PhD Thesis

Danish cancer patients' rehabilitation needs, participation in rehabilitation activities and unmet needs

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PhD thesis

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Preface

In 2006 just after finishing my internship as a medical doctor, I was employed for a year at a clinical ward for cancer patients. That year left me with so many impressions from the patients, which I could not forget. Although only watching from the sideline, I felt how the cancer disease threatened not only life and physical functioning, but also so many other aspects, including social, emotional and existential issues. I could ask about the patients' concerns and offer to listen to them, but I often wondered how they could be helped in the most optimal way, and to where they could be referred for additional help. Although some rehabilitation initiatives existed and were used to the extent possible, cancer rehabilitation was not yet an integrated part of cancer care. Thus, my interest for research in different aspects of cancer patients' trajectory grew. In the years 2007 to 2013 I was allowed to pursue this interest, since I was engaged for a PhD project at the Research Unit of General Practice in Odense, Institute of Public Health, University of Southern Denmark.

First, I wish to express my gratitude to all of my supervisors, who helped me design and carry through this PhD study. I wish to thank Professor Jens Søndergaard, my main supervisor, who said yes to join the project at a critical moment in the planning phase, for his never failing optimism (no matter how dark I felt things were), his enthusiasm in discussing all clinical aspects that could explain our findings in the study, and for helpful feedback on many draft articles. Also thanks for fruitful talks on career opportunities and on children being sick and steeling your sleep at night. I also wish to thank Associate Professor, Dorte Gilså Hansen (project supervisor), for her commitment to the project, and for many fruitful discussions on cancer rehabilitation and the whole research area surrounding it. Furthermore, for thorough, constructive and always timely criticism of many article drafts. I wish to thank my two external supervisors, Professor Peter Vedsted and Professor Christoffer Johansen, for many e-mail correspondences with opinions on and competent comments of numerous article drafts. Thanks to the two statisticians that were involved in the project, Pia Veldt Larsen in the first two articles and René dePont Chistensen in the third article, for their enormous patience in introducing me to STATA, help with many do-files and invaluable discussions on statistics. I owe a special thanks to Professor Jakob Kragstrup for engaging me to the project, for always believing that I could do it and encouraging me to move forward, and for stepping in whenever I was in need of his special gift of seeing a common thread in everything.

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Finally, I wish to thank my husband Kenneth for always wanting the best for me, and for being willing to do everything to make that happen! Thank you for always believing in me and for managing and enduring so much at home days and nights, and at the same time being so wonderful with our children, throughout the years and in this final critical phase. I love you. May the last words be dedicated to our two children, Joachim and Gustav, who I had while doing my PhD research. I feel so grateful that I had you. Thank you for being my wonderful children. You have already given me so many fantastic moments and are constantly reminding me what is important in life. I love you.

Lise Vilstrup Holm

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Abbreviations

CCI	Charlson Comorbidity Index
CI	Confidence Interval
CPR	Unique personal identification number
CRS	Civil Registration System
EORTC-QLQ-30	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30
GP	General Practitioner
ICD-10	International Classification of Diseases version 10
LVH	Lise Vilstrup Holm
NRP	National Patient Register
PAS	Patient Administrative System
POMS-SF	Profile Of Mood State – short form questionnaire
SES	Socioeconomic Status
WHO	World Health Organisation

List of papers

This PhD thesis is based on the following three papers:

I. **Participation in cancer rehabilitation and unmet needs: a population-based cohort study**. Holm LV, Hansen DG, Johansen C, Vedsted P, Larsen PV, Kragstrup J, Søndergaard J. *Support Care Cancer* 2012; 20:2913-2924

II. **Social inequality in cancer rehabilitation: a population-based cohort study**. Holm LV, Hansen DG, Larsen PV, Johansen C, Vedsted P, Bergholdt SB, Kragstrup J, Søndergaard J. *Acta Oncol* 2013; 52:410-422

III. **Influence of comorbidity on cancer patients' rehabilitation, participation in rehabilitation activities and unmet needs: a population-based cohort study**. Holm LV, Hansen DG, Kragstrup J, Johansen C, Christensen R, Vedsted P, Søndergaard J. (Submitted for publication).

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Background

General introduction

Cancer patients are at risk of experiencing adverse physical and psychosocial consequences of their cancer and its treatment (1-4). With an increasing number of patients treated for or living with cancer, these consequences have become still more apparent. During the past two decades cancer rehabilitation has gone from being a virtually unknown concept to being a field of increasing interest, politically as well among health care professionals (5-8). In order to support the patients in the most optimal way, this has resulted in an increased need for gaining more knowledge of different aspects of cancer patients' rehabilitation course. This PhD project was planned in the years just after the second national cancer plan was published (9), which emphasised that rehabilitation efforts should be evidence-based and provided to all cancer patients based on their individual needs, and furthermore, that knowledge should be obtained about already established rehabilitation offers with the purpose of nationwide implementation. In this PhD project we chose to focus on the aspects of needs for rehabilitation, participation in rehabilitation activities and unmet needs for rehabilitation among cancer patients in a 14-month period after diagnosis, which had previously only been scarcely studied.

Needs for rehabilitation

How to define, implement and organise cancer rehabilitation efforts has also in Denmark become an area of focus, especially within the last decade (9-11). In this regard, the patient perspective and identification of individual rehabilitation needs are considered increasingly important (12). *"Needs"* can be defined as the requirement of some action or resource that is necessary, desirable, or useful to attain optimal well-being (13). Need for rehabilitation is often used synonymously with supportive care needs, with supportive care defined as care "that helps the patients and their family to cope with cancer and treatment of it - from the pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximize the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment" (14). Many studies investigating needs have focused on the needs of a particular patient group, for example specific age groups (15-17), in relation to treatment modalities (18-20) or one type of cancer (21-28), often breast cancer (18, 19, 29, 30). However, in comparison fewer studies have assessed the extent of diverse rehabilitation needs of cancer patients across a range of cancer types and have often not distinguished between needs and unmet needs (13, 31, 32). These studies provide insight into the diverse nature of the needs cancer patients may experience, ranging from physical effects of cancer and its treatment to psychosocial consequences such as anxiety, depression, family-oriented, work-related and financial issues. However, these studies included cancer patients at different times in their cancer trajectory. It has been estimated that up to 70% of newly diagnosed Danish cancer patients may have a need for rehabilitation during a one-year period (33). This estimate was, however, based on register data concerning survival rates and did not include the perceived needs of the cancer patients. To date, there is still insufficient knowledge of the actual number of newly diagnosed cancer patients in need of rehabilitation in a one year period after diagnosis.

Participation in rehabilitation activities

There is an increasing evidence of the beneficial effects of specific exercise interventions aiming to improve different aspects of quality of life and physical capacity among cancer patients (34-36). Multidimensional interventions including both a physical and psychosocial component have suggested that there are more benefits with regard to the physical component (37). In addition, although there is still is a gap in the evidence, psychosocial interventions may have a beneficial effect on mood and quality of life (38, 39). In contrast, little knowledge exists on the extent to which extent cancer patients participate in rehabilitation activities outside such interventions, what types of activities are used, and whether participation is associated with certain patient characteristics. Two cross-sectional studies, including patients with one or a few types of cancers (mainly breast cancer) two or more years after diagnosis, assessed the patients' utilisation of rehabilitation activities. Both studies found that a third of patients had participated in rehabilitation activities, and that participants were more likely to be younger (40, 41). One of the studies also found that participants were of higher socioeconomic status (40), while the other study found no difference (41). Rehabilitation Centre Dallund was founded in 2001 and is the first and only place in Denmark offering 1-week rehabilitation retreats for cancer patients (42, 43). Although all cancer patients can apply for a stay at the centre, younger patients, women and in particular women with breast cancer are overrepresented (42). A research project (FOCARE) evaluating the psychosocial intervention programme at the centre has, furthermore shown that the women participating were generally well-educated and working (43). Overall, there is, however, a lack of knowledge as to whether these findings regarding demographic, socioeconomic and other patients characteristics are related to participation across various diagnoses and offers.

Rehabilitation of cancer patients includes a broad range of activities from the more specialised disease-specific rehabilitation, e.g. physical therapy aimed at preventing lymphedema for women with breast cancer (44) or pelvic floor exercises for men operated for prostate cancer (45), to the more generalized rehabilitation services relevant for cancer patients across diagnoses, e.g. physical training, and psychosocial, work-related and financial support (46). In Denmark today, the disease specific rehabilitation activities are incorporated in national guidelines for cancer care (47). When this study was designed and carried out, planning and implementation of the more generalised rehabilitation services were only in the making, and as for today, the supply of offers is still varying across the country.

Unmet needs for rehabilitation

Unmet needs can be classified as 'needs that are not addressed and where additional support is required' (48). As previously stated, needs and unmet needs are often used interchangeably. Identification of the unmet needs of cancer patients is, however, equally important in order to develop and refine services to address any gaps in cancer care (49). Furthermore, studies have shown that higher levels of unmet needs are associated with higher levels of psychological distress and poorer quality of life among cancer patients (50-53). 'The Cancer Patient's World', a large Danish study regarding cancer patients' needs and problems (n= 1,490) published in 2006 showed that unmet needs for rehabilitation among cancer patients seemed to be pronounced with regard to a variety of physical, psychological and sexual problems (1, 54). The study concerned patients at different times in the cancer trajectory from a few months and up to ten years after diagnosis. A review assessed studies on unmet needs among patients with one cancer type and in mixed populations according to the time point of the cancer trajectory (48). Compared to the treatment phase, few studies were conducted in the post treatment phase that ranged from 3 months to more than 5 years after treatment, making it difficult to generalise findings. Still, the studies reported high levels of unmet needs in physical, psychosocial and sexual domains (48).

Overall, there is a lack of knowledge on rehabilitation needs, participation in rehabilitation activities and unmet needs among cancer patients in the first year after diagnoses. In addition, knowledge on factors associated with needs, participation and unmet needs is needed to target rehabilitation efforts.

Cancer rehabilitation – definitions and theoretical frame

WHO defines rehabilitation of people with disabilities as "a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination"(55) . With the growing interest in rehabilitation from citizens, healthcare professionals and politicians in Denmark, a national mutual understanding of the concept was needed. Consequently, a Danish definition of rehabilitation was published in a White Paper from 2004 (56): "Rehabilitation is a targeted, temporary process of cooperation between a citizen, relatives and professionals. The aim is that citizens, who have or are at risk of gaining substantial limitations in their physical, psychological and/or social functional capacity, attain an independent and meaningful life. Rehabilitation is based on the entire life situation of and decisions made by the citizen and consists of coordinated, coherent and knowledge-based efforts". The two definitions are quite similar, both focusing on the individual's functional capacity, where the goal is to achieve or maintain the best possible function. Furthermore, both definitions comprise physical, psychological and social aspects of the functional capacity. Hence, rehabilitation efforts must include a wide continuum of services and supports. A difference between the two definitions is that the White Paper operates with a temporary rehabilitation process, while this is not applied in the definition of the WHO. Both definitions could as such serve as the theoretical frame for this PhD thesis, but because of the absence of the time perspective, the definition of WHO was chosen as the conceptual frame.

Related to the different definitions of rehabilitation is the International Classification of Disability and Health (ICF) (57). The ICF model can be used as a frame to assess an individual's functional capacity and thereby estimate e.g. rehabilitation needs. In the model of ICF the evaluation of the functional capacity is based on interactions between the individual and contextual factors and comprises physical, psychological and social aspects. The ICF is also available in a Danish version (58) and is being used in the settings of municipalities in Denmark related to health care. However, in hospitals and in primary care the tool is at the moment not applied in every day routines. At a national level it has been debated whether the ICF could serve as a frame of reference across sectors in the field of rehabilitation, but no consensus was reached (59). Although many of the considerations in the ICF model were regarded as relevant, it was not applied as a conceptual foundation in this PhD thesis.

Cancer epidemiology in Denmark

Cancer incidence in Denmark has increased during the last decade from 28 187 cases in 2002 to 36 559 in 2011 (60). The most frequent cancer types diagnosed in 2011 were colorectal and lung cancer, each accounting for 12% of all incident cases. Among women, breast cancer was the most frequent type, accounting for 26% of incident cases, followed by colorectal and lung cancer (12% each). Among men, prostate cancer was the most frequent type accounting for 23% of incident cases, and also as among women followed by colorectal and lung cancer (12% each).

In 2011, 246 143 Danish citizens were living with one or more cancer diagnoses compared with 173 166 in 2002 (60). This is partly due to the fact that the age distribution in the population has changed with a larger proportion of elderly, accounting for the majority of cancer incidents. In Denmark, the percentage of people over the age of 65 years has increased from 14.8% to 16.8% over the last decade, and projection of demography predicts that this number will reach almost 25% by 2040 (61). Furthermore, introduction of new screening programmes as well as improvements in diagnosis and treatment also contribute to the increasing numbers (60). The increase in incidence as well in prevalence is a phenomenon seen not only in Denmark, but worldwide, which has brought the physical, psychological and social consequences that may arise from living with cancer into focus (6). With that development in mind, cancer can more and more be regarded as a chronic disease, and there is a need to look beyond just survival (62). In Denmark, this has been reflected in the shift of focus in the national recommendations for cancer care published within the last ten years. This development is described in detail in the section below concerning organisation of cancer care and cancer rehabilitation in Denmark.

The Danish healthcare system

The Danish healthcare system is primarily tax-funded and based on a strong welfare tradition to ensure all citizens have free and equal access to health care (63) . Thus, the vast majority of healthcare services are free of charge for the users including access to general practitioners (GPs), public hospital services and office-based medical specialists. Patient co-payment represents approximately 17% of the total health expenditures, and the two biggest co-payments services are prescription medicines and adult dental care (64). Rehabilitation provided by the hospitals and as part of the municipal health services is also free of charge, and is described in detail in the next section regarding organisation of cancer care and rehabilitation.

Almost the entire Danish population (98%) is listed with a GP (65). Besides being the family doctor, the GP acts as gatekeeper to the more specialised part of the healthcare system. The GPs are independent contractors with the Regional Health Administration and are remunerated on a fee-for-service and capitation basis (64).

The majority of Danish hospitals are owned and managed by the 5 regions (covering a total of 98 municipalities). These public hospitals provide free hospital and emergency treatment. Danish citizens have free choice of hospital regarding diagnosis and treatment, but most patients are treated at hospitals in their own region. Referral to highly specialised treatment outside a patient’s region may in some cases be needed. Private hospitals are available, but only deliver 3 % of all hospital services and do not normally undertake cancer treatment (64).

Organisation of cancer care and cancer rehabilitation in a Danish context

Cancer care in Denmark has undergone a large development during the last decade based on recommendations from three national cancer plans. Furthermore, in this period of time, the concept of rehabilitation has been widely introduced in the political arena and among health care professionals in the hospitals, in general practice and in the municipalities.

In the late nineties it became clear that cancer survival in Denmark was much lower compared to other Nordic countries. Along with a general increase in cancer incidence, primarily accounted for by the growing elderly population, action was needed. Consequently, the first national cancer plan published in 2000 focused mainly on prevention and opportunities for strengthening diagnosis and treatment (66). Rehabilitation of cancer patients was acknowledged as an important aspect to develop in the future, covering physical, psychological, social, work-related and financial issues. However, until then, cancer rehabilitation had mainly consisted of supportive care with pain relievers and antiemetics and a few local offers of physical retraining for women after mastectomy (66).

The second cancer plan in 2005 (9) also had a strong focus on prevention, diagnosis and treatment, and as a consequence the introduction of the so-called ‘fast-track cancer packages’ with the aim of minimising delays for patients in the diagnostic phase (47). In the second cancer plan was also stated the need for evidence regarding the actual number of Danish cancer patients in need of rehabilitation, and a recommendation of clarification of the different individual rehabilitation needs in order to develop targeted rehabilitation efforts. Furthermore, it was highlighted that there was a need to collect information regarding rehabilitation offers already established.

In 2007, a structural reform reorganised the entire public sector in Denmark (67, 68). The municipalities were given the responsibility for the more generalised rehabilitation of patients with chronic diseases, including cancer. Hospitals were to carry out the more specialised rehabilitation for cancer patients admitted to a hospital. Following this reform and the recommendations regarding rehabilitation given in the second national cancer plan, various rehabilitation initiatives have been introduced in selected municipalities across the country (46). Rehabilitation activities may include physiotherapy, other physical training, counselling by psychologist, dietary advice, counselling by social worker, occupational therapy, patient education and smoking cessation counselling, but the offers vary across the country. Rehabilitation provided by the public healthcare system and the municipalities is free of charge. Cancer patients may also participate in rehabilitation activities outside the public health care system and the municipalities, for example free of charge in the setting of the private patient organisation, the Danish Cancer Society (69), or self-financed at e.g. private physiotherapist, psychologist and alternative practitioners.

In 2010 the third national cancer plan was published (10), emphasising the importance of coherent patient pathways with special focus on areas beyond the diagnosis and treatment phases: prevention, early detection, rehabilitation and palliative care. Recommendations from the third plan included among other things development of national guidelines for rehabilitation. Subsequently, a national care programme regarding recommendations for organisation of rehabilitation and palliative care has been published and describes the generalised rehabilitation efforts, for which the municipalities and general practice are accountable (70). Guidelines regarding the disease-specific rehabilitation, for which the hospitals are accountable, are now included in above mentioned ‘cancer packages’ (47).

The national course programme suggested that the hospitals, general practice and the municipalities undertook continuous needs assessments during the cancer patients’ trajectory (70). The needs assessment should include physical, psychological, social and existential areas in accordance with WHO’s definition of rehabilitation and should be followed up by relevant rehabilitation services. A working group appointed by the Danish Health and Medicines Authority has discussed, whether a single instrument for needs assessment to use across sectors and settings could be identified, but no consensus has been reached (59). At the time being, more research is needed to identify or develop the most appropriate instrument to cover all these areas of needs, to apply in different settings and across sectors at different times in the cancer trajectory. Furthermore, although recommendations regarding cancer rehabilitation are now given in national guidelines, the implementation and efforts are still varying across the country. Thus, from the time this current PhD project was planned and conducted, cancer rehabilitation has become a well-known concept, but the full implementation of efforts and collaboration across sectors still lack behind.

Social inequality in cancer rehabilitation?

Social inequality in health can be described as a systematic relationship between people’s social position and their health (71). Social position or socioeconomic status (SES) is not strictly defined, but education, income, occupation are considered key measures (72). Education is a frequently used indicator, as it is easy to measure and can be obtained independently of age or working circumstances. Furthermore, education is often considered a stable measure, as it is attained in early adulthood (72).The amount of education and knowledge is assumed to reflect a person’s awareness and understanding of different health outcomes and may thereby affect the person’s choice of lifestyle and health behaviour (72, 73). Furthermore, education provides the basis for future opportunities for occupation and income, although a high education does not necessarily lead to high income and a high occupational standing (74). Occupation indicates social status and also health status, as it reflects the ability to be on the labour market (72). Occupation may also reflect social networks and thereby affect health outcomes through psychosocial processes (72). Occupation is strongly related to income, which is the indicator that most directly has an effect on material resources (72). Income can affect health by determining the ability to buy healthy food, to have proper housing conditions, and by giving access to medications and (leisure or health) services that may improve health (72). Income can change rapidly over time, and reverse causality, where people with poor health suffer from a loss of income, can occur (73). Cohabitation status is a fourth indicator of social position that reflects social support (75). Some of the underlying mechanisms for effect on health outcomes may be a partner's support or encouragement to take part in everything from the diagnostic phase to rehabilitation (76).

A growing inequality in health reflected in mortality rates has been demonstrated since the 1970s in a large number of European countries, including Denmark (77). In Denmark, within the past 25 years inequality in life expectancy at the age of 30 years has more than doubled, when comparing the less educated with the highest educated (78). This is despite the fact that Denmark has extensive welfare policies with equal access to health care irrespective of socioeconomic status (78). Social inequality has been demonstrated with regard to attendance in screening programmes for breast cancer (79), and with regard to cancer incidence and survival across several cancer sites (80). Among Danish heart patients attending cardiac rehabilitation, low participation is associated with living alone and having a low education or income (81, 82). We hypothesised that a social gradient would also be present in cancer rehabilitation with regard to expression of needs, participation in activities and unmet needs for rehabilitation.

Influence of comorbidity on cancer rehabilitation?

Comorbidity is defined as the presence of one or more additional diseases in a patient with an index disease (83). The number of comorbidities increases with increasing age (84). With the improvement of cancer care and the ageing of the population, rehabilitation of older cancer patients will become increasingly relevant (7, 85, 86). Numerous studies have shown that comorbidity increases overall and cancer-specific survival across different cancer sites (87-92). In subpopulations of cancer survivors, comorbidity is found to be associated with poorer quality of life (93-95), more somatic symptoms and decreased physical function (96, 97). A recent review pointed out that there is a lack of studies assessing the influence of comorbidity on the level of unmet needs for rehabilitation (98). We hypothesised that comorbidity would be positively associated with expression of needs and unmet needs, and inversely associated with participation in rehabilitation activities.

Background at a glance

- The growing number of cancer patients treated for or living with cancer has increased focus on the possible physical, psychological and social consequences of cancer and its treatment
- Cancer rehabilitation has become a field of increasing interest among politicians and health care professionals, and in guidelines rehabilitation efforts is recommended on equal terms with usual cancer care
- Cancer rehabilitation services include a range of activities from physical, psychological to work-related and financial support
- The evidence for the extent of newly diagnosed cancer patients in need of rehabilitation during a one-year period is scarce
- There is a lack of studies examining the extent to which cancer patients participate in rehabilitation activities, and what kind of activities are used
- Unmet needs for rehabilitation seem to be pronounced for physical, psychological, social and sexual problems, but this has not been studied in a large cohort of newly diagnosed cancer patients in a one-year period
- Patient-related factors like age, gender, cancer type, socioeconomic factors and comorbidities may influence cancer patients' needs, participation in rehabilitation activities and unmet needs for rehabilitation

Aims of the thesis

The overall aim of this thesis is to analyse the extent to which cancer patients express rehabilitation needs, participate in rehabilitation activities and have unmet rehabilitation needs in a 14-month period following date of diagnosis. Furthermore, to assess if specific patient characteristics are associated with rehabilitation with regard to needs, participation and unmet needs.

The more detailed aims are the following:

1. To assess the extent to which cancer patients express rehabilitation needs, participate in rehabilitation activities and have unmet rehabilitation needs in a 14-month period following date of diagnosis and to assess if age, gender and cancer diagnosis are associated with these outcomes (Article 1)
2. To assess whether there are associations between socioeconomic factors including education, income, labour market affiliation, cohabitation status and cancer patients' rehabilitation needs, participation in rehabilitation activities and unmet rehabilitation needs in a 14-month period following date of diagnosis (Article 2).
3. To assess whether there are associations between comorbidity status and cancer patients' rehabilitation needs, participation in rehabilitation activities and unmet rehabilitation needs in a 14-month period following date of diagnosis (Article 3).

Material and methods

Setting and design

The study was designed as a population-based cohort study and conducted among incident cancer patients, apart from patients with non-melanoma skin cancer, diagnosed in the period from 1 October 2007 to 30 September 2008 in the Regions of Southern and Central Denmark. The two regions (out of five) have approx. 2.4 million residents corresponding to 44% of the Danish population (99) and approx. 15,000 new cancer cases per year (100). Patients were included into the study based on administrative hospital-based data, and information about rehabilitation issues was obtained from a patient questionnaire administered 14 months after diagnosis. Survey data were combined with register data to obtain information on patient characteristics, including SES and comorbidity.

Data sources

The Danish Civil Registration System

All Danish residents are assigned a unique personal identification number (CPR-number) and are registered for administrative purposes in the Danish Civil Registration System (101). Since 1968, the Civil Registration System has contained information on name, gender, date of birth, citizenship and identity of parents of each individual. Furthermore, the system is continuously updated with regard to each individual’s vital status, full address and marital status. The unique CPR number assigned to each individual enables linkage of data between all national Danish registers (102).

The Patient Administrative System

The Patient Administrative System (PAS) is a regional system registering administrative information on hospital activities (103). All hospital contacts are registered and each record includes the patient’s CPR number and information on e.g. date of admission and discharge, diagnosis classified according to the International Classification of Diseases (ICD-10), codes for undertaken procedures, the GP’s provider number and various other codes. Of particular relevance for the sampling procedure used in this study is the additional code AZCA-1, which is a code required by law when a cancer diagnosis is reported for the first time (104). The PAS of each region collects data to the National Patient Register (NPR), and all hospitals are obliged to report to the NPR for the previous month by the 10th of each month (103). All data registration in the PAS is made in accordance with national guidelines (104).

The Danish National Patient Register

The National Patient Register (NPR) gathers information from all five regional PAS, although not all information from PAS is transferred, e.g. the GP provider number. The NPR is run by the Danish Health and Medicines Authority, who performs ongoing validation of the data from PAS, and thus both systems are continuously updated. Since 1977 all hospital admissions have been registered, and from 1995 onwards, all outpatient visits and emergency room contacts have been included. Each record includes the patient's CPR number, date of admission or contact, identification of hospital ward and diagnostic and procedure codes (105).

The Danish National Health Service Provider Register

This register contains information on every health contractor in primary care in Denmark (106). Information is based on the health professionals' invoices to the regional health administrations. Among others, the register contains names and addresses of every provider number, assigned to each practice. A provider number may refer to several providers, if several GPs form a medical practice partnership.

Socioeconomic registers

Statistics Denmark has a vast number of registers containing socioeconomic and demographic information at an individual level for the entire Danish population (102). The data are collected for statistical and scientific purposes and obtained from administrative registries, such as the Tax and Customs register and educational institutions, and are updated annually. Data on highest attained education was obtained from the Population's Education Register (PER) (107), income was obtained from the E-income register (108), labour market affiliation was obtained from the Employment Classification Module (109) and cohabitation status from the E-family register.

The patient questionnaire

The patient questionnaire comprised 171 items (Appendix A) and was designed to give information on various aspects of cancer rehabilitation for different research projects. The questionnaire was developed in a research group with researchers in the field of cancer rehabilitation. Dr. Stinne Holm Bergholdt from the Research Unit of General Practice in Odense conducted a randomised controlled trial evaluating the general practitioner's role in cancer rehabilitation among newly diagnosed cancer patients at Vejle Hospital (110) at the same time, as this project was carried out. Since there was overlap between study cohorts, construction of items and administration of questionnaires were coordinated.

The study was conducted with the intention to analyse different aspects of the rehabilitation process including rehabilitation needs, participation in rehabilitation activities and unmet needs and to assess different dimensions of these aspects. Before designing the questionnaire, a theoretical basis regarding common needs and problems among cancer patients was established through review of papers, reports and books (1, 2, 4, 5, 9, 13, 22, 23, 28, 31, 40, 41, 56, 66, 111-130). This literature review formed the basis of establishing the different dimensions regarding needs and unmet needs, i.e. physical, emotional, family-oriented, sexual, work-related and financial. The list of rehabilitation activities was guided by activities present in the municipalities, as well as activities provided to resident by the Danish Cancer Society (69).

Several validated questionnaires regarding cancer patients' needs assessment and quality of life were considered (131-136), but none of them were found to cover all these different aspects and dimensions. Ad hoc questions were therefore formulated based on the literature and previously used questions within the research area (1, 137), keeping WHO's definition of rehabilitation in mind. Different approaches to defining, operationalisation and measuring of needs exist (1, 138). One approach is to ask the patient if he/she experiences something as a problem (139). Another approach is to ask the patient if a matter is essential to him/her (127). These approaches can, however, not reveal if the patient wishes to be helped with the problem or the essential matter. A third approach is to ask the patient is he/she needs (additional) support or help, or simply if he/she has a need (140). Elements from all three approaches are considered to supplement each other (1), and were included when formulating the questions regarding needs and unmet needs. In each dimension several 'guiding' questions were asked before 'the study-specific' question regarding need or unmet need in that area. For example, in the emotional dimension, 'guiding' questions were asked concerning feelings about depression, fear of death, guilt feelings about being sick, troubles adjusting to new self-image and concerns about well-being of relatives, before the question regarding 'need for professional help' was asked. The term *'professional'* was used in order to distinguish from help received from persons other than professionals, e.g. spouse, other relatives or friends.

The questionnaire further comprised five validated instruments including the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30 (EORTC-QLQ-30) (131), the Profile Of Mood State-Short Form (POMS-SF) (133), the Danish Patients Evaluate Practice Care (Dan-PEP) (141), the Multidimensional Health Locus of Control (MHLC) scale (142) and part of the FACIT-sp. questionnaire concerning religious and spiritual beliefs (143), and furthermore ad hoc questions regarding social support, satisfaction with the healthcare system in general and the general practitioner in particular, but none of those were used in this thesis.

Pilot testing of the patient questionnaire

The patient questionnaire was pilot tested and revised through a three-step procedure. First, researchers active in the field of rehabilitation were asked to comment on content, layout, volume and intelligibility of the draft. Secondly, a qualitative pilot test was performed by LVH at the oncological ward at Odense University Hospital. Ten cancer patients (diagnoses breast cancer, malignant melanoma and head and neck cancer, age 48-85 years, half of them women) were observed filling in the questionnaire and subsequently interviewed using a semi-structured approach (144) focusing on content, layout, volume and intelligibility. This qualitative pilot test showed that the distinction between having a need and an unmet need was not understood by all patients. Consequently, the questions regarding needs and unmet needs were placed in separate sections with guiding texts elaborating each of the issues. Finally, the last pilot test included 100 cancer patients treated at the oncological ward at Odense University Hospital, who were asked to fill in a mailed version, enabling us to examine discrimination and acceptability. The overall participation rate in this pilot study was 75%, and subsequent revisions primarily consisted of changes in the phrasing of a few questions to avoid ceiling effects.

Data collection and logistics of the patient questionnaire

Distribution of questionnaires, reminders to non-respondents after three weeks and entry of data from returned questionnaires were handled by the Public Health and Quality Improvement unit at the Central Denmark Region. The returned questionnaires were scanned at this unit, converted into a dataset and transferred to the statistical program Stata Release 11 (StataCorp, College Station, TX, USA).

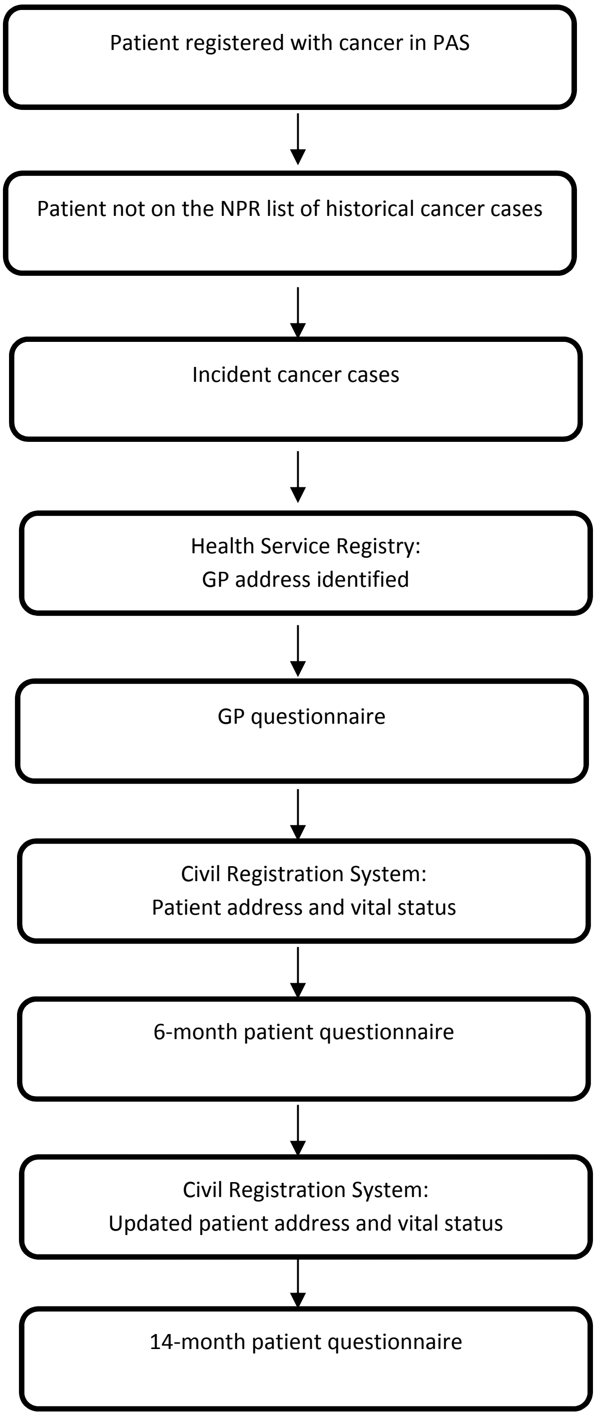
Study population

The study cohort was sampled for several PhD projects, and the sampling procedure and the questionnaires used in this process were developed at the Research Unit of General Practice in Aarhus before study start of this PhD project (145, 146). The sampling algorithm used to identify incident cancer patients from PAS in the Regions of Southern and Central Denmark was developed based on advice from an expert panel (145).

From the regional hospitals Patient Administrative Systems information was obtained on adult patients (18+ years) diagnosed with cancer during the study period (See Appendix B for list of included cancer diagnoses), assigned the registration code ‘AZCA1’ specifying that the cancer was reported for the first time, and listed with a GP in the one of the two regions.

Patients were sampled on the 15th of each month, and data on all patients registered during the preceding month were collected. Patients with prior cancer were excluded based on a list of cancer cases from 1994 to 2007 extracted from the NPR. This list was updated monthly by adding the sampled patients. Following identification by the administrative sampling procedure, GP addresses were identified using the Health Services Registry, and each patient's GP was mailed a questionnaire to confirm that a cancer was diagnosed. As mentioned above, this cohort of incident cancer patients was established for several research projects, and six months following date of diagnoses patients were mailed a questionnaire, which included a request for them to confirm that they had cancer for the first time and giving them the possibility of declining the use of information provided by their GP. Prior to distribution of the 14-month patient questionnaires used in the present PhD project, vital status and postal addresses were updated by linkage to the Civil Registration System. All letters included the questionnaire and a prepaid envelope.

Figure 1 Overall sampling procedure



After the sampling period it became clear that the initial sampling algorithm had been incomplete, since fewer patients than expected had been included (146). Two main reasons for this were identified: firstly, some patients were registered later than one month after their diagnosis and were therefore missed because the algorithm only sampled one month back. Secondly, the AZCA1 code was not used consistently for all incident cancer patients, even though it is mandatory. Thus, eligible patients lacking the AZCA1 code were not included. To ensure that all incident cancer patients were identified, an additional sampling was done in October 2009, referred to as sample 2 (patients were excluded from sample 2 if already included in the study cohort) (146). At that time distribution of the 14-month patient questionnaires to the primarily included patients (referred to as sample 1) were, however, almost completed. Therefore it was decided not to send out questionnaires to patients sampled in the second round, as data collection would be up to two years after their cancer diagnosis. The total sample of patients thus consists of sample 1 and sample 2. Patient characteristics in the two samples are shown in Table 2 under Results.

Outcome variables

The outcome variables used in all three studies were *Needs for rehabilitation yes/no*, *Participation in rehabilitation activities yes/no* and *Unmet needs for rehabilitation yes/no*. Each outcome variable included different subcategories, described in detail below. Information regarding these outcomes was collected from the 14-month patient questionnaires (Appendix A).

Needs for rehabilitation

“Need for rehabilitation” during the 14-month period was asked for similarly in each of six dimensions, including “physical”, “emotional”, “family-oriented”, “sexual”, “work-related” and “financial”.

As an example, in the physical dimension the following question was asked:

To what extent from diagnosis and until now have you needed professional help with physical problems? (“not at all”, to a small extent”, “to some extent” and “to a great extent”).

The variable “At least one rehabilitation need” is an expression of having at least one rehabilitation need in one of the six above-mentioned dimensions and was constructed based on answers in these categories.

Participation in rehabilitation activities

"Participation in rehabilitation activities" during the 14-month period was assessed by asking:

Have you from diagnosis and until now participated in any of the following activities due to problems caused by your cancer disease? (listing of possible providers/activities).

Three categories of activities were defined based on the profession of the provider/activity: 1) "Physical activities" (physiotherapist, occupational therapist, chiropractor, patient education, smoking cessation counselling, nutritional information, physical training and alternative practitioner including acupuncturist and reflexologist), 2) "Psychological activities" (psychologist, marriage counsellor or sexologist, supportive group sessions or patient associations and spiritual counselling), and 3) "Work-related/financial activities" (social worker, union representative or employer, financial or insurance counsellor).

The variable "Participation in at least one activity" is an expression of participation in at least one of the three above-mentioned categories.

Unmet needs for rehabilitation

"Unmet rehabilitation needs" during the 14-month period were asked for similarly in each of six dimensions, including "physical", "emotional", "family-oriented", "sexual", "work-related" and "financial".

As an example in the physical dimension the following question was asked:

Until now, to what extent have you had your needs fulfilled in terms of help with physical problems? ("not at all", "to a small extent", "to some extent", "to a great extent" and "not relevant").

Patients were categorised as having an "unmet need", if they had expressed a "need for rehabilitation" during the 14-month period and the need to some extent was not fulfilled after the 14 months.

