engl) 2012;**21**:296-320.

26 Frederiksen BL, Osler M, Harling H, et al. Do patient characteristics, disease, or treatment explain social inequality in survival from colorectal cancer? Soc Sci Med 2009;**69**:1107-1115.

27 Ferlay J, Steliarova-Foucher E, Lortet-Tieulent J, et al. Cancer incidence and mortality patterns in Europe: Estimates for 40 countries in 2012. Eur J Cancer 2013;**49**:1374-1403.

28 Tariq S, Woodman J. Using mixed methods in health research. JRSM Short Rep 2013;**4**:1-8.

29 Kehlet H, Slim K. The future of fast-track surgery. Br J Surg 2012;**99**:1026.

30 National Institute for Clinical Excellence. Principles for best practice in clinical audit. Radcliffe Medical Press Ltd; 2002.

31 Guest G, MacQueen KM, Namey EE. Applied thematic analysis. Sage; 2011.

32 World Medical Association. World Medical Association Declaration of Helsinki. Ethical Principles for Medical Research Involving Human Subjects. 2008. http://www.wma.net/en/30publications/10policies/b3/17c.pdf (accessed 1 Jul 2013)

BMJ open

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

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-003775.R1
Article Type:	Protocol
Date Submitted by the Author:	09-Oct-2013
Complete List of Authors:	Kristiansen, Maria; University of Copenhagen, Department of Public Health Adamsen, Lis; Copenhagen University Hospital, UCSF Hendriksen, Carsten; Copenhagen University, Faculty of Health, Instute of Public Health
Primary Subject Heading:	Oncology
Secondary Subject Heading:	Health services research
Keywords:	REHABILITATION MEDICINE, Adult oncology < ONCOLOGY, Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Protocols & guidelines < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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

Maria Kristiansen, Lis Adamsen, Carsten Hendriksen

Department of Public Health, University of Copenhagen, Oester Farimagsgade 5A, 1014 Copenhagen K, Denmark.
Maria Kristiansen, associate professor
Lis Adamsen, professor
Carsten Hendriksen, associate professor

Correspondence to: Maria Kristiansen
Email: Makk@sund.ku.dk
Telephone: +45 35326250
Fax: +45 35327629

Keywords: rehabilitation medicine, adult oncology, organisation of health services, quality of health care, protocols & guidelines

ABSTRACT

Introduction: Rehabilitation is a key element in most cancer care policies in recognition of the often unmet physical, psychological and social needs among rising numbers of cancer patients. 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 upon assessments 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 assessment of rehabilitation needs and referral to services. Substudy 3 involves a retrospective clinical audit and semistructured interviews at 4 randomly selected surgical and oncological departments treating colorectal cancer patients 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 transferral of implications into practice. Results will be published in international peer-reviewed scientific journals and presented at conferences, seminars and as short reports.

ARTICLE SUMMARY

Article focus

- This cross-sectional, mixed methods study explores the organisation and practice of cancer rehabilitation in Denmark with specific emphasis on assessments of patients' needs and availability of services in different phases of the cancer treatment trajectory.

Key messages

- Systematic assessment of cancer patients' rehabilitation needs is a necessity in order to identify patients with unmet needs and refer these patients to appropriate rehabilitation services.
- There is a need for more attention to potential gaps between policies on cancer rehabilitation on the one hand and the emphasis placed on rehabilitation in actual patient-provider encounters in different phases of the cancer treatment trajectory on the other.

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 both 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 organization of cancer rehabilitation (e.g. 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 contextualized and caution must be taken in transferring implications for practice to healthcare systems characterized by different funding, governance and provision compared to the Danish publicly funded healthcare system.

INTRODUCTION

Increasing attention focuses on how to adapt healthcare systems to meet the complex physical, psychological and social needs among the growing number of cancer patients.[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, co-morbid 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 both needs and resources for the individual patients and his/her relatives.[2,3,6] Timely, comprehensive and coordinated cancer rehabilitation entails both systematic screening of those 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 cancer patients 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 cancer patients 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 cancer patients' rehabilitation needs and subsequent referral to appropriate rehabilitation services across sectors and across time is a challenge that needs to be 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 needs 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 e.g. the U.S. 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 upon 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 substudy 2 and 3, we narrow our focus to colorectal cancer patients who comprise a large, divers and understudied group of cancer patients 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 cancer patients.

