

**REHABILITATION IN CANCER SURVIVORS –  
WITH FOCUS ON PHYSICAL ACTIVITY**

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## Definitions and concepts

**Cancer survivor** is defined as “an individual is considered a cancer survivor from the time of diagnosis and through the balance of life” (National Cancer Institute 2006). This definition is adapted from the National Coalition for Cancer Survivorship and used by the National Cancer Institute in the U.S.

Within Norwegian tradition individuals getting cancer are defined as **cancer patients** from time of diagnosis until five years after diagnosis and a **cancer survivor** if they remained cancer free for a minimum of 5 years after diagnosis (Fossa *et al.* 2008c) (Ganz 2007).

In the present thesis both terms are used. When we use the term cancer patient, it corresponds to the definition of Fossa et al and Ganz (Fossa *et al.* 2008c) (Ganz 2007). And when we use the term cancer survivor it corresponds to the definition by the National Cancer Institute (National Cancer Institute 2006).

**Rehabilitation** is defined as “processes intended to enable people with disabilities to reach and maintain optimal physical, sensory, intellectual, psychological and/or social function. Rehabilitation encompasses a wide range of activities including rehabilitative medical care, physical, psychological, speech, and occupational therapy and support services” (World Health Organization 2009).

In the current thesis, rehabilitation is services offered both as single and complex rehabilitation. Single rehabilitation is services such as an exercise program, physiotherapy, psychological or nutrition counselling given by one profession. Complex rehabilitation is more than one service offered by several professions either put together in a rehabilitation program or used independently of each other.

**Cancer rehabilitation** is defined as “a process that assists the patient and their family to obtain the best possible physical, social, psychological and occupational functions with the limitations that the malignancy and its treatment cause” (Gerber & Vargo 1998).

**Late effects** refer to adverse effects which become clinically apparent months or years after end of treatment (Aziz 2007). In this thesis late effects also include long-term effects (adverse

effects beginning during the treatment and continue after end of treatment (Aziz 2007)) as suggested by Fosså and colleagues (Fossa *et al.* 2009b).

**Physical activity** is defined as “any bodily movement produced by skeletal muscles that results in energy expenditure” (Caspersen *et al.* 1985). Physical activity is a complex behavior and may occur in a variety of forms and context involving occupational, sports, household, play, work or other activities (Caspersen *et al.* 1985). **Exercise** is defined as “a subset of physical activity that is planned, structured, and repetitive and has a final or an intermediate objective to improve or maintain physical fitness” (Caspersen *et al.* 1985). In this thesis we will use both the terms physical activity and exercise.

**Exercise counselling** includes general information given to a person about physical exercise through for example a face-to-face meeting, on telephone, by a brochure, internet or videotape. **Exercise programming** represents a structured specific plan for physical exercise created around a person’s daily schedule to be completed within a defined amount of time. Such a plan might include location, type of activity, duration, frequency, intensity, who to exercise with etc.



## Summary of the thesis

The number of cancer survivors in the Western world has markedly increased over the last few decades. With the growing number of survivors, it has become relevant to address the health of cancer survivors and how to improve it. The malignancy, and more often the cancer treatment, might have negative effects upon physical and psychological aspects of the survivors' health. For those who experience such adverse effects, professional assistance in addition to their own efforts might be needed in order to reach their optimal functional level. The overriding aim of this thesis was to investigate different aspects of rehabilitation in cancer survivors, with a focus on physical activity. This was examined in three different studies (data sets) and published in four separate papers.

In *Paper I (Study A)* we examined cancer patients' needs for rehabilitation services and factors associated with such needs. In addition we identified unmet needs for rehabilitation services and factors associated with such unmet needs. More than 1300 cancer patients with the ten most prevalent cancers received a questionnaire two-three years after diagnosis. Approximately two thirds of the participants reported a need for at least one rehabilitation service. Need for physical therapy was most reported, followed by physical training and psychological counselling. Changes in employment status due to cancer and having received chemotherapy were associated with reporting needs for all rehabilitation services. Forty percent reported unmet needs, which most frequently were reported among persons living alone, who had changed their employment status due to cancer, had received chemotherapy or reported comorbidities.

In *Paper II (Study B)* we investigated the interest and preferences for exercise counselling and exercise programming among Norwegian cancer survivors and identified associated demographic and medical factors. More than 1200 cancer patients within five years after treatment, with six different diagnoses, completed a questionnaire. Overall, approximately 75% of the participants were somewhat interested in receiving exercise counselling at some point during their cancer trajectory. In men, the interest in exercise counselling was associated with younger age, presence of comorbidities, and having received chemotherapy. In women, the interest was associated with younger age, higher education and reduced physical activity level. The participants preferred face-to-face exercise counselling with an exercise specialist from a cancer center. Nine out of ten cancer survivors were somewhat interested in an

exercise program, with walking as the preferred activity, at moderate intensity, and they wanted to start exercise immediately after end of treatment.

In *Paper III (Study B)* we estimated the proportion of cancer survivors who were physically active after treatment and examined changes in activity level from before diagnosis to after end of treatment. We also identified medical and demographic factors associated with activity level and change in activity level. Almost 1000 patients, within five years after treatment, with six different diagnoses, completed the Godin Leisure-Time Exercise Questionnaire (GLTEQ). Exercise was reported before diagnosis (retrospectively) and after end of treatment (at time of survey). Less than half of the survivors were physically active after treatment. One third was active both before diagnosis and after treatment, whereas 40% were inactive at both time points. Fifteen percent were active before diagnosis but inactive after treatment, and 12% were inactive before diagnosis but active after treatment. Increasing age and weight, low education level, presence of comorbidity and smoking were associated with physical inactivity after treatment. Change in activity level from active to inactive was associated with presence of comorbidities, distant disease and smoking, while changing from being inactive to active was associated with a high education level.

In *Paper IV (Study C)* we explored the effects of a 1-week inpatient course including information, physical activity (PA) and group sessions on physical and mental health-related outcomes in prostate cancer (PCa) patients. The PCa patients (N = 51) completed a questionnaire assessing PA (GLTEQ), fatigue (Fatigue Questionnaire), mental distress (Memorial Anxiety Scale for PCa and Hospital Anxiety and Depression Scale) and quality of life (QoL) (Global QoL from The European Organisation for Research and Treatment of Cancer Core Quality of Life Questionnaire C30) one month before (T0) and three months after (T1) the course. Total fatigue, physical fatigue and PSA-anxiety decreased significantly from T0 to T1. No significant changes were observed for the other outcomes. In spite of minor reductions in levels of fatigue and PSA-anxiety, the findings indicate that a 1-week inpatient course does not influence substantially on the health-related outcomes in PCa patients three months after the course.

In conclusion, the majority of cancer survivors reported need and interest for rehabilitation services, especially physical support as physiotherapy and exercise counselling. Several

demographic and medical factors were associated with need for different rehabilitation services. Such knowledge can contribute to offer suitable rehabilitation services to specific groups of cancer survivors. In addition a significant amount reported an unmet need. Less than half of cancer survivors were physically active after treatment. In order to increase or maintain the level of PA in cancer patients, special efforts should be directed towards identified cancer survivors in risk of physical inactivity after treatment. Minor effects were observed from a 1-week inpatient course. More research is needed directed towards more homogenous group of patients with anticipated recovery capacity for documentation of effects of ongoing types of courses. The length of the interventions should also be further investigated.

## List of papers

- I. Thorsen L., Gjerset G.M., Kiserud C.E., Fosså S.D., Skovlund E., Fløtten T. and Loge J.H.: Cancer patients' need for rehabilitation services. *Acta Oncologica*, 2011; 50 (2): 212-222.
- II. Gjerset G.M., Fosså S.D., Courneya K., Jacobsen A.B., Skovlund E. and Thorsen L.: Interest and preferences for exercise counselling and programming among Norwegian cancer survivors. *European Journal of Cancer Care*, 2011; 20 (1): 96–105.
- III. Gjerset G.M., Fosså S.D., Courneya K., Skovlund E. and Thorsen L.: Exercise behavior in cancer survivors and associated factors. *Journal of Cancer Survivorship*, 2011; 5 (1):35-43.
- IV. Gjerset G.M., Fosså S.D., Dahl A.A., Loge J.H., Ensby T. and Thorsen L.: Effects of a 1-week inpatient course including information, physical activity, and group sessions for prostate cancer patients. *Journal of Cancer Education*, published online 31<sup>st</sup> of May 2011, DOI 10.1007/s13187-011-0245-8.

## 1.0 Introduction

The number of cancer survivors in the Western world has increased over the last few decades and is steadily increasing (Cancer Registry of Norway 2009). Estimates from the National Cancer Institute show that there are approximately 12 million cancer survivors in the United States (National Cancer Institute 2011). By the end of 2008 more than 190.000 persons were alive in Norway after having a cancer diagnosis (Cancer Registry of Norway 2009). This increasing number of cancer survivors is explained by the growing cancer incidence, improved diagnostics and the use of more effective treatment (Cancer Registry of Norway 2009). Approximately 65% of cancer patients in the Western world live for more than five years after their diagnosis (Cancer Registry of Norway 2009) (Horner *et al.* 2009).

Despite the success in improvement of survival rates, many cancer survivors experience both physical and psychosocial late effects due to the malignancy itself and/or the cancer treatment (Fossa *et al.* 2008c) (Ganz 2009). Late effects are diverse and include among others fatigue, impaired physical function, mental distress, lymphedema, weight changes, cardiovascular diseases, second cancers and various localized symptoms such as incontinence (Aziz 2007) (Baker *et al.* 2005) (Minton & Stone 2008) (Ness *et al.* 2006). For those experiencing late effects it can be hard to reach their optimal health and quality of life (QoL). The need for professional assistance in order to deal with these problems will, however, vary depending on the severity of the late effects, as well as the type of late effects and their duration. The individual's ability on how to cope with the late effects will also be of significance for the assistance needed. Some will manage to get through the cancer experience on their own or with help from family and friends. Some patients will need a complex set of rehabilitation services in case of multiple or complex late effects. For others with only one specific late effect, support from one profession can be sufficient assistance.

Over the last years, there has been an increasing focus on identifying effective rehabilitation strategies that would help cancer survivors to deal with individual problems. Rehabilitation after cancer is regarded as a relatively new area within oncology and we therefore lack sufficient empirical documentation of needs and effects of different programs. Knowledge is still limited on which patients that are in need of rehabilitation services and how to make suitable and effective interventions, as to

content, target groups, timing, location, duration and effect. We believe that with more knowledge in this field, rehabilitation services could be optimized and resources could be allocated more efficiently.

This thesis contains different aspects of rehabilitation of cancer survivors. We explore the needs for different rehabilitation services and factors associated with these needs. We assess the level of physical activity (LPA) in cancer survivors after treatment and examine the changes in LPA from before diagnosis to after treatment in order to identify patients with risk for inactivity. We finally investigated the effects of a 1-week course for prostate cancer (PCa) patients.

## 2.0 Background

### 2.1 Cancer epidemiology, cancer treatment and late effects

Cancer can emerge in almost every tissue in the human body and each cancer type has a unique feature which results in different traits of the malignancies (Adami *et al.* 2002). The characteristics of the cellular malignancy are uncontrolled cell division, lack of differentiation, abnormal length of life, and ability to invade and spread (Levitt *et al.* 1980). A malignant tumor gradually invades an organ, a system or an organism in whole (DeVita *et al.* 2011).

The annual number of cancer cases is increasing and this increase is expected to continue (Boyle & Levin 2008). The increasing incidence is mainly due to the fact that the risk of cancer increases with increasing age and life expectancy, secondly by improved screening and diagnostic measures, and thirdly by an increasing number of persons being exposed to unfavourable environmental factors, including lifestyle factors such as smoking, physical inactivity, unhealthy diet and overweight (Boyle & Levin 2008). In 2008, more than 26 000 individuals were diagnosed with cancer in Norway, slightly more men than women. The most common types of cancer are breast cancer, PCa, colo-rectal cancer and lung cancer, covering almost half of all new cancer cases in Norway (Cancer Registry of Norway 2009).

The major modalities of cancer treatments are surgery, radiotherapy, chemotherapy and hormone therapy, separately or in combinations (Fossa *et al.* 2009a) (Kåresen & Wist 2000). New treatment modalities have emerged the recent decades as targeted therapy or immunotherapy (Fossa *et al.* 2009a). More than half of cancer patients undergo surgery and about half of cancer patients receive radiotherapy at least once in their cancer trajectory (Fossa *et al.* 2009a) (Schroeder 2007). A number of factors are considered when type of treatment and combinations of modalities are chosen for the individual patient, involving cancer type and stage, patient's age and health status, expected sensitivity to each of the mentioned treatment modalities, the risk of acute and late effects and patient's own wishes (Fossa *et al.* 2009a) (Nome 2001).

Cancer itself and cancer treatment may lead to short-term and late effects, affecting both physical and psychosocial aspects of the patients' lives (Minton & Stone 2008) (Ness *et al.* 2006) (Peuckmann *et al.* 2009). Acute adverse effects such as nausea, vomiting, weight loss and fatigue generally develop during treatment and for most they gradually diminish after end of treatment.

Late effects such as reduced physical health including cardio-respiratory capacity and muscle strength, poorer psychological health in terms of depression and anxiety, and fatigue are well known among cancer patients both during cancer treatment and may for some last for several months or even years after end of treatment (Baker *et al.* 2005) (Minton & Stone 2008) (Ness *et al.* 2006) (Fig. 1). Cancer and its treatment might directly and/or through these late effects negatively affect several domains such as the patients’ work situation, family situation and social function, in term of reduced work-ability and early retirement, strain on the families and reduced social functioning. Furthermore, many patients experience an overall reduced health-related QoL (Loge *et al.* 1999b) (Montazeri *et al.* 2008) (Vistad *et al.* 2006). All these impairments can potentially be improved by rehabilitative interventions as for example rehabilitative medical care, physical therapy, psychological therapy, speech therapy, occupational therapy and support services as proposed in WHO’s definition of rehabilitation (World Health Organization 2009).

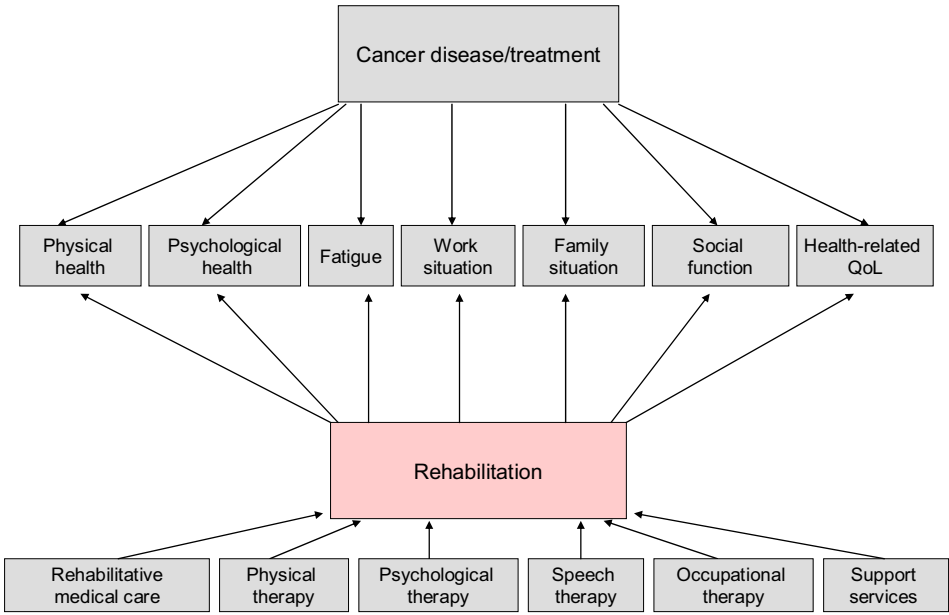


Figure 1. Domains of late effects after cancer and cancer treatment, and possible rehabilitation areas.

Below is a brief overview of the late effects after treatment most relevant for this thesis.



### *Physical health*

Cancer and its treatment often include long periods of inactivity accompanied by reduced physical health, which includes impaired cardiorespiratory capacity, muscle strength and range of motion (Courneya 2003). These can all influence on the ability to carry out daily life activities and other work-related or leisure-time activities (Stevinson *et al.* 2007a). In a National Health and Nutrition Examination Survey of 279 cancer survivors assessed less than 5 years since diagnosis, 434 long-term cancer survivors assessed 5 years or more since diagnosis and 9370 controls, a higher percentage of physical performance limitations were reported both among the recent cancer survivors (54%) and among the long-term cancer survivors (53%) compared to controls (21%) (Ness *et al.* 2006). Both groups of cancer survivors showed limited ability to complete tasks that required either sustained muscle activities such as walking a certain distance or standing up for a long period, or tasks that required large whole body movements such as bending, lifting and moving from sitting to standing position (Ness *et al.* 2006). The risk of experiencing physical performance limitations was 80% higher for recent cancer survivors and 50% higher for long-term cancer survivors compared to those with no history of cancer. Also the ability to perform daily tasks or activities related to self-care, home management, work, community and leisure was reduced among 30% of the cancer survivor groups compared to 13% in the controls (Ness *et al.* 2006).

In a cross-sectional case-control study, 256 breast cancer survivors were examined approximately 4 years after surgery (Nesvold *et al.* 2010). On the background of both objective examination and self-report, one third of the women had arm/shoulder problems. Arm/shoulder problems were associated with minimal physical activity (PA) and impaired physical QoL (Nesvold *et al.* 2010).

Men undertaking androgen deprivation therapy (ADT) had significantly reduced muscle strength both in upper- and lower body, as well as reduced functional performance assessed by walk-tests and repeated rise from a chair compared to healthy controls (Galvao *et al.* 2009). Galvao and colleagues also found that reduced strength was associated with reduced physical function (Galvao *et al.* 2009). Inactivity and cancer treatment (hormone therapy and chemotherapy) also negatively impacted upon body composition, in terms of an increased body mass index (BMI) and body fat mass, and a decrease in lean body mass (Berruti *et al.* 2002) (Galvao *et al.* 2009) (Chlebowski *et al.* 2002) (Partridge *et al.* 2001).

### *Psychological health*

Along the course of cancer, many patients will experience psychological distress reactions (Loge 2009). Psychological distress includes feelings such as increased tension, anxiety, depressed mood associated with the experience of physical or mental stressors (Holland 1997).

Psychological distress both includes normal reactions and psychiatric disorders such as depression. The most commonly experienced psychological symptoms are anxiety and/or depression symptoms (Loge 2009). A review stated that the prevalence of depression among breast cancer survivors varied from 5% to 30% (Fann *et al.* 2008). However, the authors pointed to the uncertainty of the findings related to differences in populations, design, timing, definition and measures in the included trials (Fann *et al.* 2008). In a large sample (n = 4496) of 14 different cancer diagnoses, overall one third reported psychological distress (Zabora *et al.* 2001). Lung cancer survivors had the highest prevalence with 43%, while gynecological cancer survivors had the lowest with 30% (Zabora *et al.* 2001). Another study among women diagnosed with breast cancer approximately one third reported having psychological distress; 38% reported having anxiety and 22% reported having depression (Vahdaninia *et al.* 2010). Some patients will experience psychological distress for several years after diagnosis. For example, long-term survivors of testicular cancer had a significantly higher level of anxiety than controls from the general population, while there was no difference in level of depression between the two groups (Dahl *et al.* 2005).

### *Fatigue*

Fatigue in cancer patients is common and can be experienced at all stages of the cancer trajectory (Minton & Stone 2009). Fatigue is one of the most frequently reported adverse effects during treatment and such fatigue is called acute fatigue (Wagner & Cella 2004). For some patients, fatigue persists for several months and even years after end of treatment and is then called chronic fatigue if duration is 6 months or more (Ganz & Bower 2007). One definition of cancer related fatigue is: “persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning” (www.nccn.org). Fatigue affects the patients’ ability to perform normal daily activities and is not relieved by sleep and rest (Bardwell & Ancoli-Israel 2008). One quarter of PCa survivors reported to be fatigued after discontinuing hormone therapy treatment, while 40% of the men with ongoing hormone therapy treatment reported to be fatigued (Kyrдалen *et al.* 2010). Research on breast cancer survivors has shown that about 20-35% reported significant fatigue (Bower *et al.* 2006) (Nieboer *et al.* 2005) (Reinertsen *et al.* 2010). Prolonged follow-up in breast cancer survivors has shown that approximately one third

reported fatigue as long as 5-10 years after diagnosis (Bower *et al.* 2006) (Reinertsen *et al.* 2010). In long-term survivors of Hodgkin's lymphoma and cervical cancer the prevalence of chronic fatigue was 30%, compared to approximately 11-13% in the general population (Hjermstad *et al.* 2005) (Vistad *et al.* 2007). Other studies of Hodgkin's lymphoma survivors have confirmed the elevated levels of fatigue compared to general population (Loge *et al.* 1999a) (Ruffer *et al.* 2003). Factors that are found to be associated with fatigue are psychological distress, pain, type of treatment and high BMI (Bower *et al.* 2006) (Nieboer *et al.* 2005) (Reinertsen *et al.* 2010) (Vistad *et al.* 2007).

### *Health-related quality of life*

QoL is defined as a multidimensional concept that refers to an individual's usual physical, emotional and social well-being (Cella & Tulsky 1993). It is subjective and is therefore most reliably measured by asking the patients themselves (Cella & Tulsky 1993). Standardized questionnaires are therefore used to measure QoL among cancer patients. In a review, long-term cancer survivors of cervical cancer reported poorer QoL compared to the general population (Vistad *et al.* 2006). Also survivors of Hodgkin's lymphoma scored significantly lower QoL than the general population in the following scales; general health, physical functioning, role limitations, and vitality (Loge *et al.* 1999b). In a prospective study of breast cancer patients, a significant reduction was found in global QoL from before diagnosis to one year after end of treatment (Montazeri *et al.* 2008).

## **2.2 Cancer rehabilitation**

In certain areas of medicine such as rheumatology, traumatology, cardiology and neurology, rehabilitation has been well established for years. The rehabilitation within these areas has a relatively specific content related to limitations of functions in each particular group of patients. As an example, national guidelines for rehabilitation of patients with stroke are available (Indredavik *et al.* 2010) and rehabilitation for cardiac patients is well documented (Perk *et al.* 2007). Also, evidence-based exercise guidelines are available for chronic illnesses such as cardiovascular diseases (Thompson *et al.* 2003), type II diabetes (Sigal *et al.* 2006) and psychiatric diseases (Meyer & Brooks 2000), and physical exercise is often part of the routine in rehabilitation of these patients. Rehabilitation of cancer patients is a rather new area and there is a lack of guidelines on how the rehabilitation should be performed. Further, the cancer patients' functional limitations are probably more diverse and often less specific for

each diagnostic group than in the other medical disciplines mentioned. This makes it more challenging to design rehabilitation programs within each diagnostic group. However, there are some exceptions to this such as need for physical therapy after surgery for sarcomas.

In general, most cancer patients will cope with their situation and regain their health by own efforts eventually supported by their own network and resources such as partner, family, friends and colleagues (Johansen 2007). However, because of persistent distress or severe physical impairments some patients need professional assistance to obtain their optimal level of health and functioning. Rehabilitation efforts to cancer patients often incorporates a broad variety of services like information and counselling, lifestyle changes such as PA or diet changes, psychological support, social welfare support and training of coping strategies among others (Johansen 2007).

Optimally provided rehabilitation can include one or several health care personnel such as physiotherapists, physical trainers, psychologists, recreational therapists, social workers, occupational therapists, rehabilitation nurses or nutritionists (Juvet *et al.* 2009). For some patients with a single problem one type of rehabilitation service (single rehabilitation) might be sufficient. For example, patients with lymphedema after radiotherapy or surgery may need assistance from a physical therapist specialized on lymphedema, or consultations with a physical trainer can guide a PCa patient having problems with reduced muscle mass and muscle strength as a consequence of hormone therapy. These single services can be offered at hospitals cancer centers or at a community level.

Other patients experience several late effects or late effects of a character or intensity that call for a more complex rehabilitation effort. In such cases, multiple rehabilitation services (complex rehabilitation) can be required in order to reach optimal functioning. In such cases the need for rehabilitation can include combined assistance from different professionals such as physical trainers for problems regarding physical impairments, social workers for problems related to the work situation and psychologists for mental distress related to coping with the cancer experience. Complex rehabilitation can be organized as different rehabilitation services assisting the patient independent of each other or by a multidisciplinary team organized as inpatient or outpatient programs. Inpatient rehabilitation involves the patient living at the rehabilitation center for a specified period of time. Outpatient rehabilitation implies that the participants stay at home and participate in e.g. bi-weekly sessions in the city where the services are delivered.

In some patients the rehabilitation starts during the treatment period, but in other cases the patient is too affected by the treatment, bedridden and in need of assistance for daily activities. In other cases, the late effects first become noticeable months or years after end of treatment creating a need for rehabilitation at that time.

#### *Cancer rehabilitation in Nordic and North-Europe countries*

Rehabilitation programs provided in the Nordic and North-European countries are mainly based upon a similar understanding of cancer rehabilitation, though the organization of the rehabilitation services differs between the countries related to the differences in health-care systems (Hellbom *et al.* 2011). In many centers in North-Europe, both outpatient and inpatient rehabilitation programs for cancer patients are performed in a group setting including psychosocial and physical aspects of rehabilitation (Hellbom *et al.* 2011).

Existing rehabilitation services for cancer patients in Norway include among others:

- ‘Teaching and coping’ centers that provide information and promote social contact between the participants, organized with one or bi-weekly sessions during a 3-4 weeks period.
- Regional hospitals offer specific rehabilitation services like physical therapy, physical training, occupational therapy, consultation with social worker or mental health personnel.
- Some hospitals also offer outpatients multidisciplinary rehabilitation programs including physical training and lectures given by different professionals such as physiotherapists, social workers and physicians often organized as weekly sessions and the courses generally last for 6-8 weeks.
- Rehabilitation- and coping courses run by the cancer societies or by community health care.
- Inpatient multidisciplinary rehabilitation programs lasting for one to four weeks have been set up at several rehabilitation centers.
- Vardesenteret, established by the Norwegian Cancer Society and Oslo University Hospital, is a place to meet where activities aiming to enhance QoL, well being and coping are offered ([www.vardesenteret.no](http://www.vardesenteret.no)).

### **2.3 Need for rehabilitation in cancer survivors**

The need for rehabilitation services and the preferred type of rehabilitation might vary among cancer patients depending on the patients' prognosis and late effects, including physical, psychological, social or emotional problems or their combinations (Fossa *et al.* 2008a). In addition, the patient's personality, coping strategies, family situation, employment status and social network might also influence the needs (Johansen 2007). As cancer is a complex disease and the impact of the malignancy and its treatment will vary between diagnostic groups, within diagnostic groups and between patients with similar disease, rehabilitation after cancer must be diverse in terms of content, timing and duration. By assessing the rehabilitation needs in cancer patients the possibility to design targeted rehabilitation services increases.

When the work of this thesis started we did not have any systematic national data on how many cancer patients utilized the rehabilitation services, who these patients were in terms of diagnosis, treatment received, comorbidities, age, gender, working status etc and for how long they used the services. Further, we did not know whether and to what degree the services actually were in accordance with the cancer patient's need for rehabilitation services.

Information on a cancer patient's physical functioning, level of mental distress level or QoL can indicate the individual's need for rehabilitation. Still, data on these aspects of the patient's health and functioning do not directly tap into the patients' perceived need for assistance. Some patients might regard poor functioning or high levels of distress as challenges they will handle themselves, while others might perceive reduced health as something they need or shall be offered professional assistance in order to improve (Cella & Tulsky 1993) (Sansone-Fisher *et al.* 2000). Information on how the patients assess their needs for rehabilitation services must therefore be addressed by direct questions. Before this thesis was initiated, no studies as far as we knew had been conducted with specified questions on needs for rehabilitation services among cancer patients, except for exercise counselling and programming, and factors associated with these needs.