The variable "At least one unmet rehabilitation need" is an expression of having at least one unmet need for rehabilitation in one of the six above-mentioned dimensions and was constructed based on answers in these categories.

Independent variables

Study I

Information on age at time of diagnosis, gender and cancer diagnosis for each individual was extracted from PAS. Age was categorised into the following categories: 18-39 years, 40-49 years, 50-59 years, 60-69 years, 70-79 years and 80+ years. The cancers were categorised into breast, prostate, colorectal, gynecological, malignant melanoma, lung, lymphoma, head and neck and other cancers based on ICD-10 codes (See Appendix B for ICD-10 codes).

Study II

On an individual level highest attained education in the year 2006 was extracted from the Personal Education Register in Statistics Denmark. Information on highest attained education in the register is based on administrative records from all Danish educational institutions. An eight-digit code defines the educational level, where the two first digits define the main education group: 10 primary care school, 15 lower secondary school, 20 upper secondary school, 25 basic vocational training, 35 vocational training with trade certificate, 40 higher education (short length), 50 higher education (medium length), 60 higher education (bachelor), 65 higher education (beyond bachelor), 70 PhD degree. We categorised highest attained education into three categories: <10 years (primary and lower secondary school), 10-12 years (vocational training and upper secondary school), >12 years (higher education).

Information on income was extracted from the E-income register in Statistics Denmark. Equivalent disposable income was used as a measure of each individual's economic capacity and is defined as the entire household income after taxation, adjusted for number of persons in the household (the first adult counts as 1, the following individuals over 15 years count as 0.5, children under 15 years count as 0.3). Disposable income was calculated on the basis of the five-year average income of respondents (2002-2006) and categorised as low (first quartile), medium (second and third quartile) and high (fourth quartile).

Labour market affiliation was extracted for the year 2006 from the Employment Classification Module (AKM) in Statistics Denmark. For each year each person is categorised according to his/her main source of income. We categorised our cohort into three groups: working (employed or enrolled in an educational programme), pensioners (early-retirement pension or old-age pension) or outside the workforce (unemployed, receiving social security and disability pension).

Cohabitation status in 2006 was extracted from the E-family register in Statistics Denmark. The following codes are used to register cohabitation status: 1 married, 2 registered partnership, 3 living together and parents to one or more children in the household, 4 two adults of the opposite sex, not related, living together with less than a 15-year age difference, 5 living alone. We categorised cohabitation status as married/cohabiting (codes 1-4) or living alone (code 5).

Study III

Information was based on all in- and outpatient hospitals contacts extracted from the NPR from 1994 and until date of cancer diagnosis for each individual. Comorbidity was classified according to the Charlson Comorbidity Index (CCI) (147). The CCI provides an overall score for comorbidity based on a weighted score from 1 to 6 assigned to 19 selected conditions. On the basis of the accumulated sum of scores, the comorbidity index was grouped into scores as CCI 0 (no comorbidity), CCI 1 (mild comorbidity) and CCI $\geq$ 2 (moderate to severe comorbidity). As our study population included only patients with first primary cancers, no cancers are included in the index (148).

Statistical analyses

Patient characteristics in all the three studies are described by categorical variables and reported using number and percentages (%).

X^2- tests were conducted to test the difference between respondents and non-respondents with regard to sex, age, diagnosis, socioeconomic variables and comorbidity status. All potentially eligible patients were due to administrative errors not invited for this study. Therefore X^2- tests were also conducted to in order to test the differences between these two groups.

All three outcome variables were treated as binary outcomes. Need for rehabilitation was dichotomised into “no need” (“not at all”) and “need” (combining “to a small extent”, “to some extent” and “to a great extent”), and similarly, unmet need was dichotomised into “unmet need” and “no unmet need”. For analyses regarding ‘unmet rehabilitation needs’ only patients expressing a ‘need for rehabilitation’ were included. Answers in the “not relevant” category were excluded from analyses. Participation in rehabilitation activities was defined as yes/no.

In Study I we tested for interactions between age and gender for each of the three outcome variables using multiple logistic regression. In Study II interactions between socioeconomic variables and sex, age groups (< 60 years and $\geq$ 60 years) and cancer type (breast, prostate, colo-rectal) were assessed through stratified analyses. These stratified analyses were carried out because we suspected that different effects of education, income, labour market affiliation and cohabitation status could occur for patients with different cancer types, age groups and sex. The age groups were divided into +/- 60 years because our group of pensioners was defined as a mix of early-retirement and old- age pensioners, and early retirement pension is available from the age of 60 years. Similarly, in Study III interactions between comorbidity status and sex, age groups (< 65 years and ≥ 65 years) and cancer type (breast, prostate, colo-rectal and the remaining cancers in one group) were assessed through stratified analyses, because we suspected different effects of comorbidity in the different groups. Here the age groups were divided into +/- 65 years, because different effects of symptom burden among cancer survivors have been demonstrated in the different age groups (149).

Logistic regression models were used to calculate crude and adjusted odds ratios (ORs) with 95% confidence intervals (CI) between independent variables and the outcome variables for rehabilitation (i.e. needs, participation and unmet needs). In Studies I and II we adjusted for age, gender and cancer type in the multiple regression analyses. In Study III, besides adjusting for age, gender and cancer diagnosis in our main model, we explored the confounding effect of socioeconomic factors in a secondary model by further adjusting for socioeconomic factors. Socioeconomic factors included education, income, labour market affiliation and cohabitation status, and were entered into the model separately. This secondary model was only carried out for analyses regarding the whole cohort and not the stratified analyses.

All tests were two-sided and p-values < 0.05 were considered statistically significant. Analyses were performed using Stata Release 11 (StataCorp, College Station, TX, USA).

Ethics

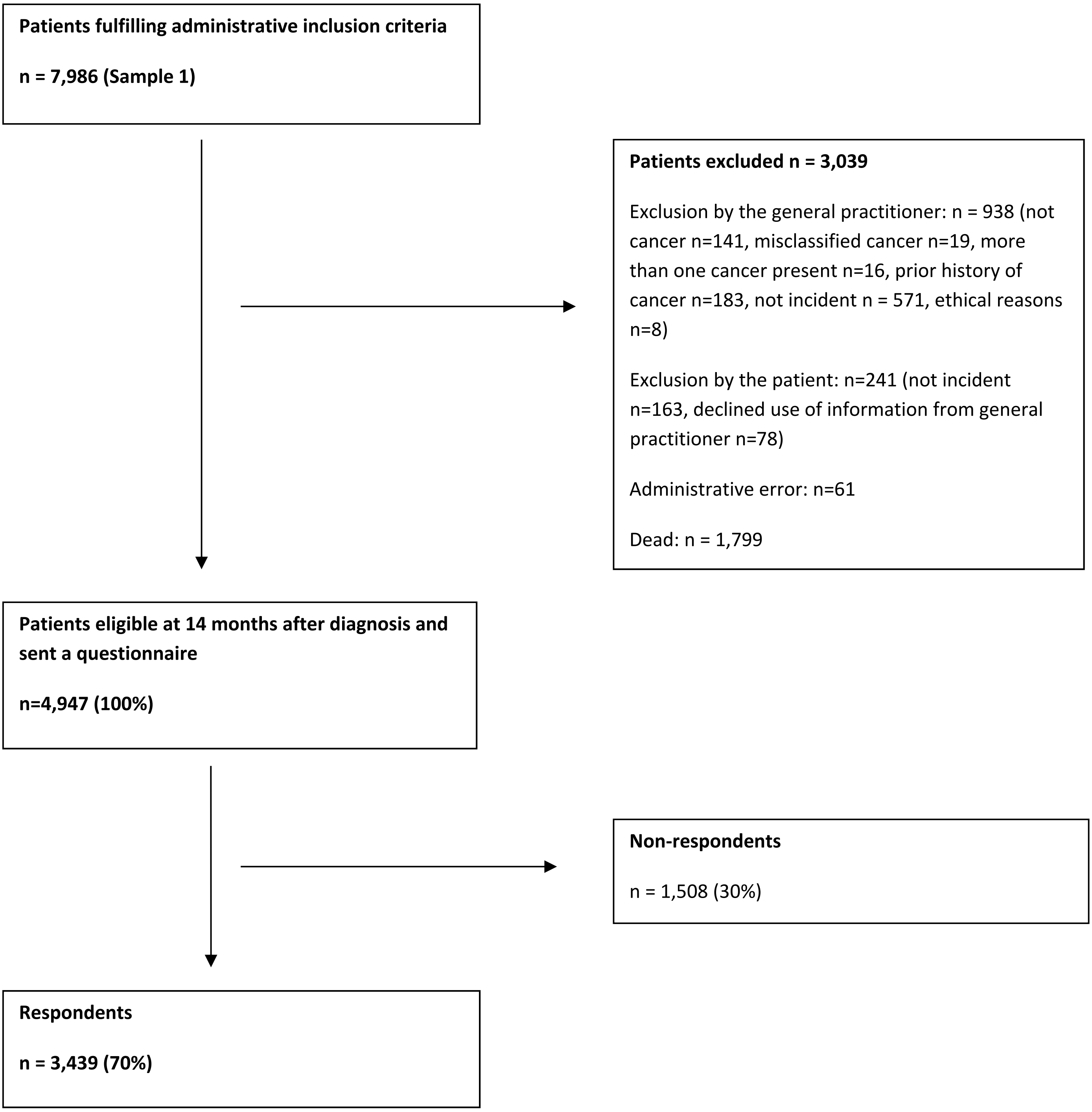
According to the “The Act on Research Ethics Review of Health Research Projects in Denmark” only questionnaire surveys and register research projects involving biological material require notification to the research ethics committee. Therefore, the research ethics committee has not been contacted. The study was approved by the Danish Data Protection Agency (J. no. 2008-41-1887).

Results

Of the 4,947 patients eligible at 14 months, 3,439 returned the questionnaire (70%) (Figure 2). Table 1 shows patient characteristics including sex, age, cancer diagnosis, socioeconomic variables and comorbidity status and illustrates that there are statistically significant differences between respondents and non-respondents with regard to all variables included. In the group of respondents, women, age 60-69 years, patients with breast cancer, patients cohabiting/married, patients who were working, patients with a higher education and income and patients with no comorbidity were overrepresented.

Table 2 shows differences between patients in sample 1 (patients identified by the primary sampling algorithm and thus eligible for inclusion into the study) and sample 2 (patients missed by the primary sampling algorithm and thus not eligible for inclusion into the study). More patients in sample 1were women, had breast cancer, were younger, of higher SES and without comorbidity.

Figure 2 Inclusion of patients into the study



Patients fulfilling administrative inclusion criteria

n = 7,986 (Sample 1)

Patients excluded n = 3,039

Exclusion by the general practitioner: n = 938 (not cancer n=141, misclassified cancer n=19, more than one cancer present n=16, prior history of cancer n=183, not incident n = 571, ethical reasons n=8)

Exclusion by the patient: n=241 (not incident n=163, declined use of information from general practitioner n=78)

Administrative error: n=61

Dead: n = 1,799

Patients eligible at 14 months after diagnosis and sent a questionnaire

n=4,947 (100%)

Non-respondents

n = 1,508 (30%)

Respondents

n = 3,439 (70%)

Table I Medical and socio-demographic characteristics of respondents and non-respondents

	Respondents n (%) 3,439 (69.5)	Non-respondents n (%) 1,508 (30.5)	P[a]
Sex			0.003
Men	1466 (42.6)	712 (47.2)	
Women	1973 (57.4)	796 (52.8)	
Age (years)			<0.001
18-39	152 (4.4)	118 (7.8)	
40-49	331 (9.6)	154 (10.2)	
50-59	660 (19.2)	292 (19.4)	
60-69	1,263 (36.8)	419 (27.8)	
70-79	802 (23.3)	338 (22.4)	
80+	231 (6.7)	187 (12.4)	
Cancer diagnosis			<0.001
Breast	976 (28.4)	314 (20.8)	
Prostate	501 (14.6)	179 (11.9)	
Colo-rectal	522 (15.2)	213 (14.1)	
Gyneacological	230 (6.7)	102 (6.8)	
Malignant melanoma	233 (6.8)	120 (7.9)	
Lung	188 (5.5)	113 (7.5)	
Lymphoma	104 (3.0)	44 (2.9)	
Head and neck	125 (3.6)	81 (5.4)	
Other	560 (16.2)	342 (22.7)	
Cohabitation status*			<0.001
Cohabiting/married	2574 (75.1)	977 (65.6)	
Living alone	854 (24.9)	513 (34.4)	
Highest attained education*			<0.001
<10 years	1284 (38.3)	639 (45.1)	
10-12 years	1305 (38.9)	546 (38.6)	
>12 years	763 (22.8)	230 (16.3)	
Income*			<0.001
Low (1st quartile)	858 (25.0)	557 (37.3)	
Medium (2nd and 3rd quartile)	1717 (50.0)	661 (44.3)	
High (4th quartile)	858 (25.0)	275 (18.4)	
Labour market status*			<0.001
Working	1527 (45.2)	604 (41.2)	
Pensioners	1565 (46.4)	690 (47.1)	
Outside the workforce	283 (8.4)	172 (11.7)	
Charlson Comorbidity Index**			<0.001
0	2,685 (78.1)	1,071 (71.4)	
1	516 (15.0)	271 (18.0)	
≥2	236 (6.9)	160 (10.6)	

*Percentage of missing data between 0.4-3.6 %

**Data on comorbidity were missing for two persons

[a] X^2 test

Table 2 Medical and socio-demographic differences between patients included in Sample 1 and Sample 2

	Sample 1 n (%) 7,986 (62.7)	Sample 2 n (%) 4,761 (37.3)	P[a]
Sex			<0.001
Men	3,839 (48.1)	2,555 (53.7)	
Women	4,147 (51.9)	2,206 (46.3)	
Age (years)			<0.001
18-39	331 (4.1)	182 (3.8)	
40-49	662 (7.8)	261 (5.5)	
50-59	1,353 (16.9)	634 (13.3)	
60-69	2,538 (31.8)	1,235 (25.9)	
70-79	2,080 (26.1)	1,372 (28.8)	
80+	1,062 (13.1)	1,077 (22.6)	
Cancer diagnosis			<0.001
Breast	1,513 (18.9)	465 (9.8)	
Prostate	1,021 (12.8)	684 (14.4)	
Colo-rectal	1,064 (13.3)	548 (11.5)	
Gyneacological	453 (5.6)	248 (5.2)	
Malignant melanoma	407 (5.1)	203 (4.3)	
Lung	902 (11.3)	591 (12.4)	
Lymphoma	222 (2.8)	159 (3.3)	
Head and neck	278 (3.5)	106 (2.2)	
Other	2,126 (26.6)	1,757 (36.9)	
Cohabitation status*			<0.001
Cohabiting/married	5,455 (68.7)	3,039 (64.1)	
Living alone	2,490 (31.3)	1,699 (35.9)	
Highest attained education*			<0.001
<10 years	3,333 (43.9)	2,093 (47.4)	
10-12 years	2,855 (37.6)	1,616 (36.6)	
>12 years	1,408 (18.5)	230 (16.0)	
Income*			<0.001
Low (1st quartile)	2,654 (33.4)	1,938 (40.8)	
Medium (2nd and 3rd quartile)	3,786 (47.6)	2,129 (44.9)	
High (4th quartile)	1,515 (19.0)	680 (14.3)	
Labour market status*			<0.001
Working	2,878 (36.7)	1,300 (27.7)	
Pensioners	4,208 (53.7)	2,974 (63.3)	
Outside the workforce	751 (9.6)	424 (9.03)	
Charlson Comorbidity Index**			<0.001
0	5,938 (74.4)	3,271 (68.7)	
1	1,408 (17.6)	966 (20.3)	
≥2	639 (8.0)	524 (11.0)	

*Percentage of missing data between 0.4-3.6 %

**Data on comorbidity were missing for two persons

[a] X^2 test

Study I

Need for rehabilitation

Need for physical and psychological rehabilitation was most frequently reported (32% and 31%, respectively) followed by a work-related need (20%), a need in the sexual area (17%), a need in the family-oriented area (14%) and finally, a need in the financial area (13%) (Table 3). Overall, higher age reduced the odds of expressing a need for rehabilitation. Women were more likely to express a rehabilitation need in the emotional, physical, family-oriented and work-related areas compared to men. When compared to patients with breast cancer, patients with malignant melanoma generally had reduced odds of expressing needs, while patients with lung cancer had increased odds in several areas.

Participation in rehabilitation activities

Overall, 52% had participated in at least one rehabilitation activity. Physical activities were used by 42%, psychological by 17% and work-related/financial by 12% (Table 4). The single most used activity was physiotherapy (31%), followed by physical training (15%), psychologist (11%), dietician (10%), alternative practitioner (7%) and social worker (6%) (data not shown). Women were more likely to participate in physical and psychological activities compared to men, while no sex difference was observed with regard to work-related/financial activities. The oldest patients were less likely to participate in activities. Patients with breast cancer had increased odds of participating in physical activities compared with other cancer patients.

Unmet needs for rehabilitation

Among patients who had expressed a need for rehabilitation during the 14-month period, unmet needs were most common for sexual problems (50%) and least common for physical problems (17%) (Table 5). Financial issues were still unsolved for one third. Men were more likely to have emotional unmet needs than women, and higher age increased the odds of unmet needs in all areas, except for physical and financial problems. Compared with patients with breast cancer, patients with colorectal, gynecological and head and neck cancers had increased odds of having unmet needs for physical rehabilitation. Patients with malignant melanoma were more likely to have emotionally unmet needs compared with patients with breast cancer.

Table 3 Needs for rehabilitation during 14 months following time of diagnosis. For each area (physical, emotional, family-oriented, sexual, work-related and financial) number, frequencies, crude and adjusted odds ratios (ORs) are shown with regard to sex, age and cancer diagnosis

	Physical area n=3,242			Emotional area n=3,254			Family-oriented area n=3,250			Sexual area n=3,197			
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	Men n=1,366 ORadj[b] (95% CI)	Women n=1,829 ORadj[b] (95% CI)
Needs, total	1,028 (31.7)	-	-	997 (30.6)	-	-	453 (13.9)	-	-	529 (16.6)	-	-	-
Sex													
Men	352 (25.4)	1.00	1.00	327 (23.5)	1.00	1.00	145 (10.4)	1.00	1.00	308 (22.5)	1.00	-	-
Women	676 (36.5)	1.69**	1.36** (1.01-1.70)	670 (35.9)	1.82**	1.72** (1.37-2.17)	308 (16.6)	1.70**	1.40* (1.04-1.88)	221 (12.1)	0.47**	-	-
Age (years)													
18-39	54 (36.0)	1.00	1.00	82 (54.3)	1.00	1.00	47 (31.3)	1.00	1.00	34 (22.5)	1.00	1.00	1.00
40-49	149 (46.4)	1.54*	1.35 (0.90-2.03)	176 (53.8)	0.98	0.86 (0.57-1.28)	96 (29.3)	0.91	0.82 (0.53-1.27)	77 (23.7)	1.07	0.83 (0.35-2.02)	0.91 (0.51-1.62)
50-59	263 (41.3)	1.25	1.13 (0.77-1.65)	279 (43.8)	0.66*	0.59** (0.40-0.85)	135 (21.2)	0.59**	0.55** (0.36-0.83)	133 (21.0)	0.91	0.93 (0.43-1.99)	0.61 (0.35-1.06)
60-69	339 (27.8)	0.68*	0.63* (0.43-0.91)	304 (25.0)	0.28**	0.25** (0.17-0.36)	117 (9.6)	0.23**	0.22** (0.14-0.33)	203 (17.0)	0.71	0.72 (0.34-1.51)	0.25** (0.14-0.44)
70-79	172 (23.6)	0.55**	0.53** (0.36-0.78)	125 (17.0)	0.17**	0.16** (0.11-0.24)	48 (6.6)	0.15**	0.15** (0.09-0.24)	69 (9.7)	0.37**	0.33** (0.15-0.72)	0.04** (0.01-0.11)
80+	51 (27.4)	0.67	0.64 (0.39-1.03)	31 (16.4)	0.17**	0.15** (0.09-0.26)	10 (5.3)	0.12**	0.12** (0.06-0.25)	13 (7.1)	0.26**	0.26** (0.10-0.69)	0.06** (0.01-0.26)
Cancer diagnosis													
Breast	367 (39.5)	1.00	1.00	338 (36.2)	1.00	1.00	152 (16.3)	1.00	1.00	111 (12.1)	1.00	-	1.00
Prostate	96 (20.7)	0.40**	0.70* (0.50-0.99)	89 (19.1)	0.42**	1.16 (0.80-1.66)	30 (6.4)	0.35**	0.85 (0.51-1.43)	159 (34.3)	3.79**	2.44** (1.67-3.56)	-
Colorectal	142 (29.0)	0.62**	0.84 (0.65-1.10)	109 (22.2)	0.51*	0.88 (0.66-1.18)	50 (10.2)	0.58**	0.96 (0.66-1.41)	68 (14.2)	1.20	1.00	1.11 (0.65-1.89)
Gynecological	69 (31.9)	0.72*	0.72* (0.52-0.99)	79 (36.1)	0.99	1.00 (0.72-1.38)	43 (19.6)	1.25	1.25 (0.85-1.85)	41 (19.1)	1.71**	-	1.83** (1.21-2.77)
Malignant	49 (22.4)	0.44**	0.48** (0.33-0.68)	51 (23.2)	0.53**	0.52** (0.35-0.75)	19 (8.6)	0.49**	0.43* (0.25-0.73)	16 (7.3)	0.57*	0.34** (0.15-0.75)	0.34** (0.16-0.75)
melanoma	71 (39.7)	1.01	1.43* (1.01-2.04)	70 (39.3)	1.14	2.19** (1.52-3.16)	28 (15.6)	0.95	1.65* (1.03-2.66)	27 (15.7)	1.35	0.99 (0.53-1.84)	1.53 (0.74-3.16)
Lung	35 (34.3)	0.80	0.92 (0.59-1.44)	49 (48.0)	1.63*	2.24 **(1.42-3.51)	24 (23.8)	1.60	1.90* (1.12-3.23)	15 (15.0)	1.28	0.87 (0.40-1.87)	0.76 (0.29-2.02)
Lymphoma	32 (26.9)	0.56**	0.69 (0.43-1.09)	39 (33.3)	0.88	1.29 (0.82-2.04)	15 (12.9)	0.76	0.97 (0.52-1.80)	12 (10.4)	0.84	0.31** (0.13-0.72)	1.49 (0.54-4.11)
Head and neck	167 (31.9)	0.72**	0.92 (0.70-1.20)	173 (32.9)	0.87	1.29 (0.98-1.70)	92 (17.6)	1.09	1.42* (1.01-2.02)	80 (15.4)	1.32	0.81 (0.52-1.25)	1.07 (0.64-1.78)
Other													

[a] Adjusted for sex, age group and cancer diagnosis

[b] Adjusted for age group and cancer diagnosis

*p<0.05

**p<0.01

Table 3 (Continued)

	Work-related area n=1,276			Financial area n=1,895		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Needs, total	252 (19.8)	-	-	257 (13.4)	-	-
Sex						
Men	77 (14.3)	1.00	1.00	118 (13.8)	1.00	1.00
Women	175 (23.7)	1.87**	1.55* (1.01-2.39)	139 (13.4)	0.97	0.86 (0.60-1.25)
Age (years)						
18-39	23 (22.3)	1.00	1.00	20 (16.7)	1.00	1.00
40-49	73 (32.0)	1.64	1.43 (0.82-2.51)	51 (19.5)	1.21	1.33 (0.74-2.38)
50-59	116 (28.9)	1.41	1.27 (0.74-2.17)	97 (19.5)	1.21	1.31 (0.76-2.27)
60-69	32 (9.8)	0.38**	0.37** (0.20-0.69)	66 (10.8)	0.61	0.65 (0.37-1.15)
70-79	6 (3.6)	0.13**	0.12** (0.05-0.32)	18 (5.6)	0.30**	0.30** (0.15-0.61)
80+	2 (4.0)	0.14*	0.14* (0.03-0.63)	5 (6.0)	0.32*	0.35 (0.12-1.00)
Cancer diagnosis						
Breast	94 (23.9)	1.00	1.00	62 (11.7)	1.00	1.00
Prostate	15 (9.7)	0.34**	1.11 (0.52-2.36)	22 (8.2)	0.67	0.93 (0.49-1.78)
Colorectal	31 (16.8)	0.64	1.17 (0.69-1.98)	32 (11.7)	0.99	1.17 (0.70-1.96)
Gynecological	26 (30.2)	1.38	1.36 (0.80-2.32)	22 (17.3)	1.58	1.64 (0.96-2.82)
Malignant melanoma	8 (8.3)	0.29**	0.36* (0.16-0.80)	13 (10.0)	0.84	0.83 (0.43-1.62)
Lung	8 (15.7)	0.59	1.09 (0.47-2.54)	18 (17.1)	1.56	2.00* (1.07-3.75)
Lymphoma	9 (19.6)	0.78	0.93 (0.41-2.10)	11 (16.2)	1.46	1.39 (0.67-2.91)
Head and neck	14 (25.5)	1.09	1.57 (0.74-3.32)	12 (15.0)	1.33	1.20 (0.58-2.50)
Other	47 (22.5)	0.93	1.38 (0.84-2.28)	65 (20.8)	1.99	2.03** (1.28-3.22)

[a] Adjusted for sex, age group and cancer diagnosis

[b] Adjusted for age group and cancer diagnosis

*p<0.05

**p<0.01

Table 4 Participation in rehabilitation activities during 14 months following time of diagnosis. For each area (one or more activities, one or more physical activities, one or more psychological activities and one of more work-related/financial activities) number, frequencies, crude and adjusted odds ratios (ORs) are shown with regard to sex, age and cancer diagnosis

	One or more activities n=3,257			One or more physical activities n=3,439			One or more psychological activities n=3,439			One or more work related/financial activities n=3,439		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Participation, total	1,697 (52.1)	-	-	1,447 (42.1)	-	-	586 (17.0)	-	-	403 (11.7)	-	-
Sex												
Men	545 (39.4)	1.00	1.00	438 (29.9)	1.00	1.00	152 (10.4)	1.00	1.00	134 (9.1)	1.00	1.00
Women	1,152 (61.5)	2.46**	1.54** (1.25-1.90)	1009 (51.1)	2.46**	1.41** (1.14-1.73)	434 (22.0)	2.44**	1.90** (1.43-2.52)	269 (13.6)	1.56**	1.03 (0.74-1.43)
Age (years)												
18-39	102 (67.1)	1.00	1.00	68 (44.7)	1.00	1.00	63 (41.5)	1.00	1.00	55 (36.2)	1.00	1.00
40-49	234 (72.2)	1.27	0.88 (0.57-1.37)	197 (59.5)	1.82**	1.29 (0.85-1.96)	118 (35.6)	0.78	0.59* (0.39-0.89)	87 (26.3)	0.63*	0.50** (0.32-0.78)
50-59	443 (69.7)	1.13	0.81 (0.54-1.22)	344 (52.1)	1.34	1.02 (0.70-1.50)	184 (27.9)	0.55**	0.42** (0.29-0.63)	163 (24.7)	0.58**	0.48** (0.32-0.72)
60-69	600 (49.6)	0.48**	0.34** (0.23-0.51)	546 (43.2)	0.94	0.74 (0.51-1.08)	154 (12.2)	0.20**	0.16** (0.11-0.24)	71 (5.6)	0.11**	0.09** (0.06-0.13)
70-79	257 (34.7)	0.26**	0.21** (0.14-0.32)	238 (29.7)	0.52**	0.48** (0.33-0.71)	53 (6.6)	0.10**	0.09** (0.06-0.14)	19 (2.4)	0.04**	0.04** (0.02-0.07)
80+	61 (31.4)	0.22**	0.18** (0.11-0.29)	54 (23.4)	0.38**	0.34** (0.21-0.55)	14 (6.1)	0.10**	0.08** (0.04-0.15)	8 (3.5)	0.06**	0.05** (0.02-0.12)
Cancer diagnosis												
Breast	694 (73.9)	1.00	1.00	652 (66.8)	1.00	1.00	239 (24.5)	1.00	1.00	152 (15.6)	1.00	1.00
Prostate	163 (35.0)	0.19**	0.41** (0.30-0.57)	139 (27.7)	0.19**	0.34** (0.25-0.47)	34 (6.8)	0.22**	0.77 (0.47-1.24)	23 (4.6)	0.26**	0.65 (0.36-1.17)
Colorectal	192 (39.8)	0.23**	0.36** (0.27-0.47)	149 (28.5)	0.20**	0.28** (0.22-0.36)	70 (13.4)	0.48**	0.91 (0.65-1.27)	47 (9.0)	0.54**	0.84 (0.56-1.27)
Gynecological	107 (47.8)	0.32**	0.31** (0.23-0.42)	78 (33.9)	0.26**	0.25** (0.19-0.34)	47 (20.4)	0.79	0.76 (0.53-1.11)	30 (13.0)	0.81	0.77 (0.49-1.21)
Malignant melanoma	71 (32.3)	0.17**	0.16** (0.11-0.22)	52 (22.3)	0.14**	0.16** (0.11-0.22)	25 (10.7)	0.37**	0.32** (0.20-0.52)	12 (5.2)	0.29**	0.20** (0.10-0.38)
Lung	93 (52.0)	0.38**	0.62** (0.43-0.89)	75 (39.9)	0.33**	0.46** (0.33-0.65)	31 (16.5)	0.61*	1.22 (0.78-1.92)	15 (8.0)	0.47**	0.82 (0.44-1.50)
Lymphoma	54 (54.0)	0.41**	0.47** (0.30-0.74)	45 (43.3)	0.38**	0.44** (0.28-0.67)	25 (24.0)	0.98	1.24 (0.74-2.08)	30 (28.9)	2.20**	2.36** (1.39-4.03)
Head and neck	69 (58.5)	0.50*	0.65 (0.42-1.01)	54 (43.2)	0.38**	0.49** (0.32-0.74)	27 (21.6)	0.85	1.35 (0.81-2.25)	11 (8.8)	0.52*	0.49* (0.24-0.99)
Other	254 (48.0)	0.33**	0.44** (0.33-0.57)	203 (36.3)	0.28**	0.37** (0.29-0.48)	88 (15.7)	0.57**	0.83 (0.60-1.15)	83 (14.8)	0.94	1.01 (0.69-1.47)

[a] Adjusted for sex, age group and cancer diagnosis
*p<0.05
**p<0.01

Table 5 Unmet needs for rehabilitation 14 months after diagnosis. For each area (physical, emotional, family-oriented, sexual, work-related and financial) number, frequencies, crude and adjusted odds ratios (ORs) are shown with regard to sex, age and cancer diagnosis

	Physical area n=922			Emotional area n=883			Family-oriented area n=380			Sexual area n=454		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Unmet needs, total	159 (17.3)	-	-	209 (23.7)	-	-	122 (32.1)	-	-	225 (49.6)	-	-
Sex												
Men	63 (19.8)	1.00	1.00	85 (31.1)	1.00	1.00	43 (34.4)	1.00	1.00	124 (46.8)	1.00	1.00
Women	96 (15.9)	0.76	0.96 (0.60-1.54)	124 (20.3)	0.56**	0.58** (0.37-0.92)	79 (31.0)	0.86	1.06 (0.58-1.93)	101 (53.4)	1.31	0.80 (0.42-1.55)
Age (years)												
<60	64 (15.3)	1.00	1.00	91 (18.3)	1.00	1.00	65 (26.9)	1.00	1.00	105 (47.7)	1.00	1.00
≥60	95 (18.9)	1.29	1.17 (0.81-1.70)	118 (30.7)	1.98**	2.05** (1.47-2.85)	57 (41.3)	1.92**	2.03** (1.27-3.25)	120 (51.3)	1.15	1.83** (1.16-2.89)
Cancer diagnosis												
Breast	40 (12.1)	1.00	1.00	55 (17.7)	1.00	1.00	33 (26.4)	1.00	1.00	54 (56.8)	1.00	1.00
Prostate	16 (18.4)	1.63	1.46 (0.65-3.27)	24 (30.8)	2.06*	0.94 (0.45-1.97)	7 (28.0)	1.08	0.83 (0.26-2.62)	51 (36.4)	0.44**	0.24** (0.10-0.56)
Colorectal	28 (22.1)	2.05**	1.93* (1.07-3.48)	18 (19.6)	1.13	0.78 (0.41-1.49)	16 (38.1)	1.72	1.62 (0.72-3.68)	29 (48.3)	0.71	0.52 (0.23-1.17)
Gynecological	14 (24.6)	2.36*	2.33* (1.17-4.65)	17 (23.9)	1.46	1.47 (0.79-2.74)	10 (30.3)	1.21	1.16 (0.49-2.72)	16 (48.5)	0.71	0.68 (0.30-1.52)
Malignant melanoma	4 (9.8)	0.78	0.75 (0.25-2.26)	17 (37.8)	2.81**	2.51* (1.24-5.05)	5 (31.3)	1.27	1.29 (0.40-4.13)	8 (72.7)	2.02	1.68 (0.40-6.99)
Lung	15 (22.7)	2.13*	1.97 (0.97-4.01)	16 (28.6)	1.85	1.31 (0.66-2.60)	10 (40.0)	1.86	1.46 (0.57-3.72)	14 (66.7)	1.52	1.13 (0.39-3.27)
Lymphoma	7 (21.9)	2.03	1.95 (0.76-5.00)	15 (34.1)	2.39*	2.05 (0.99-4.27)	9 (40.9)	1.93	2.19 (0.81-5.89)	8 (53.3)	0.87	0.72 (0.22-2.36)
Head and neck	9 (32.1)	3.43**	3.32** (1.34-8.22)	13 (35.1)	2.51*	2.00 (0.90-4.43)	6 (42.9)	2.09	2.09 (0.64-6.85)	7 (63.6)	1.33	1.24 (0.32-4.81)
Other	26 (16.9)	1.47	1.41 (0.77-2.57)	34 (22.7)	1.36	0.98 (0.56-1.72)	26 (33.3)	1.39	1.48 (0.72-3.04)	38 (55.9)	0.96	0.77 (0.35-1.69)

[a] Adjusted for sex, age group and cancer diagnosis

*p<0.05

**p<0.01

Table 5 (Continued)

	Work-related area n=222-230			Financial area n=230		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Unmet needs, total	43 (18.7)	-	-	79 (34.4)	-	-
Sex						
Men	18 (26.1)	1.00	1.00	42 (39.3)	1.00	1.00
Women	25 (15.5)	0.52	0.53 (0.19-1.47)	37 (30.1)	0.67	0.53 (0.24-1.19)
Age (years)						
<60	33 (16.6)	1.00	1.00	53 (33.3)	1.00	1.00
≥60	10 (32.3)	2.40*	2.98* (1.14-7.80)	26 (36.6)	1.16	1.08 (0.58-2.03)
Cancer diagnosis						
Breast	12 (14.1)	1.00	1.00	19 (38.0)	1.00	1.00
Prostate	2 (15.4)	1.11	0.30 (0.04-2.35)	10 (55.6)	2.04	1.06 (0.27-4.13)
Colorectal	4 (14.8)	1.06	0.55 (0.13-2.36)	6 (23.1)	0.49	0.32 (0.09-1.08)
Gynecological	5 (19.2)	1.45	1.45 (0.45-4.62)	6 (28.6)	0.65	0.65 (0.21-1.96)
Malignant melanoma	0 (0)	-	-	3 (23.1)	0.49	0.31 (0.07-1.46)
Lung	4 (50.0)	6.08*	4.02 (0.75-21.7)	7 (43.8)	1.27	0.86 (0.25-3.02)
Lymphoma	2 (22.2)	1.74	1.65 (0.29-9.26)	4 (36.4)	0.93	0.69 (0.17-2.88)
Head and neck	4 (28.6)	2.43	1.63 (0.36-7.29)	6 (50.0)	1.63	0.97 (0.23-4.10)
Other	10 (25.0)	2.03	1.25 (0.39-4.05)	18 (28.6)	0.65	0.43 (0.16-1.13)

[a] Adjusted for sex, age group and cancer diagnosis

*$p<0.05$

**$p<0.01$

Study II

In some analyses we found that effects of SES on the outcomes for rehabilitation differed for men and women, and analyses were therefore stratified for gender.

Need for rehabilitation

Among women, living alone increased the odds of expressing a rehabilitation need in the physical, emotional and financial area compared to those who were cohabiting/married (Table 6). A high education increased the odds of expressing a need in the emotional area, but reduced the odds of having a financial need. Women outside the workforce had increased odds of expressing a financial need compared to women working. A high income reduced the odds of expressing a financial and work-related rehabilitation need.

Among men, similar tendencies were seen, but the associations were less pronounced and non-significant.

Participation in rehabilitation activities

Overall, women with a higher education and to some extent higher income had significantly increased odds of participating in rehabilitation activities (Table 7). Women who were pensioners or otherwise outside the workforce had reduced odds of participating in activities compared to women working. Women living alone had increased odds of participating in psychological activities.

Among men, a higher income increased odds of participating in physical activities, while a high education was associated with participation in psychological activities. Male pensioners and men outside the workforce showed a tendency towards reduced odds of participating in all areas, but this was only statistically significant in work-related/financial area.