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 patients' 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.

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

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

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 4 cancer rehabilitation researchers. A combination of closed and open-ended questions is chosen in order to solicit additional information from respondents.

Items concern available rehabilitation services for cancer patients; 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; 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 (e.g. 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 send via SurveyXact in January 2013. Two reminders are sent; one in written 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 cancer patients

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.

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 cancer patients. Items are developed based on 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 upon 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 that they are unable to answer.

The size and management structures of departments treating colorectal cancer patients 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 cancer patients

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 cancer patients. 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 upon 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 oral presentations 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. Due 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 published by the National Institute for Clinical 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 assessment of patients' rehabilitation needs across the cancer treatment trajectory will be developed. Criteria will encompass direct measures for rehabilitation needs assessments (e.g. functional ability, co-morbid conditions, mental distress, social network structure) and indirect measures (e.g. referral to physiotherapy/dietician/psychologist, information given to the patient regarding municipal rehabilitation services). Patient files comprise – albeit with varying degrees of completeness - quantitative, standardised data e.g. related to waiting times, referral patterns, co-morbidity 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 into improvements of clinical practice.[30] 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 patient files whilst 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 semi-structured interview after the completion of the first part of the audit. Written invitations to participate in a 30-60 minutes semi-structured 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 protecting 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 e.g. related to degree of disease severity, socioeconomic status, age or co-morbidity?
c. How is 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 identity rehabilitation needs?
i. How can assessment of rehabilitation needs among colorectal cancer patients be integrated more systematically into clinical practice?

Audit data will be entered into SPSS and analysed using descriptive statistics. Interviews will be audiotaped and transcribed, and 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 upon completion of the study.
No approval from ethical committees is needed for surveys and interview studies according to official Danish research guidelines. The study was approved by the Danish Data Protection Agency (j. No. 2013-41-1478) which is a national agency overseeing data collection and management.

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 cancer patients 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 e.g. 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 CIRE research network) and at biannually meetings with a steering committee consisting of experienced researchers from both 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 both 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.

Funding: The research is supported by grants from 'The Center for Integrated Rehabilitation of Cancer patients' (CIRE), a center established and supported by The Danish Cancer Society and The Novo Nordisk Foundation.

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

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 authors. CH is guarantor.

Competing interests: None.

REFERENCES

1 Hewitt M, Greenfield S, Stovall E. From Cancer Patient to Cancer Survivor: Lost in Transition. Institute of Medicine, National Academies of Sciences; 2005.

2 Stubblefield MD, Hubbard G, Cheville A, et al. Current perspectives and emerging issues on cancer rehabilitation. Cancer 2013;**119**:2170-2178.

3 Hellbom M, Bergelt C, Bergenmar M, et al. Cancer rehabilitation: A Nordic and European Perspective. Acta Oncol 2011;**50**:179-186.

4 von Heymann-Horan AB, Dalton SO, Dziekanska A, et al. Unmet needs of women with breast cancer during and after primary treatment: A prospective study in Denmark. Acta Oncol 2013;**52**:382-390.

5 Veloso AG, Sperling C, Holm LV, et al. Unmet needs in cancer rehabilitation during the early cancer trajectory - a nationwide patient survey. Acta Oncol 2013;**52**:372-381.

6 Dalton SO, Johansen C. New paradigms in planning cancer rehabilitation and survivorship. Acta Oncol 2013;**52**:194.

7 Hansen DG, Larsen PV, Holm LV, et al. Association between unmet needs and quality of life of cancer patients: a population-based study. Acta Oncol 2013;**52**:391-399.

8 Ross L, Petersen MA, Johnsen AT, et al. Are different groups of cancer patients offered rehabilitation to the same extent? A report from the population-based study "The Cancer Patient's World". Support Care Cancer 2012;**20**:1089-1100.