### **2.3.1 Need for physical activity and psychological support**

#### *Physical activity support*

PA support and psychological support are two examples on single rehabilitation. Important elements within PA support after cancer are exercise counselling and exercise programming. To be able to design suitable PA intervention programs for cancer survivors, information is needed on their perceived needs for type of exercise counselling and programming. The availability of programs that meet the preferences of the cancer survivors would presumably increase participation in the programs.

When this thesis was initiated studies examining exercise preferences among cancer survivors had only been conducted in North-America (Jones & Courneya 2002a) (Karvinen *et al.* 2006) (Rogers *et al.* 2004) (Vallance *et al.* 2006). Results from studies of prostate, breast, colorectal, lung and Non-Hodgkin's lymphoma cancer survivors had shown that 77-84% were somewhat interested in exercise counselling (Jones & Courneya 2002a) (Vallance *et al.* 2006). The majority preferred the exercise counselling to be at a cancer center, face-to-face, and with an exercise specialist from a cancer center (Jones *et al.* 2007) (Karvinen *et al.* 2006).

In terms of exercise programs, a study of Demark-Wahnefried *et al.* including 978 cancer patients showed that more than half of the patients preferred an exercise program at the time of diagnosis or immediately thereafter (Demark-Wahnefried *et al.* 2000). Other cross-sectional studies of 386 survivors of endometrial cancer and 431 survivors of Non-Hodgkin's lymphoma reported that more than three quarters felt somewhat able and interested in participation in an exercise program, and the preferred time to start was 3-6 months after treatment (Karvinen *et al.* 2006) (Vallance *et al.* 2006). The most commonly reported activity of choice was walking (55-81%), the preferred level was moderate intensity (Jones & Courneya 2002a) (Karvinen *et al.* 2006) (Rogers *et al.* 2004) (Vallance *et al.* 2006). These studies indicate that cancer survivors are interested in exercise counselling and programming, however, there are some variations in the preferred exercise structure, exercise schedule and exercise location (Jones & Courneya 2002a; Karvinen *et al.* 2006) (Rogers *et al.* 2004) (Vallance *et al.* 2006).

Both Jones and Courneya and Vallance *et al.* found that patients who were female and had a high education level were more interested in receiving exercise counselling than those who were male and had low education (Jones & Courneya 2002a) (Vallance *et al.*

2006). Jones and Courneya also found that those who were younger and had breast cancer more frequently preferred to receive exercise counselling compared to those who were older and had another cancer diagnosis than breast cancer (Jones & Courneya 2002a). Different demographic, medical and behavioral factors were associated with specific exercise program preferences. For example; being highly educated was associated with being interested in an exercise program, these individuals preferred a moderate-to high intensity program, supervised exercise sessions, starting an exercise program before cancer treatment and exercising away from home (Jones & Courneya 2002a) (Vallance *et al.* 2006). Those who were overweight or obese or had received adjuvant treatment were less likely to participate in an exercise program compared to those who were of normal weight or had not received adjuvant treatment (Karvinen *et al.* 2006) (Vallance *et al.* 2006).

On the starting point of this thesis, we had no information on the interests and preferences for exercise counselling and programming among Norwegian cancer survivors. Due to different cultures and social structures, we did not know the relevance of other researchers' findings for the Norwegian cancer survivors. Overall, there was a lack of knowledge on specific differences in interests in exercise counselling related to diagnosis, and including several diagnoses would give us the possibility to do subgroup analyses in order to analyse for differences related to both medical and demographic factors.

### *Psychological support*

Approximately 25% of cancer patients experience psychological distress during and after cancer treatment (Strong *et al.* 2007). Most of them will experience lessen of the symptoms as time passes after end of treatment, but many will fear a relapse and experience increased symptom levels in relation to control checkups or other types of contact with the hospital (Dahl 2009). Psychological support can either be psychotherapy during a long period of time or can be help within a single consultation. At this time, there are no standards for how psychological support should be presented to patients. As possible method for doing so, could be to suggest supplementary psychological support at control checkups. Many physicians do not feel comfortable addressing patients' psychological symptoms. Also it is this type of support that most patients are hesitant or often do not express their desire for such help with their physicians (Dahl 2009). Due to the significant amount of cancer patients struggling with distress (Strong *et al.* 2007), there are reasons to believe that there is a need for psychological



services among cancer survivors. Though, experiencing increased levels of distress periodically or permanently does not imply that all want professional assistance (Sanson-Fisher *et al.* 2000). As opposed to needs for exercise counselling, we were not aware at that time of any studies asking cancer survivors directly on their perceived needs for psychological services and therefore we found that timely and relevant to investigate.

### **2.3.2 Complex rehabilitation**

Generally, little knowledge exists on the need for complex rehabilitation among cancer survivors. Still, several complex rehabilitation programs have been initiated and run in Norway during the recent years. In Norway, about 5% of all cancer patients participate in a 1-week stay at an inpatient course at the Montebello Centre of Norway (MBC) (Fossa *et al.* 2008b). Less than one third of the participants were men and the largest group represented was breast cancer patients (Fossa *et al.* 2008b). In Germany all cancer patients are offered a rehabilitation stay. However, only one third utilizes their right by law and is admitted to rehabilitation centers for on average 3-4 weeks of inpatient stay (Fossa *et al.* 2008a). This information may indicate that the need for complex rehabilitation is not very big. However, we do not know if the patients are aware of the rehabilitation programs existing or whether these programs are suitable. Additionally, differences in participation rates between different patient groups, genders and countries could indicate that we lack more precise knowledge on the cancer survivors' needs for complex rehabilitation programs.

### **2.3.3 Unmet needs for rehabilitation**

An unmet need means that a patient has a need for a specific rehabilitation service that is not covered, while an overestimated need will be rehabilitation services offered but not needed. If a need is not identified or we do not know how many need a particular service, there is a risk for too few services offered to meet the need. On the other hand, rehabilitation services might be offered to meet a need that does not exist or a need that might have already been fulfilled by existing services. The aim is to avoid imbalance of supply and demand.

Almost two thirds of breast cancer survivors, diagnosed 2-10 years before completing the questionnaires, reported at least one unmet need (Hodgkinson *et al.* 2007). Women struggling with anxiety or depression had approximately three times as many unmet needs compared to women without anxiety or depression (Hodgkinson *et al.* 2007).

At the time of the onset of this thesis, to our knowledge, only the above mentioned study had investigated the unmet needs for direct rehabilitation services. Since these data were collected in Australia we could not directly transfer them to Norway. There might be differences in relation to health status and availability of services between the two countries. In this regard we wanted to explore the unmet needs for rehabilitation.

## **2.4 Physical activity behavior**

### *Level of physical activity*

Generally, PA is a central component in a healthy lifestyle. The World Health Organization estimates that 1.9 million deaths per year worldwide are associated to physical inactivity (Blair & Brodney 1999) (World Health Organization 2004). PA has shown to be effective not only in prevention of diseases, but also in treatment and as an important part in rehabilitation of several somatic diseases and mental disorders (Pedersen & Saltin 2006). Studies have also showed beneficial effects of PA during and after cancer treatment in cancer patients (Knols *et al.* 2005) (McNeely *et al.* 2006) (Speck *et al.* 2010) (Schmitz *et al.* 2010) (Schmitz *et al.* 2005). In a recent meta-analysis, Speck and colleagues conclude that there is a positive effect of physical exercise on aerobic fitness, body strengths, LPA, functional QoL, body weight, self-esteem and anxiety in cancer patients during treatment (Speck *et al.* 2010). An extensive supervised exercise intervention involving high intensity has shown to be beneficial for cancer patients undergoing chemotherapy in terms of reduced fatigue, improved vitality, aerobic capacity, muscular strength, physical and functional activity and emotion wellbeing (Adamsen *et al.* 2009). After treatment, convincing results have shown that physical exercise has a positive effect on body strength, breast cancer-specific concerns, fatigue, QoL, aerobic fitness, LPA, symptoms and side-effects (Speck *et al.* 2010). Also, results from observational studies have shown that PA was correlated with a decreased risk of recurrence and/or death from breast cancer and colon cancer (Haydon *et al.* 2006) (Holick *et al.* 2008) (Pierce *et al.* 2007).

In order to reduce possible late effects of cancer treatment and to rebuild physical and mental function, one goal should be to increase the LPA in cancer survivors. Identifying those who are inactive is important in order to increase their LPA. It is important to be active at a certain level to achieve desired effects. Exercise recommendations are intended to identify the minimum LPA required for achieving or maintaining good health. Guidelines for PA have

changed over time and are sequentially modified as new knowledge is gained. There are also differences in public health exercise guidelines between countries. In 2007, The American College of Sports Medicine and the American Heart Association recommended at least 30 minutes 5 times per week (150 minutes a week) of moderate intensity or 60 minutes of vigorous intensity per week (Haskell *et al.* 2007). In 2008, U.S. Department of Health and Human Services published new guidelines in which a minimum of 150 minutes weekly activity of moderate-intensity exercise (not exhausting, light perspiration) or 75 minutes of vigorous-intensity exercise (rapid heart beats, sweating) or an equivalent combination were recommended (U.S. Department of Health and Human Services 2008). Slightly different from these, The Norwegian health authorities recommend at least 30 minutes of moderate- and/or high-intensity exercise every day (210 minutes per week) to maintain health for healthy adults (Norwegian Directorate of Health 2005). Besides these recommendations, there are few specific exercise guidelines for cancer survivors.

Despite well documented benefits of exercise in cancer patients, the majority of cancer survivors do not meet public health exercise guidelines (Courneya *et al.* 2005) (Karvinen *et al.* 2007a) (Lynch *et al.* 2007) (Milne *et al.* 2007) (Stevinson *et al.* 2007b) (Vallance *et al.* 2005). These studies showed that the prevalence of cancer survivors meeting exercise guidelines after treatment ranged from approximately 25% to 30% in survivors of Non-Hodgkin's lymphoma (Vallance *et al.* 2005), endometrial cancer (Courneya *et al.* 2005), breast cancer (Milne *et al.* 2007), ovarian cancer (Stevinson *et al.* 2007b), colorectal cancer (Lynch *et al.* 2007) and in bladder cancer (Karvinen *et al.* 2007a). A higher number of those physically active were found in PCa survivors where 50% reported to be active (Demark-Wahnefried *et al.* 2004). In the general population 60% reported to be sufficiently active in Western Australia (Rosenberg *et al.* 2010) and 49% in the U.S. (Centers for Disease control and prevention 2007), indicating that the numbers of active cancer survivors are lower compared to the general population in these countries.

In order to characterize those who are physically active and those who are physically inactive after treatment, related medical and demographic variables are of interest. A study of 386 survivors of endometrial cancer showed that those meeting exercise guidelines were more likely to have a normal weight and less likely to be overweight or obese compared to those who were not meeting exercise guidelines (Courneya *et al.* 2005). Another study of 2819 breast cancer survivors observed a negative correlation between LPA and BMI (Hong *et al.*

2007). Additionally, a third study found an association between meeting exercise guidelines and having a healthy BMI in 1996 colorectal cancer survivors (Lynch *et al.* 2007). Further, Lynch *et al.* described associations between meeting exercise guidelines and being male, having a high education, not smoking and having only had surgery as treatment (Lynch *et al.* 2007). Among long-term survivors of Hodgkin's lymphoma being physically active was associated with a higher level of education, younger age and non-smoking (Oldervoll *et al.* 2007).

#### *Change in level of physical activity*

Another aspect of interest is the change in LPA during the cancer trajectory. The change in LPA will give us information on the prevalence of patients who reduce, stay stable or increase their LPA. Previous studies have indicated that about 30-55% of cancer survivors who were active before diagnosis did not return to their pre-diagnosis LPA (Blanchard *et al.* 2003) (Irwin *et al.* 2003). In the latter study, Irwin *et al.* demonstrated that in their survey with over 800 breast cancer survivors 4-12 months postdiagnosis, overall LPA decreased by 2 hours (Irwin *et al.* 2003). In two studies investigating the change in exercise across the cancer experience, Courneya and Friedenreich found that colorectal cancer survivors (n = 130) and breast cancer survivors (n = 167) did not return to their pre-diagnosis LPA after treatment, within 4 and 2 years after diagnosis, respectively (Courneya & Friedenreich 1997a) (Courneya & Friedenreich 1997b). A reason for this could be the long and intensive treatment period which makes it difficult to regain LPA or that exercise is hard to prioritize in such a situation. PA behavior change is a big challenge in any population but especially tough among people with chronic diseases such as cancer (Courneya *et al.* 2007). However, some studies have shown opposite results, where the participants reported higher LPA after treatment than before diagnosis (Demark-Wahnefried *et al.* 2000) (Hounshell *et al.* 2001). Another study showed no difference in LPA comparing pre-diagnosis and after treatment levels (Pinto *et al.* 2002). The variation in results between studies could be a result of methodological differences such as different measures of LPA or differences in study participation, time since diagnosis and cancer differences etc.

In order to characterize those who reduce their LPA or those who increase their LPA from before diagnosis to after treatment, associated medical and demographic variables are of interest. With such knowledge identifying those in need for PA support is possible. Factors associated with change in LPA have received limited attention. However, Lynch and

colleagues found that being female, having a low level of education and having received adjuvant therapy compared to surgery alone were associated with a decrease in LPA from pre-diagnosis to post-treatment among colorectal cancer patients (Lynch *et al.* 2007).

At the onset of the current thesis there were some studies done on LPA after cancer treatment and medical and demographic factors associated with being active or not (Courneya *et al.* 2005) (Hong *et al.* 2007) (Lynch *et al.* 2007) (Oldervoll *et al.* 2007). Few studies were performed investigating the changes in LPA from before diagnosis to after treatment, and only one study as far as we know had looked into the medical and demographic factors associated with the change in LPA (Lynch *et al.* 2007). Also, as far as we know, no Norwegian data on change in PA behavior within 5 years after end of cancer treatment were available.

## **2.5 Effects of rehabilitation programs**

Fosså and colleagues looked at satisfaction of courses in a sample of more than 10 000 patients, and found that the majority of the participants report that they are highly satisfied with their content (Fossa *et al.* 2008b). A Swedish study compared the participants' satisfaction of three different 7-week outpatient rehabilitation programs in PCa patients: including only physical training, only information or a combination of physical training and information. The patients preferred the combined program (Berglund *et al.* 2003). Although, estimates of participants' satisfaction are important, evidence of effects on health outcomes is also highly relevant in the evaluation of rehabilitation services.

Before this thesis was initiated, the effects of PA interventions had been tested rather extensively in cancer patients (Schmitz *et al.* 2010). In contrast to these studies, less research had been published on the health effects of PA in combination with other elements in complex rehabilitation programs for cancer patients, either organized as inpatient or outpatient programs.

### *Inpatient programs*

A longitudinal non-randomized intervention study evaluated a 3-4 weeks complex inpatient rehabilitation program for breast cancer patients by assessing QoL, anxiety and depression at three time points (Heim *et al.* 2001). More than half of the patients were less than 8 months from diagnosis to the beginning of the rehabilitation. The program consisted of one or more of

the following activities: physiotherapy, aerobic exercise training, physical therapy, psychosocial counselling and therapy. The 183 participants improved significantly in different functional dimensions of QoL and anxiety both at the end of the program and after 3 months. Depression was significantly improved only at the end of the program. Participants who were severely distressed and had multiple somatic problems were those who benefited most from the rehabilitation program (Heim *et al.* 2001).

### *Outpatients programs*

A research group from Netherlands looked into the effect of a 12-weeks non-randomized outpatient rehabilitation program consisting of physical training combined with psycho-education. The participants improved significantly in QoL (Korstjens *et al.* 2006). Courneya and colleagues found that a combination of an outpatients, 10-week, physical exercise program and group psychotherapy significantly improved the QoL in cancer survivors beyond the effects of group psychotherapy alone (Courneya *et al.* 2003). A randomized controlled study among 55 breast cancer women investigated the effects of a 10-week (three times per week) comprehensive outpatient rehabilitation, including psycho-education, PA and support group activity (Cho *et al.* 2006). The intervention group had a significantly higher improvement in QoL, psychological adjustment and motion of the shoulder compared to the control group (Cho *et al.* 2006).

In spite of these promising findings, there was a scarcity of systematically collected data on participation and effects of complex rehabilitation. Further, the samples were relatively small and collected in specific groups, thus limiting their generalization. At the onset of this thesis, we could only identify one study that had investigated the effect of an inpatients rehabilitation program. This study had tested the effects of a 4-week program. It was therefore open to question whether a shorter duration would show similar beneficial effects. So far there is no conclusive evidence that longer programs are more beneficial than short ones. This is highly relevant since longer lasting programs are expensive to run and also more demanding for the participants in term of time spent away from home and work.

### 3.0 Aims of the thesis

The overall aim of this thesis was to investigate different aspects of rehabilitation in cancer survivors. We explored the needs for different rehabilitation services and factors associated with these needs, we assessed the LPA after treatment and the changes in LPA in cancer survivors from before diagnosis to after treatment. We further analyzed the effects of an information course. The specific study aims were as follows:

#### Study A: (Paper I):

- To assess the percentage of cancer survivors who report a need for seven different rehabilitation services and to explore demographic and medical factors associated with these needs
- To estimate the need for complex rehabilitation and to explore associated factors
- To assess unmet needs for rehabilitation services and to explore factors associated with unmet needs

*Hypothesis:* Based on knowledge on late effects after cancer, we hypothesized that the majority of cancer patients are in need of one or several rehabilitation services. Compared to other diagnoses we hypothesized that breast cancer patients will more frequently report need for physical therapy due to arm function limitation and lymphedema. Intensive cancer treatment will increase the need for complex rehabilitation based on the potentially higher prevalence of several late effects after such treatments. In addition comorbidities will increase the need for complex rehabilitation services. We also hypothesize that a low educational level, increasing age and living alone also will increase the need for one or several rehabilitation services.

#### Study B: (Paper II and Paper III):

- To investigate the interest and preferences for exercise counselling and exercise programming among Norwegian cancer survivors (Paper II)
- To identify demographic and medical factors associated with interest in exercise counselling (Paper II)

*Hypothesis:* We hypothesized that more than 50% of all cancer survivors will express interest in such exercise counselling. Interest in exercise counselling will be more frequently reported among younger survivors compared to older survivors and among higher educated compare with lower educated survivors.

- To estimate the proportion of physically active cancer survivors and to assess the percentage of individuals who change their LPA from before diagnosis to after treatment (Paper III)
- To identify demographic and medical factors associated with LPA after treatment and changes of LPA from before diagnosis to after treatment (Paper III)

*Hypothesis:* At least one quarter of Norwegian cancer survivors will be physically active and about one third of cancer survivors will report a lower LPA after treatment than before diagnosis based on previous findings in groups of cancer survivors. Age, weight, education, comorbidity and smoking, treatment or extent of the disease will be associated with LPA and its changes from before diagnosis to after treatment.

Study C: (Paper IV):

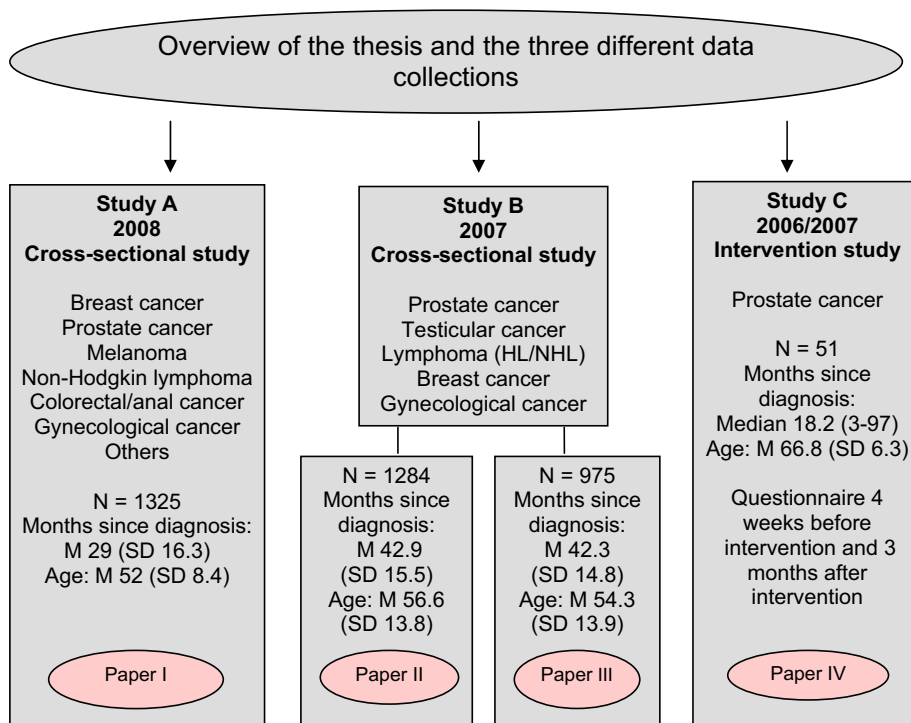
- To explore the effects of a PCa specific course on LPA, fatigue, mental distress and global quality of life three months after the course
- To assess the patients' satisfaction with the course

*Hypothesis:* A 1-week inpatient course will result in significant increase of LPA and health-related outcomes in PCa patients as evaluated three months after the course compared to baseline.



## 4.0 Materials and methods

The thesis utilizes data collected through two separate cross-sectional studies and one intervention study (Fig. 2).



Figur 2. Overview of the thesis and the three different data collections

### 4.1 Design, study population and procedure

#### 4.1.1 Study A: Cancer patients' needs for rehabilitation services (Paper I)

In 2008, an extensive survey of cancer patients' work and socio-economic situation was conducted by Fafo Research Foundation (Fafo) (Fløtten *et al.* 2008). Fafo is an independent foundation that conducts scientific work in the field of employment, welfare policy and living conditions, both nationally and internationally ([www.faf.no](http://www.faf.no)). This thesis only deals with the

one part of the cross-sectional survey, the need for rehabilitation services, as explored in the Fafo survey.

Eligible patients were identified through the Cancer Registry of Norway (CRN) in 2008. Inclusion criteria were: cancer patients aged 25-60 years, diagnosed with first cancer in 2005/2006 with one of the ten most frequent types of cancer within each gender in Norway (breast-, prostate-, colorectal/anal-, cervical/corpus-, fallopian tube/ovarian-, lung- and testicular cancer, melanoma, Non-Hodgkin's lymphoma, leukemia, tumor in bladder/urethra, nerve system and thyroid) and having a current address in Norway. Active disease or currently receiving cancer treatment were not exclusion criteria. Patients were excluded if one or more of the following criteria were present: 1) being unaware of having cancer, 2) being in such a medical condition that it was considered unethical to ask the patients to complete the questionnaire (i.e. very advanced or terminal disease), 3) mental retardation, reduced cognitive function or a diagnosis of major psychiatric disorder. To ensure geographical representativeness, the patients should have had their initial treatment at one of four hospitals located in different health regions of the country. After identification at the CRN, each hospital received a list of patients who had been treated at that particular hospital and all patients were contacted via this hospital. The eligible patients received a questionnaire together with the invitation letter. All answers were anonymous and reminders were therefore not sent.

The CRN identified 2848 eligible patients. According to exclusion criteria, 346 were excluded. Thereafter, 2502 questionnaires were sent out. Twenty-nine questionnaires were returned due to invalid address and seven were returned because of death or by individuals reporting not to have had cancer. From the remaining 2466 eligible patients 1325 completed questionnaires were returned, yielding a response rate of 54% (1325 of 2466) (Fig. 3)

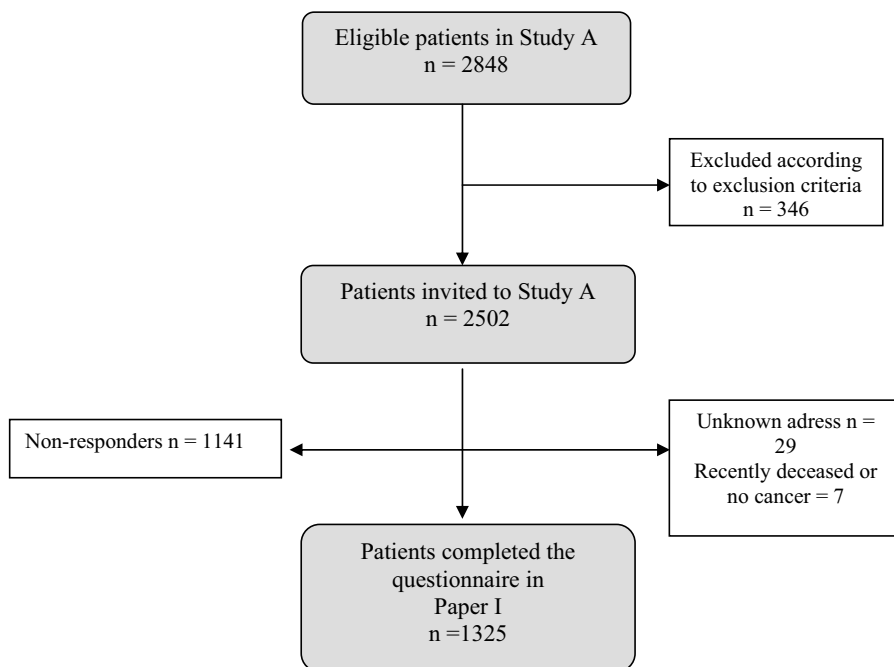


Figure 3. Flow chart of Study A (Paper I)

#### 4.1.2 Study B: Interest and preferences for exercise counselling and programming among Norwegian cancer survivors (Paper II) and Exercise behavior in cancer survivors and associated factors (Paper III)

Paper II and Paper III are based on a cross sectional study. Between February 2007 and September 2007 a survey concerning PA was conducted among cancer patients with six different diagnoses who had received treatment at The Norwegian Radium Hospital (NRH) (Oslo University Hospital) from 01.01.2002 to 31.12.2005. Patients included were aged between 18 and 75 years when first admitted at NRH, they had received curatively intended treatment for testicular cancer, breast cancer, ovarian cancer, cervical cancer, PCa or malignant lymphoma (Hodgkin's or Non-Hodgkin's). Primary treatment (+/- surgery, +/- radiotherapy, +/- chemotherapy or +/- hormone therapy) was finished (except for hormone therapy) ½ - 4 ½ years before receiving the questionnaire. Consecutive eligible patients were identified from NRH's patient registry, with a few exceptions as follows. Only a random third of the breast cancer patients were selected because of the large number in this group. To avoid overlap with an

ongoing study at the hospital, prostate patients were only identified in a time period of two years from 01.01.2002 to 31.12.2003. Patients with active disease registered in the medical databases at the time of survey were excluded, with exception of testicular cancer and malignant lymphoma. Because of the high survival in these two groups, despite metastasis at time of diagnosis, they were not excluded.

A questionnaire package, consisting of an information letter, a consent form, a questionnaire with instructions and a pre-paid return envelope, was mailed to 2024 patients. A follow-up reminder was sent to non-responders after four weeks. Forty-three envelopes were returned unopened (19 people had moved to unknown addresses and 24 were recently deceased). Of the 1981 eligible participants, 1356 returned the questionnaire. Of these, 72 individuals were subsequently excluded because of recurrence at time of survey according to the medical database. This resulted in a number of 1284 participants and a response rate of 67% in Paper II (1284 of 1909). Due to missing responses on LPA before diagnosis (retrospectively assessed) and/or after treatment (at time of survey), only a number of 975 analyzable participants were available in Paper III. The resulting response rate was thus 51% (975 of 1909) (Fig. 4).