Unmet needs for rehabilitation

Table 8 presents unmet needs among the male and female patients, who had expressed a need for rehabilitation during the 14-month period.

Among women, living alone increased the odds of unmet needs in the family-oriented and sexual area. Women with a high education were less likely to have unmet needs in the physical and emotional area. There was a tendency towards women outside the workforce being more likely to have unresolved needs. However, this only showed statistical significance in the work-related area.

Among men, a high education also reduced the odds of having unmet needs in the physical area, while living alone increased the odds in the same area. Men outside the workforce had increased odds of unmet needs in the physical and sexual area.

Stratified analyses for the different cancer types and age groups (data not shown)

Stratified analyses for women with breast and colorectal cancer showed similar tendencies, although for breast cancer results were often more pronounced. With regard to single women expressing a need for and participating in psychological rehabilitation, this was only found for breast cancer. Analyses on men with prostate and colorectal cancer revealed minor differences, e.g. a higher income reduced the odds of having a sexually related need for colorectal cancer, while it increased for prostate cancer alone. However, none of the results were statistically significant.

Comparing stratified analyses on different age groups we found some differences, with the most pronounced being that single older patients had significantly increased odds of expressing a need for physical rehabilitation, which was not found among single younger patients.

Table 6 Needs for rehabilitation during 14 months following time of diagnosis. For each area number, frequencies, crude and adjusted odds ratios (ORs) are shown separately for men (grey) and women (white) with regard to cohabitation status, highest attained education, income and labour market status.

	Physical area n=1388-1854			Emotional area n=1390-1864			Family-oriented area n=1390-1860			Sexual area n=1368-1829		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[b] (95% CI)
Needs, total												
Men	352 (25.4)	-	-	327 (23.5)	-	-	145 (10.4)	-	-	308 (22.5)	-	-
Women	676 (36.5)	-	-	670 (36.0)			380 (16.6)	-	-	221 (12.1)	-	-
Cohabitation status												
Men												
Cohabiting/married	286 (25.4)	1.00	1.00	259 (22.9)	1.00	1.00	117 (10.4)	1.00	1.00	254 (22.9)	1.00	1.00
Living alone	66 (26.0)	1.03	0.98 (0.71-1.35)	65 (25.8)	1.17	1.01 (0.72-1.41)	27 (10.7)	1.03	0.84 (0.53-1.33)	52 (20.6)	0.87	0.91 (0.64-1.29)
Women												
Cohabiting/married	474 (35.9)	1.00	1.00	465 (35.2)	1.00	1.00	227 (17.2)	1.00	1.00	187 (14.3)	1.00	1.00
Living alone	201 (37.9)	1.09	1.34* (1.07-1.68)	204 (37.8)	1.12	1.59** (1.26-2.00)	80 (14.9)	0.84	1.14 (0.85-1.54)	34 (6.6)	0.42**	0.57** (0.38-0.86)
Highest attained education												
Men												
<10 years	104 (23.2)	1.00	1.00	93(20.6)	1.00	1.00	39 (8.6)	1.00	1.00	98 (22.2)	1.00	1.00
10-12 years	159 (26.0)	1.16	1.10 (0.82-1.47)	147 (24.1)	1.22	1.02 (0.75-1.40)	72 (11.8)	1.43	1.17 (0.76-1.80)	137 (22.8)	1.04	1.02 (0.75-1.40)
>12 years	78 (27.3)	1.24	1.16 (0.82-1.64)	77 (26.9)	1.42*	1.18 (0.82-1.71)	28 (9.7)	1.14	0.86 (0.50-1.47)	68 (23.7)	1.09	0.99 (0.69-1.45)
Women												
<10 years	248 (34.0)	1.00	1.00	230 (31.4)	1.00	1.00	109 (15.0)	1.00	1.00	63 (8.9)	1.00	1.00
10-12 years	224(34.8)	1.04	0.89 (0.70-1.13)	217 (33.8)	1.11	0.86 (0.67-1.10)	98 (15.3)	1.02	0.74 (0.54-1.02)	80 (12.6)	1.48*	1.04 (0.72-1.50)
>12 years	190 (42.9)	1.46**	1.13 (0.87-1.48)	214 (47.4)	1.96**	1.34* (1.03-1.10)	94 (20.8)	1.50**	0.93 (0.66-1.30)	75 (16.8)	2.07**	1.22 (0.83-1.81)
Income												
Men												
Low (1st quartile)	63 (19.9)	1.00	1.00	55 (17.4)	1.00	1.00	28 (8.8)	1.00	1.00	51 (16.4)	1.00	1.00
Medium (2nd and 3rd quartile)	199 (29.3)	1.66**	1.54 (1.09-2.17)	185 (27.0)	1.76**	1.32 (0.92-1.91)	90 (13.1)	1.56	1.15 (0.71-1.87)	153 (22.7)	1.50*	1.15 (0.78-1.68)
High (4th quartile)	90 (23.2)	1.22	1.10 (0.74-1.64)	87 (22.7)	1.40	1.06 (0.69-1.62)	27 (7.0)	0.78	0.57 (0.31-1.05)	103 (27.1)	1.90**	1.27 (0.83-1.93)
Women												
Low (1st quartile)	157 (34.8)	1.00	1.00	147 (31.9)	1.00	1.00	70 (15.4)	1.00	1.00	33 (7.5)	1.00	1.00
Medium (2nd and 3rd quartile)	349 (36.7)	1.08	0.86 (0.66-1.11)	356 (37.5)	1.28*	0.81 (0.62-1.06)	175 (18.4)	1.25	0.73 (0.52-1.03)	127 (13.5)	1.92**	1.05 (0.68-1.62)
High (4th quartile)	170 (38.0)	1.15	0.86 (0.63-1.17)	167 (37.11)	1.26	0.77 (0.56-1.06)	63 (14.0)	0.90	0.50** (0.33-0.76)	61 (13.7)	1.94**	1.01 (0.62-0.63)
Labour market status												
Men												
Working	182 (29.9)	1.00	1.00	191 (31.5)	1.00	1.00	85 (14.0)	1.00	1.00	157 (26.3)	1.00	1.00
Pensioners	143 (20.9)	0.62**	0.62* (0.43-0.91)	106 (15.4)	0.39**	0.74 (0.49-1.12)	44 (6.4)	0.42**	0.92 (0.48-1.76)	127 (18.7)	0.64**	0.80 (0.55-1.18)
Outside the workforce	23 (31.5)	1.08	1.04 (0.61-1.80)	23 (31.9)	1.02	1.04 (0.60-1.81)	12 (16.9)	1.25	1.52 (0.75-3.06)	20 (28.2)	1.10	1.25 (0.70-2.23)
Women												
Working	368 (41.8)	1.00	1.00	389 (43.9)	1.00	1.00	184 (20.7)	1.00	1.00	148 (16.8)	1.00	1.00
Pensioners	206 (27.9)	0.54**	0.87 (0.62-1.23)	175 (23.7)	0.40**	1.02 (0.71-1.44)	64 (8.7)	0.37**	1.15 (0.70-1.88)	32 (4.5)	0.23**	0.91 (0.51-1.60)
Outside the workforce	91 (46.4)	1.21	1.29 (0.93-1.78)	93 (47.0)	1.13	1.32 (0.95-1.83)	51 (25.6)	1.32	1.56* (1.07-2.28)	36 (18.4)	1.11	1.29 (0.85-1.96)

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[a] Adjusted for sex, age group and cancer diagnosis *p<0.05 **p<0.001

Table 6 (Continued)

	Work-related area n=380-598			Financial area n=856-1039		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Needs, total						
Men	72 (19.0)	-	-	118 (13.8)	-	-
Women	169 (28.3)	-	-	139 (13.4)	-	-
Cohabitation status						
Men						
Cohabiting/married	54 (18.3)	1.00	1.00	91 (13.5)	1.00	1.00
Living alone	16 (19.5)	1.08	1.01 (0.53-1.93)	26 (14.9)	1.13	0.98 (0.60-1.61)
Women						
Cohabiting/married	133 (28.1)	1.00	1.00	87 (11.5)	1.00	1.00
Living alone	36 (29.0)	1.05	1.11 (0.71-1.75)	51 (18.0)	1.69**	2.26** (1.51-3.37)
Highest attained education						
Men						
<10 years	13 (14.3)	1.00	1.00	32 (11.5)	1.00	1.00
10-12 years	40 (22.6)	1.77	1.99 (0.97-4.09)	59 (16.2)	1.49	1.20 (0.74-1.96)
>12 years	17 (16.7)	1.22	1.43 (0.62-3.28)	22 (11.6)	1.01	0.81 (0.44-1.49)
Women						
<10 years	45 (30.2)	1.00	1.00	51 (13.6)	1.00	1.00
10-12 years	58 (26.6)	0.84	0.77 (0.48-1.25)	50 (13.9)	1.02	0.78 (0.50-1.22)
>12 years	61 (27.2)	0.86	0.77 (0.47-1.25)	33 (11.7)	0.84	0.59* (0.35-0.98)
Income						
Men						
Low (1st quartile)	8 (26.7)	1.00	1.00	17 (9.1)	1.00	1.00
Medium (2nd and 3rd quartile)	41 (22.0)	0.78	0.85 (0.34-2.17)	77 (18.9)	2.32	1.47 (0.81-2.69)
High (4th quartile)	23 (14.1)	0.45	0.61 (0.22-1.69)	24 (9.2)	1.01	0.59 (0.29-1.21)
Women						
Low (1st quartile)	22 (40.0)	1.00	1.00	36 (16.3)	1.00	1.00
Medium (2nd and 3rd quartile)	100 (28.7)	0.60	0.53* (0.28-0.98)	83 (15.3)	0.93	0.57* (0.36-0.92)
High (4th quartile)	47 (24.4)	0.48*	0.44* (0.23-0.85)	20 (7.3)	0.40**	0.23** (0.12-0.42)
Labour market status						
Men						
Working	64 (18.5)	1.00	1.00	82 (17.9)	1.00	1.00
Pensioners	-	-	-	24 (7.2)	0.35**	0.75 (0.35-1.59)
Outside the workforce	4 (16.0)	0.84	0.75 (0.23-2.39)	9 (18.8)	1.06	1.03 (0.46-2.30)
Women						
Working	149 (28.0)	1.00	1.00	90 (14.0)	1.00	1.00
Pensioners	-	-	-	18 (6.4)	0.42**	0.78 (0.35-1.76)
Outside the workforce	18 (31.6)	1.19	1.26 (0.68-2.33)	29 (27.9)	2.37**	2.73** (1.65-4.54)

[a] Adjusted for age group and cancer diagnosis *p<0.05 **p<0.01

Table 7 Participation in rehabilitation activities during 14 months following time of diagnosis. For each category of activity number, frequencies, crude and adjusted odds ratios (ORs) are shown separately for men (grey) and women (white) with regard to cohabitation status, highest attained education, income and labour market status.

	Participation in at least one activity n=1384-1873			One or more physical activities n=1466-1973			One or more psychological activities n=1466-1973			One or more work-related/financial activities n=1466-1973		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Participation, total												
Men	545 (39.4)	-	-	438 (29.9)	-	-	152 (10.4)	-	-	134 (9.1)	-	-
Women	1152 (61.5)	-	-	1,009 (51.5)	-	-	434 (22.0)	-	-	269 (13.6)		
Cohabitation status												
Men												
Cohabiting/married	435 (38.7)	1.00	1.00	357 (30.0)	1.00	1.00	118 (9.9)	1.00	1.00	103 (8.7)	1.00	1.00
Living alone	105 (41.7)	1.13	1.02 (0.76-1.36)	77 (28.7)	0.94	0.90 (0.67-1.22)	30 (11.2)	1.15	0.95 (0.61-1.49)	31 (11.6)	1.38	1.01 (0.63-1.62)
Women												
Cohabiting/married	833 (63.2)	1.00	1.00	727 (52.6)	1.00	1.00	309 (22.3)	1.00	1.00	205 (14.8)	1.00	1.00
Living alone	318 (57.8)	0.80*	1.09 (0.86-1.38)	281 (48.0)	0.83	1.07 (0.86-1.34)	124 (21.2)	0.93	1.38* (1.06-1.80)	63 (10.8)	0.69*	1.05 (0.75-1.47)
Highest attained education												
Men												
<10 years	161 (35.6)	1.00	1.00	133 (26.8)	1.00	1.00	39 (7.9)	1.00	1.00	26 (5.2)	1.00	1.00
10-12 years	246 (40.7)	1.24	1.05 (0.80-1.36)	195 (31.1)	1.24	1.11 (0.85-1.45)	61 (9.7)	1.27	0.96 (0.62-1.48)	73 (11.6)	2.39**	1.74* (1.05-2.89)
>12 years	125 (43.6)	1.39*	1.20 (0.88-1.65)	98 (32.9)	1.34	1.22 (0.88-1.68)	45 (15.1)	2.09**	1.65* (1.02-2.67)	31 (10.4)	2.10**	1.47 (0.81-2.67)
Women												
<10 years	378 (51.4)	1.00	1.00	332 (42.2)	1.00	1.00	112 (14.2)	1.00	1.00	71 (9.0)	1.00	1.00
10-12 years	409 (62.9)	1.60**	1.34* (1.05-1.70)	357 (52.7)	1.52**	1.38** (1.10-1.74)	151 (22.3)	1.73**	1.31 (0.98-1.75)	92 (13.6)	1.58**	1.03 (0.72-1.47)
>12 years	350 (77.8)	3.31**	2.55** (1.90-3.43)	306 (65.8)	2.63**	2.26** (1.73-2.96)	167 (35.9)	3.38**	2.17** (1.61-2.93)	103 (22.2)	2.87	1.48* (1.03-2.13)
Income												
Men												
Low (1st quartile)	87 (27.4)	1.00	1.00	72 (20.5)	1.00	1.00	24 (6.8)	1.00	1.00	21 (6.0)	1.00	1.00
Medium (2nd and 3rd quartile)	299 (43.8)	2.06**	1.63** (1.19-2.24)	238 (33.2)	1.94**	1.67** (1.21-2.30)	82 (11.5)	1.77*	1.15 (0.69-1.93)	71 (9.9)	1.74*	0.95 (0.53-1.70)
High (4th quartile)	157 (41.2)	1.85**	1.43* (1.01-2.06)	126 (31.9)	1.82**	1.55* (1.07-2.24)	44 (11.1)	1.71*	1.14 (0.64-2.04)	42 (10.6)	1.88*	1.04 (0.55-1.97)
Women												
Low (1st quartile)	222 (47.5)	1.00	1.00	198 (39.1)	1.00	1.00	71 (14.0)	1.00	1.00	47 (9.3)	1.00	1.00
Medium (2nd and 3rd quartile)	616 (64.9)	2.04**	1.57** (1.21-2.03)	525 (52.5)	1.72**	1.40** (1.09-1.79)	241 (24.1)	1.94**	1.30 (0.94-1.80)	156 (15.6)	1.80**	0.94 (0.64-1.40)
High (4th quartile)	314 (69.2)	2.48**	1.83** (1.33-2.51)	286 (61.8)	2.51**	2.07** (1.52-2.80)	122 (26.4)	2.19**	1.41 (0.98-2.05)	66 (14.3)	1.62*	0.74 (0.47-1.17)
Labour market status												
Men												
Working	295 (48.9)	1.00	1.00	217 (35.0)	1.00	1.00	98 (15.8)	1.00	1.00	111 (17.9)	1.00	1.00
Pensioners	203 (29.6)	0.44**	0.74 (0.53-1.04)	185 (24.8)	0.61**	0.77 (0.55-1.08)	39 (5.2)	0.29**	0.72 (0.40-1.27)	16 (2.1)	0.10**	0.32** (0.14-0.73)
Outside the workforce	37 (50.7)	1.07	0.96 (0.58-1.59)	28 (36.8)	1.08	0.97 (0.58-1.61)	9 (11.8)	0.72	0.64 (0.30-1.36)	6 (7.9)	0.39*	0.39* (0.16-0.96)
Women												
Working	649 (73.1)	1.00	1.00	556 (61.3)	1.00	1.00	293 (32.3)	1.00	1.00	219 (24.1)	1.00	1.00
Pensioners	354 (47.2)	0.33**	0.68* (0.49-0.95)	322 (39.4)	0.41**	0.60** (0.44-0.84)	93 (11.4)	0.27**	0.89 (0.58-1.38)	25 (3.1)	0.10**	0.25** (0.12-0.50)
Outside the workforce	125 (64.1)	0.66*	0.61**(0.42-0.86)	109 (52.7)	0.70*	0.61** (0.44-0.84)	42 (20.3)	0.53**	0.60** (0.41-0.88)	21 (10.1)	0.35**	0.40** (0.24-0.65)

[a] Adjusted for age group and cancer diagnosis *p<0.05 **p<0.01

Table 8 Unmet needs for rehabilitation 14 months after diagnosis. For each area number, frequencies, crude and adjusted odds ratios (ORs) are shown separately for men (grey) and women (white) with regard to cohabitation status, highest attained education, income and labour market status.

	Physical area n=318-604			Emotional area n=273-610			Family-oriented area n=125-255			Sexual area n=189-265		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Unmet needs, total												
Men	63 (19.8)	-	-	85 (31.1)	-	-	43 (34.4)	-	-	124 (46.8)	-	-
Women	96 (15.4)	-	-	124 (20.3)	-	-	79 (31.0)	-	-	101 (53.4)	-	-
Cohabitation status												
Men												
Cohabiting/married	45 (17.4)	1.00	1.00	65 (30.2)	1.00	1.00	33 (32.0)	1.00	1.00	98 (45.2)	1.00	1.00
Living alone	18 (30.5)	2.09*	2.36* (1.20-4.66)	20 (35.7)	1.28	1.34 (0.71-2.52)	10 (47.6)	1.93	1.99 (0.74-5.36)	26 (56.5)	1.58	1.50 (0.77-2.94)
Women												
Cohabiting/married	62 (14.8)	1.00	1.00	80 (19.0)	1.00	1.00	52 (27.2)	1.00	1.00	81 (50.0)	1.00	1.00
Living alone	34 (18.6)	1.32	1.32(0.81-2.14)	44 (23.5)	1.32	1.16 (0.74-1.79)	27 (42.9)	2.00*	1.88* (1.02-3.48)	20 (74.1)	2.86*	2.59* (1.01-6.63)
Highest attained education												
Men												
<10 years	24 (26.1)	1.00	1.00	26 (32.9)	1.00	1.00	10 (28.6)	1.00	1.00	48 (59.3)	1.00	1.00
10-12 years	30 (21.0)	0.75	0.88 (0.42-1.54)	41 (33.3)	1.02	1.06 (0.57-1.97)	26 (41.3)	1.76	2.12 (0.80-5.62)	52 (44.8)	0.56*	0.53* (0.29-0.96)
>12 years	8 (10.8)	0.34*	0.40* (0.16-0.97)	17 (26.2)	0.72	0.82 (0.39-1.73)	6 (25.0)	0.83	1.28 (0.35-4.71)	20 (31.8)	0.32**	0.28** (0.13-0.58)
Women												
<10 years	46 (20.8)	1.00	1.00	55 (27.0)	1.00	1.00	33 (38.8)	1.00	1.00	33 (64.7)	1.00	1.00
10-12 years	31 (16.2)	0.73	0.77 (0.45-1.30)	39 (19.8)	0.67	0.75 (0.46-1.23)	25 (29.4)	0.66	0.75 (0.38-1.15)	35 (53.0)	0.62	0.59 (0.27-1.29)
>12 years	17 (9.6)	0.40**	0.43** (0.23-0.81)	27 (13.5)	0.42**	0.47** (0.28-0.82)	19 (24.4)	0.51*	0.59 (0.28-1.26)	31 (44.9)	0.44*	0.48 (0.22-1.04)
Income												
Men												
Low (1st quartile)	12 (23.1)	1.00	1.00	15 (32.6)	1.00	1.00	6 (24.0)	1.00	1.00	23 (57.5)	1.00	1.00
Medium (2nd and 3rd quartile)	38 (20.4)	0.86	0.90 (0.41-1.93)	53 (33.3)	1.03	1.12 (0.55-2.28)	33 (44.6)	2.55	3.36* (1.08-10.5)	68 (52.7)	0.82	0.80 (0.38-0.96)
High (4th quartile)	13 (16.3)	0.65	0.66 (0.27-1.62)	17 (25.0)	0.69	0.71 (0.31-1.66)	4 (15.4)	0.58	0.76 (0.17-3.39)	33 (34.7)	0.39*	0.43* (0.20-0.94)
Women												
Low (1st quartile)	33 (23.7)	1.00	1.00	36 (27.5)	1.00	1.00	14 (27.5)	1.00	1.00	11 (44.0)	1.00	1.00
Medium (2nd and 3rd quartile)	50 (15.9)	0.61*	0.62 (0.37-1.04)	65 (19.7)	0.65	0.72 (0.44-1.19)	45 (29.4)	1.10	1.28 (0.61-2.68)	60 (54.1)	1.50	1.63 (0.66-4.01)
High (4th quartile)	13 (8.6)	0.30**	0.32** (0.15-0.64)	23 (15.4)	0.48*	0.55 (0.30-1.01)	20 (39.2)	1.71	1.90 (0.78-4.61)	30 (56.6)	1.66	1.88 (0.69-5.11)
Labour marked status												
Men												
Working	26 (15.8)	1.00	1.00	49 (29.2)	1.00	1.00	24 (32.0)	1.00	1.00	53 (37.3)	1.00	1.00
Pensioners	28 (21.9)	1.50	1.30 (0.63-2.67)	26 (32.1)	1.15	0.73 (0.36-1.51)	15 (42.9)	1.59	0.72 (0.20-2.56)	57 (56.4)	2.18**	2.56** (1.35-4.85)
Outside the workforce	9 (40.9)	3.70**	3.33* (1.21-9.19)	8 (42.1)	1.77	1.54 (0.55-4.34)	4 (36.4)	1.21	0.84 (0.19-3.75)	12 (66.8)	3.36*	3.03* (1.01-9.06)
Women												
Working	45 (13.9)	1.00	1.00	58 (15.8)	1.00	1.00	40 (26.1)	1.00	1.00	65 (49.6)	1.00	1.00
Pensioners	31 (16.9)	1.26	1.21 (0.59-2.52)	45 (30.0)	2.28**	1.58 (0.82-3.05)	18 (36.0)	1.59	0.84 (0.31-2.25)	15 (62.5)	1.69	0.62 (0.17-2.24)
Outside the workforce	16 (18.4)	1.40	1.55 (0.81-2.97)	16 (19.8)	1.31	1.35 (0.71-2.57)	18 (41.9)	2.03*	1.99 (0.96-4.15)	18 (60.0)	1.52	1.30 (0.56-3.02)

[a] Adjusted for sex, age group and cancer diagnosis *p<0.05 **p<0.01

Table 8 (Continued)

	Work-related area n=66-157			Financial area n=107-123		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Unmet needs, total						
Men	15 (22.7)	-	-	65 (60.8)	-	-
Women	24 (15.3)	-	-	37 (30.1)	-	-
Cohabitation status						
Men						
Cohabiting/married	10 (20.0)	1.00	1.00	29 (35.4)	1.00	1.00
Living alone	5 (33.3)	2.00	1.42 (0.31-6.53)	12 (50.0)	1.83	2.31 (0.84-6.3)
Women						
Cohabiting/married	17 (13.9)	1.00	1.00	22 (26.5)	1.00	1.00
Living alone	7 (20.0)	1.54	1.41 (0.51-3.88)	15 (38.5)	1.73	1.28 (0.53-3.07)
Highest attained education						
Men						
<10 years	4 (36.4)	1.00	1.00	12 (40.0)	1.00	1.00
10-12 years	8 (21.1)	0.47	0.67 (0.13-3.48)	19 (37.3)	0.89	1.13 (0.42-3.03)
>12 years	2 (12.5)	0.25	0.33 (0.04-2.76)	8 (38.1)	0.92	1.01 (0.30-3.44)
Women						
<10 years	6 (15.0)	1.00	1.00	16 (36.4)	1.00	1.00
10-12 years	8 (15.4)	1.03	1.19 (0.35-4.07)	13 (28.3)	0.69	0.64 (0.25-1.70)
>12 years	7 (11.7)	0.75	0.82 (0.24-2.78)	7 (24.1)	0.56	0.58 (0.18-1.84)
Income						
Men						
Low (1st quartile)	3 (42.9)	1.00	1.00	5 (33.3)	1.00	1.00
Medium (2nd and 3rd quartile)	55(13.9)	0.22	0.21** (0.03-1.48)	30 (42.3)	1.46	1.58 (0.46-5.44)
High (4th quartile)	7 (30.4)	0.58	0.69 (0.09-5.28)	7 (33.3)	1.00	0.82 (0.19-3.64)
Women						
Low (1st quartile)	6 (33.3)	1.00	1.00	7 (25.9)	1.00	1.00
Medium (2nd and 3rd quartile)	12 (12.8)	0.29*	0.25* (0.08-0.86)	25 (31.7)	1.32	1.37 (0.48-3.87)
High (4th quartile)	6 (13.3)	0.31	0.28 (0.08-1.08)	5 (29.4)	1.19	1.35 (0.32-5.72)
Labour market status						
Men						
Working	14 (23.7)	1.00	1.00	26 (34.7)	1.00	1.00
Pensioners	-	-	-	11 (55.0)	2.30	4.45 (0.96-20.7)
Outside the workforce	1 (33.3)	1.61	4.77 (0.22-102.9)	4 (44.4)	1.51	0.95 (0.21-4.32)
Women						
Working	16 (11.4)	1.00	1.00	21 (25.9)	1.00	1.00
Pensioners	-	-	-	5 (35.7)	1.59	4.39 (0.71-27.1)
Outside the workforce	7 (46.7)	6.84**	6.01** (1.85-20.0)	11 (42.3)	2.10	1.29 (0.46-3.59)

[a] Adjusted for sex, age group and cancer diagnosis *$p<0.05$ **$p<0.01$

Study III

Our primary model comprised analyses both for the all participants and stratified for gender, age and the largest cancer types. Results for the whole cohort are shown in tables, while results from stratified analyses are only reported in text. A secondary model explored the potential confounding of socioeconomic variables of the associations found for the whole cohort, and results are also only reported in text.

Need for rehabilitation

In the physical area patients with both mild and moderate to severe comorbidity had increased odds of expressing a need for rehabilitation (Table 9). Patients with moderate to severe comorbidity had increased odds of expressing a rehabilitation need in the emotional, family-oriented and financial areas compared to those without comorbidity.

Stratified analyses of the different cancer types, sex and age groups (data not shown in table)
The increased need for physical rehabilitation among patients with comorbidity was seen for all subgroups and was statistically significant on one or two levels for most patients groups, i.e. above the age of 65 years (OR 1.38 (95% CI 1.01-1.88) CCI 1 and OR 1.94 (95% CI 1.33-2.84) CCI ≥2 compared with CCI 0), less than 65 years (OR 1.44 (1.06-1.96) CCI 1 compared with CCI 0), women (OR 1.37 (1.01-1.85) CCI 1 and OR 1.78 (1.15-2.77) CCI ≥2 compared with CCI 0), men (OR 1.47 (1.07-2.02) CCI 1 compared with CCI 0), patients with colorectal cancer (OR 2.89 (1.43-5.84) CCI ≥2 compared with CCI 0) and prostate cancer (OR 1.98 (1.14-3.43) CCI 1 compared with CCI 0). The statistically significantly increased need for rehabilitation in the emotional area was found among men (OR 1.64 (1.04-2.59) CCI ≥2 compared with CCI 0), patients with prostate cancer (OR 2.29 (1.01-5.22) CCI≥2 compared with CCI 0) and patients above 65 years (OR 1.60 (1.06-2.40) CCI ≥2 compared with CCI 0). In the family-oriented area significant results were found for patients above the age of 65 years (OR 2.12 (1.20-3.73) CCI≥2 compared with CCI 0), while in the financial area results were significant for men (OR 2.24 (1.08-4.62) CCI ≥2 compared with CCI 0) and patients above 65 years (OR 2.53 (1.12-5.68) CCI≥2 compared with CCI 0).

Participation in rehabilitation activities

Patients with moderate to severe comorbidity had increased odds of participating in physical activities compared with patients with no comorbidity (Table 10).

Stratified analyses of the different cancer types, sex and age groups (data not shown in table)

Although similar patterns were observed in subgroups, statistically significantly increased participation in physical activities was only seen among men (OR 2.00 (1.35-2.97) CCI>2 compared with CCI 0), patients with colorectal cancer (OR 3.15 (1.59-6.26) CCI≥2 compared with CCI 0) and prostate cancer (OR 2.05 (1.01-4.14) CCI≥2 compared with CCI 0). Regarding psychological activities patients with breast cancer (OR 2.84 (1.36-5.94) CCI >2 compared with CCI 0) and prostate cancer (OR 3.46 (1.11-10.75) CCI≥2 compared with CCI 0) participated more often. Patients less than 65 years had decreased odds of participating in work-related and financial activities (OR 0.30 (0.11-0.76) CCI≥2 compared with CCI 0), while a non-significant tendency was seen in the opposite direction for patients above 65 years.

Unmet needs for rehabilitation

Table 11 presents unmet needs among the patients, who had expressed a need for rehabilitation during the 14-month period.

No statistically significant associations between CCI score and expression of unmet needs were observed following adjustment (Table 11).

Stratified analyses of the different cancer types, sex and age groups (data not shown in table)

A relatively limited number of patients were included in the subgroup analyses of unmet needs. Patients with prostate cancer had increased odds of unmet needs in the physical area (OR 3.81 (1.10-13.19) CCI 1 compared with CCI 0).

A secondary model including further adjustment for socioeconomic variables

Further adjustment for socioeconomic factors showed similar results as our main model, where we only adjusted for age, gender and cancer type. One result regarding expression of a financial rehabilitation need did, however, not remain statistically significant when adjusted for socioeconomic variables.

Table 9 Needs for rehabilitation during the 14-months following time of diagnosis as a function of comorbidity

	At least one need for rehabilitation n=3,437			Physical area n=3,240			Emotional area n=3,252			Family-oriented area n=3,248		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Needs, total	1,691 (49.2)	-	-	1,028 (31.7)	-	-	997 (30.7)	-	-	453 (14.0)	-	-
CCI												
0	1,342 (50.0)	1.00	1.00	789 (30.9)	1.00	1.00	814 (31.8)	1.00	1.00	365 (14.2)	1.00	1.00
1	239 (46.3)	0.86	1.13 (0.92-1.38)	161 (34.3)	1.17	1.43** (1.15-1.78)	117 (24.7)	0.71**	0.96 (0.75-1.22)	59 (12.6)	0.86	1.12 (0.89-1.66)
>2	110 (46.6)	0.87	1.27 (0.95-1.68)	78 (36.5)	1.28	1.69** (1.24-2.29)	66 (30.6)	0.95	1.55** (1.12-2.14)	29 (13.5)	0.94	1.61* (1.04-2.49)

	Sexual area n=3,195			Work-related area n=1,275			Financial area n=1,893		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Needs, total	529 (16.6)	-	-	252 (19.8)	-	-	257 (13.6)	-	-
CCI									
0	416 (16.5)	1.00	1.00	219 (21.1)	1.00	1.00	205 (13.6)	1.00	1.00
1	76 (16.5)	0.99	1.10 (0.83-1.47)	26 (14.9)	0.66	1.04 (0.64-1.68)	35 (12.7)	0.93	1.14 (0.76-1.71)
≥2	17 (17.4)	1.06	1.44 (0.96-2.14)	7 (10.8)	0.45	1.01 (0.42-2.37)	17 (15.2)	1.14	1.79* (1.01-3.17)

For each area (at least one need for rehabilitation, physical, emotional, family-oriented, sexual, work-related and financial) number, frequencies, crude and adjusted odds ratios (ORs) are shown with regard to comorbidity status (CCI)

[a] Adjusted for sex, age group and cancer diagnosis

*p<0.05

**p<0.01

Table 10 Participation in rehabilitation activities during the 14 months following time of diagnosis as a function of comorbidity

	At least one activity n=3,255			One or more physical activities n=3,255			One or more psychological activities n=3,255			One or more work-related activities n=3255		
	n (%)	ORcrude	ORadj[a] (95% CI)		ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Participation, total	1,696 (52.1)	-	-	1,447 (44.5)	-	-	585 (18.0)	-	-	403 (12.4)	-	-
CCI												
0	1,372 (53.6)	1.00	1.00	1,164 (45.5)	1.00	1.00	493 (19.3)	1.00	1.00	344 (13.4)	1.00	1.00
1	220 (46.2)	0.74**	1.05 (0.85-1.30)	184 (38.7)	0.75**	1.01 (0.81-1.25)	62 (13.0)	0.63**	0.91 (0.68-1.24)	49 (10.3)	0.74	1.18 (0.83-1.67)
≥2	104 (47.3)	0.78*	1.34 (0.99-1.81)	99 (45.0)	0.98	1.57** (1.16-2.13)	30 (13.6)	0.66*	1.22 (0.80-1.87)	10 (4.6)	0.31**	0.58 (0.29-1.14)

For each area (at least one activity, one or more physical, one or more psychological and one or more work-related/financial) number, frequencies, crude and adjusted odds ratios (ORs) are shown with regard to comorbidity status (CCI)

[a] Adjusted for sex, age group and cancer diagnosis

*p<0.05

**p<0.01

Table 11 Unmet needs for rehabilitation 14 months after diagnosis as a function of comorbidity

	At least one unmet need for rehabilitation n=1,691			Physical area n=922			Emotional area n=883			Family-oriented area n=380		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	N (%)	ORcrude	ORadj[a] (95% CI)
Unmet needs, total	848 (50.2)	-	-	159 (17.3)	-	-	209 (23.7)	-	-	122 (32.1)	-	
CCI												
0	660 (49.2)	1.00	1.00	119 (16.8)	1.00	1.00	165 (22.7)	1.00	1.00	93 (30.3)	1.00	1.00
1	123 (51.5)	1.09	1.07 (0.81-1.42)	28 (19.9)	1.23	1.06 (0.66-1.71)	32 (30.8)	1.51	1.28 (0.79-2.06)	18 (39.1)	1.48	1.10 (0.55-2.20)
≥2	65 (59.1)	1.49*	1.41 (0.94-2.13)	12 (16.7)	0.99	0.84 (0.43-1.67)	12 (22.6)	0.99	0.68 (0.33-1.38)	11 (40.7)	1.58	1.11 (0.45-2.75)

	Sexual area n=454			Work-related area n=230			Financial area n=230		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Unmet needs, total	225 (49.6)	-	-	43 (18.7)	-	-	79 (34.4)	-	-
CCI									
0	175 (48.2)	1.00	1.00	35 (17.4)	1.00	1.00	64 (34.0)	1.00	1.00
1	33 (53.2)	1.22	1.23 (0.69-2.17)	3 (13.0)	0.71	0.78 (0.21-2.90)	9 (34.6)	1.03	0.96 (0.37-2.49)
≥2	17 (58.6)	1.52	1.24 (0.54-2.86)	5 (83.3)	23.71*	10.31 (0.94-113.61)	6 (37.5)	1.16	0.54 (0.15-1.92)

For each area (at least one unmet need for rehabilitation, physical, emotional, family-oriented, sexual, work-related and financial) number, frequencies, crude and adjusted odds ratios (ORs) are shown with regard to comorbidity status (CCI)

[a] Adjusted for sex, age group and cancer diagnosis

*p<0.05

*p<0.01

Discussion

Main findings

One third of the cancer patients alive 14 months post diagnosis had experienced a need for physical and psychological rehabilitation, followed by a work-related need expressed by one fifth, a sexually-related need by 17%, a family-oriented by 14%, and finally a financial need expressed by 13%. Half of the patients participated in at least one rehabilitation activity, and unmet needs for rehabilitation were most common in the sexual, financial and family-oriented areas. We found that female gender and younger age were associated with increased odds of expressing needs and participating in activities. Among those who had expressed a need for help, we found, however, that men had increased odds of having emotionally unmet needs, and that elderly were more likely to have unmet needs in a number of areas. Patients with breast cancer had increased odds of participating in physical activities compared with patients with other cancer types. We found several significant associations between SES and expression of rehabilitation needs, participation in activities and unmet needs. In general, women and to a lesser extent men with short education and low income were less likely to participate and were more likely to have unmet needs. For women, living alone increased the odds of expressing needs in the physical, emotional and financial area and for having unmet needs in a number of areas. Men outside the workforce and men living alone had increased odds of having unmet physical needs. Comorbidity was at all levels statistically significantly associated with expression of physical rehabilitation needs, and furthermore, moderate to severe comorbidity was significantly associated with other areas of needs and participation in physical activities. Results from the stratified analyses showed that significant results most often were related to being older than 65 years and having colorectal or prostate cancer.

Methodological considerations

Study design

The purpose of this thesis was to assess to what extent cancer patients' express needs, participate in rehabilitation activities and report unmet needs in a 14-month period from date of diagnosis, and to assess if patient-related factors were associated with these outcomes. To answer these questions we established a large cohort of incident cancer patients with the possibility of follow-up, and with the major strength of being population-based. The strength of a cohort study is, furthermore, the observational approach that reflects daily clinical practice, both in terms of the heterogeneous patient populations and the interventions they receive (150). Inherent in the observational study design is, however, the susceptibility to bias and confounding, thereby limiting the ability to define causality (150). Furthermore, although we asked the patients to evaluate the previous 14 months, the data was only collected once and the analyses therefore had character of being cross-sectional in design. Associations found in our study can therefore only generate hypotheses on cause-effect relationship and guide further research in hypothesis testing.