9 Holm LV, Hansen DG, Johansen C, et al. Participation in cancer rehabilitation and unmet needs: a population-based cohort study. Support Care Cancer 2012;**20**:2913-2924.

10 Gjerset GM. Rehabilitation in cancer survivors - with focus on physical activity. Faculty of Medicine, University of Oslo, Norway; 2012.

11 Thorsen L, Gjerset GM, Loge JH, et al. Cancer patients' needs for rehabilitation services. Acta Oncol 2011;**50**:212-222.

12 Holm LV, Hansen DG, Larsen PV, et al. Social inequality in cancer rehabilitation: a population-based cohort study. Acta Oncol 2013;**52**:422.

13 Parry C, Kent EE, Forsythe LP, et al. Can't see the forest for the care plan: a call to revisit the context of care planning. J Clin Oncol 2013;**31**:2651-2653.

14 Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? J Health Soc Behav 1995;**36**:1-10.

15 Carlson LE, Waller A, Mitchell AJ. Screening for distress and unmet needs in patients with cancer: review and recommendations. J Clin Oncol 2012;**30**:1160-1177.

16 Chubak J, Tuzzio L, Hsu C, et al. Providing care for cancer survivors in integrated health care delivery systems: practices, challenges, and research opportunities. Health Policy 2012;**8**:184-189.

17 Forsythe LP, Alfano CM, Leach CR, et al. Who provides psychosocial follow-up care for post-treatment cancer survivors? A survey of medical oncologists and primary care physicians. J Clin Oncol 2012;**30**:2897-2905.

18 Alfano CM, Ganz PA, Rowland JH, et al. Cancer survivorship and cancer rehabilitation: revitalizing the link. J Clin Oncol 2012;**30**:904-906.

19 Richards M, Corner J, Maher J. The National Cancer Survivorship Initiative: new and emerging evidence on the ongoing needs of cancer survivors. Br J Cancer 2011;**105**:1-4.

20 National Institute for Clinical Excellence. Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. The Manual. NHS: National Institute for Clinical Excellence; 2004.

21 Rudkjøbing A, Olejaz M, Birk HO, et al. Integrated care: a Danish perspective. BMJ 2012;**345**(e4451).

22 National Board of Health. Forløbsprogram for rehabilitering og palliation i forbindelse med kræft - del af samlet forløbsprogram for kræft 2012. [Care programme for rehabilitation and palliation in cancer - part of the total care programme for cancer 2012]. Copenhagen: 2012.

23 National Board of Health. Pakkeforløb for kræft i tyk- og endetarm. [Integrated care plan for colorectal cancer]. Copenhagen: 2012.

24 de Vries E, Soerjomataram I, Lemmens VEPP, et al. Lifestyle changes and reduction of colon cancer incidence in Europe: A scenario study of physical activity promotion and weight reduction. Eur J Cancer 2010;**46**:2605-2616.

25 Van Mossel C, Leitz L, Scott S, et al. Information needs across the colorectal cancer care continuum: scoping the literature. Eur J Cancer Care (Engl) 2012;**21**:296-320.

26 Frederiksen BL, Osler M, Harling H, et al. Do patient characteristics, disease, or treatment explain social inequality in survival from colorectal cancer? Soc Sci Med 2009;**69**:1107-1115.

27 Ferlay J, Steliarova-Foucher E, Lortet-Tieulent J, et al. Cancer incidence and mortality patterns in Europe: Estimates for 40 countries in 2012. Eur J Cancer 2013;**49**:1374-1403.

28 Tariq S, Woodman J. Using mixed methods in health research. JRSM Short Rep 2013;**4**:1-8.

29 Kehlet H, Slim K. The future of fast-track surgery. Br J Surg 2012;**99**:1026.

30 National Institute for Clinical Excellence. Principles for best practice in clinical audit. Radcliffe Medical Press Ltd; 2002.

31 Guest G, MacQueen KM, Namey EE. Applied thematic analysis. Sage; 2011.

32 World Medical Association. World Medical Association Declaration of Helsinki. Ethical Principles for Medical Research Involving Human Subjects. 2008. http://www.wma.net/en/30publications/10policies/b3/17c.pdf (accessed 1 Jul 2013)