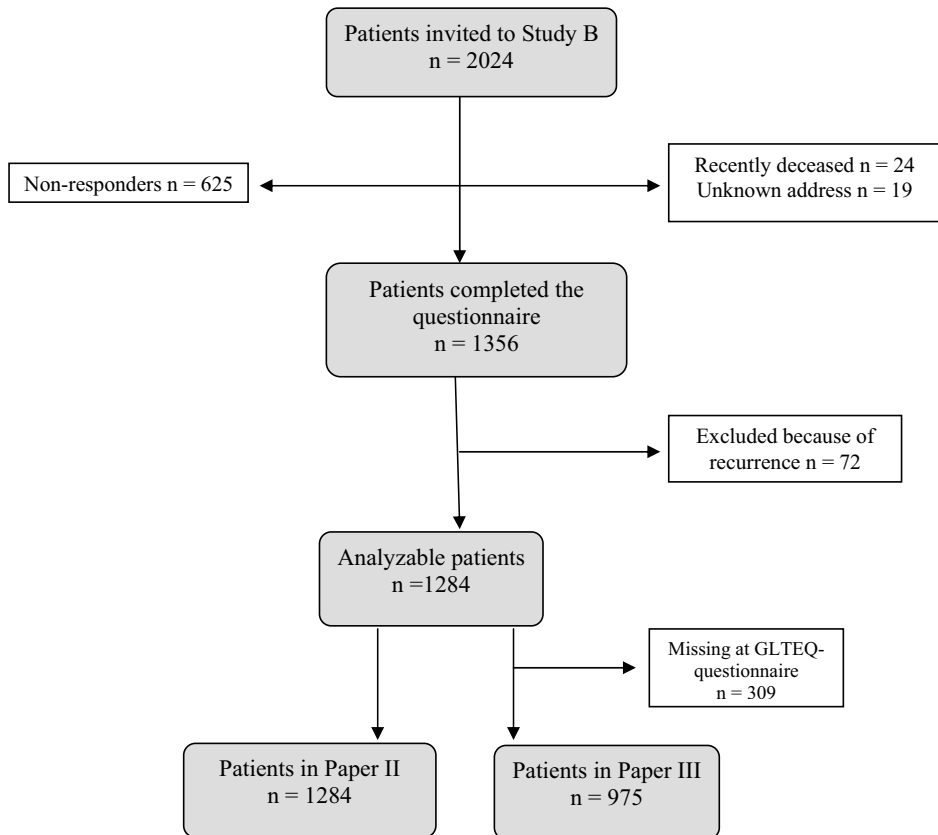


Figure 4. Flow chart of Study B (Paper II and Paper III)

#### 4.1.3 Study C: Effects of a 1-week inpatient course including information, physical activity, and group sessions for prostate cancer patients (Paper IV)

A pre-post intervention study was conducted among men who participated in a “Prostate cancer” course at the MBC in October 2006, December 2006 or Mars 2007. Course attendance required that the men should have PCa, a referral from a physician confirming ‘need for rehabilitation’ and be self-reliant. There were no restrictions for participation concerning time since diagnosis, stage of PCa, previous or current treatment or age. The participants were allowed to be accompanied by wives or partners. Seventy-five men were invited to participate in the study by an information letter and a questionnaire when they received the general information on the course by mail four weeks ahead of the course (T0).

Sixty-seven agreed to participate and answered the questionnaire at T0, these men received a second questionnaire three months after the course (T1). No reminder was sent to those who did not respond, neither at T0 nor at T1. In total, the response rate resulted in 68% (51 of 75).

#### **4.2 A 1-week inpatient course for prostate cancer patients (Study C, Paper IV)**

The MBC was established in 1990 in order to provide courses with information and activities for cancer patients and their families. The MBC offers intensive inpatient courses of 5-10 days duration for different groups of cancer patients and their spouses/relatives. The aim is to improve the patients' coping strategies towards the disease and the late effects of their treatment through information, lectures and activities.

The PCa courses lasted for six days and consisted of lectures, PA and group sessions. In the *lectures* a physician presented medical facts about PCa, treatment modalities, and late-effects. A social worker and a physiotherapist/sport instructor informed about social benefits and the expected effects of PA, respectively. Lectures about sexuality/partnership and urinary problems were given by a sexual therapist and a cancer nurse. Finally, information on psychological distress after PCa was lectured by a psychologist or a psychiatrist. *PA* was performed in groups of 6-9 participants two times per day, and was led by a physiotherapist or a sports instructor. PA included water gymnastics, walking, Nordic walking, resistance training, pelvic floor training, stretching and relaxation. The sessions included a warm-up phase, the phase of main activity and a phase of cool-down. The duration of a session varied from 30-90 minutes. According to the patients' subjective training experience, the activities were done at a moderate intensity level. The alternatives of such rating were: very mild, mild, moderate, strenuous and very strenuous. Each day the participants met for a one-hour *group session* which was led by a nurse experienced in group counselling. The themes of the sessions were related to the content of the lectures, and the purpose was to discuss the themes in relation to the participant's personal experiences. Totally, the active hours of the program amounted to about 30 hours. Of these hours, lectures amounted to approximately 45%, the PA to approximately 35% and group sessions amounted to about 20%. The participants could also make appointments for individual consultations with the professionals who gave the lectures. Additionally, social and cultural activities were a part of the evenings. The spouses/partners

attended in the lectures and PA, while they had group sessions separately. The effects of the course on the spouses/partners were not investigated in this study.

## **4.3 Measurements**

### **4.3.1 Study A: Cancer patients' needs for rehabilitation services (Paper I)**

In *Study A (Paper I)* there were three outcome variables: 1) Need for seven rehabilitation services, 2) Need for complex rehabilitation services and 3) Unmet need. These were assessed by two questions: *“To what extent have you experienced need for the following rehabilitation services in relation to your cancer?”* and *“To what extent have you been offered and used the following rehabilitation services in relation to your cancer?”*, respectively. Under both questions seven rehabilitation services were listed; physical therapy, physical training, psychological counselling, consultation with social worker, occupational therapy, supportive group sessions and admittance to a convalescent home. The questions regarding rehabilitation services are presented in Appendix A.

Related to the first question, the respondent was asked to rate his/her need for each rehabilitation service on a 3–point verbal rating scale (*“no need”*, *“some need”* and *“large need”*). In the analyses, the responses were dichotomized into *“no need”* and *“need”* (*“need”* including *“some need”* and *“large need”*). To explore the need for complex rehabilitation (more than one service needed), we computed a variable by summarizing the numbers of rehabilitation needs the individual responder reported for (response range: 0-7, continuous variable). Thus, a higher number indicated need for more complex rehabilitation.

The question about rehabilitation services offered/used contained four alternatives for each service (*“Have not been offered this program”*, *“Have been offered this program but did not use it”*, *“Have been offered and used it to little extent”* and *“Have been offered and used it to large extent”*).

Having unmet need was reported for persons who reported need for a specific rehabilitation service (first question), but were not offered this particular service (second question). This categorization was done for all seven rehabilitation services separately. The number of unmet needs per person was counted (response: 1-7 unmet needs).

The questions and response alternatives were constructed specifically for this survey and were not formally validated, they were however pilot-tested for clarity and understandability with subsequent adjustment.

#### *Demographic and medical variables (explanatory variables)*

For this thesis the following self-reported variables were used: age, gender, living with a partner (yes, no), children below 18 years living at home (yes, no), education level (primary/secondary/high school, university/college), employment status (working/studying, not working/other), changes in employment status (no changes, changes due to cancer, changes not due to cancer), health regions were categorized as three alternatives (south-east, west, middle), months since diagnosis, type of cancer [breast-, prostate-, colorectal/anal-, cervical/corpus-, fallopian tube/ovarian cancer (merged into ‘gynecological cancer’), melanoma, Non-Hodgkin’s lymphoma, other cancer sites (defined as cancer types reported by  $n < 50$  patients), more than one cancer diagnosis], recurrence (yes, no), treatment status at time of survey (after treatment, current treatment, no statement/not sure), type of treatment (patients treated with chemotherapy and radiotherapy +/- surgery, hormone therapy or others, patients treated with chemotherapy without radiotherapy +/- surgery, hormone therapy or others, patients undergone surgery/ radiotherapy or radiotherapy only, patient undergone surgery only, or patient treated with other combinations) and comorbidity (yes, no). Comorbidity was defined as presence of at least one of the following medical conditions: cardiovascular- or respiratory disease, psychological disorder, thyroid dysfunction, trauma or neurological disorders. Self-reported general QoL was assessed by a non-validated question: “*All things considered, how do you feel?*” with response alternatives were as follows: (very good, quite good, neither good or bad, quite bad or very bad).

#### **4.3.2 Study B: Interest and preferences for exercise counselling and programming among Norwegian cancer survivors (Paper II) and Exercise behavior in cancer survivors and associated factors (Paper III)**

##### *Interest and preferences for exercise counselling (Paper II only)*

Interest and preferences for exercise counselling were assessed by five questions from Jones and Courneya (Jones & Courneya 2002a) (see Appendix B). The first question addresses the interest in exercise counselling at some point after the cancer diagnosis (yes, maybe, no). Subsequent questions pertain to whom the patients would prefer to receive exercise counselling from, the preferred point of time for exercise counselling, the preferred location for exercise counselling and the preferred method to receive exercise counselling.



### *Preferences for exercise programming (Paper II only)*

Interest and preferences for exercise programming were assessed by twelve questions from Jones and Courneya (Jones & Courneya 2002a) and Vallance et al (Vallance *et al.* 2006) (see Appendix B). These items were designed to identify the interest of an exercise program and the preferred details of an exercise program. The two first questions addressed whether the patients would have been interested in and would be able to participate in a exercise program designed for cancer survivors at some point after their diagnosis (yes, maybe, no). The subsequent questions were about their preferred type of exercise, when to start the exercise program, preferred company, preferable exercise location, preferred time of day to exercise, preferred intensity, type of activities, how to perform these exercises, preferred structure of the exercise program and what type of activities.

All questions about interest and preferences for exercise counselling and exercise programming were translated from English to Norwegian by two independent translators following standard forward and backward translation procedure (Guillemin *et al.* 1993). These questions had not been specifically tested for validity or reliability but were chosen based upon their face validity.

### *Exercise behavior (both Paper II and Paper III)*

LPA was assessed by a modified version of the Leisure Score Index from the Godin Leisure-Time Exercise Questionnaire (GLTEQ) (Godin *et al.* 1986) (Godin & Shephard 1985). The patients reported their LPA both before diagnosis (retrospectively assessed) and after treatment (at the time of survey) (see Appendix C). The GLTEQ consists of three questions that assess mean frequency of mild (minimal effort, no perspiration as during e.g. easy walking), moderate (not exhausting, light perspiration as during e.g. brisk walking) and vigorous (rapid heart beats, sweating as during e.g. running) intensity exercise during an average week. The average duration for each intensity level was also provided as suggested by Jones and Courneya (Jones & Courneya 2002a). The total minutes of moderate intensity and vigorous exercise per week were calculated considering the LPA before diagnosis and after treatment separately. In *Paper II*, individuals exercising  $\geq 150$  minutes of moderate intensity per week or  $\geq 60$  minutes of vigorous intensity per week, or a equivalent combination of moderate and vigorous intensity, were categorized as meeting public health exercise guidelines (versus not meeting public health exercise guidelines) in accordance to exercise guidelines from 2007 (Haskell *et al.* 2007). In *Paper III*, individuals exercising  $\geq 150$  minutes

of moderate intensity per week or  $\geq 75$  minutes of vigorous intensity per week, or an equivalent combination of moderate and vigorous intensity, were categorized as meeting public health exercise guidelines (versus not meeting public health exercise guidelines) in accordance to exercise guidelines from 2008 (U.S. Department of Health and Human Services 2008). The different cut-point used in *Paper III* was constructed based upon the new exercise guidelines released in 2008 (U.S. Department of Health and Human Services 2008). In this thesis patients not meeting exercise guidelines were defined as physically inactive, regardless of the level of sub-optimal activity. GLTEQ has been found reliable and valid (Godin *et al.* 1986) (Jacobs *et al.* 1993). The translation of GLTEQ from English to Norwegian was done by two independent translators following standard forward and backward translation procedure (Guillemin *et al.* 1993).

According to Courneya and Friedenreich, exercise patterns across the cancer experience were categorized and labeled with some modifications (Courneya & Friedenreich 1997b). Change in LPA resulted in four categories, taken into account whether or not respondents were meeting exercise guidelines at the two time points. If the patient reported to be active both prediagnosis and after treatment, they were categorized as “*maintainers*”, whereas those who were inactive at both time points were categorized as “*persistently inactives*”. Those active before diagnosis and inactive after treatment were categorized as “*relapsers*”, while those who were inactive before diagnosis but active after treatment were categorized as “*adopters*”.

#### *Demographic and medical variables (both Paper II and Paper III)*

Information about age, gender, diagnosis and time since diagnosis and disease stage was collected from the medical databases at the hospital. In the analyses, patients with cervical cancer and ovarian cancer were merged into one group, ‘patients with gynecological cancer’, to avoid small groups. For this thesis the following medical and demographic variables were included based upon patients’ responses in the questionnaire: weight and height (for BMI calculation), living with a partner (yes, no), educational level (primary/secondary school, high school, college/university <4 years and college/university  $\geq 4$  years), employment status, comorbidity (yes, no), treatment: surgery (yes, no), radiotherapy (yes, no), chemotherapy (yes, no) and hormone therapy (yes, no), and daily smoking (yes, no). BMI was calculated as weight (kilos) divided by the square of the height (meters). Comorbidity was defined as any prolonged physical or psychological disease or injury that had reduced daily life functions during the last 12 months. Smoking included the use of cigarettes only.

In *Paper II* only, BMI was dichotomized into overweight/obese ( $\geq 25$  kg/m<sup>2</sup>) versus non-obese ( $< 25$  kg/m<sup>2</sup>). Employment status was categorized into five categories; fulltime/student/military service, part-time/homemaker, retired, disability benefit/sick leave and unemployed.

In *Paper III* only, five treatment groups were made: one local treatment, two local treatments, systemic treatment, one local treatment + systemic treatment and two local treatments + systemic treatment. Local treatment included surgery and/or radiotherapy and systemic treatment included chemotherapy and/or hormone therapy. Disease stage was included categorized into localized disease, regional disease and distant disease. BMI was tripartite into healthy ( $< 25$  kg/m<sup>2</sup>), overweight (25-29.9 kg/m<sup>2</sup>) and obese ( $\geq 30$  kg/m<sup>2</sup>). Employment status was categorized into four categories; fulltime/student/military service, part-time/homemaker, retired, disability benefit/sick leave/unemployed.

#### **4.3.3 Study C: Effects of a 1-week inpatient course including information, physical activity, and group sessions for prostate cancer patients (Paper IV)**

##### *Exercise behavior*

Questions about PA were assessed by a modified version of GLTEQ (Godin *et al.* 1986) (Godin & Shephard 1985). LPA and categorization of who were meeting public health exercise guidelines (versus not meeting public health exercise guidelines) were done as described previously under Paper III. See 4.3.2 Study B (Paper II and Paper III), Exercise behavior.

##### *The Fatigue Questionnaire*

Fatigue was assessed by the Fatigue Questionnaire (FQ) (Chalder *et al.* 1993) (see Appendix D). FQ consists of 11 items, seven items cover physical fatigue (PF) and four items cover mental fatigue (MF) experienced during the last month. Each question has four response alternatives, scored on a Likert scale (0-3). The scores are summarized for calculation of PF (possible range of scores: 0-21) and MF (0-12). Total fatigue score is the sum of PF and MF (0-33). Higher scores imply more fatigue (Chalder *et al.* 1993). FQ has robust psychometric properties (Minton & Stone 2009).

### *The Memorial Anxiety Scale for Prostate Cancer*

The Memorial Anxiety Scale for Prostate Cancer (MAX-PC) consists of 18 items divided into three subscales: general PCa anxiety (11 items), anxiety related to prostate specific antigen (PSA) (3 items), and fear of recurrence (4 items) (Roth *et al.* 2003) (see Appendix E). Responses are scored on a 4-point Likert scale from 0 to 3, and higher scores imply more cancer-related anxiety. Summarized scores for each subscale and total MAX-PC score are calculated. Total score on the subscales ranges from 0-33, 0-9 and 0-12, respectively. Total MAX-PC score range from 0 to 54. The MAX-PC has shown to have acceptable validity and reliability (Roth *et al.* 2003).

### *The Hospital anxiety and depression scale*

Anxiety and depression were assessed by the Hospital anxiety and depression scale (HADS) (Zigmond & Snaith 1983) (see Appendix F). The HADS includes 14 items; seven constitute the depression subscale (HADS-D) and seven constitute the anxiety subscale (HADS-A). Each item is scored on a 0 to 3 Likert scale, and a higher score implies higher level of depression/anxiety. The range of scores is from 0 to 21 for each subscale, and total HADS (HADS-T) is the sum of the two subscales (Zigmond & Snaith 1983). The psychometric properties of HADS are considered to be good (Bjelland *et al.* 2002).

### *Global Quality of Life*

QoL was assessed by two items constituting the Global QoL scale in The European Organisation for Research and Treatment of Cancer Core Quality of Life Questionnaire C30 (EORTC QLQ-C30) (Aaronson *et al.* 1993). These two questions assess patients' overall QoL and overall health condition, providing a global QoL score (see Appendix G). The range of transformed scores is 0-100. A higher score implies better QoL (Aaronson *et al.* 1993). The Norwegian version of the whole EORTC-QLQ C30 has been evaluated with regard to both validity and reliability (Hjermstad *et al.* 1995). It has shown satisfactory internal consistency (Hjermstad *et al.* 1998) and good test-retest reliability (Hjermstad *et al.* 1995).

### *Satisfaction with the course*

Satisfaction with the course was evaluated by two questions ad hoc developed for this study in order to cover two aspects of satisfaction. The first question "*Did the course change your expectations towards everyday life?*" (to a high extent/to a fair extent, only partially, not at all) and the second question "*Did the program help you to cope better with your prostate*

*cancer and/or the late effects associated with the treatment?"* (to a high extent, to a fair extent, only partially, not at all). The questions are not validated.

#### *Demographic and medical variables*

The questionnaire contained items such as age, height, weight, civil status, education level, employment status, time since diagnosis, treatment, disease stage, time since treatment and physical comorbidity. Height and weight were used to calculate BMI. Marital status was dichotomized into married/cohabiting or not, education was dichotomized into two levels (elementary school/high school or college/university) and employment status was categorized into employed (fulltime/parttime), retired, disability benefit or sick leave. Treatment was categorized into five groups; surgery +/- radiotherapy, radiotherapy alone, hormone therapy alone, wait and see, and hormone therapy + others. Based on the self-reported treatment information, an oncologist (Professor Sophie D. Fosså) categorized the participants into either localized disease/pelvis-confined advanced disease or metastatic disease. Physical comorbidity (yes, no) included self-reported cardiovascular disease, diabetes, asthma or allergy.

#### **4.4 Ethical considerations**

All three studies were approved by the regional Committee for Medical Research Ethics. Additionally, *Study A* was approved by the Data Inspectorate and the Norwegian Social Science Data Services, while *Study B* and *Study C* were approved by the personal protection representative at Rikshospitalet HF. All participants in *Study B* signed a written informed consent form. In *Study A* and *Study C*, returning the questionnaire was viewed as the patients' agreement to participate.

#### **4.5 Statistical analyses**

All the statistics were performed using Statistical Package of Social Science (SPSS) 15 or 16 (SPSS, Chicago IL). A two-tailed p-value of less than 0.05 was considered statistically significant. In *Paper I*, *Paper II* and *Paper III* adjusted odds ratios (aOR) were presented with 95% confidence intervals (95% CI).

### *Paper I*

To explore the associations between the reported need for each rehabilitation service (outcome variables) and demographic and medical variables (explanatory variables), logistic regression analyses were applied. Significant explanatory variables in the unadjusted analyses were included in the multivariate analyses. Step-wise multivariate analyses were performed, resulting in a step by step exclusion of explanatory variables not statistically significant with the outcome variable until the model included significant variables only. The same approach was performed to explore the association between the unmet needs for rehabilitation services (outcome variables) and demographic and medical variables (explanatory variables). Unadjusted and adjusted linear regression analyses were used to identify demographic and medical variables associated with need for increasing number of rehabilitation services (complex rehabilitation) (outcome variable). The multivariate linear regression model was reduced step-wise to include statistically significant variables only. Due to difficulties of separating gender specific diagnoses and gender in the overall analyses, gender was not included as an explanatory variable in the analyses. Because of missing data on one or more items the number of patients varies in the different analyses.

### *Paper II*

Sample size considerations were performed on the basis of the main outcome in Paper II, interest and preferences for exercise counselling and exercise programming. With the assumption that at least 50% of patients would endorse a particular preference, we were interested in any subgroup differences of 20% (50% vs 70%). A power calculation showed that we would be able to detect this difference with 97% power with 150 patients in each diagnostic subgroup. In order to be able to detect even smaller group differences, and to be able to perform subgroup analyses in cases of imbalanced groups, we included as many eligible patients as possible in terms of time, capacity and costs.

The chi-square test and the two sample t-test were used to assess group differences. Multiple logistic regressions were used to investigate the association between the explanatory variables (demographic and medical variables) and outcome variable (interest in exercise counselling). In the univariate and multiple analyses the outcome categories 'yes' and 'maybe' in interest in exercise counselling were combined, referring to some interest in exercise counselling. Variables that were found statistically significant in the univariate analyses were included as explanatory variables in the multivariate models. The logistic regression model was reduced step-wise to

include statistically significant variables only. These analyses were performed separately for men and woman as four out of five diagnoses were gender-specific.

### *Paper III*

Descriptive statistics were performed to describe the sample. Logistic regression analyses were performed to evaluate factors associated with each of three outcome variables 1: being physically active versus being inactive after treatment, 2: being a relapser *versus* being a maintainer and 3: being an adopter *versus* being persistently inactive. Demographic and medical variables statistically significant in unadjusted analyses were included as explanatory variables in the multiple regression analyses. The final models were reduced to include statistically significant variables only. Gender was not included as an explanatory variable in the logistic regression analyses because four out of five diagnoses were gender-specific, which made it impossible to separate diagnosis and gender in overall analyses.

### *Paper IV*

To analyze the difference between completers and non-completers, descriptive statistics were performed with chi-square test for categorical data and independent sample t-test for continuous data. To determine the changes from T0 to T1, paired sample t-test was used on continuous data and Mc Nemar's test for paired samples was used on categorical data.

## 5.0 Main results

### 5.1 Paper I

#### *Need for rehabilitation services and factors associated with need for rehabilitation services*

A total of 63% reported a need for at least one of the rehabilitation services; hence 37% reported no need for any type of rehabilitation service. The rehabilitation service reported to be needed most was physical therapy (43%), thereafter physical training (34%), followed by psychological counselling (27%), supportive group sessions (24%), admittance to a convalescent home (24%), consultation with social worker (19%) and occupational therapy (6%) (Fig. 5).

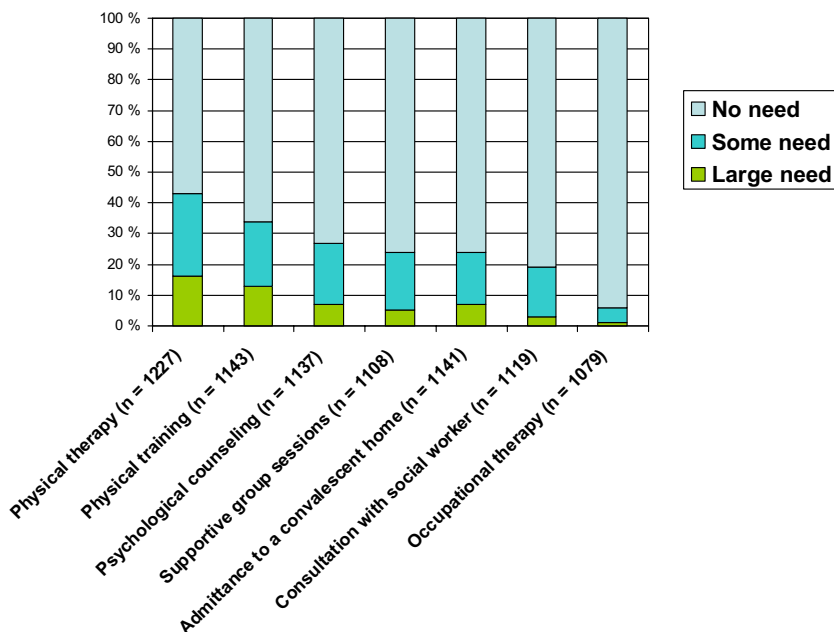


Figure 5. Proportions of cancer survivors reporting need for seven rehabilitation services



In multivariate logistic regression analyses we found that patients who had changed their employment status due to the cancer diagnosis, or those who had received chemotherapy (with or without radiotherapy and/or other treatment modalities) were more likely to report need for all rehabilitation services than those who did not change their employment status or those who had not received chemotherapy. Need for physical training was reported more frequently among those with children below 18 years living at home. Patients with high education (college/university) were more likely to report need for physical training, psychological counselling, consultation with social worker and admittance to a convalescent home compared to those with a low education. Reporting a need for psychological counselling, consultation with social worker and admittance to a convalescent home decreased by increasing age. Breast cancer patients were more likely to report a need for physical therapy and supportive group sessions than patients with other diagnoses. Physical training and admittance to a convalescent were more frequently needed among breast cancer patients than patients with melanoma.

#### *Need for complex rehabilitation and associated factors*

The average number of reported need for rehabilitation was 1.58 areas (median 1.0, range 0-7). Forty percent of the patients needed two or more rehabilitation services. In multivariate analysis factors associated with complex rehabilitation were young age, living alone, high education, not working, changes in employment status due to cancer diagnosis, presence of comorbidity, having breast cancer and having received chemotherapy and radiotherapy together with or without other treatment modalities.

#### *Unmet need for rehabilitation and associated factors*

Forty percent reported unmet needs and unmet needs were most frequently reported by patients living alone, those who had changed their employment status due to cancer diagnosis, those who had received chemotherapy (together with or without radiotherapy and other treatment modalities) or those with presence of comorbidity. Twenty-two percent of those in need of physical training and 17% of those in need of psychological counselling were not offered these services (Fig. 6).

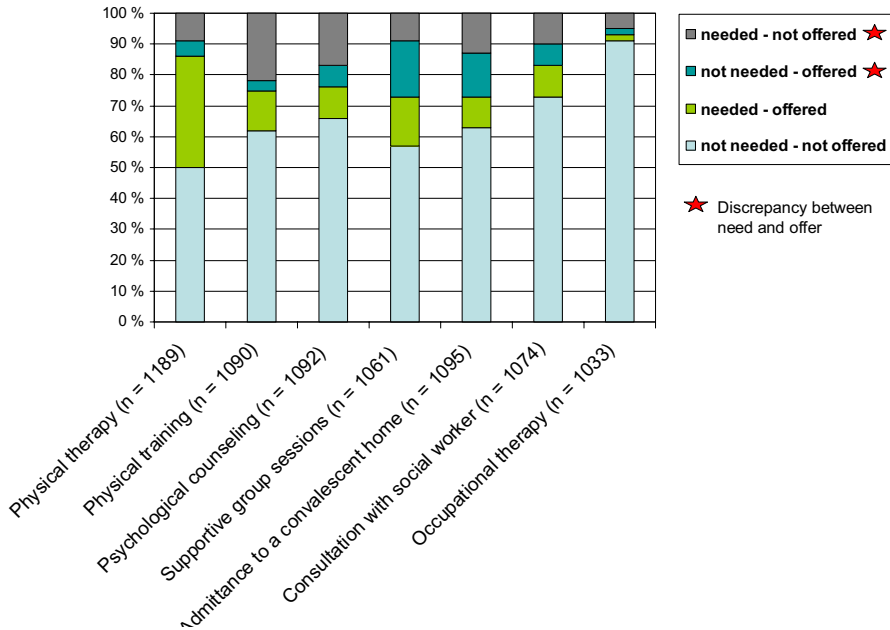


Figure 6. Rehabilitation services – needed and offered

## 5.2 Paper II

### *Interest in exercise counselling*

Overall, 55% of participants reported to be interested in and 21% reported to maybe be interested in receiving exercise counselling at some point during their cancer experience. Overall, 76% were somewhat interested in exercise counselling. The percentage of men with a somewhat interest in exercise counselling was 64% in prostate, 74% in testicular and 78% in malignant lymphoma. In women, prevalence of a somewhat interest in exercise counselling was 79% in breast cancer, 81% in gynecological cancer and 82% in malignant lymphoma.