The main causes of bias in a cohort study are patient selection and loss to follow-up (150). To obtain information on patient characteristics we exclusively used register data, established independent of the hypothesis and free of selection bias based on the unique civil registration number. Further, we were able to obtain information on patient characteristics for the whole cohort, including those lost to follow-up and lost to inclusion, which is discussed in following sections. Information regarding our outcomes for rehabilitation was questionnaire-based data, which introduces a risk of recall bias as discussed below. Confounding is also discussed in a separate section.

Time of follow-up at 14 months

The time of follow-up at 14 months after diagnosis was based on the following considerations. First, we were able to distinguish between patients with very short-time survival that could be assumed to primarily have palliative needs instead of rehabilitation needs (33, 151). Second, the most acute phase, including curative intended and adjuvant treatment, was expected to be completed for most cancer types after a one-year period (151). Finally, the time frame of a one-year period gave the patients a possibility to adapt after the initial phase of shock after being diagnosed with cancer (152), and a chance to have experienced some rehabilitation needs, as well as the chance to participate in activities.

Assessment of rehabilitation outcomes among patients with different cancer diagnoses

In this study we aimed to investigate different aspects of rehabilitation for patients with a variety of cancer diagnoses. This was based on the assumption that some rehabilitation needs do not arise from having a specific cancer type, but are generic, and arising from a person being diagnosed with a potentially life-threatening disease, with the consequences it may have in several aspects of the person’s life (1, 2). It did, however, introduce some limitations to the content of some of the areas of the patient questionnaire, especially in the physical area, where we were unable to ask about specific potential side effects or symptoms linked to a certain cancer type. Furthermore, the content of rehabilitation activities could have been more detailed, if only patients with one type of cancer had been included. This could have led to an underestimation of certain needs and activities used among patients with a specific cancer type.

Selection bias

Sampling procedure

As described in the Material and methods section under Study population, 37% of potentially eligible patients (referred to as sample 2) were not identified through the sampling procedure and thus not included into the study. This was not discovered until the end of the inclusion period, and it meant that patient questionnaires had not been distributed to patients in the second sample. Distribution of questionnaires to patients in the second sample would be up to two years after diagnosis, and we believed that answers from patients included from the different samples would introduce differences in the concepts measured. Analyses showed that patients from the two samples differed statistically significantly in all measured patient characteristics as described in the result section. The fact that more patients in Sample 1 were women, had breast cancer, were younger and had higher SES could have slightly overestimated the absolute figures of needs for and participation in rehabilitation and underestimated unmet needs in some areas. Patients with no comorbidity were overrepresented in sample 1, which could have underestimated the absolute figures of needs in several areas as well as participation in physical activities. However, with regard to the relative associations analysed we adjusted for differences in sex, age and cancer type, and this selection bias should not affect the direction of the associations found, although the confidence intervals may be a little wider.

Non-response

As described in the section above, patient questionnaires were only sent to patients from sample 1.

Responding patients were more likely to be younger, female, diagnosed with breast cancer, of higher SES and with no comorbidity compared to non-responding patients. Thus, those who completed the questionnaire were also those who were overrepresented in the sample. Again, this might slightly influence the absolute figures for needs, activities and unmet needs, and in the associations found the confidence intervals may be a little wider, but the direction of the associations found should not be affected.

Selection bias may be introduced in terms of respondents being different from non-respondents in health behaviour, cancer stage and other factors we did not have information about, and thus potentially not being representative of the entire target population.

Information bias

Recall bias

Recall bias may be introduced as the patients were asked to reflect over a little more than a one year period and some needs or participation in activities may not be remembered if not relevant anymore at the time of filling in the questionnaire. The answers may furthermore be affected by factors like outcome of treatment. However, we were unable to estimate either the direction or the extent of this information bias.

Confounding

The analyses were adjusted for known confounders including age, gender and cancer type. In Study III we furthermore explored the confounding effect of SES by further adjusting the analyses for socioeconomic variables, including highest attained education, income, labour market affiliation and cohabitation status. Residual confounding of other factors cannot be ruled out, e.g. we did not have information on clinical parameters such as cancer stage and treatment, and not adjusting for these factors might have underestimated our results on the effects of SES and comorbidity.

Effect modification

A challenge arose when we were to analyse the data in Studies II and III. We suspected there might be different effects of SES and comorbidity on patients' rehabilitation for patients with different cancer types, gender and age. E.g. we were concerned that the level of education could have different effects on rehabilitation for younger and older patients (72). We also speculated if the burden or severity of comorbidity could have different effects for patients with different cancer types (89). In order to obtain more detailed information about the effects of SES and comorbidity on rehabilitation, and thus to assess for interactions, we carried out stratified analyses for different age groups, gender and cancer types in Studies II and III. However, the stratified analyses entail a risk of losing the overview and introducing both type 1errors (due to a high number of tests) and type 2 errors (due to loss of power because fewer patients are included in each of the stratified analyses compared to analyses comprising the whole cohort) (153). In study II we found that the effects of SES on rehabilitation in some of the analyses differed for men and women, and we therefore chose to stratify for gender. In study III we showed overall results for the whole cohort in tables and only in the text reported the slight differences between patients groups.

The quality of register data

Data on cancer diagnoses and diagnosis included in the CCI

The validity of data from the National Patient Register has been evaluated at an overall level in 1993 (154) and showed that the validity of administrative data including CPR number and discharge date was very high (91-97%), while the validity of clinical data including the correct diagnosis was lower (65.5-82.7%). Tumors were evaluated overall, and the diagnosis was correct in 75.4% to 86.9%, depending on the level of detail in the codes used. For haematological malignancies overall completeness has be shown to be 91.5% and positive predictive value 84.5%, when compared with data from the Danish Cancer Registry (155). Other studies evaluating the validity of specific diagnoses in the NPR for the purposes of quality monitoring and research concluded that minor misclassifications exist, but that these misclassifications are non-differential and do not influence the overall validity (156, 157). The coverage of diagnoses in the NPR is generally found to be good (158). Furthermore, to reduce potential misclassification in the cohort for this study, the patients' GPs were asked to confirm the cancer diagnosis (145).

The accuracy of diagnosis included in the CCI has proven to be very high, when data from the NPR are compared with diagnoses obtained from medical records (159). We found levels of comorbidity comparable with others, who have used the register for assessing comorbidity among cancer patients (90, 160). If misclassifications, under- or overreporting should be present, we hypothesise that this imprecision is non-differential with regard to patient characteristics, and thus does not influence the associations studied.

Socioeconomic data

SES is not strictly defined and multiple variables can be used and assessed at an individual level, which can make comparison across studies a challenge. In Denmark detailed information on a variety of socioeconomic variables is available. We chose four variables, all considered important measures of SES (72, 75).

Other Danish studies have shown a small but increased risk of unemployment following cancer (161), and increased risk of divorce among survivors of cervix cancer (162). We obtained information on education, cohabitation status and labour market affiliation one year before the cancer diagnosis, and income five years up to diagnosis in order to, as far as possible, obtain SES values not affected by the cancer trajectory.

The four chosen variables are based on administrative data, and defined in Statistics Denmark (163). The validity of data is high with a low risk of misclassification. The few risks of misclassifications are described below.

With regard to cohabitation status persons are classified as cohabiting, if they have the same housing registration, are adults living together with no family relation, of the opposite sex and with less than a 15-year age gap (164). Consequently, adults living together on a purely platonic basis will be misclassified as cohabiting, and homosexuals or couples with more than a 15-year gap between them will be misclassified as living alone. An alternative approach could be to only use registered partnerships as 'cohabiting', but as many couples in Denmark live together without being married or registered, we believe that our approach misclassified fewer persons.

Labour market affiliation is based on tax information in Statistics Denmark and therefore assumed to be quite accurate. A person is categorised according to his or hers main income source each year. However, if a person has received sickness benefits or maternity pay most of the year, this person will be classified as being unemployed, although in fact in employment. If so, associations between being unemployed and outcomes for rehabilitation may be slightly diluted. Misclassification in the other categories (working and pensioners) is unlikely.

The income variable in Statistics Denmark is also based on tax information. Only a few persons were registered with no or negative income. As individuals living in Denmark with no capital or income by law are guaranteed social benefits, the individuals not entitled to social benefits may have a large capital that is difficult to assess. Therefore patients with no or negative income were set to missing values (Table 1). We used average disposable income during the past 5 years, which accounted for family size and short-term changes in income (165).

Generation of the variable 'Highest attained education' is based on the educational institutions' administrative data. Misclassification of subjects as having a higher education than was actually the case is unlikely, but a few work-related skills may not be registered in the education register, and these individuals may be misclassified (166).

Patient questionnaire

All outcomes in this study were based on ad hoc questions. These questions were pilot tested as described previously and showed an acceptable variability. The response rate at approximately 70% reflects a high acceptability of the questionnaire among patients.

Existing questionnaires identified in the literature search were, as discussed earlier, not considered appropriate for the overall goal of the survey. Ideally, a fully validated instrument should have been used in order to ensure the accuracy of what the instrument was supposed to measure (167). This is important with regard to determining the degree of confidence one can place on inferences based on scores from the scales (167). In more detail, three main types of validity, including construct validity (the extent to which operationalisation of a construct actually measures what the theory says it does), content validity (whether the instrument samples all the relevant or important content or domains) and criterion validity (the correlation of a scale with some other measure of the concept under study, ideally a 'gold standard' accepted and used in the field) should be examined beforehand (167). Furthermore, different aspects of reliability (how reproducible the results of a scale are under different conditions) should optimally be explored (167). The validity of the items in this study was in the development process primarily tested regarding content, since no other comparable instruments were available for testing of criteria validity. Furthermore, validation was limited to the extent of time and resources available in the context of this PhD project. However, subsequently a strong association between the questions regarding unmet needs and health-related quality of life and psychological distress, measured by the validated scales EORTC QLQ C-30 and POMS-SF, studied in the same population, has supported the construct validity (50). Impairment according to global health status (EORTC) and total mood disturbance (POMS) increased with increasing number of up to five areas, in which unmet needs were reported (50). Furthermore, large mean differences in the EORTC-QLQ-30 and POMS-SF scores between patients with one or more unmet needs and patients with no unmet needs were found (50). These differences were well above levels usually considered clinically relevant in clinical trials (51, 168). These results support the relevance of using unmet needs questions in clinical practice to identify cancer patients in need of rehabilitation. However, in-depth validation of all questions would have strengthened the study and needs further attention.

The Charlson Comorbidity Index

The CCI is the most widely used comorbidity index in the context of cancer, validated for many different cancer types and the use of administrative data (169). The CCI has been rated in the top three of indexes useful in relation to cancer generally, so although other indexes were considered none of them were found superior (169, 170).

As previously described, data on comorbid diseases included in the index were obtained from the National Patient Register. This register does not consistently include information on diseases not requiring a hospital visit. This is a general problem when using administrative databases for assessing comorbidity, because more serious diseases, including the disease for which the patient was admitted, and complications during hospitalisation have a higher chance of being recorded than chronic conditions (170). Some of the conditions included in the Charlson Index, including diabetes (type 2) and chronic pulmonary disease, will not necessarily require a hospital contact, but can be diagnosed and treated solely in general practice.

Consequently, there might be an underestimation of the prevalence of these specific comorbid conditions in this study, and thereby an underestimation of the impact of comorbidity on cancer patients' needs, participation in rehabilitation and unmet needs. On the other hand, the diseases in the CCI are generally of such serious nature that at some point in the 13-year period preceding the cancer diagnosis, the patient would need a hospital admission or outpatient contact. However, as the CCI was originally developed to predict the risk of one-year mortality, some comorbid conditions that might affect a cancer rehabilitation course, such as musculoskeletal or psychiatric disorders, are not included. All in all, with the administrative hospital-based data that were available in this study, we found the CCI to be the best option for a valid measure of comorbidity.

Generalisability

The results from this study are considered to be generalisable to other regions in Denmark owing to the fact that that there are only small regional differences with respect to organisation of the health care system and prevalence of diseases. Furthermore, all cancer types, except for very rare ones, are diagnosed and treated within the regions according to national guidelines and do not differ between the different hospitals. The population-based approach including a representative sample of all incident cancer patients supported the external validity of our findings. Hence, generalisability to countries with similar healthcare settings is likely, too. However, cultural differences with regard to expression of symptoms/needs and utilisation as well as availability of rehabilitation activities may be different across countries and influence results.

Discussion of study results

Study I

Our study demonstrated that the most frequent reported need was a need for physical rehabilitation, just followed by a need for psychological rehabilitation. These findings are consistent with a recent large Danish study on cancer survivors' experiences during and after treatment (n=4,401), and a Norwegian study on cancer patients' needs for rehabilitation services (n=1,325) similarly showing that a need for physical rehabilitation followed by a need for psychological rehabilitation was the most frequent (171, 172). The Norwegian study included the ten most frequent cancer types (on average 29 months after diagnosis) and found that breast cancer patients were more likely to express a need for physical rehabilitation compared to patients with other cancer types. In our study we found that breast cancer patients were more frequent participants in physical rehabilitation. These findings could reflect a rehabilitation need in relation to physical problems such as limitation in arm mobility and lymphedema, and, furthermore, that preventive physiotherapy is systematically offered at hospitals to this patient group. Interventions with a physical component have been found to reduce fatigue and improve physical activity, strength and emotional well-being among cancer patients undergoing chemotherapy (34) and cancer survivors post-treatment (173). In the latter, Danish cancer survivors (n=214) were randomised to a one-year counselling and high-intensity exercise training versus health evaluations (feedback on fitness testing and education on health benefits of exercise) with three follow-ups in the same period. Interestingly, even the control group showed significant improvements in physical activity behavior and cardiovascular fitness (173). Hence, a systematic approach even with minimal efforts with regard to physical rehabilitation would most likely benefit the majority of cancer patients.

Our results showed that compared to men, women to a higher extent expressed needs and participated in rehabilitation. This could reflect the fact that women to a higher extent have a need for rehabilitation, more often articulate a need for help, or that current rehabilitation offers appeal more to women, i.e. activities match female demands and values. A cross-sectional study of 1,876 Danish cancer survivors participating in a one-week residential rehabilitation course, offered to all cancer patients, supports this explanation, as 85% of the participants were women (43). In another cross-sectional study of 396 cancer patients with various diagnoses, significant gender differences were found with regard to healthcare preferences in cancer care including rehabilitation initiatives (174). Furthermore, our results show that men have significantly higher emotional unmet needs, indicating that rehabilitation efforts should be gender-tailored.

Two smaller cross-sectional studies assessed utilisation of rehabilitation activities among cancer patients (40, 41). As these studies mainly included patients with breast cancer or assessed utilisation of one single activity, direct comparison with our study is difficult. However, utilisation of activities in these studies was also significantly higher among younger age groups. Our study adds to present knowledge that younger patients in general express a greater need for rehabilitation, presumably related to multiple challenges to handle in that period of life. At the same time it could be an indication that the healthcare system does not always identify the needs among elderly, for whom it may be more difficult to ask for and seek out services (175). We found that elderly, who had expressed rehabilitation needs, more often had them unresolved.

A Danish survey, ‘The Cancer Patient’s World’, including cancer patients with various diagnoses (n=1,490), found that half of the patients who needed psychological counselling did not receive it (54). In our study we distinguished between three different psychological unmet needs, showing a much higher extent of sexually unmet needs compared to emotional and family-oriented unmet needs. This differentiation has also been made in another recent large Danish study on cancer patients’ needs (172), similarly showing that unmet needs were most frequent in the sexual area, followed by family-oriented an emotional unmet needs. When designing this study we believed that it was crucial to discriminate between different psychological needs, and our findings have confirmed a need for health care professionals to address delicate issues, including sexual problems. Several other studies of women with breast cancer have confirmed that unmet needs in both the sexual and other psychological areas are of relevance (29, 30, 111, 176-178).

Study II

Overall, we saw several significant associations between socioeconomic factors and the different outcomes for rehabilitation.

Patients and in particular female patients, who attended rehabilitation activities, generally had higher SES than those who did not attend activities. Social position, measured by education, employment status and marital status among others, has previously been shown to be associated with cancer survivors' participation in rehabilitation, which was illustrated in two other studies from Denmark. The authors investigated 1,876 cancer patients attending a rehabilitation intervention programme (43) and a psychosocial intervention study of 399 patients with malignant melanoma (179), finding in both studies that participants were of higher SES and, furthermore, mainly women compared to non-participants. Higher SES is probably a proxy for more personal and network resources, and a better ability to seek and demand additional help (180, 181). Higher expectations to own health, quality of life etc. in this patient group may also facilitate participation in activities and thus problem-solving (180, 181). It is also possible that patients, who have higher income and education, may be provided with more biomedical information and psychosocial counselling by the physicians (182), or that rehabilitation services offered may seem less appealing to patients of lower SES groups. The associations observed in our study were most pronounced for female cancer patients and may reflect the fact that women with high SES in general are better at articulating a rehabilitation need or that current offers appeal more to those women. However, the less pronounced results for men could also reflect the relative small number of male participants and consequently lower statistical power.

Overall, we observed a tendency towards more unmet needs in all rehabilitation areas for patients living alone, with differences being significant in the physical area for men and in the family-oriented and sexual areas for women. There was also a tendency towards both men and women outside the workforce more often expressing unmet needs, although this was only significant for male patients in two areas and for women in one area, probably reflecting the limited number of patients in the analyses. Our findings are in line with a cross-sectional study of 1,490 Danish cancer patients and a Norwegian study of 1,325 cancer patients, which both reported that patients living alone or patients who were unemployed were more likely to report unmet needs for rehabilitation (54, 171). Living with a partner might reflect the fact that the close social network has a 'rehabilitative effect' per se, but also that a partner could encourage the patient to seek help within the healthcare system as well among relatives and friends (76). Further, to support this argument a cross-sectional study of patients with colorectal cancer (n=339) from Israel showed a significantly higher level of psychological distress among unmarried patients (183). Pertinent to this discussion, patients outside the workforce might represent a vulnerable group in relation to successful rehabilitation. Different explanations may contribute to this, such as a weaker social network, a worse financial situation, or the more manual working tasks in the lower SES groups making it difficult to return to work if having a deteriorated health condition. Several studies have shown that lower SES is a risk factor for early retirement, unemployment and long-term sick leave among cancer survivors (184-186). Finally, among patients with low SES, more and more complex problems and poorer health following their cancer may contribute to higher levels of unmet needs.

Our results showed that, in particular among female cancer patients, social inequality of clinical relevance exists in cancer rehabilitation despite free and equal access to health care and supports the fact that “equal access” is not sufficient to avert social disparities. As cancer rehabilitation is not a fully integrated part of the standard cancer treatment, “getting the help” may require additional resources from the patient, thus causing an even bigger barrier to “equal access”.

Study III

In accordance with our results, a cross-sectional study of 1,325 Norwegian mixed-sited cancer patients found comorbidity to be significantly associated with a need for physical rehabilitation (171). This is also in line with other studies that have demonstrated a higher somatic symptom burden among cancer survivors with comorbidity (96, 97). An American case-control study of 1,904 cancer survivors and 29,092 controls further supports this, as the researchers found that cancer survivors reported a higher symptom burden with increasing comorbidities compared to controls, and the overall symptom burden increased with number of comorbidities (149). For patients with moderate to severe comorbidity we found, besides the association in the physical area, also an association with emotional, family-oriented and financial needs. This most likely reflects the fact that an increased burden of somatic comorbidity can also affect other areas of life. A study of 3,792 cancer survivors showed that comorbidity affected health-related quality of life, both with regard to pain, fatigue, physical and emotional function (187). Thus, in order to effectively address rehabilitation needs among cancer survivors, the healthcare system will need not only to manage the cancer disease, but also to address multiple coexisting diseases. Our stratified analyses showed that significant results were most often related to being older than 65 years or having colorectal or prostate cancer. This may reflect a higher number and/or more severe comorbidities in these groups (89), but should be explored further in future research.

We found that comorbidity was not associated with unmet needs in our overall analyses. This is in contrast to the Norwegian study mentioned above (171). However, compared to our respondents where only one fifth had comorbidity, a total of 47% of the Norwegian patients reported to have comorbidity and, in addition to different somatic disorders, psychological disorders were also included. Hence, identifying the types of disorders included when defining comorbidity may be essential. Differences between patient-reported comorbidity and doctor-registered comorbidity may also be of influence (188).

A significant association was found between a CCI score of two or more and participation in physical rehabilitation activities, which could reflect the increased somatic symptom burden among those patients (96, 97). In addition, only a few stratified analyses demonstrated either reduced or increased participation among patients with comorbidity. A Danish cohort study investigating participation in a six-day rehabilitation course among women with breast cancer found no difference in comorbidity status (measured by CCI with data obtained from the National Patient Register) between attenders (n=856) and non-attenders (n=1805) (189). When looking at other chronic diseases a Danish study regarding pulmonary rehabilitation similarly found no difference in comorbidity status between participants and non-participants (190). We have previously shown that younger age, female gender, having breast cancer and higher socioeconomic status were associated with participation in activities (191, 192), but whether or not patients participate in rehabilitation activities is probably the result of a much more complex process influenced by many different factors, including psychosocial, family-related and contextual factors (193). Furthermore, availability and knowledge of local rehabilitation offers by patients and healthcare professionals may also play a role (193, 194).

Conclusion

This study showed that needs for rehabilitation among cancer patients in a 14 month period after diagnosis were most frequent and expressed by one third of patients in the physical and psychological areas, but also present in the other investigated areas, i.e. work-related, sexual, family-oriented and financial areas. Only half of patients participated in at least one rehabilitation activity. Among those who had expressed a need for professional help, there were high frequencies of unmet needs in the sexual, family-oriented and financial areas.

A substantial variation in rehabilitation needs, participation in activities and unmet needs with regard to sex, gender and cancer type was observed. Overall, older age and male gender was associated with being less likely to express needs for and participate in rehabilitation, but being more likely to have unmet needs in some areas. Cancer type was associated with expression of certain needs, and having breast cancer increased the odds of participating in physical activities compared with other cancer types.

Despite free and equal access to health care we identified several significant associations between socioeconomic status and needs, participation and unmet needs, indicating a social gradient in rehabilitation. Vulnerable groups included patients with low education and to a lesser extent low income, patients outside the workforce and patients living alone. In general, we found the associations were most pronounced for female cancer patients.

Comorbidity, regardless of severity, was associated with expression of a physical rehabilitation need. Subgroup analyses indicated that patient groups most in need were patients above the age of 65 years with colorectal or prostate cancer.

Implications and perspectives

Clinical implications

Our study identified several significant associations between patient characteristics and needs, participation and unmet needs. The differentiation between the existence of a need and the extent to which it was unfulfilled after 14 month (i.e. unmet) gave new insight into the fact some patients groups were less likely to express needs, e.g. the elderly or male patients, but were more likely to have unmet needs in some areas. This could indicate that these patient groups are more reluctant to express needs or at higher risk of the needs being overlooked and thereby at increased risk of having unmet needs. Hence, these findings could help guide health professionals in a clinical setting by drawing more attention towards patients not spontaneously revealing needs or requesting rehabilitation.

Cancer rehabilitation is still in a phase where overall organisation and implementation is not fully accomplished. Stratified rehabilitation programmes that take social and demographic differences into account should be considered. In this regard, it may be useful to study the success of rehabilitation programmes in other areas of health care. In cardiac rehabilitation non-attenders are also more likely to be older, to live alone and have a low SES (82). A systematic approach in screening and referral to socially differentiated cardiac rehabilitation has shown to reduce unequal referral, attendance and adherence. Extended rehabilitation programmes provided to the socially vulnerable heart patients, has resulted in significantly higher participation rates and improved treatment goals among these groups (195). The extended programme included, in addition to the standard programme, extra individual nurse-led consultations, enhanced information to the GP with encouragement to a preventive consultation after completed programme, as well as education in lifestyle chances and instruction in exercise up to 18 months after completed programme. Our study indicates that similar differentiated programmes could be useful in cancer rehabilitation.

Overall, we found that only around half of the cancer patients participated in one or more rehabilitation activities. Similar low rates have been shown in in pulmonary and cardiac rehabilitation in a Danish setting (ranging from 30% to 50%) (81, 190). As previously discussed, awareness from patients and healthcare professionals about rehabilitation activities, availability of local offers, or that offers not appealing to certain patient groups may influence. The much higher participation rates in physical activities for patients with breast cancer compared to patients with other cancer types, may to a certain extent reflect the more integrated rehabilitation initiatives for this patient group and may inspire when planning initiatives for patients with other cancer types. However, when evaluating the success of rehabilitation programmes, it should also be taken into account that not all patients may benefit from or be motivated for participation in rehabilitation activities.

Future research

Our study focused on rehabilitation needs by means of measures applicable for all cancer types, and thus some of the more disease-specific rehabilitation needs may not be captured by this study. Hence, the frequencies of both needs and unmet needs found in this study may account for a minimum of the actual burden. More research is needed to develop a more comprehensive instrument that covers differential areas of needs and which can be applied in different settings and across sectors at different times in the cancer trajectory with the purpose of both identification and monitoring of needs.

We found that comorbidity, regardless of severity, was associated with expression of a physical rehabilitation need. With an increasing elderly population, this is a result that should be taken into account when planning interventions for cancer survivors. We did, however, not find such strong associations between comorbidity and all the outcomes for rehabilitation as expected, and this needs further exploration in future research. There is a need to further investigate if comorbidity registered outside hospitals contacts, e.g. diagnoses obtained from primary care, could influence cancer patients' rehabilitation. Furthermore, there is a need to reevaluate the most optimal way of assessing comorbidity among cancer patients in need of rehabilitation.

Future studies should explore if stratified rehabilitation interventions can enhance participation in rehabilitation and fulfillment of needs among subgroups of cancer patients identified in this study as less likely to participate and more likely to have unmet needs. In this regard, a simple systematic screening procedure, as described above (and with similar instruments as used in cardiac rehabilitation), may be useful to identify vulnerable patients, i.e. patients living alone, patients with low education etc. However, although several patient characteristics in our study was associated with expression of rehabilitation needs, participation in rehabilitation and unmet needs, it must be remembered that the associations found cannot reveal cause-effect relationships, and further exploration of the underlying causes and mechanisms is warranted.

Summary in English

This PhD thesis was written during my employment at the Research Unit of General Practice in Odense, University of Southern Denmark. It comprises an overview and three papers, all published or submitted for publication in international peer-reviewed scientific journals.

Background: Cancer survivors are at risk of experiencing adverse physical and psychosocial effects of their cancer and its treatment. The goal of rehabilitation is to ‘enable people with disabilities to reach and maintain optimal physical, sensory, intellectual, psychological and social function’. Hence, rehabilitation is wide-ranging and may encompass physical, psychological, work-related and financial support. The growing number of cancer survivors has brought rehabilitation into focus in the healthcare system, as well as politically, and has resulted in an increased need for gaining more knowledge of different aspects of cancer patients’ rehabilitation course. It has been estimated that up to 70% of all Danish cancer patients diagnosed in a one-year period may have a rehabilitation need. However, the evidence in this area is scarce. Since 2007 the municipalities in Denmark have been responsible for rehabilitation of patients with chronic diseases, including cancer, although hospitals still carry out specialised rehabilitation. Implementation and supply of offers do, however, vary across the country, and very little knowledge on cancer patients’ participation in rehabilitation activities exists. Unmet needs for rehabilitation seem to be pronounced with regard to physical, emotional and sexual problems, but the majority of evidence in this area is based on studied including patients at different times in their cancer trajectory. In order to help plan and implement cancer rehabilitation there is a need to gain knowledge of the extent of cancer patients’ rehabilitation needs, participation in rehabilitation activities and unmet needs for rehabilitation, and in order to target interventions in this field, improved knowledge on patient characteristics associated with these outcomes is needed.

Aims: Among incident cancer patients in a 14-month period following date of diagnosis we aimed:

- To assess the extent of rehabilitation needs, participation in rehabilitation activities and unmet needs, and further to assess if age, gender and diagnosis were associated with these outcomes (*Study I*)
- To assess if socioeconomic status (SES) was associated with expression of rehabilitation needs, participation in rehabilitation activities and unmet needs (*Study II*)
- To assess if comorbidity status was associated with expression of rehabilitation needs, participation in rehabilitation activities and unmet needs (*Study III*)

Methods: The study was conducted as a population-based cohort study among incident cancer patients in the period 1 October 2007 – 30 September 2008 in the Regions of Southern and Central Denmark. The patients were identified based on administrative data from the regional Patient Administrative Systems and prior cancer cases excluded based on data from the National Patient Register. All patients alive 14 months after diagnosis were sent a questionnaire regarding their rehabilitation needs, participation in various rehabilitation activities and unmet needs in six different dimensions (physical, emotional, family-oriented, sexual, work-related and financial). We linked the answers to socioeconomic, demographic variables and information on comorbidities from national registers to assess their association with expression of rehabilitation needs, participation in rehabilitation activities and having unmet needs. Socioeconomic variables included highest attained education (short, medium, high), income (low, medium, high), labour market affiliation (working, pensioners, otherwise outside the labour market) and cohabitation status (cohabiting/single). Comorbidity was classified according to the Charlson Comorbidity Index (CCI) and grouped into CCI 0 (no comorbidity), CCI 1 (mild comorbidity) and CCI 2 (moderate to severe comorbidity).

Results: A total of 3,439 patients participated (70%). One third of the cancer patients had experienced a need for physical and psychological rehabilitation, followed by a work-related need expressed by one fifth, a sexually related need by 17%, a family-oriented by 14% and finally a financial need expressed by 13%. Half of the patients participated in at least one rehabilitation activity, and unmet needs for rehabilitation were most common in the sexual, financial and family-oriented areas. We found that female gender and younger age were associated with increased odds of expressing needs and participating in activities. Among those who had expressed a need for help, we found that men had increased odds of having emotionally unmet needs and that elderly patients were more likely to have unmet needs in a number of areas. Patients with breast cancer had increased odds of participating in physical activities compared with patients with other cancer types. We found several significant associations between SES and expression of rehabilitation needs, participation in activities and unmet needs. In general, women and to a lesser extent men with short education and low income were less likely to participate and were more likely to have unmet needs. For women, living alone increased the odds of expressing needs in physical, emotional and financial areas and for having unmet needs in a number of areas. Men outside the workforce and men living alone had increased odds of having unmet physical needs. Comorbidity was at all levels statistically significantly associated with expression of physical rehabilitation needs, and furthermore moderate to severe comorbidity significantly associated with other areas of needs and participation in physical activities. Results from the stratified analyses showed that most often significant results were related to being older than 65 years and having colorectal or prostate cancer.

Conclusion and perspectives: This study has shown that one third of the cancer patients expressed a need for physical and psychological rehabilitation, that half of patients participated in rehabilitation activities and that unmet needs were most common in the emotional, sexual and financial areas. A substantial variation in rehabilitation needs, participation in rehabilitation activities and unmet needs was observed with regard to age, gender, cancer type and SES. Comorbidity was strongly associated with expression of physical rehabilitation needs. Identification of these variations can help guide healthcare professionals in a clinical setting and help target future interventions for patients in cancer rehabilitation.

Summary in Danish

Denne ph.d. afhandling er udført i løbet af min ansættelse ved Forskningsenheden for Almen Praksis i Odense, Syddansk Universitet. Den består af en oversigt og tre artikler, der alle er publicerede eller indsendt til publikation i peer-reviewede videnskabelige tidsskrifter.

Baggrund: Kræftpatienter er i risiko for at få fysiske og psykosociale følger af deres kræftsygdom og behandlingen heraf. Målet med rehabilitering er, at 'mennesker med nedsat funktion eller handikap opnår og vedligeholder en optimal fysisk, sensorisk, intellektuel, psykologisk og social funktion'. Således er rehabilitering vidt omspændende og kan omfatte fysisk, psykologisk, arbejdsrelateret og økonomisk rådgivning eller tilbud. Det er estimeret at op til 70 % af alle danske kræftpatienter diagnosticeret i en et-års periode kan have et rehabiliteringsbehov, men evidensen på området er sparsom. Implementering og udbud af tilbud er dog nationalt meget varierende, og der er meget sparsom viden omkring kræftpatienters deltagelse i rehabilitering. Uopfyldte rehabiliteringsbehov er formentlig udtalte på det fysiske, psykiske og seksuelle område, men hovedvægten af evidens på dette område omfatter studier, hvor kræftpatienter er inkluderet på forskellige tidspunkter i deres forløb. I forhold til at planlægge og implementere kræftrehabilitering er der behov for at opnå viden omkring omfanget af kræftpatienters rehabiliteringsbehov, deltagelse i rehabiliteringsaktiviteter og uopfyldte rehabiliteringsbehov, og for at kunne målrette indsatsen på dette område er der behov for viden om patient karakteristika associeret med disse forhold.

Formål: Blandt incidente kræftpatienter i en 14 måneders periode efter diagnose var formålet at:

- Afdække omfanget af rehabiliteringsbehov, deltagelse i rehabiliteringsaktiviteter og uopfyldte rehabiliteringsbehov, og derudover om køn, alder og kræfttype var associeret med disse forhold (Artikel I)
- Afdække om patienternes socioøkonomiske status var associeret med rehabiliteringsbehov, deltagelse i rehabiliteringsaktiviteter og uopfyldte behov (Artikel II)
- Afdække om patienternes komorbiditet var associeret med rehabiliteringsbehov, deltagelse i rehabiliteringsaktiviteter og uopfyldte behov (Artikel III)

Metode: Studiet blev gennemført som en populations-baseret kohorteundersøgelse blandt incidente kræftpatienter i perioden 1. oktober 2007 til 30. september 2008 i Region Syddanmark og Region Midtjylland. Patienterne blev identificeret på baggrund af administrative data fra de regionale patientadministrative systemer, og tidligere kræfttilfælde blev ekskluderet på baggrund af oplysninger fra Landspatientregisteret. Alle patienter, der var i live 14 måneder efter diagnose, blev sendt et spørgeskema om deres rehabiliteringsbehov, deltagelse i forskellige rehabiliteringsaktiviteter og uopfyldte behov på seks forskellige områder (fysisk, følelsesmæssigt, familiemæssigt, seksuelt, arbejdsrelateret og økonomisk). Vi

koblede svarene til socioøkonomiske, demografiske variable og information om komorbiditet fra nationale registre, for at afdække hvorvidt disse variable var associeret med rehabiliteringsbehov, deltagelse i aktiviteter og uopfyldte behov. Socioøkonomiske variable inkluderede højest fuldførte uddannelse (kort, mellem, lang), indkomst (lav, mellem, høj), arbejdsmarkedstilknytning (i arbejde, pensionist, på anden måde udenfor arbejdsmarkedet) og samlivsstatus (samlevende/enlig). Komorbiditet blev klassificeret i henhold til 'Charlson Comorbidity Index' (CCI) og grupperet i CCI 0 (ingen komorbiditet), CCI 1 (mild komorbiditet) og CCI$\geq$2 (moderat til svær komorbiditet).

Resultater: 3,439 patienter deltog (70 %). En tredjedel af kræftpatienterne havde oplevet et behov for fysisk og psykisk rehabilitering, efterfulgt af et arbejdsrelateret behov af en femtedel, et seksuelt relateret behov af 17 %, et familiemæssigt behov af 14 % og endeligt et økonomisk relateret behov oplevet af 13 %. Halvdelen af patienterne deltog i mindst en rehabiliteringsaktivitet, og uopfyldte behov var hyppigst på det seksuelle, økonomiske og familiemæssige område. Vi fandt, at det at være kvinde samt yngre alder var associeret med øgede odds for at udtrykke behov og for at deltage i aktiviteter. Blandt de der havde udtrykt behov for hjælp fandt vi, at mænd havde øgede odds for at have uopfyldte følelsesmæssige behov, og at ældre generelt havde større odds for at have uopfyldte behov. Patienter med brystkræft havde øgede odds for at deltage i fysiske aktiviteter sammenlignet med patienter med andre kræfttyper. Vi fandt adskillige signifikante associationer mellem socioøkonomiske faktorer og rehabiliteringsbehov, deltagelse i aktiviteter og uopfyldte behov. Generelt set havde kvinder, og i mindre grad mænd, med kort uddannelse og lav indkomst nedsatte odds for deltagelse og øgede odds for at have uopfyldte behov. Kvinder, der boede alene, havde øgede odds for at have fysiske, følelsesmæssige og økonomiske behov, og i øvrigt uopfyldte behov på en række områder. Mænd uden for arbejdsmarkedet og mænd, der boede alene, havde øgede odds for at have uopfyldte fysiske behov. Komorbiditet var uanset sværhedsgrad statistisk signifikant associeret med fysiske rehabiliteringsbehov, og derudover var moderat til svær komorbiditet associeret med andre områder af behov og deltagelse i fysiske aktiviteter. Resultater fra de stratificerede analyser viste at signifikante resultater oftest var relateret til det at være ældre end 65 år og det at have colorektal eller prostatakræft.

Konklusion og perspektiver: Dette studie har vist at en tredjedel af kræftpatienter udtrykte behov for fysiske og psykisk rehabilitering i de første 14 måneder efter diagnose, at halvdelen af patienterne deltog i rehabiliteringsaktiviteter og at uopfyldte behov var mest hyppige på det følelsesmæssige, seksuelle og økonomiske område. En betydelig variation i rehabiliteringsbehov, deltagelse i rehabiliteringsaktiviteter og uopfyldte behov blev fundet i forhold til køn, alder, kræfttype og socioøkonomi. Komorbiditet var stærkt associeret med det at have et fysisk rehabiliteringsbehov. Identificering af disse variationer kan vejlede sundhedsprofessionelle i den kliniske hverdag samt hjælpe med at målrette interventioner for patienter indenfor kræftrehabilitering.

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The papers

I Participation in cancer rehabilitation and unmet needs: a population-based cohort study. Holm LV, Hansen DG, Johansen C, Vedsted P, Larsen PV, Kragstrup J, Søndergaard J. *Support Care Cancer* 2012; 20:2913-2924

II Social inequality in cancer rehabilitation: a population-based cohort study. Holm LV, Hansen DG, Larsen PV, Johansen C, Vedsted P, Bergholdt SB, Kragstrup J, Søndergaard J. *Acta Oncol* 2013; 52:410-422

III Influence of comorbidity on cancer patients' rehabilitation, participation in rehabilitation activities and unmet needs: a population-based cohort study. Holm LV, Hansen DG, Kragstrup J, Johansen C, Christensen R, Vedsted P, Søndergaard J. (Submitted for publication).

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ORIGINAL ARTICLE

Participation in cancer rehabilitation and unmet needs: a population-based cohort study

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Abstract
Purpose To investigate associations between cancer survivors' sex, age, and diagnosis in relation to their (1) need for rehabilitation, (2) participation in rehabilitation activities, and (3) unmet needs for rehabilitation in a 14-month period following date of diagnosis.
Methods A population-based cohort study was performed on incident cancer patients diagnosed from 1 October 2007 to 30 September 2008. Fourteen months after diagnosis, participants completed a questionnaire developed to measure the aspects of rehabilitation. Logistic regression analyses were used to explore the association between sex, age, and diagnosis, and the outcome variables for rehabilitation.
Results A total of 3,439 patients participated, yielding an overall response rate of 70%. One third of the cancer patients reported a need for physical rehabilitation and one third for psychological rehabilitation. Half of the patients participated in at least one activity. Unmet needs were most often reported in psychological, sexual, and financial areas. Women expressed more needs, participated more often in rehabilitation activities, and had, to a higher extent, their emotional needs fulfilled. Breast cancer patients participated more often in physical rehabilitation. Elderly who expressed rehabilitation needs more often had them unresolved.
Conclusions A substantial variation in rehabilitation needs, participation in activities, and unmet needs in relation to sex, age, and cancer type was observed. Cancer care ought to systematically address the wide range of needs in all groups through integration of systematic needs assessment and targeted supply of offers.

Keywords Cancer · Patient · Rehabilitation · Unmet needs · Participation

Introduction

Cancer survivors experience physical, psychological, work-related, and financial challenges and are potentially in need of individual and targeted rehabilitation [1, 2]. The World Health Organization (WHO) has defined rehabilitation as: "a process intended to enable people with disabilities to reach and maintain optimal physical, sensory, intellectual, psychological and social function" [3]. Hence, rehabilitation is wide-ranging and may encompass physical, psychological, work-related interventions, and financial support.

There is little knowledge about the overall number of cancer patients in need of rehabilitation efforts at different time points in the cancer trajectory. A Dutch cross-sectional study of patients with breast and bowel cancer ($n=147$) found that 26% of the patients indicated a need for rehabilitation [4], while a cross-sectional study from Norway including the ten most frequent cancer types ($n=1,325$) observed that 63% of the cancer patients reported a need for at least one rehabilitation service [5]. Based on nationwide and population-based

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register data, it has been estimated that up to 70% of all Danish cancer patients diagnosed within 1 year may have a need of rehabilitation of some kind [6]. Differences in the estimations of rehabilitation needs most likely reflect that most studies include different cancer types, obtain information at different points in time following diagnosis, and finally, define rehabilitation in various ways.

Besides needs, aspects of rehabilitation can also be illustrated through participation in rehabilitation and unmet needs. Two studies including only one or a few types of cancers (mainly breast cancer; $n=132$ resp. $n=731$) have assessed cancer patients' actual utilization of rehabilitation activities, and typically, a third of the patients participated in an activity [7, 8]. The unmet needs for rehabilitation among cancer patients seem to be pronounced with regard to a variety of physical, psychological, and sexual problems [9, 10]. In smaller surveys among breast cancer patients, the problems have been shown to persist beyond the treatment phase [11, 12], and generally, most of the evidence in this area is derived from small studies including only patients with one type of cancer and most often, breast cancer [13–16].

It is reasonable to hypothesize that there is a substantial variation in cancer patients' needs for and participation in rehabilitation, which, to some degree, can be explained by patient- and disease-related factors. Therefore, the aim of this study was to investigate associations between cancer survivors' sex, age, and diagnosis in relation to their (1) need for rehabilitation, (2) participation in rehabilitation activities, and (3) unmet needs for rehabilitation in a 14-month period following date of diagnosis.

Materials and methods

Design

We performed a population-based cohort study including incident cancer patients, except patients with non-melanoma skin cancer, diagnosed from 1 October 2007 to 30 September 2008 in the Regions of Southern and Central Denmark (2.4 million residents) by obtaining information from hospital-based and national administrative registers. Information about rehabilitation issues was obtained from a patient questionnaire administered 14 months after diagnosis.

Setting

The Danish health care system is primarily a publicly funded system [17]. More than 98% of the Danish population is listed with a general practitioner (GP), who acts as a gatekeeper to the rest of the health care system [18]. Since 2007, the 98 municipalities have had the responsibility for most rehabilitation of patients with chronic disease, including cancer, while hospitals are still responsible for highly specialized rehabilitation [19]. The activities may include physiotherapy, other physical training, counseling with psychologist, dietary advice, counseling with social worker, occupational therapy, patient education, and smoking cessation counseling, but the offers vary across the country. Like other health services, rehabilitation provided by the public healthcare system and the municipalities is free of charge.

Cancer patients may participate in rehabilitation activities outside the public healthcare system and the municipalities. The Danish Cancer Society is a private patient organization offering patient support and counseling free of charge at counseling centers all over the country [20]. Furthermore, patients may seek self-financed rehabilitation from, e.g., private physiotherapists, psychologists, and alternative practitioners.

Study population

The study population was defined by the following means:

All residents of Denmark are assigned a unique ten-digit personal identification number, which includes information on date of birth and sex. This Personal Identification Number (CPR) is the key variable in linkages between public, health, and disease registries in the country [21].

From the regional hospitals' Patient Administrative System [22], we obtained information on all patients diagnosed with cancer (ICD 10 codes DC00-96, DD37-48) during the study period. The cancers were grouped into breast cancer, prostate, colo-rectal, gynecological, malignant melanoma, lung, lymphoma, head and neck, and other cancers. Furthermore, the cancers should be given an additional code, "the AZCA-1 code," which was the code for the first time the department had an encounter with the patient regarding the cancer. We included only patients aged 18 years or older listed with a GP in the two regions. Based on the National Patient Registry [23], we identified all patients in our sample with a previous diagnosis of cancer to ensure that the study population comprised incident cancer patients only.

Following identification by the administrative sampling procedure, each patient's GP was mailed a questionnaire to confirm that a cancer was diagnosed.

This cohort of incident cancer patients was established for the use in several research projects, and 6 months following date of diagnosis, patients were mailed a questionnaire, which included a request for them to confirm that they had cancer for the first time and giving them the possibility of declining the use of the information given by their GP. Prior to the distribution of the 14-month patient questionnaires, vital status and postal address were confirmed by linkage to the Civil Registration System [21], which is continuously updated on these matters. Non-responders were sent a reminder after 3 weeks. All letters included the questionnaire and a prepaid return envelope.

Development of the 14-month patient questionnaire

The patient questionnaire comprised 171 items and was designed to give information about various aspects of cancer rehabilitation [24], including those presented in this study. Ad hoc questions covering the three different aspects of rehabilitation (1) perceived needs, (2) participation, and (3) unmet needs were developed with an empirical background established through extensive literature review, as well as a report and a PhD thesis on the subject [25, 26], keeping WHO's definition of rehabilitation in mind. The list of rehabilitation activities was guided by activities present in the municipalities, as well as activities provided to residents by the Danish Cancer Society.

The questionnaire was pilot-tested and revised in a three-step procedure. Researchers active in the field of cancer rehabilitation were asked to comment on content, layout, volume, and intelligibility of the draft. Subsequently, ten cancer patients were asked to fill in the questionnaire, and in a semi-structured interview with the first author, these patients provided comments on content, layout, volume, and intelligibility. Based on all these pilot activities, questions were revised and a new draft was completed. The last pilot study included 100 cancer patients, who were asked to fill in a mailed version, enabling us to examine discrimination and acceptability and make the final corrections. The overall participation rate in this pilot study was 75%.

Data on rehabilitation

The rehabilitation variables covered self-assessed perceived need for rehabilitation, participation in rehabilitation activities, and unmet rehabilitation needs from time of cancer diagnosis until the day of filling in the questionnaire.

"Need for rehabilitation during the 14-month period" and "unmet rehabilitation after 14 months" were asked for thematically, i.e., "physical," "emotional," "family oriented," "sexual," "work-related," and "financial" areas.

As an example, the following questions were asked with regard to physical needs:

1. To what extent from diagnosis and until now have you needed professional help with physical problems? (response: "not at all," "to a small extent," "to some extent," and "to a great extent")
2. Until now, to what extent have you had your needs fulfilled in terms of help with physical problems? (response: "not at all," "to a small extent," "to some extent," "to a great extent," and "not relevant")

Similar questions were asked for all areas. Patients were categorized as having an "unmet need" if they had expressed a "need for rehabilitation" during the 14-month period, and the need, to some extent, was not fulfilled after 14 months.

"Participation in rehabilitation activities" was assessed by asking:

3. Have you from diagnosis and until now participated in any of the following activities due to problems caused by your cancer disease? (listing of possible providers/activities)

Three categories of activities were defined based on profession of the provider/activity: (1) "Physical activities" (physiotherapist, occupational therapist, chiropractor, patient education, smoking cessation counseling, nutritional information, physical training, and alternative practitioner including acupuncturist and reflexologist), (2) "Psychological activities" (psychologist, marriage counselor or sexologist, supportive group sessions or patient associations, and spiritual counseling), and (3) "work-related/financial activities" (social worker, union representative or employer, financial or insurance counselor). Furthermore, the variable "Participation in one or more activities" was defined based on the above-mentioned categories.

Statistical analysis

Need for rehabilitation was dichotomized into "no need" ("not at all") and "need" (combining "to a small extent," "to some extent", and "to a great extent"), and similarly, unmet need was dichotomized into "unmet need" and "met need." Answers in the "not relevant" category were excluded from the analyses. For analyses regarding "unmet rehabilitation needs after 14 months," only patients expressing a "need for rehabilitation" were included.

Univariate and multiple logistic regression analyses were used to explore the association between sex, age, and diagnosis, and the rehabilitation variables. In presence of an interaction between age group and sex, the analyses were stratified on sex. All tests were two-sided, and $p<0.05$ was considered statistically significant. Adjusted odds ratios (OR_{adj}) are presented with 95% confidence intervals (95% CI). Analyses were performed using Stata Release 11 (StataCorp, College Station, TX, USA).

Results

Of the 4,947 subjects eligible at 14 months, 3,439 returned the questionnaire (70%) (Fig. 1). Table 1 shows

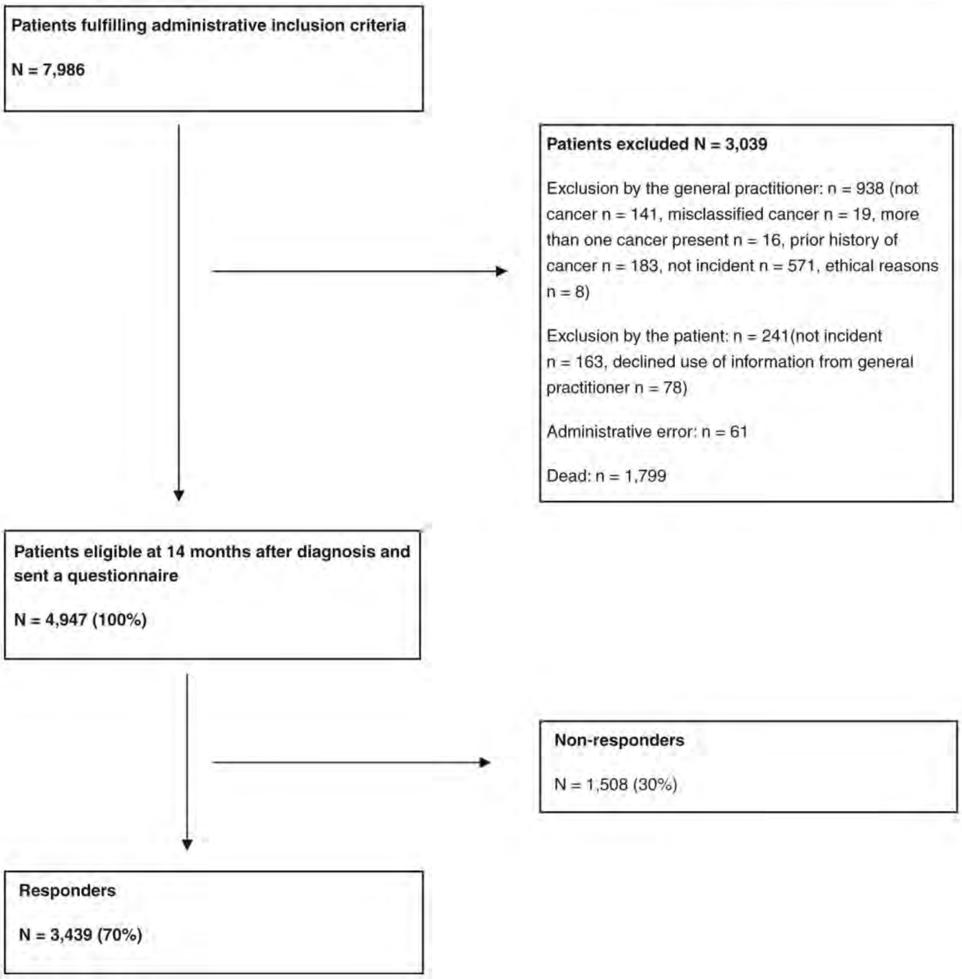

Fig. 1 Inclusion of patients into the study

responders and non-responders with regard to sex, age, and diagnoses.

Need for rehabilitation during the 14-month period

Self-perceived need for physical and psychological rehabilitation was equally frequent, 32% and 31%, respectively (Table 2). Overall, the higher the age, the less likely the patients were to express a need for rehabilitation. Women expressed rehabilitation needs in emotional, physical, family oriented, and work-related areas more often than men.

Participation in rehabilitation activities

Overall, 52% had participated in at least one rehabilitation activity (Table 3). Physical activities were used by 42%, psychological by 17%, and work-related/finance-related activities by 12%. The single most used activity was physiotherapy (31%), followed by physical training (15%), psychologist (11%), dietician (10%), alternative practitioner (including acupuncturist or reflexologist) (7%), and social worker (6%) (data not shown). Women were more likely to participate in physical and psychological activities, while no sex difference was observed with regard to counseling about work/economy. The oldest patients were less likely to participate in activities. Patients with breast cancer participated more frequently in physical activities compared with other cancer patients.

Unmet rehabilitation needs after 14 months

Among patients who had expressed a need for rehabilitation during the 14-month period, unmet needs were most common for sexual problems (50%) and least common for physical problems (17%) (Table 4). Financial issues were still unsolved for one third. Men were more likely to have emotional unmet needs than women, and higher age was associated with a greater likelihood of unmet needs in all areas, except for physical and financial problems. Compared with patients with breast cancer, unmet needs for physical rehabilitation were more common among patients with colo-rectal, gynecological, and head and neck cancers.

Table 1 Medical and demographic characteristics of responders and non-responders in a cohort study of cancer rehabilitation

	Responders, *n* (%) 3,439 (69.5)	Non-responders, *n* (%) 1,508 (30.5)
Sex		
Men	1,466 (42.6)	712 (47.2)
Women	1,973 (57.4)	796 (52.8)
Age (years)		
18–39	152 (4.4)	118 (7.8)
40–49	331 (9.6)	154 (10.2)
50–59	660 (19.2)	292 (19.4)
60–69	1,263 (36.8)	419 (27.8)
70–79	802 (23.3)	338 (22.4)
80+	231 (6.7)	187 (12.4)
Cancer diagnoses		
Breast	976 (28.4)	314 (20.8)
Prostate	501 (14.6)	179 (11.9)
Colo-rectal	522 (15.2)	213 (14.1)
Gynecological	230 (6.7)	120 (7.9)
Malignant melanoma	233 (6.8)	102 (6.8)
Lung	188 (5.5)	113 (7.5)
Lymphoma	104 (3.0)	44 (2.9)
Head and neck	125 (3.6)	81 (5.4)
Other	560 (16.2)	342 (22.7)

Discussion

Main findings

Needs for physical and psychological rehabilitation were equally frequent. One third of the cancer patients alive at 14 months post- diagnosis experienced these needs. Women were more likely to express a need for rehabilitation; they took part more often in activities relevant for psychological and physical problems and had, to a higher extent, fulfilled their emotional needs. In general, older cancer patients were less likely to express a need for and participate in rehabilitation. Unmet needs among elderly who wanted professional help were, however, more frequent compared with younger patients.

Strengths and weaknesses

Our results are based on a large population-based, consecutively sampled cohort of patients diagnosed with an incident cancer during a 1-year period in two representative regions in Denmark. The sampling was based on administrative data. Misclassification of the cancer diagnosis is a potential limitation. However, the regional hospital's Patient Administrative System is used for administrative purposes, and the validity is high [23]. In addition, we reduced misclassification by asking the GPs whether the cancer diagnosis was correct.

Due to incomplete use of the additional AZCA-1 code which was not known until after the sampling, 38% of potentially eligible patients were not identified by the administrative sampling procedure. However, it was random patients who did not get the code, and analyses showed only minor differences between the patients included and the full sample of all eligible patients (data not shown). The two most pronounced differences were that of the primarily included patients 19% had breast cancer compared with 16% in the full sample. This could have slightly overestimated our results regarding need for and participation in rehabilitation. Secondly, an under-sampling of the oldest patients (+80 years) was seen compared with the full sample (13% vs. 17%). This could have underestimated the absolute figures for unmet rehabilitation needs. However, as we calculated the relative associations and adjusted for differences in sex, age, and cancer type, this selection bias can be regarded as negligible.

The response rate was high among the patients who received the questionnaire. Among responders, there was a slight overrepresentation of women, the 60–69-year-olds and patients with breast cancer (Table 1). Hence, the absolute figures for needs and activities might be overestimated. This could also be caused by the fact that individuals who respond may tend to be those in need and active in relation to rehabilitation. However, as this might have made the group included in the analyses slightly more homogeneous with less variation, the relative associations found in this study may actually be underestimated.

Participants were asked about needs and activities for a 14-month period, but the cancer disease and cancer-related activities are likely to be of major importance to most patients and therefore remembered for a long time. Hence, recall bias is supposedly low.

An important question is whether our results are generalizable. In Denmark, there are relatively small regional differences with respect to organization of the health care system and prevalence of diseases. Therefore, we assume that our results are generalizable to all of Denmark. Furthermore, our findings that patient characteristics were associated with needs, participation, and unmet needs are likely to be generalizable to other countries with similar health care systems. It must be kept in mind that the results represent cancer patients who survived for more than 1 year and therefore may not apply to short-time survivors.

Comparison with other studies

Similar to our results, a Norwegian study including the ten most frequent cancer types (n=1,325) showed that need for physical rehabilitation followed by psychological rehabilitation

Table 2 Needs for rehabilitation during 14 months following time of diagnosis

	Physical area			Emotional area			Family oriented area		
	n=3,242			*n*=3,254			*n*=3,250		
	n (%)	ORcrude	ORadj[a] (95% CI)	*n* (%)	ORcrude	ORadj[a] (95% CI)	*n* (%)	ORcrude	ORadj[a] (95% CI)
Needs, total	1,028 (31.7)	–	–	997 (30.6)	–	–	453 (13.9)	–	–
Sex									
Men	352 (25.4)	1.00	1.00	327 (23.5)	1.00	1.00	145 (10.4)	1.00	1.00
Women	676 (36.5)	1.69**	1.36** (1.01–1.70)	670 (35.9)	1.82**	1.72** (1.37–2.17)	308 (16.6)	1.70**	1.40* (1.04–1.88)
Age (years)									
18–39	54 (36.0)	1.00	1.00	82 (54.3)	1.00	1.00	47 (31.3)	1.00	1.00
40–49	149 (46.4)	1.54*	1.35 (0.90–2.03)	176 (53.8)	0.98	0.86 (0.57–1.28)	96 (29.3)	0.91	0.82 (0.53–1.27)
50–59	263 (41.3)	1.25	1.13 (0.77–1.65)	279 (43.8)	0.66*	0.59** (0.40–0.85)	135 (21.2)	0.59**	0.55** (0.36–0.83)
60–69	339 (27.8)	0.68*	0.63* (0.43–0.91)	304 (25.0)	0.28**	0.25** (0.17–0.36)	117 (9.6)	0.23**	0.22** (0.14–0.33)
70–79	172 (23.6)	0.55**	0.53** (0.36–0.78)	125 (17.0)	0.17**	0.16** (0.11–0.24)	48 (6.6)	0.15**	0.15** (0.09–0.24)
80+	51 (27.4)	0.67	0.64 (0.39–1.03)	31 (16.4)	0.17**	0.15** (0.09–0.26)	10 (5.3)	0.12**	0.12** (0.06–0.25)
Cancer diagnosis									
Breast	367 (39.5)	1.00	1.00	338 (36.2)	1.00	1.00	152 (16.3)	1.00	1.00
Prostate	96 (20.7)	0.40**	0.70* (0.50–0.99)	89 (19.1)	0.42**	1.16 (0.80–1.66)	30 (6.4)	0.35**	0.85 (0.51–1.43)
Colo-rectal	142 (29.0)	0.62**	0.84 (0.65–1.10)	109 (22.2)	0.51*	0.88 (0.66–1.18)	50 (10.2)	0.58**	0.96 (0.66–1.41)
Gynecological	69 (31.9)	0.72*	0.72* (0.52–0.99)	79 (36.1)	0.99	1.00 (0.72–1.38)	43 (19.6)	1.25	1.25 (0.85–1.85)
Malignant melanoma	49 (22.4)	0.44**	0.48** (0.33–0.68)	51 (23.2)	0.53**	0.52** (0.35–0.75)	19 (8.6)	0.49**	0.43* (0.25–0.73)
Lung	71 (39.7)	1.01	1.43* (1.01–2.04)	70 (39.3)	1.14	2.19** (1.52–3.16)	28 (15.6)	0.95	1.65* (1.03–2.66)
Lymphoma	35 (34.3)	0.80	0.92 (0.59–1.44)	49 (48.0)	1.63*	2.24 **(1.42–3.51)	24 (23.8)	1.60	1.90* (1.12–3.23)
Head and neck	32 (26.9)	0.56**	0.69 (0.43–1.09)	39 (33.3)	0.88	1.29 (0.82–2.04)	15 (12.9)	0.76	0.97 (0.52–1.80)
Other	167 (31.9)	0.72**	0.92 (0.70–1.20)	173 (32.9)	0.87	1.29 (0.98–1.70)	92 (17.6)	1.09	1.42* (1.01–2.02)

	Sexual area				Work-related area			Financial area		
	n=3,197				*n*=1,276			*n*=1,895		
	n (%)	ORcrude	Men *n*=1,366 ORadj[b] (95% CI)	Women *n*=1,829 ORadj[b] (95% CI)	*n* (%)	ORcrude	ORadj[a] (95% CI)	*n* (%)	ORcrude	ORadj[a] (95% CI)
Needs, total	529 (16.6)	–	–	–	252 (19.8)	–	–	257 (13.4)	–	–
Sex										
Men	308 (22.5)	1.00	–	–	77 (14.3)	1.00	1.00	118 (13.8)	1.00	1.00
Women	221 (12.1)	0.47**	–	–	175 (23.7)	1.87**	1.55* (1.01–2.39)	139 (13.4)	0.97	0.86 (0.60–1.25)
Age (years)										
18–39	34 (22.5)	1.00	1.00	1.00	23 (22.3)	1.00	1.00	20 (16.7)	1.00	1.00
40–49	77 (23.7)	1.07	0.83 (0.35–2.02)	0.91 (0.51–1.62)	73 (32.0)	1.64	1.43 (0.82–2.51)	51 (19.5)	1.21	1.33 (0.74–2.38)
50–59	133 (21.0)	0.91	0.93 (0.43–1.99)	0.61 (0.35–1.06)	116 (28.9)	1.41	1.27 (0.74–2.17)	97 (19.5)	1.21	1.31 (0.76–2.27)

Table 2 (continued)

	Sexual area				Work-related area			Financial area		
	n=3,197				n=1,276			n=1,895		
	n (%)	ORcrude	Men n=1,366 ORadj[b] (95% CI)	Women n=1,829 ORadj[b] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
60–69	203 (17.0)	0.71	0.72 (0.34–1.51)	0.25** (0.14–0.44)	32 (9.8)	0.38**	0.37** (0.20–0.69)	66 (10.8)	0.61	0.65 (0.37–1.15)
70–79	69 (9.7)	0.37**	0.33** (0.15–0.72)	0.04** (0.01–0.11)	6 (3.6)	0.13**	0.12** (0.05–0.32)	18 (5.6)	0.30**	0.30** (0.15–0.61)
80+	13 (7.1)	0.26**	0.26** (0.10–0.69)	0.06** (0.01–0.26)	2 (4.0)	0.14*	0.14* (0.03–0.63)	5 (6.0)	0.32*	0.35 (0.12–1.00)
Cancer diagnosis										
Breast	111 (12.1)	1.00	–	1.00	94 (23.9)	1.00	1.00	62 (11.7)	1.00	1.00
Prostate	159 (34.3)	3.79**	2.44** (1.67–3.56)	–	15 (9.7)	0.34**	1.11 (0.52–2.36)	22 (8.2)	0.67	0.93 (0.49–1.78)
Colo-rectal	68 (14.2)	1.20	1.00	1.11 (0.65–1.89)	31 (16.8)	0.64	1.17 (0.69–1.98)	32 (11.7)	0.99	1.17 (0.70–1.96)
Gynecological	41 (19.1)	1.71**	–	1.83** (1.21–2.77)	26 (30.2)	1.38	1.36 (0.80–2.32)	22 (17.3)	1.58	1.64 (0.96–2.82)
Malignant melanoma	16 (7.3)	0.57*	0.34** (0.15–0.75)	0.34** (0.16–0.75)	8 (8.3)	0.29**	0.36* (0.16–0.80)	13 (10.0)	0.84	0.83 (0.43–1.62)
Lung	27 (15.7)	1.35	0.99 (0.53–1.84)	1.53 (0.74–3.16)	8 (15.7)	0.59	1.09 (0.47–2.54)	18 (17.1)	1.56	2.00* (1.07–3.75)
Lymphoma	15 (15.0)	1.28	0.87 (0.40–1.87)	0.76 (0.29–2.02)	9 (19.6)	0.78	0.93 (0.41–2.10)	11 (16.2)	1.46	1.39 (0.67–2.91)
Head and neck	12 (10.4)	0.84	0.31** (0.13–0.72)	1.49 (0.54–4.11)	14 (25.5)	1.09	1.57 (0.74–3.32)	12 (15.0)	1.33	1.20 (0.58–2.50)
Other	80 (15.4)	1.32	0.81 (0.52–1.25)	1.07 (0.64–1.78)	47 (22.5)	0.93	1.38 (0.84–2.28)	65 (20.8)	1.99	2.03** (1.28–3.22)

For each area (physical, emotional, family oriented, sexual, work-related, and financial) number, frequencies and crude and adjusted odds ratios (ORs) are shown with regard to sex, age, and cancer diagnosis

[a] Adjusted for sex, age group, and cancer diagnosis

[b] Adjusted for age group and cancer diagnosis

*$p<0.05$

**$p<0.01$

Table 3 Participation in rehabilitation activities during 14 months following time of diagnosis

	One or more activities			One or more physical activities			One or more psychological activities			One or more work-related/financial activities		
	n=3,257			*n*=3,439			*n*=3,439			*n*=3,439		
	n (%)	ORcrude	ORadj[a] (95% CI)	*n* (%)	ORcrude	ORadj[a] (95% CI)	*n* (%)	ORcrude	ORadj[a] (95% CI)	*n* (%)	ORcrude	ORadj[a] (95% CI)
Participation, total	1,697 (52.1)	–	–	1,447 (42.1)	–	–	586 (17.0)	–	–	403 (11.7)	–	–
Sex												
Men	545 (39.4)	1.00	1.00	438 (29.9)	1.00	1.00	152 (10.4)	1.00	1.00	134 (9.1)	1.00	1.00
Women	1,152 (61.5)	2.46**	1.54** (1.25–1.90)	1009 (51.1)	2.46**	1.41** (1.14–1.73)	434 (22.0)	2.44**	1.90** (1.43–2.52)	269 (13.6)	1.56**	1.03 (0.74–1.43)
Age (years)												
18–39	102 (67.1)	1.00	1.00	68 (44.7)	1.00	1.00	63 (41.5)	1.00	1.00	55 (36.2)	1.00	1.00
40–49	234 (72.2)	1.27	0.88 (0.57–1.37)	197 (59.5)	1.82**	1.29 (0.85–1.96)	118 (35.6)	0.78	0.59* (0.39–0.89)	87 (26.3)	0.63*	0.50** (0.32–0.78)
50–59	443 (69.7)	1.13	0.81 (0.54–1.22)	344 (52.1)	1.34	1.02 (0.70–1.50)	184 (27.9)	0.55**	0.42** (0.29–0.63)	163 (24.7)	0.58**	0.48** (0.32–0.72)
60–69	600 (49.6)	0.48**	0.34** (0.23–0.51)	546 (43.2)	0.94	0.74 (0.51–1.08)	154 (12.2)	0.20**	0.16** (0.11–0.24)	71 (5.6)	0.11**	0.09** (0.06–0.13)
70–79	257 (34.7)	0.26**	0.21** (0.14–0.32)	238 (29.7)	0.52**	0.48** (0.33–0.71)	53 (6.6)	0.10**	0.09** (0.06–0.14)	19 (2.4)	0.04**	0.04** (0.02–0.07)
80+	61 (31.4)	0.22**	0.18** (0.11–0.29)	54 (23.4)	0.38**	0.34** (0.21–0.55)	14 (6.1)	0.10**	0.08** (0.04–0.15)	8 (3.5)	0.06**	0.05** (0.02–0.12)
Cancer diagnosis												
Breast	694 (73.9)	1.00	1.00	652 (66.8)	1.00	1.00	239 (24.5)	1.00	1.00	152 (15.6)	1.00	1.00
Prostate	163 (35.0)	0.19**	0.41** (0.30–0.57)	139 (27.7)	0.19**	0.34** (0.25–0.47)	34 (6.8)	0.22**	0.77 (0.47–1.24)	23 (4.6)	0.26**	0.65 (0.36–1.17)
Colo-rectal	192 (39.8)	0.23**	0.36** (0.27–0.47)	149 (28.5)	0.20**	0.28** (0.22–0.36)	70 (13.4)	0.48**	0.91 (0.65–1.27)	47 (9.0)	0.54**	0.84 (0.56–1.27)
Gynecological	107 (47.8)	0.32**	0.31** (0.23–0.42)	78 (33.9)	0.26**	0.25** (0.19–0.34)	47 (20.4)	0.79	0.76 (0.53–1.11)	30 (13.0)	0.81	0.77 (0.49–1.21)
Malignant melanoma	71 (32.3)	0.17**	0.16** (0.11–0.22)	52 (22.3)	0.14**	0.16** (0.11–0.22)	25 (10.7)	0.37**	0.32** (0.20–0.52)	12 (5.2)	0.29**	0.20** (0.10–0.38)
Lung	93 (52.0)	0.38**	0.62** (0.43–0.89)	75 (39.9)	0.33**	0.46** (0.33–0.65)	31 (16.5)	0.61*	1.22 (0.78–1.92)	15 (8.0)	0.47**	0.82 (0.44–1.50)
Lymphoma	54 (54.0)	0.41**	0.47** (0.30–0.74)	45 (43.3)	0.38**	0.44** (0.28–0.67)	25 (24.0)	0.98	1.24 (0.74–2.08)	30 (28.9)	2.20**	2.36** (1.39–4.03)
Head and neck	69 (58.5)	0.50*	0.65 (0.42–1.01)	54 (43.2)	0.38**	0.49** (0.32–0.74)	27 (21.6)	0.85	1.35 (0.81–2.25)	11 (8.8)	0.52*	0.49* (0.24–0.99)
Other	254 (48.0)	0.33**	0.44** (0.33–0.57)	203 (36.3)	0.28**	0.37** (0.29–0.48)	88 (15.7)	0.57**	0.83 (0.60–1.15)	83 (14.8)	0.94	1.01 (0.69–1.47)

For each area (one or more activities, one or more physical activities, one or more psychological activities, and one of more work-related/financial activities) number, frequencies and crude and adjusted odds ratios (ORs) are shown with regard to sex, age, and cancer diagnosis

[a] Adjusted for sex, age group, and cancer diagnosis

*$p<0.05$

**$p<0.01$

Table 4 Unmet needs for rehabilitation 14 months after diagnosis

	Physical area			Emotional area			Family oriented area		
	n=922			n=883			n=380		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Unmet needs, total	159 (17.3)	–	–	209 (23.7)	–	–	122 (32.1)	–	–
Sex									
Men	63 (19.8)	1.00	1.00	85 (31.1)	1.00	1.00	43 (34.4)	1.00	1.00
Women	96 (15.9)	0.76	0.96 (0.60–1.54)	124 (20.3)	0.56**	0.58** (0.37–0.92)	79 (31.0)	0.86	1.06 (0.58–1.93)
Age (years)									
<60	64 (15.3)	1.00	1.00	91 (18.3)	1.00	1.00	65 (26.9)	1.00	1.00
≥60	95 (18.9)	1.29	1.17 (0.81–1.70)	118 (30.7)	1.98**	2.05** (1.47–2.85)	57 (41.3)	1.92**	2.03** (1.27–3.25)
Cancer diagnosis									
Breast	40 (12.1)	1.00	1.00	55 (17.7)	1.00	1.00	33 (26.4)	1.00	1.00
Prostate	16 (18.4)	1.63	1.46 (0.65–3.27)	24 (30.8)	2.06*	0.94 (0.45–1.97)	7 (28.0)	1.08	0.83 (0.26–2.62)
Colo-rectal	28 (22.1)	2.05**	1.93* (1.07–3.48)	18 (19.6)	1.13	0.78 (0.41–1.49)	16 (38.1)	1.72	1.62 (0.72–3.68)
Gynecological	14 (24.6)	2.36*	2.33* (1.17–4.65)	17 (23.9)	1.46	1.47 (0.79–2.74)	10 (30.3)	1.21	1.16 (0.49–2.72)
Malignant melanoma	4 (9.8)	0.78	0.75 (0.25–2.26)	17 (37.8)	2.81**	2.51* (1.24–5.05)	5 (31.3)	1.27	1.29 (0.40–4.13)
Lung	15 (22.7)	2.13*	1.97 (0.97–4.01)	16 (28.6)	1.85	1.31 (0.66–2.60)	10 (40.0)	1.86	1.46 (0.57–3.72)
Lymphoma	7 (21.9)	2.03	1.95 (0.76–5.00)	15 (34.1)	2.39*	2.05 (0.99–4.27)	9 (40.9)	1.93	2.19 (0.81–5.89)
Head and neck	9 (32.1)	3.43**	3.32** (1.34–8.22)	13 (35.1)	2.51*	2.00 (0.90–4.43)	6 (42.9)	2.09	2.09 (0.64–6.85)
Other	26 (16.9)	1.47	1.41 (0.77–2.57)	34 (22.7)	1.36	0.98 (0.56–1.72)	26 (33.3)	1.39	1.48 (0.72–3.04)

	Sexual area			Work-related area			Financial area		
	n=454			n=222–230			n=230		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Unmet needs, total	225 (49.6)	–	–	43 (18.7)	–	–	79 (34.4)	–	–
Sex									
Men	124 (46.8)	1.00	1.00	18 (26.1)	1.00	1.00	42 (39.3)	1.00	1.00
Women	101 (53.4)	1.31	0.80 (0.42–1.55)	25 (15.5)	0.52	0.53 (0.19–1.47)	37 (30.1)	0.67	0.53 (0.24–1.19)
Age (years)									
<60	105 (47.7)	1.00	1.00	33 (16.6)	1.00	1.00	53 (33.3)	1.00	1.00
≥60	120 (51.3)	1.15	1.83** (1.16–2.89)	10 (32.3)	2.40*	2.98* (1.14–7.80)	26 (36.6)	1.16	1.08 (0.58–2.03)
Cancer diagnosis									
Breast	54 (56.8)	1.00	1.00	12 (14.1)	1.00	1.00	19 (38.0)	1.00	1.00
Prostate	51 (36.4)	0.44**	0.24** (0.10–0.56)	2 (15.4)	1.11	0.30 (0.04–2.35)	10 (55.6)	2.04	1.06 (0.27–4.13)
Colo-rectal	29 (48.3)	0.71	0.52 (0.23–1.17)	4 (14.8)	1.06	0.55 (0.13–2.36)	6 (23.1)	0.49	0.32 (0.09–1.08)
Gynecological	16 (48.5)	0.71	0.68 (0.30–1.52)	5 (19.2)	1.45	1.45 (0.45–4.62)	6 (28.6)	0.65	0.65 (0.21–1.96)

Table 4 (continued)

	Sexual area			Work-related area			Financial area		
	n=454			n=222–230			n=230		
	n (%)	ORcrude	ORadj^a (95% CI)	n (%)	ORcrude	ORadj^a (95% CI)	n (%)	ORcrude	ORadj^a (95% CI)
Malignant melanoma	8 (72.7)	2.02	1.68 (0.40–6.99)	0 (0)	–	–	3 (23.1)	0.49	0.31 (0.07–1.46)
Lung	14 (66.7)	1.52	1.13 (0.39–3.27)	4 (50.0)	6.08*	4.02 (0.75–21.7)	7 (43.8)	1.27	0.86 (0.25–3.02)
Lymphoma	8 (53.3)	0.87	0.72 (0.22–2.36)	2 (22.2)	1.74	1.65 (0.29–9.26)	4 (36.4)	0.93	0.69 (0.17–2.88)
Head and neck	7 (63.6)	1.33	1.24 (0.32–4.81)	4 (28.6)	2.43	1.63 (0.36–7.29)	6 (50.0)	1.63	0.97 (0.23–4.10)
Other	38 (55.9)	0.96	0.77 (0.35–1.69)	10 (25.0)	2.03	1.25 (0.39–4.05)	18 (28.6)	0.65	0.43 (0.16–1.13)

For each area (physical, emotional, family oriented, sexual, work-related, and financial) number, frequencies and crude and adjusted odds ratios (ORs) are shown with regard to sex, age, and cancer diagnosis.