In multivariate logistic regression analysis in men, interest in exercise counselling was associated with younger age [aOR per 10 years increase 0.84; 95% CI (0.72, 0.99), p=0.048], presence of comorbidity [aOR 1.79; 95% CI (1.1, 2.92), p=0.019], and

receiving chemotherapy [aOR 1.67; 95% CI (1.04, 2.69), p=0.035]. For women, interest in exercise counselling was associated with younger age [aOR per 10 years increase 0.77; 95% CI (0.62, 0.96), p=0.017], high education college/university less than 4 years [aOR 2.68; 95% CI (1.21, 5.93), p=0.021] and high education college/university 4 years or more [aOR 2.73; 95% CI (1.16, 6.43), p=0.021], and being a relapser [aOR 5.57; 95% CI (1.67, 18.55), p=0.047].

### *Exercise counselling and programming preferences*

Concerning preferences for exercise counselling, more than fifty percent preferred to receive exercise counselling from an exercise specialist at a cancer center. Nearly half of the respondents preferred to get exercise counselling immediately after treatment, half wanted to receive the counselling at a hospital and nearly all respondents wanted the exercise counselling face-to-face.

The results regarding to exercise programming showed that 67% of participants reported to be interested in and 24% reported to be maybe interested in an exercise programming designed for cancer survivors at some point during their cancer experience. Overall, 91% were somewhat interested in an exercise programming. Further, the majority of the cancer survivors also reported to be able to participate in an exercise program. Concerning preferences of exercise counselling, the participants preferred walking as type of activity, followed by resistance training and stretching. The preferred time to start an exercise programme was immediately after treatment, followed by 3-6 months after treatment. One quarter wished to exercise with other cancer survivors, while another quarter preferred to exercise with friends and family. The preferred place to exercise was at a community fitness centre. Most cancer survivors wanted a supervised, scheduled exercise programme with activities on a moderate intensity level.

## **5.3 Paper III**

### *Prevalence of physically active cancer survivors and changes in LPA*

Forty-eight percent of the participants reported to be physically active before diagnosis and 45% were physically active after treatment (Fig. 7). Totally, 323 (33%) were physically active before diagnosis and continued to be physically active after treatment, 392 (40%) were persistently inactive, 149 (15%) reduced their LPA after treatment compared to before

diagnosis (relapsers), while 111 (12%) increased their LPA after treatment compared to before diagnosis (adopters) (Figure 1). Of those physically active pre-diagnosis (n = 492), 149 (32%) of these relapsed in LPA and 323 (68%) maintained their LPA after treatment. Of those physically inactive pre-diagnosis (n = 503), 111 (22%) became adopters and 392 (78%) remained persistently inactive after treatment (Fig. 7).

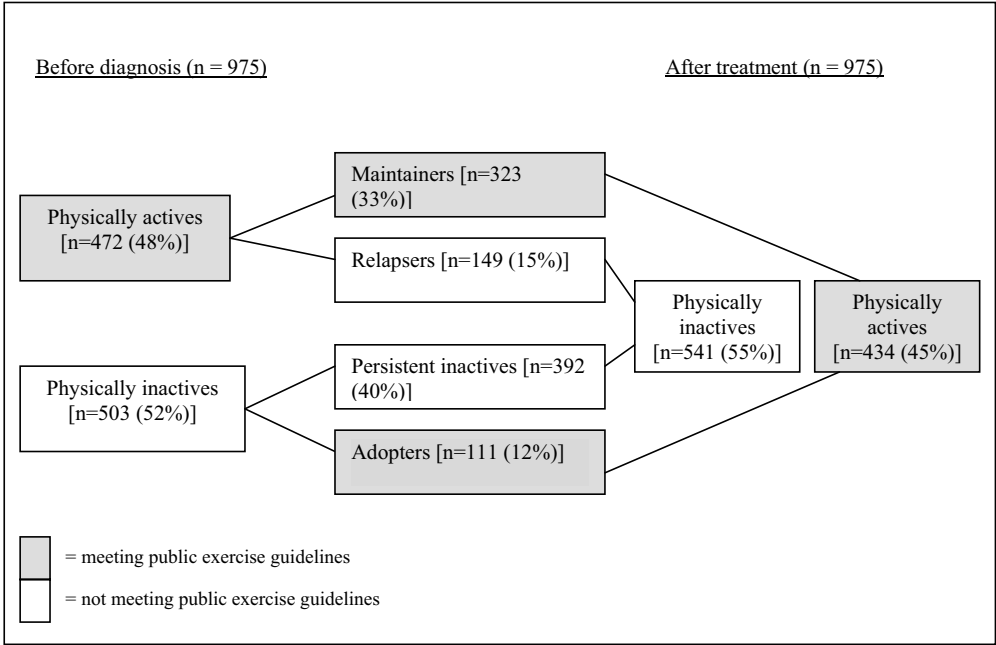


Figure 7. Categorizing cancer survivors based on whether or not they were meeting exercise guidelines before diagnosis and after treatment (n=975)

*Factors associated with being physically active after treatment*

Multivariate logistic regression analyses showed that older age remained negatively associated with being physically active [aOR 0.62; 95% CI (0.44-0.88), p=0.008]. Also being overweight or obese was negatively associated with being physically active [aOR 0.73; 95% CI (0.54-0.98), p=0.03 and aOR 0.46; 95% CI (0.3-0.71), p=0.001, respectively]. Participants with presence of comorbidity had approximately 50% reduced odds for being physically active compared to those with no comorbidity [aOR 0.56; 95% CI (0.41-0.76), p<0.001]. Compared to non-smokers, smokers were approximately half as likely to be physically active

[aOR 0.53; 95% CI (0.36-0.78), p=0.001]. High education was positively associated with being physically active [aOR 2.05; 95% CI (1.26-3.33), p=0.004].

#### *Factors associated with being a relapser or an adopter*

Presence of comorbidity was significantly associated with being a relapser in the multivariate logistic regression analysis [aOR 2.47; 95% CI (1.6-3.81), p<0.001] and cancer survivors with distant disease were more than twice as likely to become a relapser compared to the ones with localized disease [aOR 2.17; 95% CI (1.28-3.66), p<0.004]. Smoking was associated with being a relapser [aOR 1.79; 95% CI (1.04-3.09), p<0.04]. The only factor statistically significantly associated with being an adopter was high education (college/university  $\geq 4$  years) [aOR 2.29; 95% CI (1.13-4.63), p<0.02].

## **5.4 Paper IV**

Those who only responded at T0 had a higher level of depression and fatigue compared to those who responded at both time points.

#### *Changes in PA, fatigue, mental distress and QoL*

The number of men meeting exercise guidelines did not change significantly from T0 to T1. The mean score of total fatigue was significantly reduced from 16.1 (4.8) at T0 to 14.0 (4.4) at T1 (p=0.001), and physical fatigue decreased from 11.1 (4.0) at T0 to 9.2 (3.4) at T1 (p=0.001). Mental fatigue also decreased, but the difference did not reach statistical significance. The mean score of PSA-anxiety was reduced from 0.8 (1.3) at T0 to 0.3 (0.9) at T1 (p=0.001), while the remaining MAX-PC subscales did not change significantly. No significant changes were observed either in HADS or global QoL.

#### *Satisfaction with the course*

At T1, 56% reported that the program had changed their everyday life expectations (to a high extent/fair extent) and 60% found that the course had helped them to cope better with their PCa and/or the late effects associated with the treatment (to a high extent/fair extent).

## 6.0 Discussion

### 6.1 Methodological considerations

#### 6.1.1 Study design

##### *Cross-sectional studies*

A cross-sectional design is suitable to estimate prevalence and associations between exposure (e.g. smoking) and outcome (e.g. lung cancer) (Rothman 2002). In cross-sectional studies information is collected only at one point of time. No statement on cause and effect-relationship can be made (Thelle & Laake 2008). Cross-sectional studies can however be hypothesis generating for future research. Cross-sectional studies are cost-effective and time-effective, especially with the choice of questionnaires as measurement tools (Lu 2009). With the available resources cross-sectional design was suitable in *Study A (Paper I)* and *Study B (Paper II and III)* as we were interested in a) the prevalence of cancer survivors in need of rehabilitation services and associated factors (*Paper I*), b) the prevalence of patients in need of exercise counselling and programming and associated factors (*Paper II*) and c) the prevalence of patients being physically active after treatment, changes in LPA and associated factors (*Paper III*). Our results show that there were significant correlations between our outcome variables and several explanatory variables, but with the given design we cannot conclude that the outcomes are caused by these variables. For example, we cannot draw inferences that being inactive after treatment is caused by having comorbidity, it can be that having comorbidity can be caused by being inactive as well. Longitudinal studies would have been preferable for the understanding of these associations and also for the understanding of LPA changes across the cancer trajectory.

##### *Intervention studies*

To examine the effects of an intervention, randomized controlled trials are considered as the gold standard study design (Altman *et al.* 2001) (Lu 2009). If randomization is not feasible, a pre-posttest design with an intervention group and a control group (preferable a matched control group) is an option. A pre-posttest design with no control group is suitable to test feasibility of new methods/assessments, interventions or logistics (Thomas & Nelson 2001). Although the latter is not optimal to examine the effect, we are able to get an indication of possible effects of the intervention. Choice of method and design should be based on the aim of the study and the current state of knowledge. At the time *Study C (Paper IV)* was initiated

little knowledge existed on the effect of a cancer specific inpatient course, and the study was therefore considered a pilot study.

Our experiences with this pilot study will be useful if planning a study with a more comprehensive study design, in terms of length of the intervention, selection of study population, power calculation and choice of assessment methods. The consequence of not having a control group is that we do not know whether the improvements in fatigue and PSA-anxiety are due to the intervention or just due to other factors such as natural course.

### **6.1.2 Validity**

#### *Internal validity*

Internal validity refers to: “the validity of the inferences drawn as they pertain to the members of the source population” (Rothman *et al.* 2008). Three factors can compromise the internal validity of the study findings; selection bias, information bias and confounding factors (Rothman *et al.* 2008).

**Selection bias** occurs when there is a systematic significant difference between the characteristics of the responders and the non-responders in the study population (Rothman 2002). It is important to differentiate systematic error from random error due to random variability, where the latter is not of biggest concern (Szklo & Nieto 2007). There is a higher risk of a non-representative sample when the response rate is low compared to high (Asch *et al.* 1997). A 100% response rate in a survey is optimal but not realistic, the average response rate in surveys published in medical journals has shown to be about 60% (Asch *et al.* 1997). The response rate might be influenced if the study title and information letter will or will not attract the responder’s attention or interest and if reminders are sent or not.

In *Study B*, the study invitation was titled: “Needs and preferences for exercise counselling among Norwegian cancer patients” and contained information about this theme. The obvious content of the survey might have caused a selection bias, where people with an interest for PA have answered more frequently than those not interested. The consequence might have been that our results on prevalence of interest in exercise counselling and programming (*Paper II*) and physically actives (*Paper III*) are overestimated.

In *Study A* the questions about need for rehabilitation services were not the main outcomes of the study, however, the questions were included in a questionnaire used in a survey called: “Survey about cancer patients’ living conditions”, involving many other parts of the patients’ life after treatment as for example work, economy, social support system and network of family and friends. The participants in *Study A* are probably more interested in life after cancer in general, not specifically in one of the areas described. This might be one reason why we found that 34 % of the participants were in need for physical exercise in *Study A (Paper I)*, whereas 55 % were interest in exercise counselling in *Study B (Paper II)*. The fact that there were several rehabilitation service alternatives additional to physical exercise in *Study A (Paper I)* could also have affected the responses, as to responders picked other alternatives who were more preferable. Other factors such as age, education, social situation diagnosis and treatment might also have affected the answers differently in the two studies.

No reminders were sent in *Study A (Paper I)* due to anonymous answers or in *Study C (Paper IV)* due to costs and time resources. In *Study B (Paper II and Paper III)*, reminders were sent to those who did not respond four weeks after first sending. The response rate increased approximately by 20% after the reminder. Having information about the non-responders is an advantage, giving the ability to reveal how they differ from the responders on key variables. This knowledge is important when interpreting the results. We have no information on the non-responders in *Study A (Paper I)* and *Study B (Paper II and III)*. In *Study B*, a formal request was sent to the Data Inspectorate but unfortunately we were not allowed to look at the information of the non-responders regarding age, gender, diagnosis, disease stage and time since diagnosis. Normally there are some inequalities between those who accept and those who decline to participate in such studies. In health surveys there is often an overrepresentation of those with a higher educated, women and the health conscious (Laake *et al.* 2007).

Certain groups were overrepresented in *Study A (Paper I)*. Compared to the general population, within the age span 25 to 60 years, women (70%), those with breast cancer and those with a higher educational dominated the sample (Fløtten *et al.* 2008). Approximately half of the respondents had a higher education compared to only one third in the general population ([www.ssb.no/utniv/tab-2008-08-21-03.html](http://www.ssb.no/utniv/tab-2008-08-21-03.html)). The reasons for why breast cancer was clearly the most overrepresented group may be explained by the overrepresentation of women in surveys in general or that women with breast cancer normally are willing to



participate in research. Following, the results from *Study A (Paper I)* reflect the need for rehabilitation among women with breast cancer and high education primarily. These considerations and due to the relatively low response rate, it is probably that the needs for rehabilitation might actually be overestimated. It might also be that the need for physiotherapy especially is overestimated due to the overrepresentation of women with breast cancer. The percentage of woman in *Study B (Paper II and Paper III)* was 56%, so men and women were approximately equally represented. On the other hand, not surprisingly also in *Study B (Paper II and Paper III)* educational level was higher compared to the general population ([www.ssb.no/utniv/tab-2008-08-21-03.html](http://www.ssb.no/utniv/tab-2008-08-21-03.html)). With the knowledge that the individuals with lower education are less active (Anderssen *et al.* 2009) (Næss *et al.* 2007), our sample may be biased including more physically active individuals and the prevalence of physical actives are overestimated.

In *Study C (Paper IV)* we compared men who responded to questionnaires at T0 and T1 (completers), with those who only responded at T0 (non-completers). We found a significant difference between completers and non-completers concerning depression, and a borderline significant difference in fatigue. This implies that those who did not respond at follow-up had the highest symptom burden at T0. It might be that those with more problems would have had greater potential for improvement of the outcome variables, leading to an overall higher effect of the intervention.

**Information bias** occurs when the instrument, the observer or the study participant do not measure, observe or report correctly what are supposed to be measured (Rothman *et al.* 2008). Because all our studies are based on self-report, we are prone to information biases to occur. Relevant in our studies are also issues related to the instrument measures.

FQ, MAX-PC, HADS, Global QoL used in *Study C (Paper IV)* and GLTEQ used in *Study B (Paper II and Paper III)* and *Study C (Paper IV)* are all established questionnaires frequently used in cancer patients. The psychometric properties are considered as good (Bjelland *et al.* 2002) (Godin *et al.* 1986) (Hjermstad *et al.* 1995) (Jacobs *et al.* 1993) (Minton & Stone 2009), i.e. being reliable and valid in order to reduce measurement biases.

The questions about rehabilitation needs (main outcome) in *Paper I* and the questionnaire about interest and preferences for exercise counselling and exercise programming (main

outcome) in *Paper II* are not validated and the questionnaires' discriminative properties are not documented. As far as we know, equivalent questionnaires do not exist. However, the questions have a concrete content thus limiting the need for psychometric testing. The questions were pilot-tested for clarity and understandability and thereafter adjusted. It is reasonable to assume that these questions have good face validity. Face validity refers to how the questions appear superficially to measure what it is suppose to measure. It is not validity in technical meaning, but rather that the questionnaire "looks valid" to the respondent (Anastasi 1988).

In spite of face validity, information bias could have occurred due to systematic difference in understanding or interpretation of the term "interested" in *Study B (Paper II)*. "Interest" might be easier to confirm and therefore resulted in a higher response compared to "need". Consequently, it might be that the interest of exercise counselling is overestimated because of the terminology used and is less committing to answer "yes". The different understanding and meaning of the terms could also be a reason for the different prevalence we found in *need* for physical training versus *interest* in exercise counselling in *Paper I and Paper II*, respectively. Based on clinical experience, there is probably a discrepancy between how many reporting a need or an interest in a survey compared to how many that actually would participate in an exercise counselling or utilize a rehabilitation service. We think our numbers might be overestimated.

Further, we do not know how the study participants understood the different terms of the seven rehabilitation services (*Paper I*) and the different terms in the questionnaire about exercise counselling and programming (*Paper II*). Participants and researchers may have different understanding of ambiguous terms such as "physical activity" and "moderate intensity" (Sallis & Saelens 2000). Hence, we do not know precisely what the patients need or prefer regarding each service. There is reason to believe that the respondents may have interpreted these terms differently, therefore influencing the random error and not the systematic error. Another limitation of the questionnaire, on need for rehabilitation, is the lack of a question assessing the need for nutritional counselling. Especially since previous surveys among cancer survivors have reported high levels of interest in diet interventions (Demark-Wahnefried *et al.* 2000).

PA questionnaires have shown to have good validity for high intensity and sedentary activities compared to more advanced objective measures (accelerometers and maximal oxygen uptake), while the validity for low and moderate intensity activity is found to be more questionable (Jacobs *et al.* 1993). Also, the reliability for high intensity activity scores was found to be higher than for moderate activity scores (Sallis & Saelens 2000). Moreover, individuals tend to overestimate their actual exercise level and intensity in self-reported surveys compared to objective measurements (Anderssen *et al.* 2009) (Troiano 2007). Another issue that might influence the information in a systematic direction is the social desirability that affects the responders, this could lead to an over-reporting of physically activity (Warnecke *et al.* 1997). It could be more or less a norm to respond that you are physical active because of the focus on health benefits of PA in our society. Self-report do not provide precise estimates of the absolute amount of PA, for more accurate estimates more advanced objective measures are recommended (Sallis & Saelens 2000). Still, self-report questionnaires to assess PA are most commonly used and are viewed to represent an appropriate and practical method to assess PA in a large population (Patterson 2000) (Sallis & Saelens 2000).

Despite GLTEQ is an established questionnaire, we have some comments on the instrument. One of the concerns is that we had problems with missing data for GLTEQ. The reasons for why approximately 25% of the respondents in *Study B (Paper II and Paper III)* and about 50% of the respondents in *Study C (Paper IV)* did not complete the GLTEQ could be that they considered the questions too difficult to answer accurately or they did not remember their activity patterns for the two time points before diagnosis and after treatment (at the present of the survey) or they were not regularly active and found it therefore difficult to answer the questions. The fact that GLTEQ includes descriptions of three intensity levels, by referring to common activities and how subsequent the exhaustion level is experienced, should have raised the understanding of the questions. Nevertheless, the subjective agreement of what is considered PA will differ. For some, a walk is not considered PA, whereas for others this would be sufficient.

From the total responders in *Study B* about 300 participants did not answer the questions about exercise, contributing to an even greater selection of the exercise data. The ones not answering the GLTEQ were significantly older and had a significantly lower educational level compared to the ones answering the GLTEQ. Based on our findings in *Paper III* and findings

in the general population (Anderssen *et al.* 2009) (Næss *et al.* 2007), those with lower education tend to be less active. Therefore this selection has probably led to a higher prevalence of physically active cancer survivors in *Paper III*.

One limitation of the GLTEQ is that it only asks for PA in leisure time, excluding PA at work or in the house. The prevalence of physically active might have been higher with those domains being included.

*Recall bias* can be a possible problem of questions regarding past history (Rothman 2002). In *Study B (Paper I and Paper III)*, the responses to questions about LPA before diagnosis (retrospectively) might have been affected by recall bias. Imprecise recall must be separated from recall bias. Imprecise recall will increase the random errors, while recall bias will affect the data in a systematic way (poorer validity) (Coughlin 1990). It could be that the responses to LPA before diagnosis are influenced by that people tend to think that things were better before, as for example that they were more active before. This could have affected our results in *Paper III*, in the way that the prevalence of participants who have decreased their LPA form before diagnosis to after treatment is overestimated. Still, this is unlikely because the rate of participants that had decreased their LPA was only 15%.

**Confounding** factors are variables in statistical models that correlate (in either directions) with both the dependent and the independent variable (Rothman *et al.* 2008). Correct use of statistical methods which take confounding factors into account will help with providing confounding bias. In *Study A* and *Study B*, we aimed to avoid such bias by adjusting for potential confounders in the multivariate analyses.

#### *External validity*

External validity refers to: “the validity of the inferences as they pertain to people outside the source population” (Rothman *et al.* 2008). Internal validity is considered as a prerequisite for external validity (Rothman *et al.* 2008).

To ensure a more representative Norwegian sample, participants in *Study A (Paper I)* were included from four different hospitals (three university hospitals), situated in three out of four health regions in Norway. All three representing both urban and rural areas. CRN is a close to complete register of all cancer cases in Norway, information from this registry was used to

identify eligible patients. The distributions of cancer types in our sample were compared to the actual distribution of cancer types in the Norwegian population aged between 25 and 60 years. It showed that anal cancer, lung cancer, melanom and tumor in nerve system were underrepresented in our sample, while breast cancer, Non-Hodgkin's lymphoma and gynecological cancer were overrepresented (Fløtten *et al.* 2008). Breast cancer was clearly the most overrepresented group in the sample, as well as in the responders. This needs to be considered when it comes to the generalization of the results, because patients with breast cancer have a higher survival rate than other diagnoses. Such factors could possibly have influenced the responses in terms of the association to treatment and health consequences' of cancer. Because of inclusion criteria, the sample in *Study A (Paper I)* is only representative for Norwegian cancer patients between 25 years and 60 years, and with the ten most common cancer types for men and women. The differences in cultures, living conditions and health care systems between countries may limit the generalizability of our results to other countries; this also applies to the findings in *Study B*.

Participants in *Study B (Paper II and Paper III)* were patients who received curatively intended treatment at the NRH. Due to inclusion criteria our results can not be generalized to patients younger than 18 and older than 65 years old, those who receive palliative treatment and for diagnosis other than testicular cancer, breast cancer, ovarian cancer, cervical cancer, PCa or malignant lymphoma (Hodgkin's lymphoma or Non-Hodgkin's lymphoma). There are possible differences between patients treated at the NRH and general Norwegian cancer patients. Patients treated at the NRH at the time when our study was conducted were mainly from Oslo west and from the southern part of Norway. Studies have shown that there are differences between Oslo west and Oslo east concerning health. People living at Oslo west have a higher level of education, higher socio-economic standard and longer life expectancy (Grøtvedt 2002). Also a higher percentage from Oslo west was found to be physically active compared to Oslo east (Grøtvedt 2002). With this knowledge it is likely to assume that people from Oslo west are more health concerned than people from Oslo east. This might have given us a higher percentage of physically actives (*Paper III*) and those interested in exercise counselling and programming (*Paper II*). In summary, we consider the representativeness of *Study B* to be satisfactory for patient treated at the NRH. The degree of which our findings can be generalized to Norwegian cancer survivors with the same criteria as our inclusion in general is more uncertain.

In *Study C (Paper IV)*, we are uncertain how our sample of PCa men reflects PCa patients in Norway. This is due to the heterogeneity of PCa patients in general and the relatively sparse information we have for each man participating. Due to the referral patterns at the MBC, which could not be changed when this study was initiated, we had limited information on the extent of our patient's disease and their treatment. As for education, more than half of the participants in our study had a college/university education, which is twice as high compared to Norwegian male population in the same age group ([www.ssb.no/utniv/tab-2011-06-09-03.html](http://www.ssb.no/utniv/tab-2011-06-09-03.html)). Additionally, our sample was relatively young and seemed to have a healthy lifestyle before the course started. This is a convenient sample and we can not say much about the representativeness.

## **6.2 Discussion of the main findings**

### **6.2.1 Need for rehabilitation services (Study A, Paper I)**

More than 60% of the cancer survivors in our sample reported to be in need of at least one rehabilitation service. Most individuals reported need for physical therapy, followed by physical training and psychological counselling. A higher desire for rehabilitation services was associated with having changed employment status due to cancer and receiving or having received chemotherapy. Totally, 40% of the participants reported unmet needs. Factors associated with unmet needs were living alone, having changed their employment status due to cancer, receiving or had received chemotherapy and self-reported comorbidities.

As far as we know our study is the only study evaluating the type and number of needs among cancer patients in a population-based sample. The way we asked directly about rehabilitation services needed, differs from asking about late effects or distress and from these answers draw conclusions on what kind of rehabilitation the patients might need. Recently, two studies assessed the need for rehabilitation by asking directly, but only addressing the need for psychological services (Ernstmann *et al.* 2009) (Weidner *et al.* 2008). Thus comparisons between different needs were not possible. In line with our result, Ernstmann and colleagues found that less than one third reported a need for psychological services (Ernstmann *et al.* 2009). Weidner *et al.* found that 43% of patient with gynecological cancer (n = 175) wanted psychological services during their stay at the hospital (Weidner *et al.* 2008) In another report among 381 cancer patients diagnosed with more than ten different cancer types, a quarter of women and one out of ten men reported a need for psychological support (Merckaert *et al.*

2010). In contrast to our findings, Steel and Fitch found a higher need for emotional services compared to physical services (Steele & Fitch 2008). However, the participants included in Steel and Fitch's study were only gynecological patients being a different study population than ours and direct comparison seems inappropriate.

Our results showed that physical services as physical therapy and physical training were more often needed than psychosocial services such as for example psychological counselling and supportive group sessions. The reasons for this could be that more than 40% respondents were breast cancer patients and they more than others need post-treatment physical therapy to improve arm function and prevent arm lymphedema, such services are also more available for this cancer group. This is also confirmed in our multivariate analyses in which being a breast cancer patient increased the likelihood of the need for physical therapy compared to all other diagnosis. In accordance with our hypothesis, the ones with more intensive treatment modalities (chemotherapy with or without radiotherapy and/or other treatment modalities) most commonly reported a need for one or several rehabilitation services. Those receiving more intensive treatment have reported to have more physical and psychological impairments (Chachaj *et al.* 2010) (Ganz & Bower 2007) and this could indicate that they are in more need of rehabilitation services. Changes in employment status due to the cancer diagnosis were associated with a need for all rehabilitation services. This indicates that these people struggle to get back to work afterwards.

Differences appeared in the responses given for *Study A (Paper I)* and *Study B (Paper II)*. In *Study A (Paper I)*, 34% reported a need for physical training, which is lower compared to the 55% interested in exercise counselling (yes) in *Paper II*. The explanation for the differences could be that in *Paper I* several services were outlined, while in *Paper II* exercise counselling was the only service option given. A cancer patient with an impaired arm function would most likely have preferred physical therapy if the option was given, but would have confirmed the interest of exercise if that was the only option. Other reasons for this discrepancy are discussed previously in 6.1.2 Validity, Selection bias. Regrettably, the questions in *Paper I* and *Paper II* are not comparable because they differ in questions and answer options.

Our study indicates that there is a discrepancy between the need for physical training and the physical training services offered. Almost a quarter of those in need for physical training were not offered this service. Supporting the focus we should have to ensure that PA services are

offered to cancer survivors. Opposite, the supportive group session was the service that was most frequently offered but needed least, reported by approximately one fifth of the respondents. Zebrack and colleagues reported that more than half of the young adult respondents reported an unmet need for information about diet and nutrition and exercise (Zebrack 2009). Our findings that about 20% reported an unmet need for psychological services was supported by Ernstmann et al who found approximately the same in their sample of 326 cancer survivors (Ernstmann *et al.* 2009).

According to our findings, the majority of cancer patients reported a need for rehabilitation services. Nevertheless, there was a noticeable portion who reported no need for rehabilitation. For those who reported a need for rehabilitation, it is important that they are offered the right rehabilitation services corresponding to their need. Compatible with our findings that the most reported needs were the physical rehabilitation services, it seems relevant that physical rehabilitation should be prioritized when making new rehabilitation programs in Norway. Given the increased survival among cancer patients, the group of cancer survivors and probably the group of cancer survivors in need for rehabilitation services will increase. However, the prevalence of reported need on the different rehabilitation services in such survey is not directly transferable to how many that would actually use the rehabilitation services if they were available and offered.