[a] Adjusted for sex, age group, and cancer diagnosis

$^*p<0.05$

$^{**}p<0.01$

was the most frequent [5]. They also reported that breast cancer patients were more likely to report a need for physical rehabilitation, and we showed that they are more frequent participants in physical activities. This most likely reflects a rehabilitation need in relation to physical problems such as limitation in arm mobility and lymphedema, and furthermore, that preventive physiotherapy is systematically offered at some hospitals to this patient group. Interventions with a physical component have been found to improve physical functioning, strengths, emotional wellbeing, and reduce fatigue among cancer survivors [27], and a more systematic approach may therefore benefit all cancer patients.

Our results showed that, compared with men, women, to a higher extent, expressed needs and participated in rehabilitation. This could reflect that women to a higher extent have a need for rehabilitation, more often articulate a need for help, or that current rehabilitation offers appeal more to women, i.e., activities match female demands and values. A cross-sectional study of 1,876 Danish cancer survivors participating in a 1-week residential rehabilitation course, offered to all cancer patients, support this explanation, as 85% of the participants were women [28]. In another cross-sectional study of 396 cancer patients with various diagnoses, significant gender differences were found with regard to health care preferences [29]. Furthermore, our results show that men have significantly higher emotional unmet needs, indicating that rehabilitation efforts should be gender-tailored.

Only a few smaller cross-sectional studies have assessed utilization of rehabilitation activities among cancer patients [7, 8]. As these studies mainly included patients with breast cancer or assessed utilization of one single activity, direct comparison with our study is difficult. However, utilization of activities in these studies was also significantly higher among younger age groups. Our study adds to present knowledge that younger patients in general express a greater need for rehabilitation, presumably related to multiple challenges to handle in that period of life. At the same time, it could be an indication that the health care system does not always identify the needs among elderly, for whom it may be more difficult to ask for and seek out services. We found that elderly, who had expressed rehabilitation needs, more often had them unresolved.

A Danish survey including cancer patients at various sites (n=1,490) found that half of the patients who needed psychological counseling did not receive it [9]. In our study, we distinguished between three different psychological unmet needs, showing a much higher extent of sexually unmet needs compared with emotional and family oriented unmet needs. We believe that it is crucial to discriminate between different psychological needs, and our findings underline a need for health care professionals to address delicate issues, including sexual problems. Several studies of women with breast cancer have confirmed that unmet needs in both the sexual and psychological area are of relevance. [12, 14–16, 30, 31].

Conclusion and implications

In conclusion, one third of the total group of cancer patients reported a need for physical rehabilitation and in one third, a need for psychological rehabilitation. Half of the patients participated in one or more rehabilitation activities. Unmet needs were most often reported in the psychological, sexual, and financial areas. We observed a substantial variation in these matters pertinent to disease and patient characteristics. This study suggests that cancer care ought to systematically address the wide range of needs in all groups through integration of systematic needs assessment and targeted supply of offers. Emphasis should be put on development of assessment and monitoring tools for use in everyday clinical practice.

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According to the Regional Scientific Ethics Committee, the Biomedical Research Ethics Committee System Act does not apply to this Project.

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ORIGINAL ARTICLE

Social inequality in cancer rehabilitation: A population-based cohort study

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Abstract

Objectives. In a healthcare system with equal access we analysed possible associations between cancer survivors' socioeconomic status (SES) and their: 1) need for rehabilitation; 2) participation in rehabilitation activities; and 3) unmet needs for rehabilitation in a 14-month period following date of diagnosis. *Methods.* A population-based cohort study including incident cancer patients diagnosed from 1 October 2007 to 30 September 2008 in Denmark. Fourteen months after diagnosis participants completed a mailed out questionnaire developed to measure different aspects and dimensions of rehabilitation. Individual information on cohabitation status, education, income and labour market status was retrieved from national registers. Logistic regression analyses were used to explore associations between socioeconomic status and rehabilitation outcomes. *Results.* A total of 3439 patients responded (70%). Significant interactions between SES and sex were demonstrated and further analyses were therefore stratified for gender. In general, women and to a lesser extent men with short education and low income participated less often in activities and had in some areas more unmet needs. Women living alone more often expressed a rehabilitation need in the physical, emotional and financial area and had to a higher extent unmet needs in a number of areas. Men living alone and men outside the workforce had increased odds of unmet needs in the physical area. *Conclusions.* Despite equal access to care, SES had a significant impact on cancer survivors' rehabilitation. In general, the associations were most pronounced for female cancer patients. We suggest that special attention should be paid to socioeconomically disadvantaged groups by taking into account differences in SES in a clinical setting and when developing targeted rehabilitation programmes.

Cancer survivors are at risk of experiencing adverse physical and psychosocial effects of their cancer and its treatment [1,2]. The goal of rehabilitation is to 'enable people with disabilities to reach and maintain optimal physical, sensory, intellectual, psychological and social function' [3]. Hence, rehabilitation comprises multidisciplinary efforts, e.g. physical, psychological, and work- related interventions.

In order to organise targeted efforts it is important to gain knowledge about the many aspects of cancer survivors' needs for rehabilitation, participation in rehabilitation activities and their unmet needs. In recent published studies needs for rehabilitation vary between 30% and 70% [4–7], which may reflect methodological differences across studies, but may also mirror the fact that cancer patients represent a heterogeneous group with respect to patient- and disease-related factors. We recently published data from a population-based cohort study of 3439 Danish cancer survivors, in which we observed a substantial variation in the above characteristics, illustrated by the fact that women and younger patients were more likely to express rehabilitation needs and utilise activities. However, among those who expressed this need for professional help, unmet needs were more common among elderly patients, and in the emotional area men more frequently had unresolved needs [7].

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Several studies, including studies from Denmark and other countries characterised by having free access to health services at all levels, have shown social inequality in the cancer incidence and survival across all cancer sites [8,9]. However, no studies have investigated to what extent socioeconomic status (SES) influences the expression of needs, participation in cancer rehabilitation activities and unmet needs.

In order to address these questions we conducted a population-based cohort study of more than 3000 cancer survivors followed up in a 14-month period from date of diagnosis.

Material and methods

Design

We performed a population-based cohort study including incident cancer patients, except patients with non-melanoma skin cancer, diagnosed from 1 October 2007 to 30 September 2008 in the Regions of Southern and Central Denmark (2.4 million residents) by obtaining information from hospital-based and national administrative registers. Information about rehabilitation issues was obtained from a patient questionnaire administered 14 months after diagnosis.

The study was approved by the Danish Data Protection Agency (File number 2008-41-1887). According to the Regional Scientific Ethics Committee, the Biomedical Research Ethics Committee System Act does not apply to this project.

Setting

The Danish healthcare system is primarily publicly funded. More than 98% of the Danish population are listed with a general practitioner (GP), who acts as gatekeeper to the rest of the healthcare system. Since 2007, the 98 municipalities in Denmark have been responsible for most rehabilitation of patients with chronic diseases, including cancer, while hospitals are responsible for highly specialised rehabilitation. Rehabilitation activities may include physiotherapy, other physical training, counselling with psychologist, dietary advice, counselling with social worker, occupational therapy, patient education and smoking cessation counselling, but the offers vary across the country. Like other health services, rehabilitation provided by the public healthcare system and the municipalities is free of charge.

Cancer patients may participate in rehabilitation activities outside the public healthcare system and the municipalities, e.g. free of charge in the setting of the private patient organisation, The Danish Cancer Society, or self-financed at, e.g. private physiotherapists, psychologists and alternative practitioners.

Study population

All residents of Denmark are assigned a unique 10-digit personal identification number (CPR) permitting linkage between registers [10].

From the regional hospitals' Patient Administrative System [11] we obtained information on all adult patients (18 + years) diagnosed with cancer during the study period (ICD-10 codes DC00-96, DD37-48), assigned the registration code 'AZCA-1', indicating first encounter at the department regarding the cancer, and listed with a GP in one of the two regions. Based on the National Patient Register [12] all patients with a previous diagnosis of cancer were excluded. The cancers were grouped according to localisation (Table I).

Following identification by the administrative sampling procedure each patient's GP was mailed a questionnaire to confirm the cancer diagnosis.

This study cohort was established for several research projects, and six months following date of diagnosis patients were mailed a questionnaire asking them to confirm that they had cancer for the first time and giving them the possibility of declining the use of the information provided by their GP. Prior to the distribution of the 14-month patient questionnaires, vital status and postal address were confirmed by linkage to the Civil Registration System [13]. Non-responders were sent a reminder after three weeks. All letters included the questionnaire and a prepaid envelope.

Data on socioeconomic status

From Statistics Denmark [14] socioeconomic information was retrieved on an individual level for the year 2006 (the year before diagnosis), except for income which was retrieved for the years 2002–2006 to calculate a five-year average. Education was categorised according to the length of highest attained educational level: < 10 years (primary and lower secondary school), 10–12 years (vocational education and upper secondary school), > 12 years (short-, medium- and long-term higher education) [15]. Equivalent disposable income for a single family member comprised all income (wages, salaries, all types of supplementary benefits and pensions) after taxation for the entire household adjusted for number of persons in the household. Disposable income was calculated on the basis of the five-year average income of responders and categorised as low (1st quartile), medium (2nd and 3rd quartile) and high (4th quartile) [16]. Labour market status

Table I. Medical and socio-demographic characteristics of responders and non-responders.

	Responders n (%) 3439 (69.5)	Non-responders n (%) 1508 (30.5)	p[a]
Sex			
Men	1466 (42.6)	712 (47.2)	0.003
Women	1973 (57.4)	796 (52.8)	
Age (years)			<0.001
18–39	152 (4.4)	118 (7.8)	
40–49	331 (9.6)	154 (10.2)	
50–59	660 (19.2)	292 (19.4)	
60–69	1263 (36.8)	419 (27.8)	
70–79	802 (23.3)	338 (22.4)	
80+	231 (6.7)	187 (12.4)	
Cancer diagnoses			<0.001
Breast	976 (28.4)	314 (20.8)	
Prostate	501 (14.6)	179 (11.9)	
Colorectal	522 (15.2)	213 (14.1)	
Gynaecological	230 (6.7)	102 (6.8)	
Malignant melanoma	233 (6.8)	120 (7.9)	
Lung	188 (5.5)	113 (7.5)	
Lymphoma	104 (3.0)	44 (2.9)	
Head and neck	125 (3.6)	81 (5.4)	
Other	560 (16.2)	342 (22.7)	
Cohabitation status*			<0.001
Cohabiting/married	2574 (75.1)	977 (65.6)	
Living alone	854 (24.9)	513 (34.4)	
Highest attained education*			<0.001
<10 years	1284 (38.3)	639 (45.1)	
10–12 years	1305 (38.9)	546 (38.6)	
>12 years	763 (22.8)	230 (16.3)	
Income*			<0.001
Low (1st quartile)	858 (25.0)	557 (37.3)	
Medium (2nd and 3rd quartile)	1717 (50.0)	661 (44.3)	
High (4th quartile)	858 (25.0)	275 (18.4)	
Labour market status*			<0.001
Working	1527 (45.2)	604 (41.2)	
Pensioners	1565 (46.4)	690 (47.1)	
Outside the workforce	283 (8.4)	172 (11.7)	

*Percentage of missing data between 0.4% and 3.6%.
[a] χ^2-test.

was categorised as working, pensioners (early retirement pension and old age pension) and outside the workforce (unemployed, receiving social security, and disability pension). Cohabitation status was categorised as living with a partner (married/cohabitating) or living alone (divorced, widowed or never married) [15].

Data on rehabilitation

The patient questionnaire comprised 171 items and addressed various aspects of cancer rehabilitation [17]. Development of the questionnaire is described in a previous paper [7].

'Need for rehabilitation during the 14-month period' and 'unmet rehabilitation after 14 months' were asked for in a similar way for each of six areas: 'physical', 'emotional', 'family-oriented' 'sexual', 'work-related' and 'financial'.

As an example the following questions were asked with regard to physical needs:

1. To what extent from diagnosis and until now have you needed professional help with physical problems? ('not at all', 'to a small extent', 'to some extent' and 'to a great extent')
2. Until now, to what extent have you had your needs fulfilled in terms of help with physical problems? ('not at all', 'to a small extent', 'to some extent', 'to a great extent' and 'not relevant')

Patients were categorised as having an 'unmet need' if they had expressed a 'need for rehabilitation' during the 14-month period and the need to some extent was not fulfilled after 14 months.

'Participation in rehabilitation activities' was assessed by asking:

3. Have you from diagnosis and until now participated in any of the following activities due

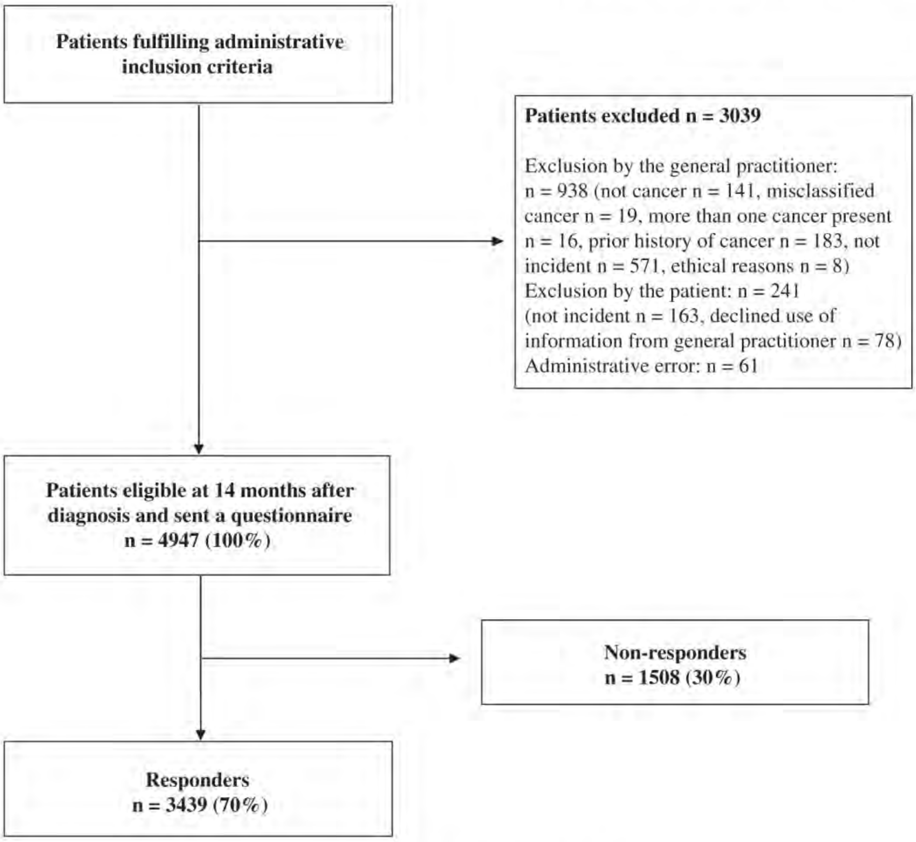

Figure 1. Inclusion of patients into the study.

to problems caused by your cancer disease? (listing of possible providers/activities)

Participation was categorised into three different dimensions of rehabilitation based on the profession of the provider/activity: 1) 'Physical activities' (physiotherapist, occupational therapist, chiropractor, patient education, smoking cessation counselling, nutritional information, physical training, alternative practitioner including acupuncturist and reflexologist); 2) 'Psychological activities' (psychologist, marriage counsellor or sexologist, supportive group sessions or patient associations, and spiritual counselling); and 3) 'Work-related/financial activities' (social worker, union representative or employer, financial or insurance consultant). Combining the three above-mentioned dimensions the variable 'Participation in at least one activity' was constructed and is an expression of participation in at least one of the above activities.

Statistical analysis

The need for rehabilitation was dichotomised into 'no need' ('not at all) and 'need' (combining 'to a small extent', 'to some extent' and 'to a great extent'), and similarly, unmet need was dichotomised into 'unmet need' and 'met need'. Answers in the 'not relevant' category were excluded from the analyses.

χ^2-tests were conducted to test the difference between responders and non-responders with regard to sex, age, diagnosis and socioeconomic variables. All potentially eligible patients were due to administrative errors not invited for this study. Therefore χ^2-test were also conducted in order to test the difference between these two groups.

We assessed interactions between SES and cancer type (breast, prostate, colorectal), SES and sex and SES and age groups (divided into ± 60 years) through stratified analyses. Univariate and multiple logistic regression analyses were used to explore associations between socioeconomic status and rehabilitation. The multiple regression analyses were adjusted for age group and cancer diagnosis (definitions of categories as shown in Table I). All tests were two-sided and $p < 0.05$ was considered statistically significant. Adjusted odds ratios (OR_{adj}) are presented with 95% confidence intervals (CI). Analyses were performed using Stata Release 11 (StataCorp, College Station, TX, USA).

Table II. Needs for rehabilitation during 14 months following time of diagnosis. For each area number, frequencies, crude and adjusted odds ratios (ORs) are shown separately for men (grey) and women (white) with regard to cohabitation status, highest attained education, income and labour marked status.

	Physical area n = 1388–1854			Emotional area n = 1390–1864			Family-oriented area n = 1390–1860	
	n (%)	OR_{crude}	OR_{adj}[a] (95% CI)	n (%)	OR_{crude}	OR_{adj}[a] (95% CI)	n (%)	OR_{crude}
Needs, total								
Men	1352 (25.4)	–	–	327 (23.5)	–	–	145 (10.4)	–
Women	676 (36.5)	–	–	670 (36.0)			380 (16.6)	–
Cohabitation status								
Men								
Cohabiting/ married	286 (25.4)	1.00	1.00	259 (22.9)	1.00	1.00	117 (10.4)	1.00
Living alone	66 (26.0)	1.03	0.98 (0.71–1.35)	65 (25.8)	1.17	1.01 (0.72–1.41)	27 (10.7)	1.03
Women								
Cohabiting/ married	474 (35.9)	1.00	1.00	465 (35.2)	1.00	1.00	227 (17.2)	1.00
Living alone	201 (37.9)	1.09	1.34* (1.07–1.68)	204 (37.8)	1.12	1.59** (1.26–2.00)	80 (14.9)	0.84
Highest attained education								
Men								
< 10 years	104 (23.2)	1.00	1.00	93 (20.6)	1.00	1.00	39 (8.6)	1.00
10–12 years	159 (26.0)	1.16	1.10 (0.82–1.47)	147 (24.1)	1.22	1.02 (0.75–1.40)	72 (11.8)	1.43
> 12 years	78 (27.3)	1.24	1.16 (0.82–1.64)	77 (26.9)	1.42*	1.18 (0.82–1.71)	28 (9.7)	1.14
Women								
< 10 years	248 (34.0)	1.00	1.00	230 (31.4)	1.00	1.00	109 (15.0)	1.00
10–12 years	224 (34.8)	1.04	0.89 (0.70–1.13)	217 (33.8)	1.11	0.86 (0.67–1.10)	98 (15.3)	1.02
> 12 years	190 (42.9)	1.46**	1.13 (0.87–1.48)	214 (47.4)	1.96**	1.34* (1.03–1.10)	94 (20.8)	1.50**
Income								
Men								
Low (1st quartile)	63 (19.9)	1.00	1.00	55 (17.4)	1.00	1.00	28 (8.8)	1.00
Medium (2nd and 3rd quartile)	199 (29.3)	1.66**	1.54 (1.09–2.17)	185 (27.0)	1.76**	1.32 (0.92–1.91)	90 (13.1)	1.56
High (4th quartile)	90 (23.2)	1.22	1.10 (0.74–1.64)	87 (22.7)	1.40	1.06 (0.69–1.62)	27 (7.0)	0.78
Women								
Low (1st quartile)	157 (34.8)	1.00	1.00	147 (31.9)	1.00	1.00	70 (15.4)	1.00
Medium (2nd and 3rd quartile)	349 (36.7)	1.08	0.86 (0.66–1.11)	356 (37.5)	1.28*	0.81 (0.62–1.06)	175 (18.4)	1.25
High (4th quartile)	170 (38.0)	1.15	0.86 (0.63–1.17)	167 (37.11)	1.26	0.77 (0.56–1.06)	63 (14.0)	0.90
Labour market status								
Men								
Working	182 (29.9)	1.00	1.00	191 (31.5)	1.00	1.00	85 (14.0)	1.00
Pensioners	143 (20.9)	0.62**	0.62* (0.43–0.91)	106 (15.4)	0.39**	0.74 (0.49–1.12)	44 (6.4)	0.42**
Outside the workforce	23 (31.5)	1.08	1.04 (0.61–1.80)	23 (31.9)	1.02	1.04 (0.60–1.81)	12 (16.9)	1.25
Women								
Working	368 (41.8)	1.00	1.00	389 (43.9)	1.00	1.00	184 (20.7)	1.00
Pensioners	206 (27.9)	0.54**	0.87 (0.62–1.23)	175 (23.7)	0.40**	1.02 (0.71–1.44)	64 (8.7)	0.37**
Outside the workforce	91 (46.4)	1.21	1.29 (0.93–1.78)	93 (47.0)	1.13	1.32 (0.95–1.83)	51 (25.6)	1.32

[a] Adjusted for age group and cancer diagnosis, $^{*}p < 0.05$, $^{**}p < 0.01$.

Results

Of the 4947 subjects eligible at 14 months, 3439 returned the questionnaire (70%) (Figure 1). Table I shows that there were statistically significant differences between responders and non-responders with regard to all variables included. There was a slight overrepresentation in the group of responders of women, 60–69-year-olds, patients with breast

Table II. Needs for rehabilitation during 14 months following time of diagnosis. For each area number, frequencies, crude and adjusted odds ratios (ORs) are shown separately for men (grey) and women (white) with regard to cohabitation status, highest attained education, income and labour marked status. *(Continued)*.

	Sexual area n = 1368–1829			Work-related area n = 380–598			Financial area n = 856–1039		
OR$_{adj}$[a] (95% CI)	n (%)	OR$_{crude}$	OR$_{adj}$[a] (95% CI)	n (%)	OR$_{crude}$	OR$_{adj}$[a] (95% CI)	n (%)	OR$_{crude}$	OR$_{adj}$[a] (95% CI)
–	308 (22.5)	–	–	72 (19.0)	–	–	118 (13.8)	–	–
–	221 (12.1)	–	–	169 (28.3)	–	–	139 (13.4)	–	–
1.00	254 (22.9)	1.00	1.00	54 (18.3)	1.00	1.00	91 (13.5)	1.00	1.00
0.84 (0.53–1.33)	52 (20.6)	0.87	0.91 (0.64–1.29)	16 (19.5)	1.08	1.01 (0.53–1.93)	26 (14.9)	1.13	0.98 (0.60–1.61)
1.00	187 (14.3)	1.00	1.00	133 (28.1)	1.00	1.00	87 (11.5)	1.00	1.00
1.14 (0.85–1.54)	34 (6.6)	0.42**	0.57** (0.38–0.86)	36 (29.0)	1.05	1.11 (0.71–1.75)	51 (18.0)	1.69**	2.26** (1.51–3.37)
1.00	98 (22.2)	1.00	1.00	13 (14.3)	1.00	1.00	32 (11.5)	1.00	1.00
1.17 (0.76–1.80)	137 (22.8)	1.04	1.02 (0.75–1.40)	40 (22.6)	1.77	1.99 (0.97–4.09)	59 (16.2)	1.49	1.20 (0.74–1.96)
0.86 (0.50–1.47)	68 (23.7)	1.09	0.99 (0.69–1.45)	17 (16.7)	1.22	1.43 (0.62–3.28)	22 (11.6)	1.01	0.81 (0.44–1.49)
1.00	63 (8.9)	1.00	1.00	45 (30.2)	1.00	1.00	51 (13.6)	1.00	1.00
0.74 (0.54–1.02)	80 (12.6)	1.48*	1.04 (0.72–1.50)	58 (26.6)	0.84	0.77 (0.48–1.25)	50 (13.9)	1.02	0.78 (0.50–1.22)
0.93 (0.66–1.30)	75 (16.8)	2.07**	1.22 (0.83–1.81)	61 (27.2)	0.86	0.77 (0.47–1.25)	33 (11.7)	0.84	0.59* (0.35–0.98)
1.00	51 (16.4)	1.00	1.00	8 (26.7)	1.00	1.00	17 (9.1)	1.00	1.00
1.15 (0.71–1.87)	153 (22.7)	1.50*	1.15 (0.78–1.68)	41 (22.0)	0.78	0.85 (0.34–2.17)	77 (18.9)	2.32	1.47 (0.81–2.69)
0.57 (0.31–1.05)	103 (27.1)	1.90**	1.27 (0.83–1.93)	23 (14.1)	0.45	0.61 (0.22–1.69)	24 (9.2)	1.01	0.59 (0.29–1.21)
1.00	33 (7.5)	1.00	1.00	22 (40.0)	1.00	1.00	36 (16.3)	1.00	1.00
0.73 (0.52–1.03)	127 (13.5)	1.92**	1.05 (0.68–1.62)	100 (28.7)	0.60	0.53* (0.28–0.98)	83 (15.3)	0.93	0.57* (0.36–0.92)
0.50** (0.33–0.76)	61 (13.7)	1.94**	1.01 (0.62–0.63)	47 (24.4)	0.48*	0.44* (0.23–0.85)	20 (7.3)	0.40**	0.23** (0.12–0.42)
1.00	157 (26.3)	1.00	1.00	64 (18.5)	1.00	1.00	82 (17.9)	1.00	1.00
0.92 (0.48–1.76)	127 (18.7)	0.64**	0.80 (0.55–1.18)	–	–	–	24 (7.2)	0.35**	0.75 (0.35–1.59)
1.52 (0.75–3.06)	20 (28.2)	1.10	1.25 (0.70–2.23)	4 (16.0)	0.84	0.75 (0.23–2.39)	9 (18.8)	1.06	1.03 (0.46–2.30)
1.00	148 (16.8)	1.00	1.00	149 (28.0)	1.00	1.00	90 (14.0)	1.00	1.00
1.15 (0.70–1.88)	32 (4.5)	0.23**	0.91 (0.51–1.60)	–	–	–	18 (6.4)	0.42**	0.78 (0.35–1.76)
1.56* (1.07–2.28)	36 (18.4)	1.11	1.29 (0.85–1.96)	18 (31.6)	1.19	1.26 (0.68–2.33)	29 (27.9)	2.37**	2.73** (1.65–4.54)

[a] Adjusted for age group and cancer diagnosis, *$p < 0.05$, **$p < 0.01$.

cancer, patients who were cohabiting/married and patients who had a higher education and income. Analyses showed significant interactions between SES and gender, and further analyses were therefore stratified for gender.

Need for rehabilitation during the 14-month period

For women, analyses showed that those living alone significantly more often expressed rehabilitation needs in the physical, emotional and financial area, compared to those who were cohabiting/married (Table II). A high education increased the odds of a need in the emotional area, but reduced the odds of having a financial need. Women outside the workforce expressed a rehabilitation need in the financial area more often. A high income reduced the odds of expressing a rehabilitation need in some areas.

For male cancer patients similar tendencies were seen, but the associations were less pronounced and non-significant.

Participation in rehabilitation activities

Overall, women with a higher education and to some extent higher income had significantly increased odds of participating in activities (Table III). Women who were pensioners or women otherwise outside the workforce participated less often in rehabilitation activities compared to women working. Women living alone had increased odds of participating in psychological activities.

For men, a higher income increased odds of participating in physical activities, while a high education was associated with participation in psychological activities. Male pensioners and men outside the workforce showed a tendency towards less participation in all areas, but only statistically significant in the work-related/financial area.

Unmet rehabilitation needs after 14 months

Table IV presents unmet needs among the male and female patients, who had expressed a need for rehabilitation during the 14-month period.

Women living alone had unmet needs in the family-oriented and sexual area. Women with a high education were less likely to have unmet needs in the physical and emotional area. There was a tendency towards women outside the workforce more often having unresolved needs. However, only in the work-related area this showed statistical significance.

Regarding men, a high education also predicted reduced odds of unmet needs in the physical area, while living alone increased the odds in the same area. Men outside the workforce more often had unresolved needs in the physical and sexual area.

Stratified analyses for different cancer types and age groups (data not shown)

Stratified analyses for women with breast and colorectal cancer showed similar tendencies, although for breast cancer results were often more pronounced. With regard to single women expressing a need for and participating in psychological rehabilitation, this was only found for breast cancer. Analyses on men with prostate and colorectal cancer revealed minor differences, e.g. a higher income reduced need for rehabilitation in the sexual area for colorectal cancer, while it increased for prostate cancer. However none of the results were statistically significant.

Comparing stratified analyses on different age groups, we found some differences, with the most pronounced being that older patients had significantly increased odds of expressing need for physical rehabilitation, which was not found among younger patients.

Discussion

Main results

SES significantly influenced cancer survivors' rehabilitation with regard to needs, participation and unmet needs. In general, women and to a lesser extent men with short education and low income participated less often in activities and had in some areas more unmet needs. Women living alone more often expressed a rehabilitation need in the physical, emotional and financial area and had to a higher extent unmet needs in a number of areas. Men living alone and men outside the workforce had increased odds of unmet needs in the physical area.

Strengths and limitations

This study has a population-based approach including a large consecutively sampled cohort of incident cancer patients during a one-year period in two representative regions in Denmark. The sampling was based on register data, and the validity of diagnoses is considered high [12]. In addition, misclassification was minimised by asking the GPs to confirm the cancer diagnosis. Information on SES from Statistics Denmark has high validity and completeness and allowed for analysis of different socioeconomic factors [16,18–20].

The aim of our study was to investigate overall associations between SES and rehabilitation. Due to interaction between SES and gender, we stratified analyses for gender. Some degree of interactions between SES and, respectively, cancer type and age group cannot be ruled out, and it could have been relevant to provide detailed information for each cancer type and age group in relation to the influence of SES on rehabilitation. However, the size of our material did not allow us present results for each of these subgroups of cancer patients and the sub-analyses performed on specific cancer types and age groups only indicated minor effect modifications.

Table III. Participation in rehabilitation activities during 14 months following time of diagnosis. For each category of activity number, frequencies, crude and adjusted odds ratios (ORs) are shown separately for men (grey) and women (white) with regard to cohabitation status, highest attained education, income and labour marked status.

	Participation in at least one activity n = 1384–1873			One or more physical activities n = 1466–1973			One or more psychological activities n = 1466–1973			One or more work related/financial activities n = 1466–1973		
	n (%)	OR_{crude}	OR_{adj}^{a} (95% CI)	n (%)	OR_{crude}	OR_{adj}^{a} (95% CI)	n (%)	OR_{crude}	OR_{adj}^{a} (95% CI)	n (%)	OR_{crude}	OR_{adj}^{a} (95% CI)
Participation, total												
Men	545 (39.4)	–	–	438 (29.9)	–	–	152 (10.4)	–	–	134 (9.1)	–	–
Women	1152 (61.5)	–	–	1009 (51.5)	–	–	434 (22.0)	–	–	269 (13.6)		
Cohabitation status												
Men												
Cohabiting/married	435 (38.7)	1.00	1.00	357 (30.0)	1.00	1.00	118 (9.9)	1.00	1.00	103 (8.7)	1.00	1.00
Living alone	105 (41.7)	1.13	1.02 (0.76–1.36)	77 (28.7)	0.94	0.90 (0.67–1.22)	30 (11.2)	1.15	0.95 (0.61–1.49)	31 (11.6)	1.38	1.01 (0.63–1.62)
Women												
Cohabiting/married	833 (63.2)	1.00	1.00	727 (52.6)	1.00	1.00	309 (22.3)	1.00	1.00	205 (14.8)	1.00	1.00
Living alone	318 (57.8)	0.80*	1.09 (0.86–1.38)	281 (48.0)	0.83	1.07 (0.86–1.34)	124 (21.2)	0.93	1.38* (1.06–1.80)	63 (10.8)	0.69*	1.05 (0.75–1.47)
Highest attained education												
Men												
< 10 years	161 (35.6)	1.00	1.00	133 (26.8)	1.00	1.00	39 (7.9)	1.00	1.00	26 (5.2)	1.00	1.00
10–12 years	246 (40.7)	1.24	1.05 (0.80–1.36)	195 (31.1)	1.24	1.11 (0.85–1.45)	61 (9.7)	1.27	0.96 (0.62–1.48)	73 (11.6)	2.39**	1.74* (1.05–2.89)
> 12 years	125 (43.6)	1.39*	1.20 (0.88–1.65)	98 (32.9)	1.34	1.22 (0.88–1.68)	45 (15.1)	2.09**	1.65* (1.02–2.67)	31 (10.4)	2.10**	1.47 (0.81–2.67)
Women												
< 10 years	378 (51.4)	1.00	1.00	332 (42.2)	1.00	1.00	112 (14.2)	1.00	1.00	71 (9.0)	1.00	1.00
10–12 years	409 (62.9)	1.60**	1.34* (1.05–1.70)	357 (52.7)	1.52**	1.38** (1.10–1.74)	151 (22.3)	1.73**	1.31 (0.98–1.75)	92 (13.6)	1.58**	1.03 (0.72–1.47)
> 12 years	350 (77.8)	3.31**	2.55** (1.90–3.43)	306 (65.8)	2.63**	2.26** (1.73–2.96)	167 (35.9)	3.38**	2.17** (1.61–2.93)	103 (22.2)	2.87	1.48* (1.03–2.13)
Income												
Men												
Low (1st quartile)	87 (27.4)	1.00	1.00	72 (20.5)	1.00	1.00	24 (6.8)	1.00	1.00	21 (6.0)	1.00	1.00
Medium (2nd and 3rd quartile)	299 (43.8)	2.06**	1.63** (1.19–2.24)	238 (33.2)	1.94**	1.67** (1.21–2.30)	82 (11.5)	1.77*	1.15 (0.69–1.93)	71 (9.9)	1.74*	0.95 (0.53–1.70)
High (4th quartile)	157 (41.2)	1.85**	1.43* (1.01–2.06)	126 (31.9)	1.82**	1.55* (1.07–2.24)	44 (11.1)	1.71*	1.14 (0.64–2.04)	42 (10.6)	1.88*	1.04 (0.55–1.97)
Women												
Low (1st quartile)	222 (47.5)	1.00	1.00	198 (39.1)	1.00	1.00	71 (14.0)	1.00	1.00	47 (9.3)	1.00	1.00
Medium (2nd and 3rd quartile)	616 (64.9)	2.04**	1.57** (1.21–2.03)	525 (52.5)	1.72**	1.40** (1.09–1.79)	241 (24.1)	1.94**	1.30 (0.94–1.80)	156 (15.6)	1.80**	0.94 (0.64–1.40)
High (4th quartile)	314 (69.2)	2.48**	1.83** (1.33–2.51)	286 (61.8)	2.51**	2.07** (1.52–2.80)	122 (26.4)	2.19**	1.41 (0.98–2.05)	66 (14.3)	1.62*	0.74 (0.47–1.17)

(Continued)

to be reliable for the entire country. The healthcare system is free and with equal access to ensure a high level of social security coverage for all residents. Compared to countries without free access, the social inequalities observed must account for a minimum. It must be kept in mind that the study concerns patients, who survived for more than one year and the results may not apply to short-time survivors. Another limitation is that we did not have information on clinical parameters such as cancer stage and treatment. Confounding due to cancer stage and treatment might have underestimated our results on the effects on SES.