### **6.2.2 Interest and preferences for exercise counselling and programming (Study B, Paper II)**

#### *Interest in exercise counselling*

As hypothesized, the majority (76%) of Norwegian cancer survivors in our sample were somewhat (yes/maybe) interested in exercise counselling. Our results are thus in line with the findings by Vallance and colleagues confirming a similar high interest (77%) in exercise counselling among non-Hodgkin's Lymphoma 62 months (mean) after diagnosis (Vallance *et al.* 2006). Also concurrent with our results, Jones and Courneya found that the majority (84%) of mainly breast cancer and PCa survivors were somewhat interested in receiving exercise counselling (Jones & Courneya 2002a). Fewer interested (51%) were found by Demark-Wahnefried et al among breast cancer and PCa survivors (Demark-Wahnefried *et al.* 2000). Variations in results could be explained by the use of different questions and scale used in their questionnaire (Demark-Wahnefried *et al.* 2000). Therefore, we can not compare directly



with that result. The strength in our (*Paper II*) is that we chose the same questionnaires and categorized the answers similar as most of the studies examine interest of exercise counselling, exercise programming and activity level, so the comparison is possible.

In line with our hypothesis, we found a higher interest in exercise counselling in younger cancer survivors compared to older in both genders. Our expectations about a higher interest in exercise counselling among higher educated cancer survivors compared to lower educated ones were confirmed in women only. These findings are supported by Jones and Courneya and Demark-Wahnefried et al who also found an association between interest in exercise counselling and younger age (Demark-Wahnefried *et al.* 2000) (Jones & Courneya 2002a). In concurrence with our results, two other studies also found an association between a high education level and interest in exercise counselling (Jones & Courneya 2002a) (Vallance *et al.* 2006). The findings indicate that recruitment to exercise counselling first of all may attract young and highly educated cancer survivors. In disagreement to other studies (Jones & Courneya 2002a) (Vallance *et al.* 2006), we found that men that had received chemotherapy were more likely to be interested in exercise counselling compared to men that had not received chemotherapy. For women, a decrease in LPA from before diagnosis to after treatment was associated with an interested in exercise counselling. As far as we know no other studies have investigated this relationship.

Nevertheless, there seems to be a discrepancy between the numbers of cancer survivors who report to be interested in exercise counselling and the numbers of cancer survivors who actually are offered such counselling. Demark-Wahnefried and colleagues found that only about one third reported that they had received recommendations for exercise by their physician (Demark-Wahnefried *et al.* 2000). Surveys of oncologists show that approximately 40% reported to have recommended or discussed PA with their patients when appropriate (Jones & Courneya 2002b) (Jones *et al.* 2005). However, more knowledge about exercise and its beneficial effects among cancer survivors (Speck *et al.* 2010), and even association between PA and survival (Holick *et al.* 2008) (Pierce *et al.* 2007), seem to have influenced on how frequently oncologists or physicians advice their patients about the importance of lifestyle changes. A recent study of Karvinen and colleagues indicates that almost two thirds of the oncologists talked about PA with their cancer patients (Karvinen *et al.* 2010).

Almost all cancer survivors preferred to receive exercise counselling face-to-face. Approximately half of the respondents preferred to receive exercise counselling immediately after treatment and preferably at a hospital given by an exercise specialist affiliated to a cancer center. These results are supported by previous studies (Jones & Courneya 2002a) (Karvinen *et al.* 2006) (Karvinen *et al.* 2007b). Contrary to this, Jones and colleagues found that brain cancer patients preferred technological solutions such as e-mail or internet. One explanation could be the younger age of patients in this study as compared to the other (Jones *et al.* 2007). Higher compared to our results, Jones and Courneya found that three quarters wanted to receive exercise counselling from an exercise specialist at a cancer center (Jones & Courneya 2002a), while Karvinen and colleagues found in two different studies a lower percentage compared to us (Karvinen *et al.* 2006) (Karvinen *et al.* 2007b). Karvinen *et al.* argues that the discrepancy observed could be explained by the different time since diagnosis in the samples (Karvinen *et al.* 2006). Shortly after treatment patients more frequently prefer to get exercise advice from someone affiliated to a cancer center, this could be due to uncertainty around exercise related to late effects from cancer and cancer treatment etc.

#### *Interest in exercise programming*

We found that the majority of Norwegian cancer survivors were both able to participate and interested in an exercise programming. In accordance, findings among survivors of bladder cancer, endometrial cancer, ovarian cancer and Non-Hodgkin's lymphoma also showed that the majority were interested in exercise programming (Karvinen *et al.* 2007b) (Karvinen *et al.* 2006) (Stevinson *et al.* 2009) (Vallance *et al.* 2006). The high number of cancer survivors interested in exercise programming, emphasizing the importance of offering exercise as part of cancer care. According to Canadian and U.S. studies, the preferred type of activity was walking (55% to 81%) (Jones & Courneya 2002a) (Karvinen *et al.* 2007b) (Karvinen *et al.* 2006) (Rogers *et al.* 2004) (Stevinson *et al.* 2009) (Vallance *et al.* 2006). In accordance, walking was also the number one preferred activity, but with a smaller proportion (33%) in our study. Resistance training (23%) appeared as the second option and the next preferred activity was stretching (20%). One possible explanation for the difference of walking in Norway compared to U.S. and Canada could be that walking for many Norwegians is more a daily activity or a means of transport, rather than an exercise program, and therefore not reported as frequently as an exercise program. Recent surveys in Norway shows that almost half of the general population walks at least 10 minutes every day (Norwegian Directorate for

Health 2008) and that walking/hiking is the number one activity (Anderssen *et al.* 2009). In Canada and the U.S. the use of a vehicle in the daily life is even more common than in Norway, so it might be that to prefer walking as an exercise program in those studies is a good opportunity to increase their daily walking. Walking chosen as number one activity is reasonable as walking is a suitable exercise type for most adults due to its nearly universal use and low impact on the skeleton (Morris & Hardman 1997). Resistance training being second most popular activity can be explained by the growing evidence of health benefits of resistance training (Kell *et al.* 2001) (Phillips & Winett 2010). In recent years in Norway there have been an increase in the numbers of new established fitness centers and accordingly an increase in people working out at such centers. Resistance training is one of the most popular types of activity at fitness centers. Not only young men, but also women are following this trend (Anderssen *et al.* 2009). Anderssen *et al.* found that one quarter of their respondents preferred fitness center as place to exercise (Anderssen *et al.* 2009). Resistance training has also shown to be beneficial for cancer survivors (Galvao *et al.* 2010) (Segal *et al.* 2009). Surprisingly many favored stretching in the present study, which has not been on top three of activity preferences in any of the other studies (Jones & Courneya 2002a) (Karvinen *et al.* 2007b) (Karvinen *et al.* 2006) (Vallance *et al.* 2006). One reason could be that one quarter of the participants was breast cancer survivors and this group might be interested in stretching to improve their arm function and flexibility in the area around. Another reason could be the recent increased popularity of yoga and stress relief programs, which focus on stretching among other things. Studies on yoga have shown potential benefit on emotional outcomes, fatigue and menopausal symptoms in breast cancer survivors (Carson *et al.* 2009) (Danhauer *et al.* 2009).

Approximately three quarters of respondents preferred to start the exercise program immediately after or 3-6 months after end of treatment. These findings are in accordance with other studies, indicating that cancer survivors want to start an exercise program after treatment rather than before or during treatment (Karvinen *et al.* 2007b) (Karvinen *et al.* 2006) (Spence *et al.* 2010) (Stevinson *et al.* 2009) (Vallance *et al.* 2006). The possible reasons for why the majority of cancer patients prefer to start after treatment could be that at the time of diagnosis and during treatment they regard themselves as too sick, physically unfit, fatigued and they are occupied with thoughts and anxiety of the cancer and its treatment. Contrary, Courneya and Jones actually found a slight preference

for starting exercise before/during treatment rather than after treatment (Jones & Courneya 2002a).

Our results indicate that half of the sample preferred to exercise together with someone else such as other cancer survivors, friends or family, rather than alone. This is consistent with some prior studies (Karvinen *et al.* 2006) (Stevinson *et al.* 2009) (Vallance *et al.* 2006). It is well-known that social support is important for exercise adherence and maintenance (McAuley *et al.* 2003). Furthermore, in our study one third preferred to exercise at a community fitness center. Other studies, in contrast to ours, found that home was the preferred place to exercise (Jones & Courneya 2002a) (Karvinen *et al.* 2007b) (Karvinen *et al.* 2006) (Stevinson *et al.* 2009) (Vallance *et al.* 2006). In summary, this indicates that cancer survivors do have some varying preferences and it could be due to differences in study samples, difference between countries and type of lifestyle.

### **6.2.3 Exercise behavior and associated factors (Study B, Paper III)**

Less than half of the cancer survivors in our study were physically active after treatment. There was a slight decrease in number of physically actives from before diagnosis to after treatment. Almost three quarters did not change their LPA; one third was active both before diagnosis and after treatment and four out of ten were inactive at both time points. Twelve percent were inactive before diagnosis but active after treatment, whereas 15% were active before diagnosis but inactive after treatment.

Our study has shown different results than other studies of similar nature, although in other countries. We found that 45% of Norwegian cancer survivors reported to be physically active after treatment, compared to similar studies where about 25-30% have reported to be physically active after treatment (Coups *et al.* 2009a) (Courneya *et al.* 2005) (Lynch *et al.* 2007) (Milne *et al.* 2007) (Peddle *et al.* 2008) (Stevinson *et al.* 2007b) (Vallance *et al.* 2005). Norwegian cancer survivors therefore seem to be somehow more active than their North-American and Australian counterparts. Recently, a report from The Norwegian Directorate of Health showed that 43% of men and 32% of women of the Norwegian general population meet exercise guidelines based on self-report (n = 3464) (Anderssen *et al.* 2009). Although, this study used a different questionnaire (International Physical Activity Questionnaire) than the North-American, Australian and our studies and the calculation of the percentage, for

meeting exercise guidelines, was done using a stricter cut-off than ours; at least 30 minutes of moderate PA every day ( $\geq 210$  minutes per week)(Anderssen *et al.* 2009). However, looking at the result from the objective activity measures collected by Andersen and colleagues, only 18% of the men and 22% of the women fulfilled the recommended amount of weekly exercise (Anderssen *et al.* 2009). A gap between objective and subjective reporting of LPA is thus evident. Based on self-reported data the Norwegian cancer survivors do not seem to be less active than the general Norwegian population. This is supported by recent findings from a population-based cohort, the Norwegian Woman and Cancer study, showing that the LPA about 2.5 years after diagnosis was similar between the survivors of breast cancer (n=563), colorectal cancer (n=130) and cancer-free women (n=43,154) (Skeie *et al.* 2009) Two studies of long-term Hodgkin's lymphoma survivors and testicular cancer survivors showed that the cancer survivors even had a higher LPA compared to the general population (Oldervoll *et al.* 2007) (Thorsen *et al.* 2003).

One explanation for the different prevalence of physically active found in Norwegian cancer survivors compared to the North-American and Australian cancer survivors might be that both traditionally and culturally Norway is a country where PA and especially outside activities have been emphasized through generations. The Norwegian Health Authorities, media and commercial companies have a high focus on a healthy lifestyle. Nevertheless, there has been a change in Norway as well as in other parts of the world in which sedentary activities such as use of computers, watching at television and playing computer games both in work situations and in leisure contribute to decreased PA. Reasons as lack of time, lack of enjoyment from exercise and lack of self-discipline are also predictors of decreasing exercise behavior in the general population (Troost *et al.* 2002).

Corresponding with our hypothesis, we found that individuals at an older age, high BMI, low education, presence of comorbidity and smokers were more likely to be physically inactive after treatment compared to individuals at a young age, low BMI, high education, absence of comorbidity and non-smokers. These results are well in line with previously and contemporary findings (Bellizzi *et al.* 2009) (Coups *et al.* 2009a) (Hong *et al.* 2007) (Lynch *et al.* 2007) (Stevinson *et al.* 2009).

Overall, we did not find a big difference in the proportion of physically actives from before diagnosis to after treatment. There was only a total decrease in 3%. It is reasonable with some

decrease in LPA because of the health condition after cancer, also the affect of recall bias might have influenced as discussed previously. In line with our results in total, in the Norwegian Woman and Cancer study the LPA did not change from the time of the first questionnaire (before diagnosis) to the second questionnaire with a mean time of 6 years in between (Skeie *et al.* 2009). Skeie et al have a good design with the information on LPA asked actually before diagnosis, however their primary outcome was dietary changes (Skeie *et al.* 2009). They used a different questionnaire for LPA than us and that could not yet be translated into PA recommendations, therefore comparisons can not be made. We found that 15% decreased their LPA (relapsers) and 12% increased their LPA (adopters). In contrast, twice as many relapsed than adopted in their LPA among bladder cancer survivors (Karvinen *et al.* 2007a). Contrary to our findings, most studies have found a higher percentage that decreases their LPA from before diagnosis to after treatment (Blanchard *et al.* 2003) (Courneya & Friedenreich 1997a) (Courneya & Friedenreich 1997b) (Irwin *et al.* 2003) . Karvinen and colleagues also found that two thirds were persistently inactive (inactive both before diagnosis and after treatment), which is a much higher prevalence compared to our results (Karvinen *et al.* 2007a). Type of cancer and older age are possible reasons for these differences.

Our findings indicate that a decrease in LPA from before diagnosis to after treatment is associated with comorbidity, disease stage and smoking. In accordance, Coups and colleagues found that lung cancer survivors with more comorbidities were more likely to become sedentary after treatment (Coups *et al.* 2009b). Somewhat in line with our findings, Lynch et al found an association between having received adjuvant treatment therapy and a decline in LPA (Lynch *et al.* 2007). It is reasonable to assume that adjuvant treatment could be a factor linked to the disease stage. Not surprisingly, our results indicate that an increase LPA from before diagnosis to after treatment is associated with higher education. Approximately half of the adopters had a higher education, whereas only one third of the persistently inactives had a higher education. It could be that the underlying knowledge about benefits of PA in general and post-treatment health benefits of PA for some can lead to positive change in exercise behavior. Also, being a cancer patient can for some have influence upon subsequent healthy behavior; in the literature this is described as a 'teachable moment' that may play an important role in guiding survivors toward a life style that improves overall health (Demark-Wahnefried *et al.* 2005). It could explain the ones who adapted from being inactive before diagnosis to becoming active after diagnosis.

Focus needs to be placed on those that are physically inactive before diagnosis and after treatment. This group and those at risk of becoming inactive after treatment are in special need of PA interventions. Several of the conditions found associated with physical inactivity mentioned above are risk factors for an overall decrease of health. So, for these subgroups exercise will not only be beneficial because of cancer-related issues, but also in a general health perspective. Compared to the general population, cancer patients have an increased risk of cardiovascular illnesses, secondary cancer, weight issues and osteoporosis (Diamond *et al.* 2004) (Kirova *et al.* 2008) (Smith 2004) (Tichelli & Socie 2005) (Yeh & Bickford 2009). This supports the importance of implementation of PA among cancer patients with morbidities which are positively influenced by PA both under and after treatment. Finally, our findings in *Paper III* indicate that interventions focusing on PA should primarily focus on the identified individuals being physical inactive or in risk of becoming inactive in order to increase or maintain their LPA.

#### **6.2.4 A 1-week inpatient course (Study C, Paper IV)**

Three months after a 1-week inpatient course for PCa patients, reductions in level of total and physical fatigue, and of PSA-anxiety were found. No significant changes were observed for general PCa anxiety subscale, fear of recurrence subscale, level of PA, anxiety/depression or Global QoL. The majority of the responders reported that the course had helped them to meet everyday requirements.

Despite some positive results for reduction in fatigue and PSA-anxiety, effects at 3-month of PCa specific courses did not influence on most of the health-related outcomes. In contrast, Johnsson *et al.* found that 46 breast cancer patients attending a two-week inpatient rehabilitation improved significantly concerning physical and mental health as well as exhaustion and fatigue at three months after the program. Women who were predicted to experience problems returning to work or managing daily activities met requirements to be a part of the rehabilitation program (Johnsson *et al.* 2010). We did not have such inclusion criteria in our study. At baseline these breast cancer patients scored lower on life satisfaction compared to Swedish women in general (Johnsson *et al.* 2010). With this starting point, the sample of Johnsson *et al.* had probably a bigger potential to improve than our sample had. More in line with our findings, Jorgensen *et al.* did not find any changes in QoL and mental

distress at 1- and 6-month follow-up of 177 breast cancer patients attending a 1-week inpatient program (Jorgensen *et al.* 2009). The strength of the latter study was the presence of a control group. A randomized study from the same rehabilitation centre did not find significant differences in changes on health behavior such as PA, smoking and alcohol consumption, BMI or self-reported health at 1- and 6-months follow up between the intervention group and the usual care group (Ibfelt *et al.* 2011). The authors argue that the lack of improvement could be due to the relatively long period of time from end of treatment to the attendance of the course (2 years), and this amount of time limits the capacity to improve (a ceiling effect) (Jorgensen *et al.* 2009).

Similar inference could be drawn from our study also. Fifty percent of our sample participated more than 1.5 years after diagnosis, assuming at the time their health conditions were stabilized. A methodological problem to consider in future studies of cancer rehabilitation is the level of global health at inclusion both for cases and controls. We think this is a general challenge for intervention studies in convenient samples. By including all subjects attending a program many will score high on the outcomes at baseline and further improvement is unrealistic. An alternate strategy would be to include subjects that at baseline have an already reported reduced mental and/or physical health. The study would thereby have a more homogeneous group. Our sample was a heterogeneous sample with regard to age and treatment. We have to admit that the rehabilitation needs among younger active men who have undergone only curative treatment of localized PCa probably differ from the needs of older men with life-long androgen-suppressive therapy due to metastatic disease.

In our study, fatigue was reduced from baseline to follow up. Due to lack of a control group in our study, we do not know whether the positive changes in fatigue and PSA-anxiety are caused by the intervention or not. One explanation for the improved fatigue observed could be “regression towards mean” rather than the intervention per se. The improvement at T1 could correspond to this spontaneous change to the patient’s habitual level of fatigue (Chernick & Friis 2003). The possibility that it was the 1-week intervention that improved fatigue scores must eventually be confirmed with a control group.

The few inpatient studies existing in this area have been performed in breast cancer populations. We have to be aware of this when comparing our results, in terms of the differences in types of cancer, late effects of treatment, gender, age etc. It might be than



women benefit more from such inpatients program than men. Berglund and colleagues have examined the effect of outpatient programs for PCa. They did not find any significant improvement in mental distress and QoL at follow-up, which are in line with our results (Berglund *et al.* 2007). The limited sample size makes it difficult to observe significant effects on the outcomes in our study and the risk for type II statistical error is therefore present.

For some patients the option of going away from home during a rehabilitation program is not optimal. The burden of leaving the family and home after months with treatment and time spent at the hospital may reduce the benefit of rehabilitation per se. In these cases, an outpatient program would be more ideal. However, to be able to participate in an outpatient program, there must be a program offered in the area and the content and structure of such programs may differ from place to place. An individual living in urban areas will probably have more options compared to an individual living in rural areas. For some, the only option for rehabilitation is to attend an inpatient program away from home because of the lack of programs in the local area.

## 7.0 Conclusions

- The majority of cancer patients reported need for at least one rehabilitation service and physical rehabilitation services were more frequently needed than other types of services. Changes in employment status due to cancer and received treatment with chemotherapy were associated with reporting needs for all rehabilitation services.
- Two thirds of those who reported a need also reported a need for two or more services. Need for complex rehabilitation were associated with younger age, living alone, high education, not working, changes in employment status due to cancer, presence of comorbidities, having breast cancer and received chemotherapy and radiotherapy together with or without other treatment modalities.
- Forty percent of cancer patients reported unmet needs for rehabilitation services and factors associated with unmet needs were living alone, changes in employment status due to cancer and presence of comorbidities.
- The majority of Norwegian cancer survivors were interested in receiving exercise counselling. The cancer survivors preferred face-to-face exercise counselling with an exercise specialist, at a hospital, immediately after treatment.
- The majority of Norwegian cancer survivors were interested in an exercise program. The cancer survivors preferred walking as activity type, at moderate intensity, to start immediately after treatment and to be scheduled and supervised.
- The interest in exercise counselling was associated with younger age for both genders. In men the interest of exercise counselling was also associated with presence of comorbidity, and having received chemotherapy, and in women interest of exercise counselling was associated with higher education and a decrease in LPA.
- Less than half of the cancer survivors were physically active after treatment. About three quarters of the cancer survivors remained stable in their LPA; 40% were inactive

both before diagnosis and after treatment and 33% were active at both time points. The remaining quarter changed their LPA with about half of them in negative direction.

- Demographical and medical factors such as older age, a non-healthy weight, lower education, presence of comorbidity and smoking were associated with being inactive after treatment. Presence of comorbidity, distant disease and smoking were associated with a decrease in LPA from before diagnosis to after treatment. High education was associated with an increase in LPA from before diagnosis to after treatment.
- The effects of an intensive 1-week inpatient course were minor reductions in fatigue and PSA-anxiety and satisfied patients. An intensive 1-week course did not have a major impact on most of the health-related outcomes in PCa patients after three months.

## 8.0 Future perspectives

- Future focus should be more directed towards content of the rehabilitation services and their effects, and prospective studies are needed in order to investigate the optimal content of the rehabilitation services for cancer patients and at what time they are mostly needed, as well as to identify patients that will benefit from the different services.
- Based on findings of preferences for exercise counselling and exercise programming, the development of targeted exercise counselling and exercise programmes for cancer survivors is relevant to test out in future studies.
- As we have more knowledge of the characteristics of cancer survivors at risk of physical inactivity after treatment, physicians and other health care personal can through a few simple questions or through the medical record identify cancer survivors at risk of physical inactivity, some of which may be accessible for exercise programmes in order to regain or maintain their physical activity level.
- Controlled trials, directed towards a more homogenous group of patients with anticipated recovery capacity are needed for documentation of efficacy rehabilitation efforts among cancer patients. There is also a need to further investigate the effects of different length of existing rehabilitation programs.

## References

- Aaronson N.K., Ahmedzai S., Bergman B., Bullinger M., Cull A., Duez N.J., Filiberti A., Flechtner H., Fleishman S.B. & de Haes J.C. (1993) The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J.Natl.Cancer Inst.* **85**, 365-376.
- Adami H., Hunter D., & Trichopoulos D. (2002) Textbook of cancer epidemiology. Oxford University Press, Oxford.
- Adamsen L., Quist M., Andersen C., Moller T., Herrstedt J., Kronborg D., Baadsgaard M.T., Vistisen K., Midtgaard J., Christiansen B., Stage M., Kronborg M.T., & Rorth M. (2009) Effect of a multimodal high intensity exercise intervention in cancer patients undergoing chemotherapy: randomised controlled trial. *BMJ* **339**, b3410.
- Altman D.G., Schulz K.F., Moher D., Egger M., Davidoff F., Elbourne D., Gotzsche P.C., & Lang T. (2001) The revised CONSORT statement for reporting randomized trials: explanation and elaboration. *Ann.Intern.Med.* **134**, 663-694.
- Anastasi A. (1988) Psychological testing. Macmillan, New York.
- Anderssen S.A., Hansen B.H., Kolle E., Steene-Johannessen J., Børsheim E., & Holme I.et.al. Physical activity among adults and elderly in Norway. SI-1754, 1-105. 2009. Norwegian Directorate of Health. Ref Type: Report
- Asch D.A., Jedrzewski M.K., & Christakis N.A. (1997) Response rates to mail surveys published in medical journals. *J Clin Epidemiol.* **50**, 1129-1136.
- Aziz N.M. (2007) Cancer survivorship research: state of knowledge, challenges and opportunities. *Acta Oncol* **46**, 417-432.
- Baker F., Denniston M., Smith T., & West M.M. (2005) Adult cancer survivors: how are they faring? *Cancer* **104**, 2565-2576.
- Bardwell W.A. & Ancoli-Israel S. (2008) Breast Cancer and Fatigue. *Sleep Med.Clin* **3**, 61-71.
- Bellizzi K.M., Rowland J.H., Arora N.K., Hamilton A.S., Miller M.F., & Aziz N.M. (2009) Physical activity and quality of life in adult survivors of non-Hodgkin's lymphoma. *J Clin Oncol* **27**, 960-966.
- Berglund G., Petersson L.M., Eriksson K.C., Wallenius I., Roshanai A., Nordin K.M., Sjoden P.O., & Haggman M. (2007) "Between Men": a psychosocial rehabilitation programme for men with prostate cancer. *Acta Oncol.* **46**, 83-89.
- Berglund G., Petersson L.M., Eriksson K.R., & Haggman M. (2003) "Between men": patient perceptions and priorities in a rehabilitation program for men with prostate cancer. *Patient.Educ.Couns.* **49**, 285-292.
- Berruti A., Dogliotti L., Terrone C., Cerutti S., Isaia G., Tarabuzzi R., Reimondo G., Mari M., Ardisson P., De L.S., Fasolis G., Fontana D., Rossetti S.R., & Angeli A. (2002) Changes in bone mineral density, lean body mass and fat content as measured by dual energy x-ray absorptiometry in patients with prostate cancer without apparent bone metastases given androgen deprivation therapy. *J Urol.* **167**, 2361-2367.
- Bjelland I., Dahl A.A., Haug T.T., & Neckelmann D. (2002) The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J.Psychosom.Res.* **52**, 69-77.
- Blair S.N. & Brodney S. (1999) Effects of physical inactivity and obesity on morbidity and mortality: current evidence and research issues. *Med.Sci.Sports Exerc.* **31**, S646-S662.

- Blanchard C.M., Denniston M.M., Baker F., Ainsworth S.R., Courneya K.S., Hann D.M., Gesme D.H., Reding D., Flynn T., & Kennedy J.S. (2003) Do adults change their lifestyle behaviors after a cancer diagnosis? *Am.J.Health Behav.* **27**, 246-256.
- Bower J.E., Ganz P.A., Desmond K.A., Bernards C., Rowland J.H., Meyerowitz B.E., & Belin T.R. (2006) Fatigue in long-term breast carcinoma survivors: a longitudinal investigation. *Cancer* **106**, 751-758.
- Boyle P. & Levin B. World Cancer Report 2008. 2008. Lyon, IARC.  
Ref Type: Report
- Cancer Registry of Norway. Cancer in Norway 2008 - Cancer incidence, mortality, survival and prevalence in Norway. 2009. Oslo, Cancer Registry of Norway.  
Ref Type: Report
- Carson J.W., Carson K.M., Porter L.S., Keefe F.J., & Seewaldt V.L. (2009) Yoga of Awareness program for menopausal symptoms in breast cancer survivors: results from a randomized trial. *Support.Care Cancer* **17**, 1301-1309.
- Caspersen C.J., Powell K.E., & Christenson G.M. (1985) Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research. *Public Health Rep.* **100**, 126-131.
- Cella D.F. & Tulsky D.S. (1993) Quality of life in cancer: definition, purpose, and method of measurement. *Cancer Invest* **11**, 327-336.
- Centers for Disease control and prevention. Behavioral risk factor surveillance system survey data. 2007. Atlanta, Georgia, USA, Departement of health and human services, Center for disease control and prevention.  
Ref Type: Report
- Chachaj A., Malyszczak K., Pyszel K., Lukas J., Tarkowski R., Pudelko M., Andrzejak R., & Szuba A. (2010) Physical and psychological impairments of women with upper limb lymphedema following breast cancer treatment. *Psychooncology.* **19**, 299-305.
- Chalder T., Berelowitz G., Pawlikowska T., Watts L., Wessely S., Wright D., & Wallace E.P. (1993) Development of a fatigue scale. *J.Psychosom.Res.* **37**, 147-153.
- Chernick M.R. & Friis R.H. (2003) Introductory Biostatistics for the Health Sciences. Modern Applications Including Bootstrap. John Wiley & Sons, Inc., Hoboken, NJ.
- Chlebowski R.T., Aiello E., & McTiernan A. (2002) Weight loss in breast cancer patient management. *J Clin Oncol* **20**, 1128-1143.
- Cho O.H., Yoo Y.S., & Kim N.C. (2006) Efficacy of comprehensive group rehabilitation for women with early breast cancer in South Korea. *Nurs.Health Sci.* **8**, 140-146.
- Coughlin S.S. (1990) Recall bias in epidemiologic studies. *J Clin Epidemiol.* **43**, 87-91.
- Coups E.J., Park B.J., Feinstein M.B., Steingart R.M., Egleston B.L., Wilson D.J., & Ostroff J.S. (2009a) Correlates of physical activity among lung cancer survivors. *Psychooncology.* **18**, 395-404.
- Coups E.J., Park B.J., Feinstein M.B., Steingart R.M., Egleston B.L., Wilson D.J., & Ostroff J.S. (2009b) Physical activity among lung cancer survivors: changes across the cancer trajectory and associations with quality of life. *Cancer Epidemiol.Biomarkers Prev.* **18**, 664-672.
- Courneya K.S. (2003) Exercise in cancer survivors: an overview of research. *Med.Sci.Sports Exerc.* **35**, 1846-1852.
- Courneya K.S. & Friedenreich C.M. (1997a) Relationship between exercise during treatment and current quality of life among survivors of breast cancer. *Journal of Psychosocial Oncology* **15**, 35-57.

- Courneya K.S. & Friedenreich C.M. (1997b) Relationship between exercise pattern across the cancer experience and current quality of life in colorectal cancer survivors. *J Altern.Complement Med.* **3**, 215-226.
- Courneya K.S., Friedenreich C.M., Sela R.A., Quinney H.A., Rhodes R.E., & Handman M. (2003) The group psychotherapy and home-based physical exercise (group-hope) trial in cancer survivors: physical fitness and quality of life outcomes. *Psychooncology.* **12**, 357-374.
- Courneya K.S., Karvinen K.H., Campbell K.L., Pearcey R.G., Dundas G., Capstick V., & Tonkin K.S. (2005) Associations among exercise, body weight, and quality of life in a population-based sample of endometrial cancer survivors. *Gynecol.Oncol.* **97**, 422-430.
- Courneya K.S., Karvinen K.H. & Vallance J.K. (2007) Exercise Motivation and Behavior Change. In: *Handbook of Cancer Survivors* (ed Feuerstein M.), pp. 113-132. Springer, New York.
- Dahl A.A. (2009) Psykiske symptomer og lidelser. In: (eds Fossa S.D., Loge J.H. & Dahl A.A.), pp.113-135. Gyldendal Norsk Forlag, Oslo.
- Dahl A.A., Haaland C.F., Mykletun A., Bremnes R., Dahl O., Klepp O., Wist E., & Fossa S.D. (2005) Study of anxiety disorder and depression in long-term survivors of testicular cancer. *J Clin Oncol* **23**, 2389-2395.
- Danhauer S.C., Mihalko S.L., Russell G.B., Campbell C.R., Felder L., Daley K., & Levine E.A. (2009) Restorative yoga for women with breast cancer: findings from a randomized pilot study. *Psychooncology.* **18**, 360-368.
- Demark-Wahnefried W., Aziz N.M., Rowland J.H., & Pinto B.M. (2005) Riding the crest of the teachable moment: promoting long-term health after the diagnosis of cancer. *J Clin Oncol* **23**, 5814-5830.
- Demark-Wahnefried W., Clipp E.C., Morey M.C., Pieper C.F., Sloane R., Snyder D.C., & Cohen H.J. (2004) Physical function and associations with diet and exercise: Results of a cross-sectional survey among elders with breast or prostate cancer. *Int.J Behav.Nutr.Phys.Act.* **1**, 16. doi:10.1186/1479-5868-1-16.
- Demark-Wahnefried W., Peterson B., McBride C., Lipkus I., & Clipp E. (2000) Current health behaviors and readiness to pursue life-style changes among men and women diagnosed with early stage prostate and breast carcinomas. *Cancer* **88**, 674-684.
- DeVita V.T., Hellmann S., & Rosenberg S.A. (2011) *Cancer: Principles and Practice of oncology*, 6th edn. Lippincott-Raven, Philadelphia.
- Diamond T.H., Bucci J., Kersley J.H., Aslan P., Lynch W.B., & Bryant C. (2004) Osteoporosis and spinal fractures in men with prostate cancer: risk factors and effects of androgen deprivation therapy. *J Urol.* **172**, 529-532.
- Ernstmann N., Neumann M., Ommen O., Galushko M., Wirtz M., Voltz R., Hallek M., & Pfaff H. (2009) Determinants and implications of cancer patients' psychosocial needs. *Support.Care Cancer* **17**, 1417-1423.
- Fann J.R., Thomas-Rich A.M., Katon W.J., Cowley D., Pepping M., McGregor B.A., & Gralow J. (2008) Major depression after breast cancer: a review of epidemiology and treatment. *Gen.Hosp.Psychiatry* **30**, 112-126.
- Fløtten T., Torp S., Kavli H., Nielsen R., Syse J., Grønningseter A.B., & Gustavsen K. Kreftrammedes levekår. Om arbeid, økonomi, rehabilitering og sosial støtte. Fafo-rapport 2008:47. 2008.  
Ref Type: Report
- Fossa S.D., Dahl A.A., Smeland S., Thorsen L., & Loge J.H. (2008a) [Rehabilitation after cancer]. *Tidsskr.Nor Laegeforen.* **128**, 2615-2616.
- Fossa S.D., Giercksky K.-E. & Smeland S. (2009a) Oversikt over kreftbehandling og bivirkninger. In: *Kreftoverlevende. Ny kunnskap og nye muligheter i et langtidsperspektiv* (eds Fossa S.D., Loge J.H. & Dahl A.A.), pp. 41-57. Gyldendal Norsk Forlag, Oslo.

- Fossa S.D., Kvaloy J., Kvaloy S., Loge J.H., & Dahl A.A. (2008b) [Courses for cancer patients--15 years' experience at The Montebello Centre in Norway]. *Tidsskr.Nor Laegeforen.* **128**, 2554-2557.
- Fossa S.D., Loge J.H., & Dahl A.A. (2008c) Long-term survivorship after cancer: how far have we come? *Ann.Oncol* **19 Suppl 5**, v25-v29.
- Fossa S.D., Loge J.H., & Dahl A.A. (2009b) Kreftoverlevende: ny kunnskap og nye muligheter i et langtidsperspektiv. Gyldendal akademisk, Oslo.
- Galvao D.A., Taaffe D.R., Spry N., Joseph D., & Newton R.U. (2010) Combined resistance and aerobic exercise program reverses muscle loss in men undergoing androgen suppression therapy for prostate cancer without bone metastases: a randomized controlled trial. *J Clin Oncol* **28**, 340-347.
- Galvao D.A., Taaffe D.R., Spry N., Joseph D., Turner D., & Newton R.U. (2009) Reduced muscle strength and functional performance in men with prostate cancer undergoing androgen suppression: a comprehensive cross-sectional investigation. *Prostate Cancer Prostatic Dis* **12**, 198-203.
- Ganz P.A. (2007) *Cancer Survivorship*. Springer, New York.
- Ganz P.A. (2009) Survivorship: adult cancer survivors. *Prim.Care* **36**, 721-741.
- Ganz P.A. & Bower J.E. (2007) Cancer related fatigue: a focus on breast cancer and Hodgkin's disease survivors. *Acta Oncol* **46**, 474-479.
- Gerber L.H. & Vargo M. (1998) Rehabilitation for patients with cancer diagnoses. In: *Rehabilitation medicine: principles and practice* (ed DeLisa J.A.), 3rd edn, pp. 1293-1317. Lippincott-Raven, Philadelphia.
- Godin G., Jobin J., & Bouillon J. (1986) Assessment of leisure time exercise behavior by self-report: a concurrent validity study. *Can.J.Public Health* **77**, 359-362.
- Godin G. & Shephard R.J. (1985) A simple method to assess exercise behavior in the community. *Can.J Appl.Sport Sci.* **10**, 141-146.
- Grøtvedt L. Helseprofil for Oslo. Voksne. 1-80. 2002. Oslo, Norwegian Institute of Public Health. Ref Type: Report
- Guillemin F., Bombardier C., & Beaton D. (1993) Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol.* **46**, 1417-1432.
- Haskell W.L., Lee I.M., Pate R.R., Powell K.E., Blair S.N., Franklin B.A., Macera C.A., Heath G.W., Thompson P.D., & Bauman A. (2007) Physical activity and public health: updated recommendation for adults from the American College of Sports Medicine and the American Heart Association. *Med.Sci.Sports Exerc.* **39**, 1423-1434.
- Haydon A.M., Macinnis R.J., English D.R., & Giles G.G. (2006) Effect of physical activity and body size on survival after diagnosis with colorectal cancer. *Gut* **55**, 62-67.
- Heim M.E., Kunert S., & Ozkan I. (2001) Effects of inpatient rehabilitation on health-related quality of life in breast cancer patients. *Onkologie.* **24**, 268-272.
- Hellbom M., Bergelt C., Bergenmar M., Gijssen B., Loge J.H., Rautalahti M., Smaradottir A., & Johansen C. (2011) Cancer rehabilitation: A Nordic and European perspective. *Acta Oncol* **50**, 179-186.
- Hjermstad M.J., Fayers P.M., Bjordal K., & Kaasa S. (1998) Health-related quality of life in the general Norwegian population assessed by the European Organization for Research and Treatment of Cancer Core Quality-of-Life Questionnaire: the QLQ=C30 (+ 3). *J Clin Oncol* **16**, 1188-1196.
- Hjermstad M.J., Fossa S.D., Bjordal K., & Kaasa S. (1995) Test/retest study of the European Organization for Research and Treatment of Cancer Core Quality-of-Life Questionnaire. *J.Clin.Oncol.* **13**, 1249-1254.



- Hjermstad M.J., Fossa S.D., Oldervoll L., Holte H., Jacobsen A.B., & Loge J.H. (2005) Fatigue in long-term Hodgkin's Disease survivors: a follow-up study. *J Clin Oncol* **23**, 6587-6595.
- Hodgkinson K., Butow P., Hunt G.E., Pendlebury S., Hobbs K.M., & Wain G. (2007) Breast cancer survivors' supportive care needs 2-10 years after diagnosis. *Support.Care Cancer* **15**, 515-523.
- Holick C.N., Newcomb P.A., Trentham-Dietz A., Titus-Ernstoff L., Bersch A.J., Stampfer M.J., Baron J.A., Egan K.M., & Willett W.C. (2008) Physical activity and survival after diagnosis of invasive breast cancer. *Cancer Epidemiol.Biomarkers Prev.* **17**, 379-386.
- Holland J.C. (1997) Preliminary guidelines for the treatment of distress. *Oncology (Williston.Park)* **11**, 109-114.
- Hong S., Bardwell W.A., Natarajan L., Flatt S.W., Rock C.L., Newman V.A., Madlensky L., Mills P.J., Dimsdale J.E., Thomson C.A., Hajek R.A., Chilton J.A., & Pierce J.P. (2007) Correlates of physical activity level in breast cancer survivors participating in the Women's Healthy Eating and Living (WHEL) Study. *Breast Cancer Res Treat.* **101**, 225-232.
- Horner M.J., Ries L.A.G., Krapcho M., Neyman N., & et.al. SEER Cancer Statistics Review. Website . 2009. National Cancer Institute. 2-11-2009.  
Ref Type: Electronic Citation
- Hounshell J., Tomori C., Newlin R., Knox K., Rundhaugen L., Tallman M., & Bennett C. (2001) Changes in finances, insurance, employment, and lifestyle among persons diagnosed with hairy cell leukemia. *Oncologist.* **6**, 435-440.
- Ibfelt E., Rottmann N., Kjaer T., Hoybye M.T., Ross L., Frederiksen K., Johansen C., & Dalton S.O. (2011) No change in health behavior, BMI or self-rated health after a psychosocial cancer rehabilitation: Results of a randomized trial. *Acta Oncol* **50**, 289-298.
- Indredavik B., Salvesen R., Næss H., & Thorsvik D. Behandling og rehabilitering ved hjerneslag. Nasjonale faglige retningslinjer. IS-1688. 2010. Norwegian Directorate of Health.  
Ref Type: Report
- Irwin M.L., Crumley D., McTiernan A., Bernstein L., Baumgartner R., Gilliland F.D., Kriska A., & Ballard-Barbash R. (2003) Physical activity levels before and after a diagnosis of breast carcinoma: the Health, Eating, Activity, and Lifestyle (HEAL) study. *Cancer* **97**, 1746-1757.
- Jacobs D.R., Ainsworth B.E., Hartman T.J., & Leon A.S. (1993) A simultaneous evaluation of 10 commonly used physical activity questionnaires. *Med.Sci.Sports Exerc.* **25**, 81-91.
- Johansen C. (2007) Rehabilitation of cancer patients - research perspectives. *Acta Oncol* **46**, 441-445.
- Johnsson A., Tenenbaum A., & Westerlund H. (2010) Improvements in physical and mental health following a rehabilitation programme for breast cancer patients. *Eur.J Oncol Nurs.*
- Jones L.W. & Courneya K.S. (2002a) Exercise counseling and programming preferences of cancer survivors. *Cancer Practice* **10**, 208-215.
- Jones L.W. & Courneya K.S. (2002b) Exercise discussions during cancer treatment consultations. *Cancer Pract.* **10**, 66-74.
- Jones L.W., Courneya K.S., Peddle C., & Mackey J.R. (2005) Oncologists' opinions towards recommending exercise to patients with cancer: a Canadian national survey. *Support.Care Cancer* **13**, 929-937.
- Jones L.W., Guill B., Keir S.T., Carter K., Friedman H.S., Bigner D.D., & Reardon D.A. (2007) Exercise interest and preferences among patients diagnosed with primary brain cancer. *Support Care Cancer.* **15**, 47-55.
- Jorgensen I.L., Frederiksen K., Boesen E., Elsass P., & Johansen C. (2009) An exploratory study of associations between illness perceptions and adjustment and changes after psychosocial rehabilitation in survivors of breast cancer. *Acta Oncol* **48**, 1119-1127.

Juvet L.K., Elvsaas I.K.Ø., Leivseth G., Anker G., Bertheussen G.F., Falkmer U., Fors E.A., Lundgren S., Oldervoll L.M., & Norderhaug I.N. Rehabilitation of breast cancer patients. 02-2009. 2009. Oslo, Norwegian Knowledge Centre for the Health Services.  
Ref Type: Report

Kåresen R. & Wist E. (2000) *Kreftsykdommer. En basisbok for helsepersonell*. Gyldendal Akademisk, Oslo.

Karvinen K.H., Courneya K.S., Campbell K.L., Pearcey R.G., Dundas G., Capstick V., & Tonkin K.S. (2006) Exercise preferences of endometrial cancer survivors: a population-based study. *Cancer Nursing* **29**, 259-265.

Karvinen K.H., Courneya K.S., North S., & Venner P. (2007a) Associations between exercise and quality of life in bladder cancer survivors: a population-based study. *Cancer Epidemiol.Biomarkers Prev.* **16**, 984-990.

Karvinen K.H., Courneya K.S., Venner P., & North S. (2007b) Exercise programming and counseling preferences in bladder cancer survivors: a population-based study. *Journal of Cancer Survivorship cancer*, 27-34.

Karvinen K.H., DuBose K.D., Carney B., & Allison R.R. (2010) Promotion of physical activity among oncologists in the United States. *J Support.Oncol* **8**, 35-41.

Kell R.T., Bell G., & Quinney A. (2001) Musculoskeletal fitness, health outcomes and quality of life. *Sports Med.* **31**, 863-873.

Kirova Y.M., De R.Y., Gambotti L., Pierga J.Y., Asselain B., & Fourquet A. (2008) Second malignancies after breast cancer: the impact of different treatment modalities. *Br J Cancer* **98**, 870-874.

Knols R., Aaronson N.K., Uebelhart D., Fransen J., & Aufdemkampe G. (2005) Physical exercise in cancer patients during and after medical treatment: a systematic review of randomized and controlled clinical trials. *J Clin Oncol* **23**, 3830-3842.

Korstjens I., Mesters I., van der P.E., Gijzen B., & van den B.B. (2006) Quality of life of cancer survivors after physical and psychosocial rehabilitation. *Eur.J.Cancer Prev.* **15**, 541-547.

Kyrdalen A.E., Dahl A.A., Hernes E., Hem E., & Fossa S.D. (2010) Fatigue in prostate cancer survivors treated with definitive radiotherapy and LHRH analogs. *Prostate* **70**, 1480-1489.

Laake P., Hjartaker A., Thelle D.S., & Veierød M.B. (2007) *Epidemiologiske og kliniske forskningsmetoder*. Gyldendal akademisk, Oslo.

Levitt P.M., Guralnick E.S., Kagan R., & Gilbert H. (1980) *Boken om kreft*. Universitetsforlaget, Oslo.

Loge J.H. (2009) Fatigue og depresjon. In: *Kreftoverlevende. Ny kunnskap og nye muligheter i et langtidsperspektiv* (eds Fossa S.D., Loge J.H. & Dahl A.A.), pp. 97-112. Gyldendal Norsk Forlag, Oslo.

Loge J.H., Abrahamsen A.F., Ekeberg O., & Kaasa S. (1999a) Hodgkin's disease survivors more fatigued than the general population. *J Clin Oncol* **17**, 253-261.

Loge J.H., Abrahamsen A.F., Ekeberg O., & Kaasa S. (1999b) Reduced health-related quality of life among Hodgkin's disease survivors: a comparative study with general population norms. *Ann.Oncol* **10**, 71-77.

Lu C.Y. (2009) Observational studies: a review of study designs, challenges and strategies to reduce confounding. *Int.J Clin Pract.* **63**, 691-697.

Lynch B.M., Cerin E., Newman B., & Owen N. (2007) Physical activity, activity change, and their correlates in a population-based sample of colorectal cancer survivors. *Ann.Behav.Med.* **34**, 135-143.

McAuley E., Jerome G.J., Elavsky S., Marquez D.X., & Ramsey S.N. (2003) Predicting long-term maintenance of physical activity in older adults. *Prev.Med.* **37**, 110-118.

- McNeely M.L., Campbell K.L., Rowe B.H., Klassen T.P., Mackey J.R., & Courneya K.S. (2006) Effects of exercise on breast cancer patients and survivors: a systematic review and meta-analysis. *CMAJ*. **175**, 34-41.
- Merckaert I., Libert Y., Messin S., Milani M., Slachmuylder J.L., & Razavi D. (2010) Cancer patients' desire for psychological support: prevalence and implications for screening patients' psychological needs. *Psychooncology*. **19**, 141-149.
- Meyer T. & Brooks A. (2000) Therapeutic impact of exercise on psychiatric diseases: guidelines for exercise testing and prescription. *Sports Med*. **30**, 269-279.
- Milne H.M., Gordon S., Guilfoyle A., Wallman K.E., & Courneya K.S. (2007) Association between physical activity and quality of life among Western Australian breast cancer survivors. *Psychooncology*. **16**, 1059-1068.
- Minton O. & Stone P. (2008) How common is fatigue in disease-free breast cancer survivors? A systematic review of the literature. *Breast Cancer Res.Treat.* **112**, 5-13.
- Minton O. & Stone P. (2009) A systematic review of the scales used for the measurement of cancer-related fatigue (CRF). *Ann.Oncol.* **20**, 17-25.
- Montazeri A., Vahdaninia M., Harirchi I., Ebrahimi M., Khaleghi F., & Jarvandi S. (2008) Quality of life in patients with breast cancer before and after diagnosis: an eighteen months follow-up study. *BMC.Cancer* **8**, 330.
- Morris J.N. & Hardman A.E. (1997) Walking to health. *Sports Med*. **23**, 306-332.
- Næss Ø., Rognerud M.A., & Strand B.H. Sosial ulikheter i helse. En faktarapport. 2007:1, 1-68. 2007. Oslo, Norwegian Institute of Public Health.  
Ref Type: Report
- National Cancer Institute. About Cancer Survivorship Research: Survivorship Definitions. 2006. <http://cancercontrol.cancer.gov/ocs/definitions.html> Accessed 12.04.2011.  
Ref Type: Electronic Citation
- National Cancer Institute. US cancer survivors grows to nearly 12 million. 2011. <http://www.cancer.gov/newscenter/pressreleases/2011/survivorshipMMWR2011> Accessed 12.04.2011.  
Ref Type: Electronic Citation
- Ness K.K., Wall M.M., Oakes J.M., Robison L.L., & Gurney J.G. (2006) Physical performance limitations and participation restrictions among cancer survivors: a population-based study. *Ann.Epidemiol.* **16**, 197-205.
- Nesvold I.L., Fossa S.D., Holm I., Naume B., & Dahl A.A. (2010) Arm/shoulder problems in breast cancer survivors are associated with reduced health and poorer physical quality of life. *Acta Oncol* **49**, 347-353.
- Nieboer P., Buijs C., Rodenhuis S., Seynaeve C., Beex L.V., van der W.E., Richel D.J., Nooij M.A., Voest E.E., Hupperets P., Mulder N.H., van der Graaf W.T., TenVergert E.M., van T.H., & de Vries E.G. (2005) Fatigue and relating factors in high-risk breast cancer patients treated with adjuvant standard or high-dose chemotherapy: a longitudinal study. *J Clin Oncol* **23**, 8296-8304.
- Nome O. (2001) Generell onkologi. In: *Kreftsykepleie* (eds Reitan A.M. & Schjølberg T.K.) Akribes Forlag, Gjøvik.
- Norwegian Directorate for Health. Survey about physical activity. 1-17. 2008. 3-9-2008.  
Ref Type: Electronic citation
- Norwegian Directorate of Health. Norske anbefalinger for ernæring og fysisk aktivitet. 2005. Sosial og Helsedirektoratet.  
Ref Type: Report
- Oldervoll L.M., Loge J.H., Kaasa S., Lydersen S., Hjermstad M.J., Thorsen L., Holte H., Jr., Jacobsen A.B., & Fossa S.D. (2007) Physical activity in Hodgkin's lymphoma survivors with and without chronic fatigue compared with the general population - a cross-sectional study. *BMC.Cancer* **7**, 210.

- Partridge A.H., Burstein H.J., & Winer E.P. (2001) Side effects of chemotherapy and combined chemohormonal therapy in women with early-stage breast cancer. *J Natl Cancer Inst Monogr* 135-142.
- Patterson P. (2000) Reliability, validity, and methodological response to the assessment of physical activity via self-report. *Res Q.Exerc.Sport* 71, S15-S20.
- Peddle C.J., Au H.J., & Courneya K.S. (2008) Associations between exercise, quality of life, and fatigue in colorectal cancer survivors. *Dis.Colon Rectum* 51, 1242-1248.
- Pedersen B.K. & Saltin B. (2006) Evidence for prescribing exercise as therapy in chronic disease. *Scand.J Med.Sci.Sports* 16 Suppl 1, 3-63.
- Perk J., Gohlke H., Hellemans I., Mathes P., McGee H., Monpere C., Saner H., & Sellier P. (2007) Cardiovascular prevention and rehabilitation. Springer, London.
- Peuckmann V., Ekholm O., Rasmussen N.K., Groenvold M., Christiansen P., Moller S., Eriksen J., & Sjogren P. (2009) Chronic pain and other sequelae in long-term breast cancer survivors: nationwide survey in Denmark. *Eur.J Pain* 13, 478-485.
- Phillips S.M. & Winett R.A. (2010) Uncomplicated resistance training and health-related outcomes: evidence for a public health mandate. *Curr.Sports Med.Rep.* 9, 208-213.
- Pierce J.P., Stefanick M.L., Flatt S.W., Natarajan L., Sternfeld B., Madlensky L., Al-Delaimy W.K., Thomson C.A., Kealey S., Hajek R., Parker B.A., Newman V.A., Caan B., & Rock C.L. (2007) Greater survival after breast cancer in physically active women with high vegetable-fruit intake regardless of obesity. *J Clin Oncol* 25, 2345-2351.
- Pinto B.M., Trunzo J.J., Reiss P., & Shiu S.Y. (2002) Exercise participation after diagnosis of breast cancer: trends and effects on mood and quality of life. *Psychooncology.* 11, 389-400.
- Reinertsen K.V., Cvancarova M., Loge J.H., Edvardsen H., Wist E., & Fossa S.D. (2010) Predictors and course of chronic fatigue in long-term breast cancer survivors. *J Cancer Surviv.* 4, 405-414.
- Rogers L.Q., Matevey C., Hopkins-Price P., Shah P., Dunnington G., & Courneya K.S. (2004) Exploring social cognitive theory constructs for promoting exercise among breast cancer patients. *Cancer Nurs.* 27, 462-473.
- Rosenberg M., Mills C., McCormack G., Martin K., Grove B., & Pratt S.a.B.R. Physical activity levels of Western Australian adults 2009: Findings from the physical activity taskforce adult physical activity survey. 2010. Perth, Health promotion evaluation unit, The university of Western Australia.  
Ref Type: Report
- Roth A.J., Rosenfeld B., Komblith A.B., Gibson C., Scher H.I., Curley-Smart T., Holland J.C., & Breitbart W. (2003) The memorial anxiety scale for prostate cancer: validation of a new scale to measure anxiety in men with prostate cancer. *Cancer* 97, 2910-2918.
- Rothman K.J. (2002) Epidemiology: an introduction. Oxford University Press, Oxford.
- Rothman K.J., Greenland S., & Lash T.L. (2008) Modern epidemiology. Wolters Kluwer/Lippincott Williams & Wilkins, Philadelphia.
- Ruffer J.U., Flechtner H., Tralls P., Josting A., Sieber M., Lathan B., & Diehl V. (2003) Fatigue in long-term survivors of Hodgkin's lymphoma; a report from the German Hodgkin Lymphoma Study Group (GHSG). *Eur.J Cancer* 39, 2179-2186.
- Sallis J.F. & Saelens B.E. (2000) Assessment of physical activity by self-report: status, limitations, and future directions. *Res Q.Exerc.Sport* 71, S1-14.
- Sanson-Fisher R., Girgis A., Boyes A., Bonevski B., Burton L., & Cook P. (2000) The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer* 88, 226-237.

- Schmitz K.H., Courneya K.S., Matthews C., Demark-Wahnefried W., Galvao D.A., Pinto B.M., Irwin M.L., Wolin K.Y., Segal R.J., Lucia A., Schneider C.M., von G., V, & Schwartz A.L. (2010) American College of Sports Medicine roundtable on exercise guidelines for cancer survivors. *Med.Sci.Sports Exerc.* **42**, 1409-1426.
- Schmitz K.H., Holtzman J., Courneya K.S., Masse L.C., Duval S., & Kane R. (2005) Controlled physical activity trials in cancer survivors: a systematic review and meta-analysis. *Cancer Epidemiol.Biomarkers Prev.* **14**, 1588-1595.
- Schroeder T.V. (2007) *Basisbog i medicin og kirurgi*. Munksgaard, København.
- Segal R.J., Reid R.D., Courneya K.S., Sigal R.J., Kenny G.P., Prud'Homme D.G., Malone S.C., Wells G.A., Scott C.G., & Slovynec D'Angelo M.E. (2009) Randomized controlled trial of resistance or aerobic exercise in men receiving radiation therapy for prostate cancer. *J Clin Oncol* **27**, 344-351.
- Sigal R.J., Kenny G.P., Wasserman D.H., Castaneda-Sceppa C., & White R.D. (2006) Physical activity/exercise and type 2 diabetes: a consensus statement from the American Diabetes Association. *Diabetes Care* **29**, 1433-1438.
- Skeie G., Hjartaker A., Braaten T., & Lund E. (2009) Dietary change among breast and colorectal cancer survivors and cancer-free women in the Norwegian Women and Cancer cohort study. *Cancer Causes Control* **20**, 1955-1966.
- Smith M.R. (2004) Changes in fat and lean body mass during androgen-deprivation therapy for prostate cancer. *Urology* **63**, 742-745.
- Speck R.M., Courneya K.S., Masse L.C., Duval S., & Schmitz K.H. (2010) An update of controlled physical activity trials in cancer survivors: a systematic review and meta-analysis. *J Cancer Surviv.*
- Spence R.R., Heesch K.C., & Brown W.J. (2011) Colorectal cancer survivors' exercise experiences and preferences: qualitative findings from an exercise rehabilitation programme immediately after chemotherapy. *Eur.J Cancer Care (Engl.)*, **20**, 257-266.
- Steele R. & Fitch M.I. (2008) Supportive care needs of women with gynecologic cancer. *Cancer Nurs.* **31**, 284-291.
- Stevinson C., Campbell K.L., Sellar C.M. & Courneya K.S. (2007a) Physical activity for cancer survivors. Potential benefits and guidelines. In: *Handbook of Cancer Survivorship* (ed Feuerstein M.), pp. 249-268. Springer, New York.
- Stevinson C., Faught W., Steed H., Tonkin K., Ladha A.B., Vallance J.K., Capstick V., Schepansky A., & Courneya K.S. (2007b) Associations between physical activity and quality of life in ovarian cancer survivors. *Gynecol.Oncol* **106**, 244-250.
- Stevinson C., Tonkin K., Capstick V., Schepansky A., Ladha A.B., Vallance J.K., Faught W., Steed H., & Courneya K.S. (2009) A population-based study of the determinants of physical activity in ovarian cancer survivors. *J Phys.Act.Health* **6**, 339-346.
- Strong V., Waters R., Hibberd C., Rush R., Cargill A., Storey D., Walker J., Wall L., Fallon M., & Sharpe M. (2007) Emotional distress in cancer patients: the Edinburgh Cancer Centre symptom study. *Br J Cancer* **96**, 868-874.
- Szklo M. & Nieto J. (2007) *Epidemiology. Beyond the basics*, 2nd edn. Jones and Bartlett Publishers, Sudbury.
- Thelle D.S. & Laake P. (2008) Epidemiologisk forskning: begreper og metoder. In: *Forskning i medisin og biofag* (eds Laake P., Olsen B.R. & Benestad H.B.), 2nd edn, pp. 282-320. Gyldendal Akademiske, Oslo.
- Thomas J.R. & Nelson J.K. (2001) *Research methods in physical activity*. Human Kinetics, Champaign, Ill.
- Thompson P.D., Buchner D., Pina I.L., Balady G.J., Williams M.A., Marcus B.H., Berra K., Blair S.N., Costa F., Franklin B., Fletcher G.F., Gordon N.F., Pate R.R., Rodriguez B.L., Yancey A.K., & Wenger N.K. (2003)

Exercise and physical activity in the prevention and treatment of atherosclerotic cardiovascular disease: a statement from the Council on Clinical Cardiology (Subcommittee on Exercise, Rehabilitation, and Prevention) and the Council on Nutrition, Physical Activity, and Metabolism (Subcommittee on Physical Activity). *Circulation* **107**, 3109-3116.