Comparison with other studies

Patients and in particular female patients, who attended rehabilitation activities, generally had higher SES than those who did not attend activities. Social position has previously been shown to be associated with cancer survivors' participation in rehabilitation, which was illustrated in two other studies from Denmark. Here the authors investigated 1876 cancer patients attending a rehabilitation intervention programme and a psychosocial intervention study of 399 patients with malignant melanoma, finding in both studies that participants were of higher SES and, furthermore, mainly women compared to non-participants [22,23]. Higher SES is probably a proxy for more personal and network resources, and a better ability to seek and demand additional help. Higher expectations to own health, quality of life, etc. in this patient group may also facilitate participation in activities and thus problem-solving. It is also possible that patients who have higher income and education may be provided with more biomedical information and psychosocial counselling by the physicians [24], or that rehabilitation services offered may seem less appealing to patients of lower SES groups. Our results were most pronounced for female cancer patients and may reflect the fact that women with high SES in general are better at articulating a rehabilitation need or that current offers appeal more to those women. However, the less pronounced results for men could also reflect the relative small number of male participants and consequently lower statistical power.

Overall, we observed a tendency to more unmet needs in all rehabilitation areas for patients living alone, with differences being significant in the physical area for men and in the family-oriented and sexual areas for women. There was also a tendency towards both men and women outside the workforce more often expressing unmet needs, although this was only significant for male patients in two areas and for women in one area, probably reflecting the limited number of patients in the analyses. Our findings are in line with a cross-sectional study of 1490 Danish cancer patients and a Norwegian study of 1325 cancer patients, which both reported that patients living alone or patients who were unemployed were more likely to report unmet needs for rehabilitation [5,25]. Living with a partner might reflect the fact that the close social network has a 'rehabilitative effect' per se, but also that a partner could encourage the patient to seek help within the healthcare system as well among relatives and friends. Further, to support this argument a cross-sectional study of patients with colorectal cancer (n = 339) from Israel showed a significantly higher level of psychological distress among the unmarried patients [26]. Pertinent to this discussion, patients outside the workforce might represent a vulnerable group in relation to successful rehabilitation. Different explanations may contribute to this, such as a weaker social network, a worse financial situation, or the more manual working tasks in the lower SES groups. Several studies have shown that lower SES is a risk factor for early retirement, unemployment and long-term sick leave among cancer survivors [27–30]. Finally, patients with low SES may also have more unmet needs than patients with high SES because they have more, and more complex, problems and poorer health following their cancer.

Our results show that, in particular among female cancer patients, social inequality of clinical relevance exists in cancer rehabilitation despite free and equal access to health care and supports the fact that 'equal access' is not sufficient to avert social disparities. As cancer rehabilitation is not an integrated part of the standard cancer treatment, 'getting the help' may require additional resources from the patient, thus causing an even bigger barrier to 'equal access'.

Conclusion and implications

We found that SES has a significant impact on cancer survivors' rehabilitation with regard to needs for and participation in rehabilitation, and with regard to unmet needs. In general, the associations were most pronounced for female cancer patients. We suggest that special attention should be paid to the most vulnerable groups, i.e. patients with low education, patients outside the workforce and patients living alone, by taking into account differences in SES in a clinical setting and when developing targeted rehabilitation programmes for cancer survivors. Further research in this area is also needed to give detailed information on the importance of age and cancer types.

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Table IV. Unmet needs for rehabilitation 14 months after diagnosis. For each area number, frequencies, crude and adjusted odds ratios (ORs) are shown separately for men (grey) and women (white) with regard to cohabitation status, highest attained education, income and labour marked status. *(Continued)*.

	Sexual area $n = 189–265$			Work-related area $n = 66–157$			Financial area $n = 107–123$		
OR_{adj}^{a} (95% CI)	n (%)	OR_{crude}	OR_{adj}^{a} (95% CI)	n (%)	OR_{crude}	OR_{adj}^{a} (95% CI)	n (%)	OR_{crude}	OR_{adj}^{a} (95% CI)
–	124 (46.8)	–	–	15 (22.7)	–	–	65 (60.8)	–	–
–	101 (53.4)	–	–	24 (15.3)	–	–	37 (30.1)	–	–
1.00	98 (45.2)	1.00	1.00	10 (20.0)	1.00	1.00	29 (35.4)	1.00	1.00
1.99 (0.74–5.36)	26 (56.5)	1.58	1.50 (0.77–2.94)	5 (33.3)	2.00	1.42 (0.31–6.53)	12 (50.0)	1.83	2.31 (0.84–6.3)
1.00	81 (50.0)	1.00	1.00	17 (13.9)	1.00	1.00	22 (26.5)	1.00	1.00
1.88* (1.02–3.48)	20 (74.1)	2.86*	2.59* (1.01–6.63)	7 (20.0)	1.54	1.41 (0.51–3.88)	15 (38.5)	1.73	1.28 (0.53–3.07)
1.00	48 (59.3)	1.00	1.00	4 (36.4)	1.00	1.00	12 (40.0)	1.00	1.00
2.12 (0.80–5.62)	52 (44.8)	0.56*	0.53* (0.29–0.96)	8 (21.1)	0.47	0.67 (0.13–3.48)	19 (37.3)	0.89	1.13 (0.42–3.03)
1.28 (0.35–4.71)	20 (31.8)	0.32**	0.28** (0.13–0.58)	2 (12.5)	0.25	0.33 (0.04–2.76)	8 (38.1)	0.92	1.01 (0.30–3.44)
1.00	33 (64.7)	1.00	1.00	6 (15.0)	1.00	1.00	16 (36.4)	1.00	1.00
0.75 (0.38–1.15)	35 (53.0)	0.62	0.59 (0.27–1.29)	8 (15.4)	1.03	1.19 (0.35–4.07)	13 (28.3)	0.69	0.64 (0.25–1.70)
0.59 (0.28–1.26)	31 (44.9)	0.44*	0.48 (0.22–1.04)	7 (11.7)	0.75	0.82 (0.24–2.78)	7 (24.1)	0.56	0.58 (0.18–1.84)
1.00	23 (57.5)	1.00	1.00	3 (42.9)	1.00	1.00	5 (33.3)	1.00	1.00
3.36* (1.08–10.5)	68 (52.7)	0.82	0.80 (0.38–0.96)	55 (13.9)	0.22	0.21** (0.03–1.48)	30 (42.3)	1.46	1.58 (0.46–5.44)
0.76 (0.17–3.39)	33 (34.7)	0.39*	0.43* (0.20–0.94)	7 (30.4)	0.58	0.69 (0.09–5.28)	7 (33.3)	1.00	0.82 (0.19–3.64)
1.00	11 (44.0)	1.00	1.00	6 (33.3)	1.00	1.00	7 (25.9)	1.00	1.00
1.28 (0.61–2.68)	60 (54.1)	1.50	1.63 (0.66–4.01)	12 (12.8)	0.29*	0.25* (0.08–0.86)	25 (31.7)	1.32	1.37 (0.48–3.87)
1.90 (0.78–4.61)	30 (56.6)	1.66	1.88 (0.69–5.11)	6 (13.3)	0.31	0.28 (0.08–1.08)	5 (29.4)	1.19	1.35 (0.32–5.72)
1.00	53 (37.3)	1.00	1.00	14 (23.7)	1.00	1.00	26 (34.7)	1.00	1.00
0.72 (0.20–2.56)	57 (56.4)	2.18**	2.56** (1.35–4.85)	–	–	–	11 (55.0)	2.30	4.45 (0.96–20.7)
0.84 (0.19–3.75)	12 (66.8)	3.36*	3.03* (1.01–9.06)	1 (33.3)	1.61	4.77 (0.22–102.9)	4 (44.4)	1.51	0.95 (0.21–4.32)
1.00	65 (49.6)	1.00	1.00	16 (11.4)	1.00	1.00	21 (25.9)	1.00	1.00
0.84 (0.31–2.25)	15 (62.5)	1.69	0.62 (0.17–2.24)	–	–	–	5 (35.7)	1.59	4.39 (0.71–27.1)
1.99 (0.96–4.15)	18 (60.0)	1.52	1.30 (0.56–3.02)	7 (46.7)	6.84**	6.01** (1.85–20.0)	11 (42.3)	2.10	1.29 (0.46–3.59)

[a] Adjusted for age group and cancer diagnosis, *$p<0.05$, **$p<0.01$.

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Table IV. Unmet needs for rehabilitation 14 months after diagnosis. For each area number, frequencies, crude and adjusted odds ratios (ORs) are shown separately for men (grey) and women (white) with regard to cohabitation status, highest attained education, income and labour marked status.

	Physical area n = 318–604			Emotional area n = 273–610			Family–oriented area n = 125–255	
	n (%)	OR_{crude}	OR_{adj}^{a} (95% CI)	n (%)	OR_{crude}	OR_{adj}^{a} (95% CI)	n (%)	OR_{crude}
Unmet needs, total								
Men	63 (19.8)	–	–	85 (31.1)	–	–	43 (34.4)	–
Women	96 (15.4)	–	–	124 (20.3)	–	–	79 (31.0)	–
Cohabitation status								
Men								
Cohabiting/married	45 (17.4)	1.00	1.00	65 (30.2)	1.00	1.00	33 (32.0)	1.00
Living alone	18 (30.5)	2.09*	2.36* (1.20–4.66)	20 (35.7)	1.28	1.34 (0.71–2.52)	10 (47.6)	1.93
Women								
Cohabiting/married	62 (14.8)	1.00	1.00	80 (19.0)	1.00	1.00	52 (27.2)	1.00
Living alone	34 (18.6)	1.32	1.32 (0.81–2.14)	44 (23.5)	1.32	1.16 (0.74–1.79)	27 (42.9)	2.00*
Highest attained education								
Men								
< 10 years	24 (26.1)	1.00	1.00	26 (32.9)	1.00	1.00	10 (28.6)	1.00
10–12 years	30 (21.0)	0.75	0.88 (0.42–1.54)	41 (33.3)	1.02	1.06 (0.57–1.97)	26 (41.3)	1.76
> 12 years	8 (10.8)	0.34*	0.40* (0.16–0.97)	17 (26.2)	0.72	0.82 (0.39–1.73)	6 (25.0)	0.83
Women								
< 10 years	46 (20.8)	1.00	1.00	55 (27.0)	1.00	1.00	33 (38.8)	1.00
10–12 years	31 (16.2)	0.73	0.77 (0.45–1.30)	39 (19.8)	0.67	0.75 (0.46–1.23)	25 (29.4)	0.66
> 12 years	17 (9.6)	0.40**	0.43** (0.23–0.81)	27 (13.5)	0.42**	0.47** (0.28–0.82)	19 (24.4)	0.51*
Income								
Men								
Low (1st quartile)	12 (23.1)	1.00	1.00	15 (32.6)	1.00	1.00	6 (24.0)	1.00
Medium (2nd and 3rd quartile)	38 (20.4)	0.86	0.90 (0.41–1.93)	53 (33.3)	1.03	1.12 (0.55–2.28)	33 (44.6)	2.55
High (4th quartile)	13 (16.3)	0.65	0.66 (0.27–1.62)	17 (25.0)	0.69	0.71 (0.31–1.66)	4 (15.4)	0.58
Women								
Low (1st quartile)	33 (23.7)	1.00	1.00	36 (27.5)	1.00	1.00	14 (27.5)	1.00
Medium (2nd and 3rd quartile)	50 (15.9)	0.61*	0.62 (0.37–1.04)	65 (19.7)	0.65	0.72 (0.44–1.19)	45 (29.4)	1.10
High (4th quartile)	13 (8.6)	0.30**	0.32** (0.15–0.64)	23 (15.4)	0.48*	0.55 (0.30–1.01)	20 (39.2)	1.71
Labour marked status								
Men								
Working	26 (15.8)	1.00	1.00	49 (29.2)	1.00	1.00	24 (32.0)	1.00
Pensioners	28 (21.9)	1.50	1.30 (0.63–2.67)	26 (32.1)	1.15	0.73 (0.36–1.51)	15 (42.9)	1.59
Outside the workforce	9 (40.9)	3.70**	3.33* (1.21–9.19)	8 (42.1)	1.77	1.54 (0.55–4.34)	4 (36.4)	1.21
Women								
Working	45 (13.9)	1.00	1.00	58 (15.8)	1.00	1.00	40 (26.1)	1.00
Pensioners	31 (16.9)	1.26	1.21 (0.59–2.52)	45 (30.0)	2.28**	1.58 (0.82–3.05)	18 (36.0)	1.59
Outside the workforce	16 (18.4)	1.40	1.55 (0.81–2.97)	16 (19.8)	1.31	1.35 (0.71–2.57)	18 (41.9)	2.03*

[a] Adjusted for age group and cancer diagnosis, $^{*}p < 0.05$, $^{**}p < 0.01$.

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Table IV. Unmet needs for rehabilitation 14 months after diagnosis. For each area number, frequencies, crude and adjusted odds ratios (ORs) are shown separately for men (grey) and women (white) with regard to cohabitation status, highest attained education, income and labour marked status. *(Continued)*.

	Sexual area n = 189–265			Work-related area n = 66–157			Financial area n = 107–123		
OR_{adj}^{a} (95% CI)	n (%)	OR_{crude}	OR_{adj}^{a} (95% CI)	n (%)	OR_{crude}	OR_{adj}^{a} (95% CI)	n (%)	OR_{crude}	OR_{adj}^{a} (95% CI)
–	124 (46.8)	–	–	15 (22.7)	–	–	65 (60.8)	–	–
–	101 (53.4)	–	–	24 (15.3)	–	–	37 (30.1)	–	–
1.00	98 (45.2)	1.00	1.00	10 (20.0)	1.00	1.00	29 (35.4)	1.00	1.00
1.99 (0.74–5.36)	26 (56.5)	1.58	1.50 (0.77–2.94)	5 (33.3)	2.00	1.42 (0.31–6.53)	12 (50.0)	1.83	2.31 (0.84–6.3)
1.00	81 (50.0)	1.00	1.00	17 (13.9)	1.00	1.00	22 (26.5)	1.00	1.00
1.88* (1.02–3.48)	20 (74.1)	2.86*	2.59* (1.01–6.63)	7 (20.0)	1.54	1.41 (0.51–3.88)	15 (38.5)	1.73	1.28 (0.53–3.07)
1.00	48 (59.3)	1.00	1.00	4 (36.4)	1.00	1.00	12 (40.0)	1.00	1.00
2.12 (0.80–5.62)	52 (44.8)	0.56*	0.53* (0.29–0.96)	8 (21.1)	0.47	0.67 (0.13–3.48)	19 (37.3)	0.89	1.13 (0.42–3.03)
1.28 (0.35–4.71)	20 (31.8)	0.32**	0.28** (0.13–0.58)	2 (12.5)	0.25	0.33 (0.04–2.76)	8 (38.1)	0.92	1.01 (0.30–3.44)
1.00	33 (64.7)	1.00	1.00	6 (15.0)	1.00	1.00	16 (36.4)	1.00	1.00
0.75 (0.38–1.15)	35 (53.0)	0.62	0.59 (0.27–1.29)	8 (15.4)	1.03	1.19 (0.35–4.07)	13 (28.3)	0.69	0.64 (0.25–1.70)
0.59 (0.28–1.26)	31 (44.9)	0.44*	0.48 (0.22–1.04)	7 (11.7)	0.75	0.82 (0.24–2.78)	7 (24.1)	0.56	0.58 (0.18–1.84)
1.00	23 (57.5)	1.00	1.00	3 (42.9)	1.00	1.00	5 (33.3)	1.00	1.00
3.36* (1.08–10.5)	68 (52.7)	0.82	0.80 (0.38–0.96)	55 (13.9)	0.22	0.21** (0.03–1.48)	30 (42.3)	1.46	1.58 (0.46–5.44)
0.76 (0.17–3.39)	33 (34.7)	0.39*	0.43* (0.20–0.94)	7 (30.4)	0.58	0.69 (0.09–5.28)	7 (33.3)	1.00	0.82 (0.19–3.64)
1.00	11 (44.0)	1.00	1.00	6 (33.3)	1.00	1.00	7 (25.9)	1.00	1.00
1.28 (0.61–2.68)	60 (54.1)	1.50	1.63 (0.66–4.01)	12 (12.8)	0.29*	0.25* (0.08–0.86)	25 (31.7)	1.32	1.37 (0.48–3.87)
1.90 (0.78–4.61)	30 (56.6)	1.66	1.88 (0.69–5.11)	6 (13.3)	0.31	0.28 (0.08–1.08)	5 (29.4)	1.19	1.35 (0.32–5.72)
1.00	53 (37.3)	1.00	1.00	14 (23.7)	1.00	1.00	26 (34.7)	1.00	1.00
0.72 (0.20–2.56)	57 (56.4)	2.18**	2.56** (1.35–4.85)	–	–	–	11 (55.0)	2.30	4.45 (0.96–20.7)
0.84 (0.19–3.75)	12 (66.8)	3.36*	3.03* (1.01–9.06)	1 (33.3)	1.61	4.77 (0.22–102.9)	4 (44.4)	1.51	0.95 (0.21–4.32)
1.00	65 (49.6)	1.00	1.00	16 (11.4)	1.00	1.00	21 (25.9)	1.00	1.00
0.84 (0.31–2.25)	15 (62.5)	1.69	0.62 (0.17–2.24)	–	–	–	5 (35.7)	1.59	4.39 (0.71–27.1)
1.99 (0.96–4.15)	18 (60.0)	1.52	1.30 (0.56–3.02)	7 (46.7)	6.84**	6.01** (1.85–20.0)	11 (42.3)	2.10	1.29 (0.46–3.59)

[a] Adjusted for age group and cancer diagnosis, $^{*}p < 0.05$, $^{**}p < 0.01$.

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Influence of comorbidity on cancer patients’ rehabilitation needs, participation in rehabilitation activities and unmet needs: a population-based cohort study

Short title:

Comorbidity and cancer rehabilitation

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Abstract

Purpose: To investigate possible associations between cancer survivors' comorbidity status and their 1) need for rehabilitation, 2) participation in rehabilitation activities and 3) unmet needs for rehabilitation in a 14-month period following date of diagnosis.

Methods: A population-based cohort study including incident cancer patients diagnosed from 1 October 2007 to 30 September 2008 in two regions in Denmark. Fourteen months after diagnosis participants completed a questionnaire measuring different aspects and dimensions of rehabilitation. Individual information on comorbidity was based on hospital contacts from 1994 and until diagnosis, subsequently classified according to the Charlson Comorbidity Index. Logistic regression analyses were used to explore the association between comorbidity and outcomes for rehabilitation. Analyses were conducted overall and stratified for gender, age and cancer type.

Results: A total of 3,439 patients responded (70%). Comorbidity at all levels was statistically significant associated with a physical rehabilitation need, and moderate to severe comorbidity was statistically significant associated with a need in the emotional, family-oriented and financial areas as well as participation in physical rehabilitation activities. Stratified analyses showed that significant results in most cases were related to being older than 65 years or having colorectal or prostate cancer.

Conclusions: Comorbidity at all levels was significantly associated with needs for physical rehabilitation. Moderate to severe comorbidity was further associated with other areas of need and participation in physical activities. This should be taken into account when planning rehabilitation interventions for cancer survivors. Differences among subgroups could help target interventions and should be explored further.

Introduction

Several studies conducted worldwide have shown that comorbidity increases overall mortality and in some cases also cancer-specific mortality across different cancer types [1-6]. Comorbidity seems to be able to predict health-related quality of life [7-8] and has been associated with unhealthy lifestyle and more somatic symptoms among cancer survivors [9]. With more than half of cancer survivors today being older than 65 years, comorbidity is brought into focus in the field of cancer rehabilitation [10-11].

The perceived needs and unmet needs of cancer patients have been thoroughly investigated and vary from physical/daily living problems to psychological, information, social and sexual problems [11-14], and few studies have investigated to what extent cancer patients participate in rehabilitation activities [14-16]. In order to guide the development of new services and tailor rehabilitation efforts to patients at most risk it is crucial to identify patient- and disease-related factors related to expression of needs, participation in activities and to what extent needs are fulfilled. In two previous studies of 3,439 Danish cancer survivors we observed substantial variation pertinent to cancer survivors' age, sex, diagnosis and socioeconomic status regarding expression of rehabilitation needs, participation in various rehabilitation activities and unmet needs [14,17]. Likewise it is reasonable to assume that comorbidity is positively associated with expression of needs and unmet needs and inversely associated with participation in rehabilitation activities. However, a recent systematic review concluded that there is a lack of knowledge about how comorbidity influences needs [18], and studies on the impact of comorbidity on cancer rehabilitation are most often limited to women with breast cancer, elderly cancer patients or relating only to physical symptoms or function with divergent results [19-22].

Thus, based on a large population-based cohort of mixed-site cancer survivors this study aimed to investigate the association between comorbidity and 1) needs for rehabilitation, 2) participation in rehabilitation activities and 3) unmet needs for rehabilitation in a 14-month period following date of diagnosis.

Material and methods

Design

We performed a population-based cohort study including incident cancer patients, except patients with non-melanoma skin cancer, diagnosed from 1 October 2007 to 30 September 2008 in the Regions of Southern and Central Denmark (2.4 million residents) using information from hospital-based and national administrative registers. Information about rehabilitation issues was obtained from a patient questionnaire administered 14 months after diagnosis.

Setting

The Danish healthcare system is primarily publicly funded [23]. More than 98% of the Danish population is listed with a general practitioner (GP), who acts as a gatekeeper to the rest of the healthcare system [24]. Since 2007, the 98 municipalities in Denmark have been responsible for most of the rehabilitation of patients with chronic diseases, including cancer, while hospitals are responsible for the highly specialised rehabilitation [25]. Rehabilitation activities may include physiotherapy, other physical training, counselling with psychologist, dietary advice, counselling with social worker, occupational therapy, patient education and smoking cessation counselling, but the offers vary across the country. Like other health services, rehabilitation provided by the public healthcare system and the municipalities is free of charge. Cancer patients may participate in rehabilitation activities outside the public healthcare system and the municipalities, for example free of charge in the setting of the private patient organisation, the Danish Cancer Society [26], or self-financed at e.g. private physiotherapists, psychologists and alternative practitioners.

Study population

All residents of Denmark are assigned a unique ten-digit personal identification number (CPR) permitting linkage between registers [27].

From the regional hospitals' Patient Administrative System [28] we obtained information on all adult patients (18+ years) diagnosed with cancer during the study period (ICD-10 codes DC00-43, DC45-96, DD37-48), assigned the registration code "AZCA-1", indicating first encounter at the department regarding the cancer, and listed with a GP in one of the two regions. Based on the National Patient Register [29] all patients with a previous diagnosis of cancer were excluded. The cancers were grouped according to localisation (Table 1).

Following identification by the administrative sampling procedure each patient's GP was mailed a questionnaire to confirm the cancer diagnosis.

This study cohort was established for several research projects, and six months following date of diagnosis patients were mailed a questionnaire asking them to confirm that they had cancer for the first time and giving them the possibility of declining the use of the information provided by their GP. Prior to the distribution of the 14-month patient questionnaires, vital status and postal address were confirmed by linkage to the Civil Registration System [27]. By linkage to national registers in Statistics Denmark we retrieved data on socioeconomic variables including highest attained education, income, labour market affiliation and cohabitation status [17].

Information on comorbidity status

Information on comorbidity was based on all in- and outpatient hospital contacts registered in the National Patient Register [29] from 1994 (ICD-10 diagnoses were registered from this year) and until date of cancer diagnosis. Comorbidity was classified according to the Charlson Comorbidity Index (CCI) [30]. The CCI provides an overall score for comorbidity based on a weighted score from 1 to 6 assigned to 19 selected conditions. On the basis of the accumulated sum of scores, the comorbidity index was grouped into scores as 0 (no comorbidity), 1 (mild comorbidity) and ≥ 2 (moderate to severe comorbidity). As our study population includes only patients with first primary cancers, no cancers are included in the index [31].

Data on rehabilitation

The patient questionnaire comprised 171 items and addressed various aspects of cancer rehabilitation [32]. Development of the questionnaire is described in a previous paper [14].

"Need for rehabilitation during the 14-month period" and "unmet rehabilitation after 14 months" were asked for in a similar way for each of six areas: "physical", "emotional", "family-oriented" "sexual", "work-related" and "financial".

As an example the following questions were asked with regard to physical needs:

1. To what extent from diagnosis and until now have you needed professional help with physical problems? ("not at all", "to a small extent", "to some extent" and "to a great extent")
2. Until now, to what extent have you had your needs fulfilled in terms of help with physical problems? ("not at all", "to a small extent", "to some extent", "to a great extent" and "not relevant").

Patients were categorised as having an "unmet need" if they had expressed a "need for rehabilitation" during the 14-month period and the need to some extent was not fulfilled after 14 months.

"Participation in rehabilitation activities" was assessed by asking:

3. Have you from diagnosis and until now participated in any of the following activities due to problems caused by your cancer disease? (listing of possible providers/activities)

Participation was categorised into three different dimensions of rehabilitation based on the profession of the provider/activity: 1) “Physical activities” (physiotherapist, occupational therapist, chiropractor, patient education, smoking cessation counselling, nutritional information, physical training, alternative practitioner including acupuncturist and reflexologist), 2) “Psychological activities” (psychologist, marriage counsellor or sexologist, supportive group sessions or patient associations, and spiritual counselling), and 3) “Work-related/financial activities” (social worker, union representative or employer, financial or insurance consultant). Combining the three above-mentioned dimensions the variable “Participation in at least one activity” was constructed and is an expression of participation in at least one of the above activities. Similar constructs were made for needs (“At least one need for rehabilitation”) and unmet needs (“At least one unmet need for rehabilitation”).

Statistical analyses

Need for rehabilitation was dichotomised into “no need” (“not at all”) and “need” (combining “to a small extent”, “to some extent” and “to a great extent”), and similarly, unmet need was dichotomised into “unmet need” and “no unmet need”. Answers in the “not relevant” category were excluded from analyses. Participation in rehabilitation activities was defined as yes/no.

Simple and multiple logistic regression analyses were used to explore associations between CCI score and the three outcomes for rehabilitation. The multiple regression analyses were adjusted for sex, age group and cancer diagnosis. Our primary analyses comprised the whole cohort and were subsequently stratified for gender, age (< 65 years and $\geq$ 65 years) and cancer type (breast, prostate, colorectal and the remaining cancers in one group). This stratification was done because we hypothesised that comorbidity status could interact with age, gender and cancer type.

In a secondary model we explored the influence of socioeconomic status by further adjusting the analyses comprising the whole cohort for socioeconomic factors, because in a previous study we found socioeconomic status to be associated with our outcomes for rehabilitation [17]. Socioeconomic factors included highest attained education, income, labour market affiliation and cohabitation status and were entered into the model separately. All tests were two-sided and $p < 0.05$ was considered statistically significant. Adjusted odds ratios (OR_{adj}) are presented with 95% confidence intervals (95% CI). Analyses were performed using Stata Release 12 (StataCorp, College Station, TX, USA).

Results

Among the 4,947 subjects eligible at 14 months, 3,439 returned the questionnaire (70%) (Figure 1). Table 1 shows baseline patient characteristics. The group of non-respondents had a statistically significantly higher average CCI score compared to respondents. Overall, around a quarter of patients suffered from comorbidity, corresponding to a CCI score of one or more.

Needs for rehabilitation

In the physical area patients with both mild and moderate to severe comorbidity had increased odds of expressing a need for rehabilitation (Table 2). Patients with moderate to severe comorbidity had increased odds of expressing a rehabilitation need in the emotional, family-oriented and financial areas compared to those without comorbidity.

Stratified analyses of the different cancer types, sex and age groups (data not shown in table)

The increased need for physical rehabilitation among patients comorbidity was seen for all subgroups, and was statistically significant on one or two levels for most patients groups, i.e. above the age of 65 years (OR 1.38 (95% CI 1.01-1.88) CCI 1 and OR 1.94 (95% CI 1.33-2.84) CCI ≥2 compared with CCI 0), less than 65 years (OR 1.44 (1.06-1.96) CCI 1 compared with CCI 0), women (OR 1.37 (1.01-1.85) CCI 1 and OR 1.78 (1.15-2.77) CCI ≥2 compared with CCI 0), men (OR 1.47 (1.07-2.02) CCI 1 compared with CCI 0), patients with colorectal cancer (OR 2.89 (1.43-5.84) CCI ≥2 compared with CCI 0) and prostate cancer (OR 1.98 (1.14-3.43) CCI 1 compared with CCI 0). The statistically significantly increased need for rehabilitation in the emotional area was found among men (OR 1.64 (1.04-2.59) CCI ≥2 compared with CCI 0), patients with prostate cancer (OR 2.29 (1.01-5.22) CCI≥2 compared with CCI 0) and patients above 65 years (OR 1.60 (1.06-2.40) CCI ≥2 compared with CCI 0). In the family-oriented area significant results were accounted for by patients above the age of 65 years (OR 2.12 (1.20-3.73) CCI≥2 compared with CCI 0), while in the financial area results were significant for men (OR 2.24 (1.08-4.62) CCI ≥2 compared with CCI 0) and patients above 65 years (OR 2.53 (1.12-5.68) CCI≥2 compared with CCI 0).

Participation in rehabilitation activities

Patients with moderate to severe comorbidity had increased odds of participating in physical activities compared with patients with no comorbidity (Table 3).

Stratified analyses of the different cancer types, sex and age groups (data not shown in table)

Although similar patterns were observed in subgroups, statistically significantly increased participation in physical activities was only seen among men (OR 2.00 (1.35-2.97) CCI>2 compared with CCI 0), patients with colorectal cancer (OR 3.15 (1.59-6.26) CCI≥2 compared with CCI 0) and prostate cancer (OR 2.05 (1.01-4.14) CCI≥2 compared with CCI 0). Regarding psychological activities patients with breast (OR 2.84 (1.36-5.94) CCI >2 compared with CCI 0) and prostate cancer (OR 3.46 (1.11-10.75) CCI≥2 compared with CCI 0) participated more often. Patients less than 65 years had decreased odds of participating in work-related financial activities (OR 0.30 (0.11-0.76) CCI≥2 compared with CCI 0), while a non-significant tendency was seen in the opposite direction for patients above 65 years.

Unmet needs for rehabilitation after the 14-month period

No statistically significant associations between CCI score and expression of unmet needs were observed following adjustment (Table 4).

Stratified analyses of the different cancer types, sex and age groups (data not shown in table)

A relatively limited number of patients were included in the subgroup analyses of unmet needs. Patients with prostate cancer had increased odds of unmet needs in the physical (OR 3.81 (1.10-13.19) CCI 1 compared with CCI 0).

The secondary model including further adjustment for socioeconomic factors

Further adjustment for socioeconomic factors showed similar results as our main model, where we only adjusted for age, gender and cancer type. One result regarding expression of a financial rehabilitation need did though not remain statistically significant when adjusted for socioeconomic variables.

Discussion

Main results

Comorbidity at all levels significantly increased the odds of expressing rehabilitation needs in the physical area. Moderate to severe comorbidity significantly increased the odds of having needs in the family-oriented, emotional and financial areas, although the latter did not remain statistically significant when further adjusted for socioeconomic factors. Patients with moderate to severe comorbidity were more likely to participate in physical rehabilitation. Stratified analyses of the different cancer types, sex and age groups revealed in a few areas slightly different patterns and in most cases significant results were related to being older than 65 years or having colorectal or prostate cancer.

Strengths and limitations

The advantages of this study include the large population-based cohort of incident cancer patients consecutively sampled during a one-year period, which formed the basis for the statistical power sufficient to detect clinically relevant effects of comorbidity. The sampling of cancer patients was based on highly valid register data [33], and furthermore, the GPs were asked to confirm the diagnosis. Hence, misclassification was low.

The CCI is the most widely used comorbidity index in the context of cancer, validated for many different cancer types and the use of administrative data [34]. Furthermore, the CCI has been rated in the top three of indexes useful in relation to cancer generally [34]. Information on comorbid diseases was obtained from the National Patient Register, and the accuracy of diagnosis coding for conditions included in the CCI has proven to be very high when compared with diagnoses obtained from medical records [35]. We found levels of comorbidity comparable with other studies using the register for accessing comorbidity among cancer patients [36]. The National Patient Register does, however, not consistently include information on diseases not requiring a hospital visit. Some of the conditions included in the Charlson Index, including diabetes (type 2) and chronic pulmonary disease, will not necessarily require a hospital contact, but can be diagnosed and treated solely in general practice. Consequently, there might be an underestimation of the prevalence of these specific comorbid conditions in this study, and thereby an underestimation of the impact of comorbidity on cancer patients’ needs, participation in rehabilitation activities and unmet needs. Further, as the CCI was originally developed to predict the risk of 1-year mortality, some comorbid conditions that might affect a cancer rehabilitation course, such as musculoskeletal or psychiatric disorders, are not included.

The response rate was relatively high (70%), but patients with no comorbidity were slightly overrepresented (Table 1). Furthermore, due to incomplete use of the additional AZCA-1 code (the code indicating the first encounter at the department regarding the cancer), which was not recognised until after the sampling, 37% of the potentially eligible patients were not identified by the administrative sampling procedure and thus not included in the study [37]. An under-sampling of patients with comorbidity was seen (CCI 0 71%, CCI 1 18%, CCI 2 11% of the patients included vs. CCI 0 63%, CCI 1 21%, CCI 2 16% of the patients not included, $p<0.001$, X^2-test). Consequently, selection bias may have caused a slight underestimation of the absolute figures of our outcomes for rehabilitation, but should not affect the direction of the associations found.

In this study we analysed different aspects of the rehabilitation process including needs, participation and unmet needs and assessed different dimensions, i.e. physical, psychological, emotional, family-oriented, sexual, work-related and financial problems. A validated questionnaire was not available, however, all the questions were inspired by already validated questionnaires and a thorough development process was conducted, including pilot testing among cancer survivors [14].

The results from this study are considered to be generalisable to other regions in Denmark owing to the fact that that there are only small regional differences with respect to organisation of the healthcare system and prevalence of diseases. Furthermore, all cancer types, except for very rare ones, are diagnosed and treated within the regions according to national guidelines and do not differ between the different hospitals. Generalisability to countries with similar healthcare settings is also likely.

Comparison with other studies

In accordance with our results a cross-sectional study of 1,325 Norwegian mixed-sited cancer patients found comorbidity to be significantly associated with a need for physical rehabilitation [19]. This is also in line with other studies that have demonstrated a higher somatic symptom burden among cancer survivors with comorbidity [9; 20]. An American case-control study of 1,904 cancer survivors and 29,092 controls further supports this, as the researchers found that cancer survivors reported a higher symptom burden with increasing comorbidities compared to controls, and the overall symptom burden increased with number of comorbidities [38]. For patients with moderate to severe comorbidity we found, besides the association in the physical area, also an association with emotional, family-oriented and financial needs. This most likely reflects that with an increased burden of somatic comorbidity, this can also affect other areas of life. A study of 3,792 cancer survivors showed that comorbidity affected health-related quality of life, both with regard to pain, fatigue, physical and emotional function [39]. Thus, in order to effectively address rehabilitation needs among cancer survivors, the healthcare system will need not only manage the cancer disease but also to address multiple coexisting diseases. Our stratified analyses showed that significant results were most often related to being older than 65 years or having colorectal or prostate cancer. This may reflect a higher number and/or more severe comorbidities in these groups [3], but should be explored further in future research.

We found that, comorbidity was not associated with unmet needs in our overall analyses. This is in contrast to the Norwegian study mentioned above [19]. However, compared to our respondents where only one fifth had comorbidity, a total of 47% of the Norwegian patients reported to have comorbidity and, in addition to different somatic disorders, psychological disorders were also included. Hence, identifying the types of disorders included when defining comorbidity may be essential. Differences between patient-reported comorbidity and doctor-registered comorbidity may also be of influence [40].

A significant association was found between a CCI score of two or more and participation in physical rehabilitation activities, which could reflect the increased somatic symptom burden among those patients [9; 20]. In addition, only a few stratified analyses demonstrated either reduced or increased participation among patients with comorbidity. A Danish cohort study investigating participation in a six-day rehabilitation course among women with breast cancer found no difference in comorbidity status (measured by CCI with data obtained from the National Patient Register) between attenders (n=856) and non-attenders (n=1805) [41]. When looking at other chronic diseases, a Danish study regarding pulmonary rehabilitation similarly found no difference in comorbidity status between participants and non-participants [42]. We have previously shown that younger age, female gender, having breast cancer and higher socioeconomic status were associated with participation in activities [14,17], but whether or not patients participate in rehabilitation activities is probably the result of a much more complex process influenced by many different factors including psychosocial, family-related and contextual factors [43]. Furthermore, availability and knowledge of local rehabilitation offers by patients and healthcare professionals may also play a role [43-44].