Thorsen L., Nystad W., Dahl O., Klepp O., Bremnes R.M., Wist E., & Fossa S.D. (2003) The level of physical activity in long-term survivors of testicular cancer. *Eur.J.Cancer* **39**, 1216-1221.

Tichelli A. & Socie G. (2005) Considerations for adult cancer survivors. *Hematology.Am.Soc.Hematol.Educ.Program*. 516-522.

Troiano R.P. (2007) Large-scale applications of accelerometers: new frontiers and new questions. *Med.Sci.Sports Exerc.* **39**, 1501.

Trost S.G., Owen N., Bauman A.E., Sallis J.F., & Brown W. (2002) Correlates of adults' participation in physical activity: review and update. *Med.Sci.Sports Exerc.* **34**, 1996-2001.

U.S.Department of Health and Human Services. 2008 Physical Activity Guidelines for Americans. Be active, healthy, and happy! 2008.  
Ref Type: Report

Vahdaninia M., Omidvari S., & Montazeri A. (2010) What do predict anxiety and depression in breast cancer patients? A follow-up study. *Soc.Psychiatry Psychiatr.Epidemiol.* **45**, 355-361.

Vallance J.K., Courneya K.S., Jones L.W., & Reiman T. (2005) Differences in quality of life between non-Hodgkin's lymphoma survivors meeting and not meeting public health exercise guidelines. *Psychooncology.* **14**, 979-991.

Vallance J.K., Courneya K.S., Jones L.W., & Reiman T. (2006) Exercise preferences among a population-based sample of non-Hodgkin's lymphoma survivors. *Eur.J.Cancer Care (Engl.)* **15**, 34-43.

Vistad I., Fossa S.D., & Dahl A.A. (2006) A critical review of patient-rated quality of life studies of long-term survivors of cervical cancer. *Gynecol.Oncol* **102**, 563-572.

Vistad I., Fossa S.D., Kristensen G.B., & Dahl A.A. (2007) Chronic fatigue and its correlates in long-term survivors of cervical cancer treated with radiotherapy. *BJOG.* **114**, 1150-1158.

Wagner L.I. & Cella D. (2004) Fatigue and cancer: causes, prevalence and treatment approaches. *Br J Cancer* **91**, 822-828.

Warnecke R.B., Johnson T.P., Chavez N., Sudman S., O'Rourke D.P., Lacey L., & Horm J. (1997) Improving question wording in surveys of culturally diverse populations. *Ann.Epidemiol.* **7**, 334-342.

Weidner K., Siedentopf F., Zimmermann K., Bittner A., Richter J., Joraschky P., Distler W., & Stobel-Richter Y. (2008) Which gynecological and obstetric patients want to attend psychosomatic services? *J Psychosom.Obstet.Gynaecol.* **29**, 280-289.

World Health Organization. Global strategy on diet, physical activity and health. 2004. World Health Organization.  
Ref Type: Report

World Health Organization. Medical care and Rehabilitation. 2009. <http://www.who.int/disabilities/care/en/>  
Accessed 07.01.2009.  
Ref Type: Electronic Citation

Yeh E.T. & Bickford C.L. (2009) Cardiovascular complications of cancer therapy: incidence, pathogenesis, diagnosis, and management. *J Am.Coll.Cardiol.* **53**, 2231-2247.

Zabora J., BrintzenhofeSzoc K., Curbow B., Hooker C., & Piantadosi S. (2001) The prevalence of psychological distress by cancer site. *Psychooncology.* **10**, 19-28.

Zebrack B. (2009) Information and service needs for young adult cancer survivors. *Support.Care Cancer* **17**, 349-357.

Zigmond A.S. & Snaith R.P. (1983) The hospital anxiety and depression scale. *Acta Psychiatr.Scand.* **67**, 361-370.

















# Exercise behavior in cancer survivors and associated factors

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## Abstract

**Introduction** Physical activity is an important component in promoting a healthy life style in cancer survivors. We estimated the proportion of cancer survivors who are physically active, defined as meeting public health exercise guidelines, and changes in level of physical activity (LPA) from before diagnosis to after treatment. We also identified medical and demographic factors associated with LPA and its changes.

**Methods** A cross-sectional survey assessing LPA before diagnosis and after treatment, together with demographic and medical variables in 975 cancer survivors.

**Results** Forty-five percent of the cancer survivors were physically active after treatment. Before diagnosis and after treatment 33% were active, whereas 40% were inactive at both time points. Fifteen percent were active before diagnosis but inactive after treatment, and 12% were inactive before diagnosis but active after treatment. Increasing age and weight, low education, comorbidity and smoking were associated with physical inactivity after treatment. Change in LPA from active to inactive was associated with comorbidity, distant disease and smoking, while a change from inactive to active was associated with high education.

**Conclusions** Less than half of cancer survivors were physically active. Almost three quarters of cancer survivors remained stable in LPA. The remaining quarter changed LPA, with slightly more cancer survivors becoming inactive than active. Age, weight, education, comorbidity, disease stage and smoking can identify survivors at risk of physical inactivity after treatment.

**Implications for cancer survivors** Recognizable variables can be used to identify physically inactive cancer survivors after treatment and give these survivors support to start or maintain LPA.

**Keywords** Exercise guidelines · Physical activity change · Cancer survivors

## Introduction

The number of cancer survivors is increasing and estimates show that over 900,000 people in the Nordic countries are living with ongoing cancer or a history of cancer [1]. Approximately 65% diagnosed with cancer in the Western world today can expect to live for at least 5 years [2, 3]. Due to the malignancy itself and its treatment, many patients experience various acute and chronic adverse effects that affect quality of life (QoL) [4–6]. Compared to the general population, cancer survivors also face a higher risk of secondary cancer, osteoporosis, overweight and cardiovascular diseases [7–10]. In general, there is substantial documentation showing that physical activity (PA) prevents or at least reduces some of these adverse effects [11]. Several studies have recently shown positive effects of PA among cancer survivors both on physical and psychological health, and overall QoL [12–14], as well as an association between PA and survival [15, 16].

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Despite documented benefits of exercise, only 25–30% of cancer survivors are reported to be physically active [17–20]. Physically active individuals are in this report defined as individuals who meet the public health exercise guidelines [21]. Admittedly these guidelines have changed over time and may vary between countries [21, 22] ([www.helsedirektoratet.no](http://www.helsedirektoratet.no)). Young age, male, high education, healthy weight and absence of comorbidity are factors shown to be to be positively associated with PA among cancer survivors [20, 23–27].

Studies indicate that about 30–60% of cancer survivors who were active before diagnosis do not return to their pre-diagnosis level of physical activity (LPA) [28, 29], but factors associated with change in LPA have received limited attention. However, Lynch and colleagues found that being female, low level of education and having received adjuvant therapy were associated with a decrease in LPA from pre-diagnosis to post-treatment among colorectal cancer patients [26]. In order to reduce morbidity after cancer treatment, the goal should be to increase the number of physically active cancer survivors. Identification of demographic and medical factors associated with LPA and its changes may provide important knowledge about the risk to be a physically active or an inactive cancer survivor. Interventions focusing on PA should primarily focus on the latter individuals.

The primary aim of the present study was 1) to estimate the proportion of physically active cancer survivors and to assess the percentage of individuals who change their LPA from before diagnosis to after treatment. The secondary aim was to identify medical and demographic factors associated with LPA and its changes. Based on previous research in cancer survivors [17–20, 23–28], we hypothesized that at least one quarter of Norwegian cancer survivors would be physically active. Further, we hypothesized that about one third of cancer survivors would report a lower LPA after treatment than before diagnosis. We expected that age, weight, education, comorbidity and smoking, treatment or extension of the disease (stage) would be associated with LPA and its changes from before diagnosis to after treatment.

## Materials and methods

### Study participants and procedure

This cross-sectional study was conducted from February 2007 to September 2007. Consecutive patients were identified from the Norwegian Radium Hospital (NRH)'s patient registry and were eligible for the analysis if the medical databases did not show any disease activity at the time of the survey, with exception of testicular cancer and malignant lymphoma, since many of these patients are cured despite metastases at time of

diagnosis. Patients were aged between 18 and 75 when first seen at the hospital. They had received curatively intended treatment at the NRH between January 2002 and December 2005 for malignant lymphoma, breast, testicular, cervical, ovarian or prostate cancer. Among all available breast cancer patients only a random third was selected because of the large number in this group. Due to small groups, cervical cancer and ovarian cancer were combined as 'gynecological cancer' in the analyses. Treatment (except for adjuvant hormone treatment) should have been finalized prior to the study.

Eligible participants received an information letter, a questionnaire and a pre-paid envelope, with a follow-up reminder letter to non-responders after four weeks. Ethical approval was obtained from the institutional review board and the regional ethics committee for medical research. All participants signed an informational consent form.

### Measures

Information on gender, age, diagnosis, time since diagnosis and disease stage (localized/regional/distant) was collected from the medical databases at the hospital. The remaining variables were obtained by self-report and included: weight and height, married/cohabitant, education, employment status, comorbidity [defined as any long-lasting physical or psychological illnesses (cancer excluded) which had led to reduced daily life functions during the last year], treatment [one local treatment/two local treatments/systemic treatment/one local treatment + systemic treatment/two local treatments + systemic treatment (local treatment including surgery and/or radiotherapy and systemic treatment including chemotherapy and/or hormone therapy)], and daily smoking.

The patients recorded their LPA prior to diagnosis and their post-treatment LPA (at the time of survey) by a modified version of the Leisure Score Index from the *Godin Leisure Time Exercise Questionnaire (GLTEQ)* [30]. The GLTEQ assesses average frequency and duration of intensity: mild (e.g. easy walking), moderate (e.g. brisk walking) and vigorous (e.g. running) exercise in a typical week. The GLTEQ has been found to be both valid and reliable [31]. Two independent translators following standard forward and backward translation procedures translated the GLTEQ into Norwegian [32]. In our study the proportion of respondents meeting exercise guidelines (counted as  $\geq 150$  min of moderate intensity or  $\geq 75$  min of vigorous intensity a week) was calculated considering LPA before diagnosis and LPA after treatment separately [21]. Patients not meeting the public exercise guidelines were categorized as physically inactive, irrespective of the individual level of sub-optimal activity.

Change in LPA resulted in four post-treatment categories, taken into account whether or not respondents were meeting exercise guidelines at the two time points: "maintainers": meeting exercise guidelines at both time points, "persistently



*inactives*”: not meeting exercise guidelines before diagnosis or after treatment, *“adopters*”: not meeting exercise guidelines before diagnosis but after treatment, *“relapsers*”: meeting exercise guidelines before diagnosis but not after treatment.

**Statistical analyses**

Except for descriptive methods, logistic regression analyses were used to evaluate factors associated with 1: being physically active versus being inactive after treatment, 2: being a relapser versus being a maintainer and 3: being an adopter versus being persistently inactive. Demographic and medical variables statistically significant in unadjusted analyses were included as explanatory variables in the multiple regression analyses. The final models were reduced to include statistically significant variables only. Gender was not included as an explanatory variable in the logistic regression analyses because four out of five diagnoses were gender-specific, which made it impossible to separate diagnosis and gender in overall analyses. Adjusted odds ratios (aOR) are presented with 95% confidence intervals (95% CI). All analyses were performed with SPSS 16.0 (SPSS, Chicago, IL). A two-tailed *P* value of less than 0.05 was considered statistically significant.

**Results**

**Participant compliance**

Of 2,024 patients who were invited to participate in the survey, 43 envelopes were returned unopened (19 persons had moved to an unknown address and 24 were recently deceased). Of 1,981 eligible participants, 1,356 returned the completed questionnaire package. Of these, 72 patients were excluded because of recurrence at the time of survey according to the medical database, resulting in 1,284 participants. Due to missing responses as to GLTEQ, we had 975 analyzable participants and a response rate of 51% (975 of 1,909). Fifty-six percent were female, 75% were married/cohabitant and 42% had high education (Table 1). The median age was 56.1 years (range 21.6–80.0) and the median number of months since diagnosis was 41.0 (range 14.3–103.5) (data not shown).

**Prevalence of cancer survivors being physically active and changes in LPA**

Based on the overall sample of 975 cancer survivors reporting their LPA both pre-diagnosis and post-treatment, 48% of the participants were physically active before diagnosis and 45% were physically active after treatment

**Table 1** Demographic and medical characteristics of participants

Variable	Total n (%)
No. of participants	975
<b>Demographic</b>	
<b>Gender</b>	
Male	432 (44)
Female	543 (56)
<b>Age (years)</b>	
Middle-aged adult 45–64	464 (48)
Young adult <45 years	265 (27)
Older adults ≥65	246 (25)
<b>BMI (n=934)</b>	
Healthy <25 kg/m <sup>2</sup>	445 (48)
Overweight 25–29.9 kg/m <sup>2</sup>	350 (37)
Obese ≥30 kg/m <sup>2</sup>	139 (15)
<b>Married/cohabitant (n=974)</b>	
No	248 (25)
Yes	726 (75)
<b>Education (n=972)</b>	
Primary/secondary school	157 (16)
High school	412 (42)
College/university <4 yrs	223 (23)
College/university ≥4 yrs	180 (19)
<b>Employment status (n=974)</b>	
Fulltime/student/military service	445 (46)
Part-time/homemaker	137 (14)
Retired	217 (22)
Disability benefit/sick leave/unemployed	175 (18)
<b>Medical</b>	
<b>Comorbidity (n=945)</b>	
No	664 (70)
Yes	281 (30)
<b>Time since diagnosis</b>	
<2 years	112 (11)
≥2 years	863 (89)
<b>Diagnosis</b>	
Lymphoma	245 (25)
Testicular	139 (14)
Breast	241 (25)
Gynecological (cervix and ovarian)	204 (21)
Prostate	146 (15)
<b>Treatment (n=970)</b>	
One local treatment	136 (14)
Two local treatments	155 (16)
Systemic treatment	109 (11)
One local treatment + systemic treatment	356 (37)
Two local treatments + systemic treatment	214 (22)
<b>Disease stage (n=972)</b>	
Localized	482 (50)
Regional	297 (30)
Distant	193 (20)
<b>Daily smoking (n=972)</b>	
No	812 (84)
Yes	160 (16)

Numbers may not add up to 975 because of missing data

(Fig. 1). The respective figure for physically inactive were 52% and 55%. In total, 323 (33%) maintained physically active both before diagnosis and after treatment, 392 (40%) were persistently inactive, 149 (15%) relapsed in LPA, while 111 (12%) adopted in LPA (Fig. 1). Of the 472 pre-diagnosis physically active survivors, 149 (32%) were categorized as relapsers and 323 (68%) maintained their LPA after treatment (Table 3). Of the 503 pre-diagnosis physically inactive survivors, 111 (22%) became adopters and 392 (78%) were persistently inactive after treatment (Table 4).

Factors associated with being physically active after treatment

In unadjusted logistic regression analyses, being physically active after treatment was negatively associated with age 65+ years, overweight and obesity, retirement, receiving disability benefit/sick leave/unemployment, comorbidity, distant disease and smoking, and was positively associated with higher education (Table 2). Results from multiple logistic regression analyses showed that older age remained negatively associated with being physically active [aOR 0.62; 95% CI (0.44–0.88),  $p=0.008$ ] (Table 2). Overweight and obesity were also negatively associated with being physically active [aOR 0.73; 95% CI (0.54–0.98),  $p=0.03$  and aOR 0.46; 95% CI (0.3–0.71),  $p<0.001$ , respectively]. Participants with comorbidity had approximately 50% reduced odds of being physically active compared to those with no comorbidity [aOR 0.56; 95% CI (0.41–0.76),  $p<0.001$ ]. Compared to non-smokers, smokers were about half as likely to be physically active [aOR 0.53; 95% CI (0.36–0.78),  $p=0.001$ ]. High education was positively associated with being physically active [aOR 2.05; 95% CI (1.26–3.33),  $p=0.004$ ] (Table 2).

Factors associated with being a relapser and an adopter

In unadjusted analyses, being a relapser was associated with obesity, receiving disability benefit/sick leave/unemployment,

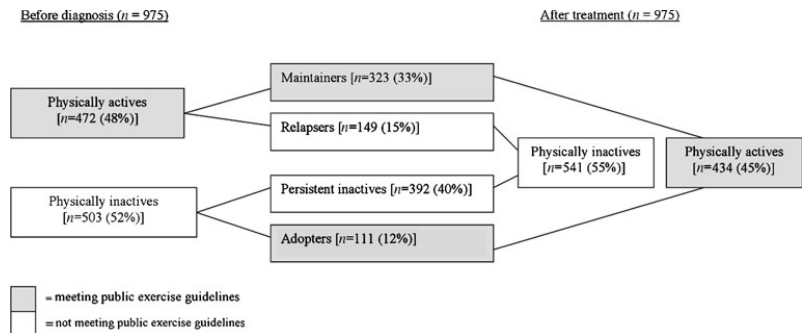
comorbidity, distant disease and smoking (Table 3). In multiple logistic regression analyses, presence of comorbidity resulted in about 2.5 higher odds of being a relapser compared to the participants with no comorbidity [aOR 2.47; 95% CI (1.6–3.81),  $p<0.001$ ] (Table 3). Cancer survivors with distant disease were more than twice as likely to become a relapser compared to the ones with localized disease [aOR 2.17; 95% CI (1.28–3.66),  $p=0.004$ ]. Smoking also remained associated with being a relapser [aOR 1.79; 95% CI (1.04–3.09),  $p=0.04$ ]. High education (college/university  $\geq 4$  years) was the only factor statistically significantly associated with being an adopter both in unadjusted and multiple logistic regression analysis [aOR 2.29; 95% CI (1.13–4.63),  $p=0.02$ ] (Table 4).

Discussion

Our study showed that almost half of all surveyed cancer survivors were physically active after treatment. In the overall sample, one third were maintainers, 40% were persistently inactive and about one quarter changed their LPA. Among those being physically active before diagnosis, about one third relapsed in LPA. Among those who were inactive before diagnosis, more than one fifth adopted in LPA. Moreover, the results demonstrated that participants who were 65+ years, those with a non-healthy weight, or low educated, had comorbidities and smoked were less likely to be physically active. Being a relapser was associated with comorbidity, distant disease and smoking, and being an adopter was associated with high education.

The large sample size made it possible to perform subgroup analyses. Further, information on LPA both before diagnosis and after treatment made it possible to perform analyses on the change of LPA across the cancer experience, even though the patients provided the relevant information retrospectively. Validated questionnaires of LPA were applied. Medical variables (diagnosis, time since diagnosis and disease stage) were collected from medical

**Fig. 1** Categorizing cancer survivors based on whether or not they were meeting exercise guidelines before diagnosis and after treatment ( $n=975$ )



**Table 2** Prevalence of physically active cancer survivors after treatment and factors associated with being physically active (versus being inactive) (*n*=975)

	Physically actives%		Unadjusted analyses			Adjusted analyses <sup>a</sup>		
	Yes	No	cOR	95%CI	P	aOR	95%CI	P
All ( <i>n</i> =975)	45	55						
N	434	541						
Diagnosis ( <i>n</i> =975)								
Lymphoma (reference)	42	58	1.0		0.68			
Testicle	47	53	1.25	0.82–1.89	0.30			
Breast	47	53	1.24	0.87–1.77	0.24			
Gynecological (cervix and ovarian)	42	58	1.01	0.69–1.46	0.98			
Prostate	45	55	1.11	0.73–1.67	0.63			
Age (years) ( <i>n</i> =975)								
Middle-aged adult 45–64 (reference)	46	54	1.0		0.06	1.0		0.03
Young adult <45 years	48	52	1.08	0.8–1.47	0.59	0.86	0.62–1.2	0.37
Older adult ≥65	38	62	0.73	0.53–0.99	0.049	0.62	0.44–0.88	0.008
BMI ( <i>n</i> =934)								
Healthy <25 kg/m <sup>2</sup> (reference)	51	49	1.0		<0.001	1.0		0.001
Overweight 25-29.9 kg/m <sup>2</sup>	43	57	0.75	0.57–0.99	0.046	0.73	0.54–0.98	0.03
Obese ≥30 kg/m <sup>2</sup>	30	70	0.42	0.31–0.69	<0.001	0.46	0.3–0.71	<0.001
Married/cohabitant ( <i>n</i> =974)								
No (reference)	48	52	1.0					
Yes	43	57	0.83	0.62–1.1	0.2			
Education ( <i>n</i> =972)								
Primary/secondary school (reference)	34	66	1.0		0.001	1.0		0.04
High school	42	58	1.42	0.97–2.09	0.07	1.42	0.93–2.16	0.11
College/university <4 yrs	48	52	1.84	1.21–2.81	0.005	1.55	0.97–2.47	0.07
College/university ≥4 yrs	55	45	2.4	1.54–3.73	<0.001	2.05	1.26–3.33	0.004
Employment status ( <i>n</i> =974)								
Fulltime/student/military service (reference)	50	50	1.0		0.004			
Part-time/homemaker	44	56	0.77	0.52–1.13	0.18			
Retired	40	60	0.66	0.48–0.92	0.01			
Disability benefit/sick leave/unemployed	35	65	0.54	0.38–0.78	0.001			
Comorbidity ( <i>n</i> =945)								
No (reference)	49	51	1.0			1.0		
Yes	33	67	0.53	0.39–0.7	<0.001	0.56	0.41–0.76	<0.001
Time since diagnosis (years) ( <i>n</i> =975)								
<2 years (reference)	48	52	1.0					
≥2 years	44	56	0.85	0.57–1.25	0.4			
Treatment ( <i>n</i> =970)								
One local treatment (reference)	39	61	1.0		0.2			
Two local treatments	46	54	1.36	0.85–2.17	0.2			
Systemic treatment	37	63	0.91	0.54–1.53	0.72			
One local treatment + systemic treatment	47	53	1.42	0.95–2.12	0.09			
Two local treatments + systemic treatment	46	54	1.32	0.86–2.05	0.21			
Disease stage ( <i>n</i> =972)								
Localized (reference)	46	54	1.0		0.04			
Regional	47	53	1.02	0.77–1.37	0.88			
Distant	36	64	0.66	0.47–0.93	0.02			
Daily smoking ( <i>n</i> =972)								
No (reference)	47	53	1.0			1.0		
Yes	34	66	0.58	0.41–0.83	0.003	0.53	0.36–0.78	0.001

Numbers may not add up to 975 because of missing data

cOR crude odds ratio, aOR adjusted odds ratio. 95% CI, 95% Confidence Interval

<sup>a</sup>Numbers included in the multivariate analyses were 902

**Table 3** Prevalence of relapsers and factors associated with being a relapser (versus those maintain active) among actives before diagnosis ( $n=472$ )

	Proportion of relapsers%		Unadjusted analyses			Adjusted analyses <sup>a</sup>		
	Yes	No	cOR	95%CI	P	aOR	95%CI	P
All physical active before diagnosis ( $n=472$ )	32	68						
N	149	323						
Diagnosis ( $n=472$ )								
Lymphoma (reference)	37	63	1.0		0.09			
Testicle	30	70	0.75	0.41–1.37	0.35			
Breast	27	73	0.64	0.37–1.11	0.12			
Gynecological (cervix and ovarian)	39	61	1.08	0.62–1.88	0.79			
Prostate	20	80	0.43	0.21–0.89	0.02			
Age (years) ( $n=472$ )								
Middle-aged adult 45–64 (reference)	31	69	1.0		0.25			
Young adult <45 years	36	64	1.28	0.83–1.98	0.26			
Older adults $\geq 65$	26	74	0.81	0.47–1.38	0.44			
BMI ( $n=454$ )								
Healthy <25 kg/m <sup>2</sup> (reference)	28	72	1.0		0.02			
Overweight 25–29.9 kg/m <sup>2</sup>	33	67	1.26	0.82–1.95	0.3			
Obese $\geq 30$ kg/m <sup>2</sup>	48	52	2.42	1.3–4.5	0.005			
Married/cohabitant ( $n=471$ )								
No (reference)	32	68	1.0					
Yes	31	69	0.97	0.63–1.49	0.89			
Education ( $n=470$ )								
Primary/secondary school (reference)	36	64	1.0		0.26			
High school	33	67	0.87	0.47–1.6	0.65			
College/university <4 yrs	33	67	0.88	0.46–1.7	0.71			
College/university $\geq 4$ yrs	23	77	0.53	0.26–1.09	0.08			
Employment status ( $n=471$ )								
Fulltime/student/military service (reference)	27	73	1.0		0.003			
Part-time/homemaker	35	65	1.43	0.78–2.62	0.25			
Retired	24	76	0.86	0.49–1.52	0.6			
Disability benefit/sick leave/unemployed	47	53	2.38	1.44–3.93	0.001			
Comorbidity ( $n=453$ )								
No (reference)	26	74	1.0			1.0		
Yes	48	52	2.7	1.77–4.15	<0.001	2.47	1.6–3.81	<0.001
Time since diagnosis (years) ( $n=472$ )								
<2 years (reference)	34	66	1.0					
$\geq 2$ years	31	69	0.89	0.51–1.54	0.67			
Treatment ( $n=469$ )								
One local treatment (reference)	32	68	1.0		0.09			
Two local treatments	19	81	0.5	0.22–1.16	0.11			
Systemic treatment	40	60	1.44	0.65–3.19	0.37			
One local treatment + systemic treatment	34	66	1.11	0.57–2.16	0.75			
Two local treatments + systemic treatment	30	70	0.9	0.43–1.89	0.78			
Disease stage ( $n=471$ )								
Localized (reference)	27	73	1.0		0.009	1.0		0.02
Regional	31	69	1.22	0.78–1.93	0.39	1.25	0.77–2.02	0.37
Distant	44	56	2.17	1.32–3.56	0.002	2.17	1.28–3.66	0.004
Daily smoking ( $n=472$ )								
No (reference)	29	71	1.0			1.0		
Yes	44	56	1.9	1.13–3.13	0.02	1.79	1.04–3.09	0.04

Numbers may not add up to 472 because of missing data

cOR crude odds ratio, aOR adjusted odds ratio. 95% CI, 95% Confidence Interval

<sup>a</sup>Numbers included in the multivariate analyses were 452

**Table 4** Prevalence of adopters and factors associated with being an adopter (versus those remain inactive) among inactives before diagnosis (*n*=503)

	Proportion of adopters%		Unadjusted analyses			Adjusted analyses <sup>a</sup>		
	Yes	No	cOR	95%CI	P	aOR	95%CI	P
All physically inactive at before diagnosis ( <i>n</i> =503)	22	78						
N	111	392						
Diagnosis ( <i>n</i> =503)								
Lymphoma (reference)	19	81	1.0		0.53			
Testicle	18	82	0.97	0.44–2.16	0.94			
Breast	24	76	1.39	0.75–2.58	0.29			
Gynecological (cervix and ovarian)	27	73	1.56	0.84–2.91	0.16			
Prostate	20	80	1.06	0.53–2.15	0.86			
Age (years) ( <i>n</i> =503)								
Middle-aged adult 45–64 (reference)	24	76	1.0		0.08			
Young adult <45 years	27	73	1.15	0.69–1.93	0.58			
Older adults ≥65	16	84	0.6	0.36–1.02	0.06			
BMI ( <i>n</i> =480)								
Healthy <25 kg/m <sup>2</sup> (reference)	23	77	1.0		0.48			
Overweight 25–29.9 kg/m <sup>2</sup>	25	75	1.11	0.7–1.77	0.65			
Obese ≥30 kg/m <sup>2</sup>	18	82	0.75	0.4–1.42	0.38			
Married/cohabitant ( <i>n</i> =503)								
No (reference)	25	75	1.0					
Yes	21	79	0.83	0.51–1.36	0.47			
Education ( <i>n</i> =502)								
Primary/secondary school (reference)	16	84	1.0		0.04	1.0		0.04
High school	19	81	1.22	0.65–2.31	0.54	1.22	0.65–2.31	0.54
College/university <4 yrs	27	73	1.94	0.97–3.86	0.06	1.94	0.97–3.86	0.06
College/university ≥4 yrs	31	69	2.29	1.13–4.63	0.02	2.29	1.13–4.63	0.02
Employment status ( <i>n</i> =503)								
Fulltime/student/military service (reference)	26	74	1.0		0.1			
Part-time/homemaker	27	73	1.09	0.61–1.97	0.77			
Retired	17	83	0.59	0.34–1.02	0.06			
Disability benefit/sick leave/unemployed	17	83	0.58	0.3–1.12	0.10			
Comorbidity ( <i>n</i> =492)								
No (reference)	24	76	1.0					
Yes	17	83	0.63	0.39–1.04	0.07			
Time since diagnosis (years) ( <i>n</i> =503)								
<2 years (reference)	23	77	1.0					
≥2 years	22	78	1.07	0.70–1.64	0.74			
Treatment ( <i>n</i> =501)								
One local treatment (reference)	22	78	1.0		0.11			
Two local treatments	16	84	0.66	0.30–1.45	0.31			
Systemic treatment	12	88	0.46	0.17–1.24	0.13			
One local treatment + systemic treatment	26	74	1.21	0.65–2.24	0.56			
Two local treatments + systemic treatment	27	73	1.28	0.67–2.46	0.45			
Disease stage ( <i>n</i> =501)								
Localized (reference)	24	76	1.0		0.21			
Regional	23	77	0.95	0.59–1.53	0.83			
Distant	15	85	0.57	0.3–1.07	0.08			
Daily smoking ( <i>n</i> =500)								
No (reference)	24	76	1.0					
Yes	15	85	0.57	0.3–1.06	0.08			

Numbers may not add up to 503 because of missing data

cOR crude odds ratio, aOR adjusted odds ratio. 95% CI, 95% Confidence Interval

<sup>a</sup>Numbers included in the multivariate analyses were 502

databases which enhanced the correctness of the data compared to self-report.