Conclusion

In conclusion, comorbidity at all levels was statistically significant associated with expression of physical rehabilitation needs, and furthermore moderate to severe comorbidity was significantly associated with other areas of needs and participation in physical activities. We suggest this should be taking into account when planning rehabilitation interventions for cancer survivors. Results from the stratified analyses indicated that the patient groups most in need were patients treated for colorectal or prostate cancer and patients older than 65 years, and further exploration and intervention could be relevant here to enhance rehabilitation efforts in these subgroups.

Ethical approval

The study was approved by the Danish Data Protection Agency (File number 2008-41-1887). According to the Regional Scientific Ethics Committee, the Biomedical Research Ethics Committee System Act does not apply to this project

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Conflicts of interest statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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Figure 1. Inclusion of patients into the study

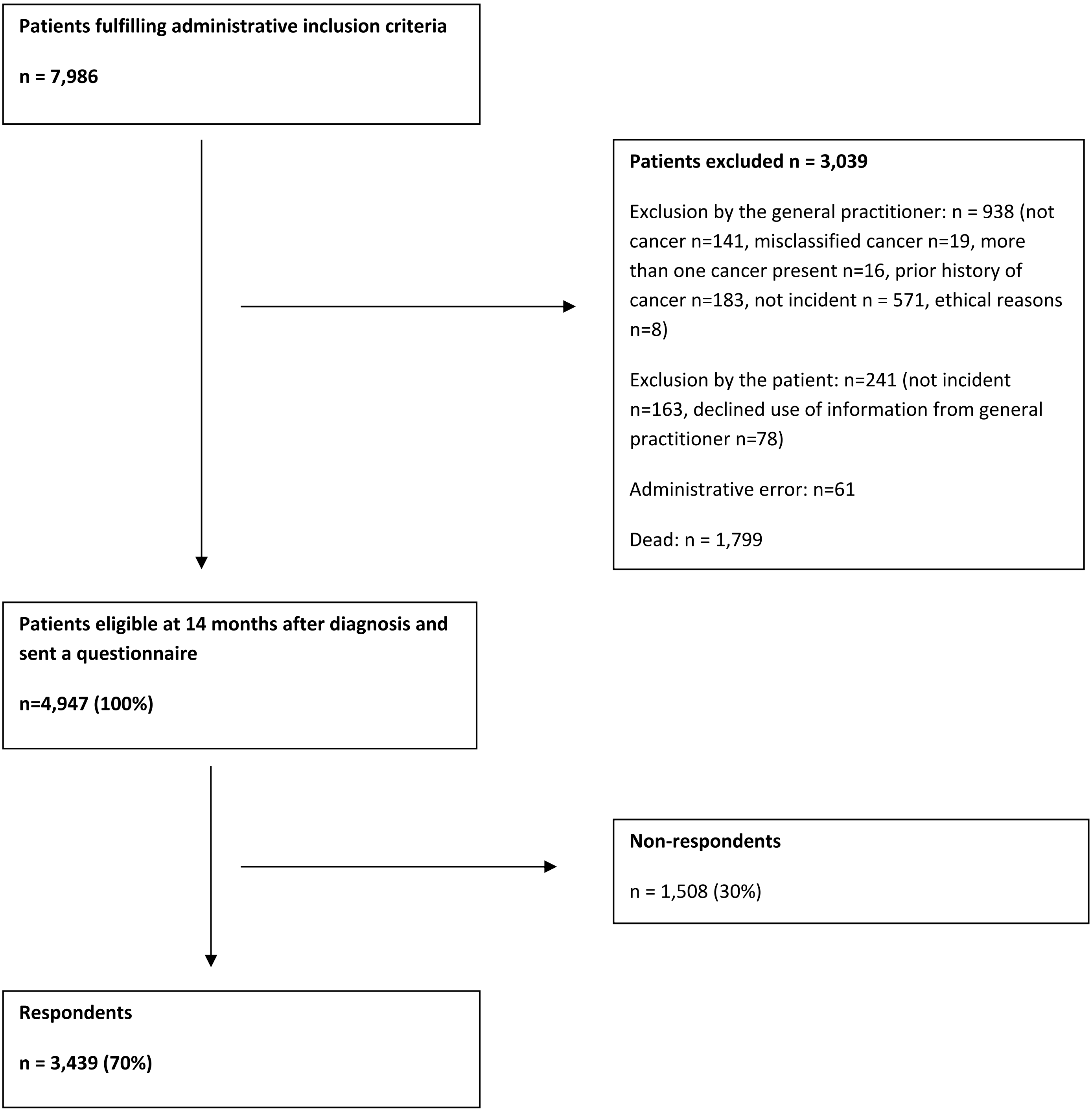

Table 1 Medical and demographic baseline characteristics of responders and non-responders in a cohort study of cancer rehabilitation

	Responders n (%) 3,349 (69.5)	Non-responders n (%) 1,508 (30.5)	p[a]
Sex			0.003
Men	1,446 (42.6)	712 (47.2)	
Women	1,973 (57.4)	796 (52.8)	
Age (years)			<0.001
18-39	152 (4.4)	118 (7.8)	
40-49	331 (9.6)	154 (10.2)	
50-59	660 (19.2)	292 (19.4)	
60-69	1,263 (36.8)	419 (27.8)	
70-79	802 (23.3)	338 (22.4)	
80+	231 (6.7)	187 (12.4)	
Cancer diagnosis			<0.001
Breast	976 (28.4)	314 (20.8)	
Prostate	501 (14.6)	179 (11.9)	
Colo-rectal	522 (15.2)	213 (14.1)	
Gynecological	230 (6.7)	120 (7.9)	
Malignant melanoma	233 (6.8)	102 (6.8)	
Lung	188 (5.5)	113 (7.5)	
Lymphoma	104 (3.0)	44 (2.9)	
Head and neck	125 (3.6)	81 (5.4)	
Other	560 (16.2)	342 (22.7)	
CCI*			<0.001
0	2,685 (78.1)	1,071 (71.4)	
1	516 (15.0)	271 (18.0)	
>2	236 (6.9)	160 (10.6)	

*Data on comorbidity was missing for two persons

[a] x^2-test

Table 2 Needs for rehabilitation during the 14-months following time of diagnosis as a function of comorbidity

	At least one need for rehabilitation n=3,437			Physical area n=3,240			Emotional area n=3,252			Family-oriented area n=3,248		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Needs, total	1,691 (49.2)	-	-	1,028 (31.7)	-	-	997 (30.7)	-	-	453 (14.0)	-	-
CCI												
0	1,342 (50.0)	1.00	1.00	789 (30.9)	1.00	1.00	814 (31.8)	1.00	1.00	365 (14.2)	1.00	1.00
1	239 (46.3)	0.86	1.13 (0.92-1.38)	161 (34.3)	1.17	1.43** (1.15-1.78)	117 (24.7)	0.71**	0.96 (0.75-1.22)	59 (12.6)	0.86	1.12 (0.89-1.66)
>2	110 (46.6)	0.87	1.27 (0.95-1.68)	78 (36.5)	1.28	1.69** (1.24-2.29)	66 (30.6)	0.95	1.55** (1.12-2.14)	29 (13.5)	0.94	1.61* (1.04-2.49)

	Sexual area n=3,195			Work-related area n=1,275			Financial area n=1,893		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Needs, total	529 (16.6)	-	-	252 (19.8)	-	-	257 (13.6)	-	-
CCI									
0	416 (16.5)	1.00	1.00	219 (21.1)	1.00	1.00	205 (13.6)	1.00	1.00
1	76 (16.5)	0.99	1.10 (0.83-1.47)	26 (14.9)	0.66	1.04 (0.64-1.68)	35 (12.7)	0.93	1.14 (0.76-1.71)
≥2	17 (17.4)	1.06	1.44 (0.96-2.14)	7 (10.8)	0.45	1.01 (0.42-2.37)	17 (15.2)	1.14	1.79* (1.01-3.17)

For each area (at least one need for rehabilitation, physical, emotional, family-oriented, sexual, work-related and financial) number, frequencies, crude and adjusted odds ratios (ORs) are shown with regard to comorbidity status (CCI)

[a] Adjusted for sex, age group and cancer diagnosis

*p<0.05

**p<0.01

Table 3 Participation in rehabilitation activities during the 14 months following time of diagnosis as a function of comorbidity

	At least one activity			One or more physical activities			One or more psychological activities			One or more work-related activities		
	n=3,255			n=3,255			n=3,255			n=3255		
	n (%)	ORcrude	ORadj[a] (95% CI)		ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Participation, total	1,696 (52.1)	-	-	1,447 (44.5)	-	-	585 (18.0)	-	-	403 (12.4)	-	-
CCI												
0	1,372 (53.6)	1.00	1.00	1,164 (45.5)	1.00	1.00	493 (19.3)	1.00	1.00	344 (13.4)	1.00	1.00
1	220 (46.2)	0.74**	1.05 (0.85-1.30)	184 (38.7)	0.75**	1.01 (0.81-1.25)	62 (13.0)	0.63**	0.91 (0.68-1.24)	49 (10.3)	0.74	1.18 (0.83-1.67)
≥2	104 (47.3)	0.78*	1.34 (0.99-1.81)	99 (45.0)	0.98	1.57** (1.16-2.13)	30 (13.6)	0.66*	1.22 (0.80-1.87)	10 (4.6)	0.31**	0.58 (0.29-1.14)

For each area (at least one activity, one or more physical, one or more psychological and one or more work-related/financial) number, frequencies, crude and adjusted odds ratios (ORs) are shown with regard to comorbidity status (CCI)

[a] Adjusted for sex, age group and cancer diagnosis

*p<0.05

**p<0.01

Table 4 Unmet needs for rehabilitation 14 months after diagnosis as a function of comorbidity

	At least one unmet need for rehabilitation n=1,691			Physical area n=922			Emotional area n=883			Family-oriented area n=380		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	N (%)	ORcrude	ORadj[a] (95% CI)
Unmet needs, total	848 (50.2)	-	-	159 (17.3)	-	-	209 (23.7)	-	-	122 (32.1)	-	
CCI												
0	660 (49.2)	1.00	1.00	119 (16.8)	1.00	1.00	165 (22.7)	1.00	1.00	93 (30.3)	1.00	1.00
1	123 (51.5)	1.09	1.07 (0.81-1.42)	28 (19.9)	1.23	1.06 (0.66-1.71)	32 (30.8)	1.51	1.28 (0.79-2.06)	18 (39.1)	1.48	1.10 (0.55-2.20)
≥2	65 (59.1)	1.49*	1.41 (0.94-2.13)	12 (16.7)	0.99	0.84 (0.43-1.67)	12 (22.6)	0.99	0.68 (0.33-1.38)	11 (40.7)	1.58	1.11 (0.45-2.75)

	Sexual area n=454			Work-related area n=230			Financial area n=230		
	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)	n (%)	ORcrude	ORadj[a] (95% CI)
Unmet needs, total	225 (49.6)	-	-	43 (18.7)	-	-	79 (34.4)	-	-
CCI									
0	175 (48.2)	1.00	1.00	35 (17.4)	1.00	1.00	64 (34.0)	1.00	1.00
1	33 (53.2)	1.22	1.23 (0.69-2.17)	3 (13.0)	0.71	0.78 (0.21-2.90)	9 (34.6)	1.03	0.96 (0.37-2.49)
≥2	17 (58.6)	1.52	1.24 (0.54-2.86)	5 (83.3)	23.71*	10.31 (0.94-113.61)	6 (37.5)	1.16	0.54 (0.15-1.92)

For each area (at least one unmet need for rehabilitation, physical, emotional, family-oriented, sexual, work-related and financial) number, frequencies, crude and adjusted odds ratios (ORs) are shown with regard to comorbidity status (CCI)

[a] Adjusted for sex, age group and cancer diagnosis

*p<0.05

*p<0.01

Appendix A The 14-month patient questionnaire

Spørgsmål 1-8 handler om **fysiske problemer** som følge af din kræftsygdom.
Tænk på hele perioden fra du fik kræft og indtil nu.

Behov for hjælp Tænk på, hvad du har haft behov for (uanset om du fik hjælp eller ej) **I hvilken grad** gælder følgende udsagn? Sæt ét kryds på hver linje		**Slet ikke**	**I mindre grad**	**I nogen grad**	**I høj grad**
1	Jeg har haft behov for genoptræning (fx gymnastik eller fysioterapi)	☐	☐	☐	☐
2	Jeg har haft behov for hjælp til at klare daglige gøremål	☐	☐	☐	☐
3	Jeg har haft behov for råd om, hvor meget jeg fysisk måtte anstrenge mig i dagligdagen	☐	☐	☐	☐
4	Jeg har haft behov for råd om kost	☐	☐	☐	☐
5	Jeg har haft behov for råd om rygestop	☐	☐	☐	☐
6	Jeg har haft behov for professionel hjælp til fysiske problemer	☐	☐	☐	☐

Opfyldelse af behov for hjælp **I hvilken grad** gælder følgende udsagn? Sæt ét kryds på hver linje		**Slet ikke**	**I mindre grad**	**I nogen grad**	**I høj grad**	**Ikke relevant**
7	Jeg har indtil nu fået opfyldt mine behov for hjælp til fysiske problemer	☐	☐	☐	☐	☐
8	Min egen læge har sørget for, at jeg har fået hjælp til fysiske problemer	☐	☐	☐	☐	☐

Spørgsmål 9-23 handler om **følelser og meget personlige forhold** som følge af din kræftsygdom. Tænk på hele perioden fra du fik kræft og indtil nu.

Oplevede følelser eller problemer **I hvilken grad** gælder følgende udsagn? Sæt ét kryds på hver linje		**Slet ikke**	**I mindre grad**	**I nogen grad**	**I høj grad**
9	Jeg har haft perioder, hvor jeg har følt mig deprimeret	☐	☐	☐	☐
10	Jeg har haft svært ved at komme videre med livet	☐	☐	☐	☐
11	Jeg har været bange for at skulle dø af sygdommen	☐	☐	☐	☐
12	Jeg har haft skyldfølelse over for mine pårørende over at være blevet syg	☐	☐	☐	☐
13	Jeg har været bekymret for, om mine pårørende fik tilstrækkelig hjælp og støtte under min sygdom	☐	☐	☐	☐
14	Jeg har haft problemer med sexlivet	☐	☐	☐	☐
15	Jeg har haft behov for professionel hjælp til psykiske problemer	☐	☐	☐	☐
16	Jeg har haft behov for professionel hjælp til familiemæssige problemer	☐	☐	☐	☐
17	Jeg har haft behov for professionel hjælp til seksuelle problemer	☐	☐	☐	☐

Opfyldelse af behov for hjælp **I hvilken grad** gælder følgende udsagn? Sæt ét kryds på hver linje		**Slet ikke**	**I mindre grad**	**I nogen grad**	**I høj grad**	**Ikke relevant**
18	Jeg oplevede samlet set, at der blev draget passende omsorg for mine pårørende	☐	☐	☐	☐	☐
19	Jeg har indtil nu fået opfyldt mine behov for hjælp til familiemæssige problemer	☐	☐	☐	☐	☐
20	Jeg har indtil nu fået opfyldt mine behov for psykisk støtte	☐	☐	☐	☐	☐
21	Jeg har indtil nu fået opfyldt mine behov for hjælp til seksuelle problemer	☐	☐	☐	☐	☐
22	Min egen læge har hjulpet mig med at håndtere mine bekymringer i forhold til mine pårørende	☐	☐	☐	☐	☐
23	Min egen læge har sørget for, at jeg har fået psykisk støtte	☐	☐	☐	☐	☐

Spørgsmål 24-33 handler om **problemer med arbejde og økonomi** som følge af din kræftsygdom. Tænk på hele perioden fra du fik kræft og indtil nu.

Oplevede problemer og bekymringer **I hvilken grad** gælder følgende udsagn? Sæt ét kryds på hver linje		**Slet ikke**	**I mindre grad**	**I nogen grad**	**I høj grad**	**Ikke relevant**
24	Jeg har været bekymret for ikke at kunne klare mit arbejde	☐	☐	☐	☐	☐
25	Jeg har haft behov for at holde kontakten med mine arbejdskolleger	☐	☐	☐	☐	☐
26	Jeg har haft behov for professionel hjælp til at fastholde kontakten til arbejdsmarkedet (fx flexjob)	☐	☐	☐	☐	☐
27	Jeg har været bekymret for, at min sygdom ville få økonomiske konsekvenser	☐	☐	☐	☐	☐
28	Min sygdom har haft økonomiske konsekvenser, der har medført betydelige forandringer i min daglige livsførelse	☐	☐	☐	☐	☐
29	Jeg har haft behov for professionel hjælp til at håndtere de økonomiske konsekvenser af min sygdom	☐	☐	☐	☐	☐

Opfyldelse af behov for hjælp **I hvilken grad** gælder følgende udsagn? Sæt ét kryds på hver linje		**Slet ikke**	**I mindre grad**	**I nogen grad**	**I høj grad**	**Ikke relevant**
30	Jeg har indtil nu fået opfyldt mine behov for hjælp til at håndtere arbejdsmæssige problemer	☐	☐	☐	☐	☐
31	Jeg har indtil nu fået opfyldt mine behov for hjælp til at håndtere økonomiske problemer	☐	☐	☐	☐	☐
32	Min egen læge har sørget for, at jeg har fået hjælp til at håndtere arbejdsmæssige problemer	☐	☐	☐	☐	☐
33	Min egen læge har sørget for, at jeg har fået hjælp til at håndtere økonomiske problemer	☐	☐	☐	☐	☐

Det næste spørgsmål handler om, hvor du har fået hjælp til problemer, som har været en følge af din kræftsygdom. Tænk på hele perioden fra du fik kræft og indtil nu.

Tilbud

34 Har du benyttet nogle af følgende tilbud?

Sæt ét eller flere krydser

Fysioterapeut	☐
Ergoterapeut	☐
Kiropraktor	☐
Patientundervisning, fx kræftskole	☐
Rygestoprådgivning	☐
Kostvejledning hos diætist eller anden rådgiver	☐
Motion på hold, i forening eller lignende	☐
Zoneterapeut, akupunktør eller anden alternativ behandler	☐
Psykolog eller psykoterapeut	☐
Parterapeut eller sexolog	☐
Selvhjælpsgrupper eller patientforeninger	☐
Præst, kirke eller lignende	☐
Socialrådgiver	☐
Tillidsmand eller arbejdsgiver	☐
Bank- eller forsikringsrådgiver	☐
Andre tilbud	☐
Jeg har ***ikke*** anvendt nogen af ovenstående tilbud	☐

Spørgsmål 35-41 drejer sig om, hvorvidt du samlet set har fået den hjælp og støtte, du havde brug for. *Med **professionel hjælp** mener vi de tilbud, der er nævnt i spørgsmål 34.*

Opfyldelse af behov samlet set **Hvor enig er du i følgende** udsagn? Sæt ét kryds på hver linje		**Meget uenig**	**Uenig**	**Enig**	**Meget enig**	**Ved ikke**	**Ikke relevant**
35	Jeg har selv sørget for at få professionel hjælp i forløbet	☐	☐	☐	☐	☐	☐
36	De tilbud om professionel hjælp der var, passede ikke til mig	☐	☐	☐	☐	☐	☐
37	Min familie eller venner har været af stor betydning for, at jeg har fået professionel hjælp i forløbet	☐	☐	☐	☐	☐	☐
38	Min familie eller venner har i sig selv været en vigtig støtte i forløbet	☐	☐	☐	☐	☐	☐
39	Andre personer med kræft har været en vigtig støtte i forløbet	☐	☐	☐	☐	☐	☐
40	Jeg føler, der er blevet lagt en plan for, hvordan jeg bedst kommer til at leve, som før jeg fik kræft	☐	☐	☐	☐	☐	☐
41	Jeg har alt i alt haft tilstrækkelig mulighed for at få hjælp	☐	☐	☐	☐	☐	☐

Det næste spørgsmål handler ikke om selve kræftbehandlingen; men om, ***hvor*** du har fået hjælp til genoptræning og støtte til at klare din kræftsygdom.
Tænk på hele perioden fra du fik kræft og indtil nu.

Hjælp og støtte i dit forløb samlet set

42 **Hvor** har du fået hjælp og støtte?

Sæt ét eller flere krydser

Sygehus	☐
Kommune	☐
Kræftens Bekæmpelse eller anden patientforening	☐
Min egen læge	☐
Selvbetalt behandler (fx fysioterapeut, psykolog eller lignende)	☐
Alternativ behandler	☐
Andet	☐
Jeg har ***ikke*** fået hjælp og støtte nogen af ovenstående steder	☐

Har du manglet støtte til noget? (skriv)

Spørgsmål 43-55 handler om **sammenhængen i dit forløb** fra du fik din kræftsygdom og indtil nu.

Oplevelse af sammenhæng **Hvor enig er du** i følgende udsagn? Sæt ét kryds på hver linje		**Meget uenig**	**Uenig**	**Enig**	**Meget enig**	**Ved ikke**	**Ikke relevant**
43	Jeg oplevede, at samarbejdet mellem min **egen læge** og **sygehuset** fungerede tilfredsstillende	☐	☐	☐	☐	☐	☐
44	Jeg oplevede, at samarbejdet mellem min **egen læge** og **kommunen** (fx hjemmeplejen) fungerede tilfredsstillende	☐	☐	☐	☐	☐	☐
45	Jeg oplevede, at samarbejdet mellem **sygehuset** og **kommunen** (fx hjemmeplejen) fungerede tilfredsstillende	☐	☐	☐	☐	☐	☐
46	Jeg er blevet tilbudt en genoptræningsplan på sygehuset	☐	☐	☐	☐	☐	☐
47	Jeg følte mig tilstrækkeligt involveret i beslutninger, der blev taget	☐	☐	☐	☐	☐	☐
48	Jeg følte mig velinformeret om det forløb, jeg skulle igennem	☐	☐	☐	☐	☐	☐
49	Jeg oplevede, at de planer, der blev lagt for mit forløb, blev overholdt	☐	☐	☐	☐	☐	☐
50	Jeg oplevede, at min egen læge havde kendskab til, hvad der skete på sygehuset	☐	☐	☐	☐	☐	☐
51	Jeg oplevede, at min egen læge selv tilbød sin støtte	☐	☐	☐	☐	☐	☐
52	Min egen læge har støttet mig tilstrækkeligt i hele mit sygdomsforløb	☐	☐	☐	☐	☐	☐
53	Jeg vidste altid, hvem jeg kunne henvende mig til, hvis jeg havde problemer	☐	☐	☐	☐	☐	☐
54	Ind imellem har jeg ønsket, at en fagperson, fx en læge eller sygeplejerske, ville kontakte mig af sig selv (fx for at høre hvordan jeg havde det eller tilbyde sin støtte)	☐	☐	☐	☐	☐	☐
55	Jeg oplevede samlet set, at hele forløbet var veltilrettelagt	☐	☐	☐	☐	☐	☐

Spørgsmål 56-69 handler om **din vurdering af din egen læge**, når du ser tilbage på det seneste år. Hvis du har haft kontakt med flere forskellige læger, fx i et lægehus, tænk da på den læge du kender bedst.

Hvad er din vurdering af din egen læge i **de seneste 12** måneder med hensyn til … Sæt ét kryds på hver linje		**Dårlig**	**Nogenlunde**	**God**	**Meget god**	**Enestående**	**Kan ikke svare**
56	… at få dig til at føle, at der er tid til dig i konsultationen	☐	☐	☐	☐	☐	☐
57	… at vise interesse for din situation	☐	☐	☐	☐	☐	☐
58	… at gøre det let for dig at fortælle om dine problemer	☐	☐	☐	☐	☐	☐
59	… at inddrage dig i beslutninger	☐	☐	☐	☐	☐	☐
60	… at lytte til dig	☐	☐	☐	☐	☐	☐
61	… at sørge for, hurtigt at lindre dine symptomer	☐	☐	☐	☐	☐	☐
62	… at hjælpe dig til at få det så godt, at du kan udføre dine normale aktiviteter	☐	☐	☐	☐	☐	☐
63	… at være omhyggelig ved behandlingen af dine problemer	☐	☐	☐	☐	☐	☐
64	… at undersøge dig	☐	☐	☐	☐	☐	☐
65	… at forklare formålet med undersøgelser og behandlinger	☐	☐	☐	☐	☐	☐
66	… at tale med dig om dine symptomer og din sygdom, så du føler dig velinformeret	☐	☐	☐	☐	☐	☐
67	… at hjælpe dig til at håndtere dine følelser omkring dine helbredsproblemer	☐	☐	☐	☐	☐	☐
68	… at forberede dig på, hvad du kunne forvente af hospital, speciallæge eller andre behandlere	☐	☐	☐	☐	☐	☐
69	… at komme til at tale med lægen i telefonen	☐	☐	☐	☐	☐	☐

Spørgsmål 70-74 handler om **dit nuværende forhold til familie og venner**.

70 Hvor ofte træffer du familie, du ***ikke*** bor sammen med?
(sæt ét kryds)

Dagligt eller næsten dagligt	☐
Et par gange om ugen	☐
Et par gange om måneden	☐
Sjældnere end et par gange om måneden	☐
Aldrig	☐

71 Hvor ofte træffer du venner eller bekendte? (sæt ét kryds)

Dagligt eller næsten dagligt	☐
Et par gange om ugen	☐
Et par gange om måneden	☐
Sjældnere end et par gange om måneden	☐
Aldrig	☐

72 Hvis du har brug for hjælp til praktiske problemer, kan du da regne med at få hjælp fra andre? (sæt ét kryds)

Ja, helt sikkert	☐
Ja, måske	☐
Nej	☐
Ved ikke	☐

73 Sker det nogensinde, at du er alene, selvom du egentlig havde mest lyst til at være sammen med andre? (sæt ét kryds)

Nej	☐
Ja, men sjældent	☐
Ja, en gang imellem	☐
Ja, ofte	☐

74 Har du nogen, du kan betro dig til, hvis du har problemer?
(sæt ét kryds)

Nej, ingen	☐
Ja, en enkelt	☐
Ja, 2-4	☐
Ja, mange	☐

Spørgsmål 75-104 handler om **dit nuværende helbred**.

Sæt ét kryds på hver linje		**Slet ikke**	**Lidt**	**En del**	**Meget**
75	Har du nogen vanskeligheder ved at udføre anstrengende aktiviteter, som fx at bære en tung indkøbstaske eller kuffert?	☐	☐	☐	☐
76	Har du nogen vanskeligheder ved at gå en lang tur?	☐	☐	☐	☐
77	Har du nogen vanskeligheder ved at gå en kort tur udendørs?	☐	☐	☐	☐
78	Er du nødt til at ligge i sengen eller at sidde i en stol om dagen?	☐	☐	☐	☐
79	Har du brug for hjælp til at spise, tage tøj på, vaske dig eller gå på toilettet?	☐	☐	☐	☐

I den forløbne uge Sæt ét kryds på hver linje		**Slet ikke**	**Lidt**	**En del**	**Meget**
80	Var du begrænset i udførelsen af enten dit arbejde eller andre daglige aktiviteter?	☐	☐	☐	☐
81	Var du begrænset i at dyrke hobbyer eller andre fritidsaktiviteter?	☐	☐	☐	☐
82	Havde du åndenød?	☐	☐	☐	☐
83	Har du haft smerter?	☐	☐	☐	☐
84	Havde du brug for at hvile dig?	☐	☐	☐	☐
85	Har du haft svært ved at sove?	☐	☐	☐	☐
86	Har du følt dig svag?	☐	☐	☐	☐
87	Har du savnet appetit?	☐	☐	☐	☐
88	Har du haft kvalme?	☐	☐	☐	☐
89	Har du kastet op?	☐	☐	☐	☐
90	Har du haft forstoppelse?	☐	☐	☐	☐

I den forløbne uge Sæt ét kryds på hver linje		**Slet ikke**	**Lidt**	**En del**	**Meget**
91	Har du haft diarré (tynd mave)?	☐	☐	☐	☐
92	Var du træt?	☐	☐	☐	☐
93	Vanskeliggjorde smerter dine daglige aktiviteter?	☐	☐	☐	☐
94	Har du haft svært ved at koncentrere dig om ting som fx at læse avis eller se fjernsyn?	☐	☐	☐	☐
95	Følte du dig anspændt?	☐	☐	☐	☐
96	Var du bekymret?	☐	☐	☐	☐
97	Følte du dig irritabel?	☐	☐	☐	☐
98	Følte du dig deprimeret?	☐	☐	☐	☐
99	Har du haft svært ved at huske?	☐	☐	☐	☐
100	Har din fysiske tilstand eller medicinske behandling vanskeliggjort dit **familieliv**?	☐	☐	☐	☐
101	Har din fysiske tilstand eller medicinske behandling vanskeliggjort din **omgang med andre mennesker**?	☐	☐	☐	☐
102	Har din fysiske tilstand eller medicinske behandling medført **økonomiske vanskeligheder for dig**?	☐	☐	☐	☐

I de næste to spørgsmål bedes du sætte ring om det tal mellem 1 og 7, som passer bedst på dig.

103 Hvordan vil du vurdere dit **samlede helbred** i den forløbne uge?

1	2	3	4	5	6	7
Meget dårligt					Særdeles godt	

104 Hvordan vil du vurdere din **samlede livskvalitet** i den forløbne uge?

1	2	3	4	5	6	7
Meget dårlig					Særdeles god	

Spørgsmål 105-141 handler om **dine følelser i den seneste uge.**

Nedenfor er en liste af ord, som beskriver følelser. Sæt ét kryds på ***hver*** linje for at svare på, i hvilken grad du har haft denne følelse i den seneste uge.		**Slet ikke**	**En smule**	**I nogen grad**	**Ret meget**	**I meget høj grad**
105	Anspændt	☐	☐	☐	☐	☐
106	Vred	☐	☐	☐	☐	☐
107	Udkørt	☐	☐	☐	☐	☐
108	Ked af det	☐	☐	☐	☐	☐
109	Livlig	☐	☐	☐	☐	☐
110	Forvirret	☐	☐	☐	☐	☐
111	Gnaven	☐	☐	☐	☐	☐
112	Trist	☐	☐	☐	☐	☐
113	Aktiv	☐	☐	☐	☐	☐
114	Irritabel	☐	☐	☐	☐	☐
115	Tvær	☐	☐	☐	☐	☐
116	Melankolsk	☐	☐	☐	☐	☐
117	Energisk	☐	☐	☐	☐	☐
118	Håbløs	☐	☐	☐	☐	☐
119	Urolig	☐	☐	☐	☐	☐
120	Rastløs	☐	☐	☐	☐	☐
121	Ukoncentreret	☐	☐	☐	☐	☐

	Nedenfor er en liste af ord, som beskriver følelser (fortsat). Sæt ét kryds på ***hver*** linje for at svare på, i hvilken grad du har haft denne følelse i den seneste uge.	**Slet ikke**	**En smule**	**I nogen grad**	**Ret meget**	**I meget høj grad**
122	Træt	☐	☐	☐	☐	☐
123	Ærgerlig	☐	☐	☐	☐	☐
124	Modløs	☐	☐	☐	☐	☐
125	Fortørnet	☐	☐	☐	☐	☐
126	Nervøs	☐	☐	☐	☐	☐
127	Ulykkelig	☐	☐	☐	☐	☐
128	Munter	☐	☐	☐	☐	☐
129	Bitter	☐	☐	☐	☐	☐
130	Udmattet	☐	☐	☐	☐	☐
131	Bekymret	☐	☐	☐	☐	☐
132	Hjælpeløs	☐	☐	☐	☐	☐
133	Mat	☐	☐	☐	☐	☐
134	Konfus	☐	☐	☐	☐	☐
135	Rasende	☐	☐	☐	☐	☐
136	Livfuld	☐	☐	☐	☐	☐
137	Værdiløs	☐	☐	☐	☐	☐
138	Glemsom	☐	☐	☐	☐	☐
139	Livskraftig	☐	☐	☐	☐	☐
140	Usikker på ting	☐	☐	☐	☐	☐
141	Udbrændt	☐	☐	☐	☐	☐

Spørgsmål 142-159 drejer sig om din **opfattelse af helbred** i al almindelighed og ***ikke*** kun dit helbred forbundet med kræftsygdommen.

Hvor enig er du i følgende udsagn? Sæt ét kryds på hver linje		**Helt uenig**	**Overvejende uenig**	**Overvejende enig**	**Helt enig**	**Ved ikke**
142	Hvis jeg bliver syg, har jeg kræfterne til selv at blive rask igen	☐	☐	☐	☐	☐
143	Jeg har selv ansvaret for at bevare mit helbred	☐	☐	☐	☐	☐
144	Hvis noget går galt med mit helbred, er det min egen skyld	☐	☐	☐	☐	☐
145	Mit helbred afhænger af, hvor godt jeg passer på mig selv	☐	☐	☐	☐	☐
146	Når jeg bliver syg, ved jeg, at det er fordi, jeg ikke har passet godt nok på mig selv	☐	☐	☐	☐	☐
147	Ved at passe godt på mig selv kan jeg stort set holde mig rask	☐	☐	☐	☐	☐
148	Hvis jeg går til læge med jævne mellemrum, har jeg mindre risiko for at få problemer med mit helbred	☐	☐	☐	☐	☐
149	Den eneste måde, jeg kan bevare mit helbred på, er ved at gå til sundhedsvæsenet	☐	☐	☐	☐	☐
150	Andre mennesker har stor betydning for, om jeg holder mig rask	☐	☐	☐	☐	☐
151	Det er sundhedsvæsenet, der holder mig rask	☐	☐	☐	☐	☐
152	Andre menneskers behandling og omsorg er afgørende for, hvor godt jeg kommer mig efter sygdom	☐	☐	☐	☐	☐
153	For mig er den bedste måde at holde sig rask på at følge lægens råd til punkt og prikke	☐	☐	☐	☐	☐
154	Tit føler jeg, at uanset hvad jeg gør, hvis jeg skal blive syg, bliver jeg syg	☐	☐	☐	☐	☐
155	Det virker, som om mit helbred i høj grad afhænger af tilfældighedernes spil	☐	☐	☐	☐	☐
156	Når jeg er syg, må jeg lade naturen råde	☐	☐	☐	☐	☐
157	Når jeg er rask, skyldes det held	☐	☐	☐	☐	☐
158	Selv hvis jeg passer på mig selv, bliver jeg let syg	☐	☐	☐	☐	☐
159	Når jeg bliver syg, skyldes det skæbnen	☐	☐	☐	☐	☐

Spørgsmål 160-171 drejer sig om **din tro og opfattelse af meningen med livet, når du tænker på den seneste uge.**

I hvilken grad gælder følgende udsagn? Sæt ét kryds på hver linje		**Slet ikke**	**En lille smule**	**I nogen grad**	**En hel del**	**Meget**
160	Jeg føler mig fredfyldt	☐	☐	☐	☐	☐
161	Jeg har grund til at leve	☐	☐	☐	☐	☐
162	Jeg har haft et produktivt liv	☐	☐	☐	☐	☐
163	Jeg har svært ved at føle fred i sindet	☐	☐	☐	☐	☐
164	Jeg føler en mening med livet	☐	☐	☐	☐	☐
165	Jeg er i stand til at finde trøst dybt inde i mig selv	☐	☐	☐	☐	☐
166	Jeg har en følelse af indre harmoni	☐	☐	☐	☐	☐
167	Mit liv savner mening og formål	☐	☐	☐	☐	☐
168	Jeg finder trøst i min tro eller i mine åndelige overbevisninger	☐	☐	☐	☐	☐
169	Jeg finder styrke i min tro eller i mine åndelige overbevisninger	☐	☐	☐	☐	☐
170	Min sygdom har styrket min tro eller mine åndelige overbevisninger	☐	☐	☐	☐	☐
171	Jeg ved, at ligegyldigt hvad der sker med min sygdom, så vil alt være ok	☐	☐	☐	☐	☐

Har du kommentarer til spørgeskemaet eller dit forløb, er du velkommen til at skrive her:

Mange tak for hjælpen!

Læge Lise Vilstrup Holm og Læge Stinne Holm Bergholdt

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Appendix B Included cancer diagnoses

Malignant neoplasm classified according to the International Classification of Disease (ICD-10)*	
C00-C14	Malignant neoplasms of lip, oral cavity and pharynx
C15-C26	Malignant neoplasms of digestive organs
C30-C39	Malignant neoplasms of respiratory and intrathracic organs
C40-C41	Malignant neoplasms of bone and articular cartilage
C43	Malignant melanoma
C45-C49	Malignant neoplasms of mesothelial and soft tissue
C50	Malignant neoplasms of breast
C51-C58	Malignant neoplasms of female genital organs
C60-C63	Malignant neoplasms of male genital organs
C64-C68	Malignant neoplasms of urinary tract
C69-C72	Malignant neoplasms of eye, brain, and other parts of central nervous system
C73-C75	Malignant neoplasms of thyroid and other endocrine glands
C76-C80	Malignant neoplasms of ill-defined, secondary and unspecified sites
C81-C96	Malignant neoplasms, stated or presumed to be primary, of lymphoid, haematopoietic and related tissue
D37-D48	Neoplasms of uncertain or unknown behavior

*http://apps.who.int/classifications/icd10/browse/2010/en#/II