Our study might be limited by the possibility of selection bias given the response rate of only 51%. Unfortunately, information about the non-responders was not available. There is a chance that participants completing the questionnaire were those with a particular interest in PA, and thus more physically active than the non-respondents, leading to a relatively high prevalence of physically active cancer survivors. Nevertheless, similar limitations would also affect other studies regarding cancer survivors' LPA [17–20]. Moreover, we have to be aware of the weakness of self-reported information and that individuals tend to overestimate their actual LPA and intensity compared with objective measurements [33]. A recent report from The Norwegian Directorate of Health shows that only about half of the self-reported physically active were confirmed physically active with objective measures [34]. A frequent gap between objective and subjective reporting of LPA is thus evident. Recall bias could also be a source of error. Finally, the cross-sectional design does not allow causal inference on associations between the independent variables and PA. Further, prospective studies following the changes in LPA across the cancer experience should be explored.

Contrary to our expectations and previous findings [17–20], our results show a relatively high prevalence of cancer survivors meeting exercise guidelines. Except for the possible above mentioned selection bias or an over-reporting of LPA, another explanation could be that Norwegian cancer survivors are more physically active than reported from Northern-America and Australia [17–20]. Other Norwegian studies showed that survivors of Hodgkins lymphoma and testicular cancer had a higher LPA compared to the general population [35, 36].

Unexpectedly, there were only 3% more relapsers than adopters in total. In contrast, Karvinen and colleagues [37] found that twice as many relapsed than adopted among bladder cancer survivors. Additionally, 68% of the participants in the Canadian study were inactive both before diagnosis and after treatment, which is much higher than in the present study. This could probably be due to unavoidable inter-study variations (age, type of cancer, culture etc.).

Consistent with our hypothesis and previous findings, low age, healthy weight, high education, absence of comorbidity and a non-smoking life style were associated with being physically active after treatment [23–27]. Contrary to our hypothesis, no association between being physically active and treatment or disease stage was observed in the multivariable analysis which indicates that these medical factors were of less importance.

The present study suggests that being a relapser is associated with comorbidity and thus that individuals with

more comorbidities may be in particular need of post-treatment assistance with physical activity in order to regain maximal health. This finding is in accordance with Coups et al. who found that lung cancer survivors with more comorbidities were more likely to become sedentary after treatment [38]. As expected, we observed an association between disease stage and a decrease in LPA. Somewhat this is in line with Lynch and colleagues who reported an association between having received adjuvant therapy (chemotherapy and/or radiotherapy) and a decrease in LPA [26]. It is reasonable to assume that treatment could be linked to the extension of the disease. Not surprisingly, our results indicate that being an adopter is associated with higher education. Approximately half of the adopters had higher education, whereas only one third of the persistently inactives had higher education. People with high education probably acknowledged post-treatment health benefits of PA, and for some the cancer diagnosis may have positively influenced upon a subsequent healthy behavior. In the literature this is described as a 'teachable moment' that may play an important role in guiding survivors toward a life style that improve overall health [39].

In conclusion, the present study indicates that less than half of the cancer survivors were physically active after treatment. Approximately three quarters of the cancer survivors remained stable in their LPA, whereas the remaining quarter changed their LPA with about half of them in a negative direction. Overall, the findings indicate a more positive trend than expected. Demographic and medical variables as age, weight, education, comorbidity, disease stage and smoking can help identify cancer survivors at risk of physical inactivity after treatment.

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**Conflicts of Interest** We state that there are no potential conflicts of interest in this study.

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## References

- Engholm G, Ferlay J, Christensen N, Bray F, Gjerstorff ML, Klint A, et al. NORDCAN-a Nordic tool for cancer information, planning, quality control and research. *Acta Oncol.* 2010;49: 725–36.

2. Cancer Registry of Norway. Cancer in Norway 2008-Cancer incidence, mortality, survival and prevalence in Norway 2009. Ref Type: Report.
3. Horner MJ, Ries LAG, Krapcho M, Neyman N, Aminou R, Howlander N et al. SEER Cancer Statistics Review 1975–2006. National Cancer Institute. Ref Type: Electronic Citation. Available from: [http://seer.cancer.gov/csr/1975\\_2006/](http://seer.cancer.gov/csr/1975_2006/). 11-02-2009.
4. Minton O, Stone P. How common is fatigue in disease-free breast cancer survivors? A systematic review of the literature. *Breast Cancer Res Treat.* 2008;112:5–13.
5. Ness KK, Wall MM, Oakes JM, Robison LL, Gurney JG. Physical performance limitations and participation restrictions among cancer survivors: a population-based study. *Ann Epidemiol.* 2006;16:197–205.
6. Peuckmann V, Ekholm O, Rasmussen NK, Groenvold M, Christiansen P, Moller S, et al. Chronic pain and other sequelae in long-term breast cancer survivors: nationwide survey in Denmark. *Eur J Pain.* 2009;13:478–85.
7. Diamond TH, Bucci J, Kersley JH, Aslan P, Lynch WB, Bryant C. Osteoporosis and spinal fractures in men with prostate cancer: risk factors and effects of androgen deprivation therapy. *J Urol.* 2004;172:529–32.
8. Smith MR. Changes in fat and lean body mass during androgen-deprivation therapy for prostate cancer. *Urology.* 2004;63:742–5.
9. Tichelli A, Socie G. Considerations for adult cancer survivors. *Hematology Am Soc Hematol Educ Program* 2005; 516–22.
10. Yeh ET, Bickford CL. Cardiovascular complications of cancer therapy: incidence, pathogenesis, diagnosis, and management. *J Am Coll Cardiol.* 2009;53:2231–47.
11. Pedersen BK, Saltin B. Evidence for prescribing exercise as therapy in chronic disease. *Scand J Med Sci Sports.* 2006;16 Suppl 1:3–63.
12. Speck RM, Courneya KS, Masse LC, Duval S, Schmitz KH. An update of controlled physical activity trials in cancer survivors: a systematic review and meta-analysis. *J Cancer Surviv.* 2010;4:87–100.
13. Conn VS, Hafidahl AR, Porock DC, McDaniel R, Nielsen PJ. A meta-analysis of exercise interventions among people treated for cancer. *Support Care Cancer.* 2006;14:699–712.
14. McNeely ML, Campbell KL, Rowe BH, Klassen TP, Mackey JR, Courneya KS. Effects of exercise on breast cancer patients and survivors: a systematic review and meta-analysis. *CMAJ.* 2006;175:34–41.
15. Holick CN, Newcomb PA, Trentham-Dietz A, Titus-Ernstoff L, Bersch AJ, Stampfer MJ, et al. Physical activity and survival after diagnosis of invasive breast cancer. *Cancer Epidemiol Biomarkers Prev.* 2008;17:379–86.
16. Pierce JP, Stefanick ML, Flatt SW, Natarajan L, Sternfeld B, Madlensky L, et al. Greater survival after breast cancer in physically active women with high vegetable-fruit intake regardless of obesity. *J Clin Oncol.* 2007;25:2345–51.
17. Stevinson C, Faught W, Steed H, Tonkin K, Ladha AB, Vallance JK, et al. Associations between physical activity and quality of life in ovarian cancer survivors. *Gynecol Oncol.* 2007;106:244–50.
18. Milne HM, Gordon S, Guilfoyle A, Wallman KE, Courneya KS. Association between physical activity and quality of life among Western Australian breast cancer survivors. *Psychooncology.* 2007;16:1059–68.
19. Vallance JK, Courneya KS, Jones LW, Reiman T. Differences in quality of life between non-Hodgkin's lymphoma survivors meeting and not meeting public health exercise guidelines. *Psychooncology.* 2005;14:979–91.
20. Courneya KS, Karvinen KH, Campbell KL, Pearcey RG, Dundas G, Capstick V, et al. Associations among exercise, body weight, and quality of life in a population-based sample of endometrial cancer survivors. *Gynecol Oncol.* 2005;97:422–30.
21. U.S.Department of Health and Human Services. 2008 Physical Activity Guidelines for Americans. Be active, healthy, and happy! Ref Type: Report.
22. Pate RR, Pratt M, Blair SN, Haskell WL, Macera CA, Bouchard C, et al. Physical activity and public health. A recommendation from the centers for disease control and prevention and the American College of Sports Medicine. *JAMA.* 1995;273:402–7.
23. Bellizzi KM, Rowland JH, Arora NK, Hamilton AS, Miller MF, Aziz NM. Physical activity and quality of life in adult survivors of non-Hodgkin's lymphoma. *J Clin Oncol.* 2009;27:960–6.
24. Coups EJ, Park BJ, Feinstein MB, Steingart RM, Egleston BL, Wilson DJ, et al. Correlates of physical activity among lung cancer survivors. *Psychooncology.* 2009;18:395–404.
25. Hong S, Bardwell WA, Natarajan L, Flatt SW, Rock CL, Newman VA, et al. Correlates of physical activity level in breast cancer survivors participating in the Women's Healthy Eating and Living (WHEL) Study. *Breast Cancer Res Treat.* 2007;101:225–32.
26. Lynch BM, Cerin E, Newman B, Owen N. Physical activity, activity change, and their correlates in a population-based sample of colorectal cancer survivors. *Ann Behav Med.* 2007;34:135–43.
27. Stevinson C, Tonkin K, Capstick V, Schepansky A, Ladha AB, Vallance JK, et al. A population-based study of the determinants of physical activity in ovarian cancer survivors. *J Phys Act Health.* 2009;6:339–46.
28. Blanchard CM, Denniston MM, Baker F, Ainsworth SR, Courneya KS, Hann DM, et al. Do adults change their lifestyle behaviors after a cancer diagnosis? *Am J Health Behav.* 2003;27:246–56.
29. Irwin ML, Crumley D, McTiernan A, Bernstein L, Baumgartner R, Gilliland FD, et al. Physical activity levels before and after a diagnosis of breast carcinoma: the Health, Eating, Activity, and Lifestyle (HEAL) study. *Cancer.* 2003;97:1746–57.
30. Godin G, Jobin J, Bouillon J. Assessment of leisure time exercise behavior by self-report: a concurrent validity study. *Can J Public Health.* 1986;77:359–62.
31. Jacobs DR, Ainsworth BE, Hartman TJ, Leon AS. A simultaneous evaluation of 10 commonly used physical activity questionnaires. *Med Sci Sports Exerc.* 1993;25:81–91.
32. Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol.* 1993;46:1417–32.
33. Troiano RP. Large-scale applications of accelerometers: new frontiers and new questions. *Med Sci Sports Exerc.* 2007;39:1501.
34. Anderssen SA, Hansen BH, Kolle E, Steene-Johannessen J, Borsheim E, Holme I et al. Physical activity among adults and elderly in Norway. Norwegian Directorate of Health 2009. Ref Type: Report.
35. Oldervoll LM, Loge JH, Kaasa S, Lydersen S, Hjermstad MJ, Thorsen L, et al. Physical activity in Hodgkin's lymphoma survivors with and without chronic fatigue compared with the general population—a cross-sectional study. *BMC Cancer.* 2007;7:210.
36. Thorsen L, Nystad W, Dahl O, Klepp O, Bremnes RM, Wist E, et al. The level of physical activity in long-term survivors of testicular cancer. *Eur J Cancer.* 2003;39:1216–21.
37. Karvinen KH, Courneya KS, North S, Venner P. Associations between exercise and quality of life in bladder cancer survivors: a population-based study. *Cancer Epidemiol Biomarkers Prev.* 2007;16:984–90.
38. Coups EJ, Park BJ, Feinstein MB, Steingart RM, Egleston BL, Wilson DJ, et al. Physical activity among lung cancer survivors: changes across the cancer trajectory and associations with quality of life. *Cancer Epidemiol Biomarkers Prev.* 2009;18:664–72.
39. Demark-Wahnefried W, Aziz NM, Rowland JH, Pinto BM. Riding the crest of the teachable moment: promoting long-term health after the diagnosis of cancer. *J Clin Oncol.* 2005;23:5814–30.









# Effects of a 1-Week Inpatient Course Including Information, Physical Activity, and Group Sessions for Prostate Cancer Patients

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**Abstract** This study aims to explore the effects of a 1-week inpatient course including information, physical activity (PA), and group sessions on physical and mental health-related outcomes for prostate cancer (PCa) patients. Further to assess the patients' satisfaction with the course. PCa patients completed a questionnaire assessing PA, fatigue, mental distress, and quality of life 1 month before (T0) and 3 months after (T1) the course. Total fatigue, physical fatigue, and PSA anxiety decreased significantly from T0 to T1. No significant changes were observed in the other measures. The majority of the participants were satisfied with the course. In spite of minor reductions in fatigue and PSA anxiety and satisfied patients, the findings indicate that a 1-week inpatient course does not influence substantially on most of the health-related outcomes in PCa patients 3 months after the course.

**Keywords** Prostate cancer · Information · Physical activity · Fatigue · Mental distress · Quality of life

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## Introduction

Prostate cancer (PCa) is the most frequent malignancy among men and mostly affecting men at older age [1]. Surgery, radiation therapy, or androgen-suppressive treatment are the most commonly used treatment modalities [2]. The 5-year survival rate of PCa is high and has increased over the past years probably due to earlier diagnosis and improved treatment [1]. However, many PCa survivors experience late effects caused by the disease and/or the treatment like decreased physical function, increased body fat mass [3], impairment of bladder, bowel, or sexual function [4], fatigue, depression, and reduced quality of life (QoL) [5].

On this background, information on the late effects after treatment for PCa and how to deal with them becomes highly relevant. Information can be downloaded from internet sites or be presented in written forms. The information can also be conveyed by courses such as those organized by cancer organizations. In Norway, hospitals by law are obliged to have 'teaching and coping' centers providing information and social contact among different groups of patients. In these courses, the participants stay at home and participate in, i.e., bi-weekly sessions at the centers. The effects of all these efforts are sparsely documented, and knowledge about the potential effects is paramount in order to establish effective and supportive interventions. In addition to the information per se, communication with other PCa survivors can also reduce psychosocial distress and enhance coping [6].

In 1990, The Norwegian Radium Hospital (NRH), a comprehensive cancer center, opened a national center [The Montebello Center (MBC)] for cancer survivors and their families. Cancer patients from all over Norway can

be referred to MBC [7]. The center offers cancer patients and their spouses/relatives intensive courses of 5–10 days duration while staying at the institution with the aim to improve the patients' coping with the disease and the side-effects of their treatment. Patients with similar diagnosis attend diagnosis-specific courses, while the basic structure of the content of the courses is quite similar across the courses including lectures, physical activity (PA), group sessions, and social gatherings. Reviewing 15 years of operation at the MBC, 10,173 cancer patients from all over Norway have participated in these courses with breast cancer patients represented the largest group. The proportion of men has increased over time. Most patients attended a course less than 2 years after diagnosis. Immediately after the courses, the majority (90%) of the patients was highly satisfied with the courses, reported increased knowledge about their cancer, and had better coping with their disease [7]. However, the effects of the courses in terms of improved health have not been assessed until now.

The objectives of the present study were to explore the effects of PCa-specific courses on: PA, fatigue, mental distress, and Global QoL assessed prior to the course and 3 months thereafter. Our secondary objective was to assess the patients' satisfaction with the courses.

## Material and Methods

### Participants

To participate in one of the PCa-specific courses, three inclusion criteria had to be fulfilled by the participants: (1) having PCa; (2) being referred by a physician confirming a 'need for the course'; and (3) being self-reliant. One month before the start of the course (T0), patients were invited to participate in the questionnaire-based study. An invitation letter and a questionnaire were sent by mail. Those who completed the first questionnaire received a second questionnaire 3 months after the course (T1). No reminder was sent to those were not responding at T0.

### The Intervention

Each course was conducted by a multidisciplinary team, lasted for 6 days, and consisted of lectures, PA, and group sessions. The lectures covered different topics. An oncologist presented basic medical facts concerning PCa, treatment modalities, and late effects. A social worker and a physiotherapist/sport instructor informed about social benefits and the expected effects of PA, respectively. Lectures about sexuality/partnership and urinary problems were given by a sexual therapist and a cancer nurse. Finally,

factual information about mental distress after PCa was presented by a psychologist or psychiatrist.

PA was performed in groups of 6–9 participants two times per day and was led by a physiotherapist or a sport instructor. PA included water gymnastic, walking, Nordic walking, resistance training, pelvic floor training, stretching, and relaxation. The length of the sessions varied from 30 to 90 min. The participants rated their subjectively experienced exertion rating after every session, with the alternatives: very mild, mild, moderate, strenuous, and very strenuous. Overall, the activities were done with moderate intensity.

The participants met 1 hour daily for a group session which was led by a nurse experienced in group counseling. The themes of the sessions were related to the content of the lectures, and the purpose was to discuss the themes in relation to the participants' personal experiences with PCa.

The total active hours of the program were approximately 30 h. The lectures amounted to about 45% of total active hours of the course, the PA to approximately 35%, and the group sessions to roughly 20%. The spouses took part in the lectures and PA, while they had group sessions separately. The effects of the course on the spouses were not part of the study.

The participants could also make appointments for individual consultations with the professionals who gave the lectures. Additionally, social and cultural activities were a large part of the course evenings.

### Measurements

Demographic and medical variables were self reported at baseline including: present age, marital status, level of education, employment status, time since diagnosis, physical comorbidity (cardiovascular diseases, diabetes, asthma, or allergy), and treatment. PA level was assessed by a modified version of the Leisure Score Index from The Godin Leisure Time Exercise Questionnaire (GLTEQ) [8]. The GLTEQ consists of three questions concerning mean frequency and duration of mild (minimal effort, no perspiration), moderate (not exhausting, light perspiration), and strenuous (heart beats rapidly, sweating) exercise in leisure time during an average week. The GLTEQ has been found to be both valid and reliable [9]. The GLTEQ was translated into Norwegian by two independent translators following standard forward and backward translation procedures [10]. The total minutes of moderate and strenuous exercise were calculated and the proportion of respondents meeting public health exercise guidelines ( $\geq 150$  min of moderate-to-strenuous intensity or  $\geq 75$  min of strenuous intensity per week) [11] was registered.

Fatigue was assessed by The Fatigue Questionnaire (FQ) [12]. The FQ consists of 11 items, seven cover physical fatigue (PF), and four cover mental fatigue (MF) experi-

enced during the last month. The sum of PF and MF constitutes total fatigue (TF). The responses are scored on a four-point Likert scale from 0 to 3 and higher scores imply more fatigue, and the range of scores for the whole scale is 0–33 (PF 0–21 and MF 0–12) [12]. The FQ has robust psychometric properties [13].

The Memorial Anxiety Scale for Prostate Cancer (MAX-PC) [14] consists of three subscales: general PC anxiety (11 items), anxiety related to prostate-specific antigen (PSA) levels (three items), and fear of recurrence (four items). Responses are scored on a four-point Likert scale from 0 to 3, and higher scores imply more cancer-related anxiety. The range of scores on the subscales is 0 to 33, 0 to 9, and 0 to 12, respectively. The scores on the three subscales are added in order to get the total MAX-PC score, which ranges from 0 to 54. The MAX-PC has shown to have an acceptable validity and reliability [14].

The Hospital Anxiety and Depression Scale (HADS) [15]. The HADS consists of two subscales with seven items on depression (HADS-D) and seven on anxiety. Each item is scored on a 0 to 3 Likert scale, and a higher score implies higher level of anxiety/depression. The HADS total score is the sum of the items scores on both subscales. The range of scores is 0 to 21 for each subscale. The psychometric properties of HADS are reported as good [16].

QoL was assessed by the two items constituting the Global QoL-Scale in The European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire C30 (EORTC QLQ-C30) [17]. The range of transformed scores is to 0–100. A higher score represents better QoL. The Norwegian version of the EORTC-QLQ C30 has shown good reliability and validity [18].

Satisfaction with the course was evaluated by two questions specially developed for this study in order to cover two aspects of satisfaction (response alternatives within a parenthesis): (1) ‘Did the course change your expectations towards everyday life?’ (to a high extent, to a fair extent, only partially, not at all) and (2) ‘Did the course help you to cope better with your prostate cancer and/or the side-effects associated with the treatment?’ (to a high extent, to a fair extent, only partially, not at all).

#### Statistical Analysis

The statistics were performed in the Statistical Package of Social Science 15.0 (Windows, Chicago, IL). Standard descriptive statistics were used to analyze differences between the completers and non-completers. Changes from T0 to T1 were examined with paired sample *t* test for continuous data and with McNemar’s test for categorical data. All tests were two-sided, and the level of significance was set at  $p < 0.05$ .

#### Ethics

The institutional review board at the MBC and the NRH and the Regional Ethics Committee for Medical Research Region South-East Norway approved the study. All the patients who participated in the study gave their consent to take part in the evaluation.

#### Results

##### Participation

Seventy-five men who signed up for a course for PCA patients at MBC in October 2006 ( $n=29$ ), December 2006 ( $n=23$ ), and February 2007 ( $n=23$ ) were invited to participate. Of the men invited, 67 (89%) were willing to participate and returned the questionnaire at T0. At T1, 51 men returned the questionnaire (participation rate 68%). Compared to those who responded at both time points, those who only responded at T0 had higher level of depression (HADS-D) ( $p=0.04$ ) and a higher level of total fatigue ( $p=0.05$ ) (Table 1).

##### Characteristics at T0

The median age of the completers ( $n=51$ ) was 67.4 years (48.5–81.2) and 86% was married or cohabiting (Table 1). According to the self report, 53% had completed college or university, 51% were retired, and 23% worked full-time or part-time. The median time since diagnosis was 18.2 months (3.0–97.0), and 23% reported physical comorbidities. Forty-three percent had undergone surgery ± radiotherapy, 20% had received radiotherapy, 16% had received hormone therapy, 8% had ‘wait and see’, and 14% had received hormone therapy + other therapies. Eighty-six percent had localized or pelvis-confirmed advanced disease and 14% had metastatic PCA.

##### Changes in PA, Fatigue, Mental Distress, and QoL

The proportion of men meeting public exercise guidelines did not change significantly from T0 to T1 (Table 2). The mean of total fatigue was significantly reduced from 16.1 (4.8) at T0 to 14.0 (4.4) at T1 ( $p=0.001$ ), and physical fatigue decreased from 11.1 (4.0) at T0 to 9.2 (3.4) at T1 ( $p=0.001$ ). The reduction in mental fatigue did not reach statistical significance. Of the MAX-PC subscales, the mean level of PSA anxiety was reduced from 0.8 (1.3) at T0 to 0.3 (0.9) at T1 ( $p=0.001$ ), while the remaining MAX-PC subscales did not change significantly. The mean scores of HADS and Global QoL did not change significantly.

**Table 1** Characteristics of completers versus non-completers at T0

	Completers ( <i>n</i> =51)	Non-completers ( <i>n</i> =16)	<i>p</i>
Age (years) <sup>a</sup>	67.4 (48.5–81.2)	66.1 (54.4–77.4)	0.90
Marital status <sup>b</sup>			
Married/cohabitating	44 (86)	14 (88)	0.90
Living alone	7(14)	2 (12)	
Level of education <sup>b</sup>			
Elementary school/high school	24 (47)	8 (50)	0.84
College/university	27 (53)	8 (50)	
Employment status <sup>b</sup>			
Employed (full/part)	12 (23)	4 (25)	0.53
Retired	26 (51)	10 (63)	
Disability benefit	7 (14)	2 (12)	
Sick leave	6 (12)	0 (0)	
Time since diagnosis (months) <sup>a</sup>	18.2 (3.0–97.0)	24.8 (4.6–150.9)	0.36
Physical comorbidity <sup>b, d</sup>			
Yes	12 (23)	4 (25)	0.93
No	31 (61)	11 (69)	
Missing	8 (16)	1 (6)	
Treatment			
Surgery +/- radiotherapy	22 (43)	8 (50)	0.3
Radiotherapy	10 (20)	1 (6)	
Hormone therapy	8 (16)	2 (13)	
Wait and see	4 (8)	0 (0)	
Hormone therapy + other	7 (14)	5 (31)	
Stage of disease <sup>b</sup>			
Localized disease/pelvis-confirmed advanced disease	44 (86)	11 (69)	0.11
Metastatic disease	7 (14)	5 (31)	
Physical activity, GLTEQ ( <i>n</i> =34)			
Weekly physical activity			
Strenuous plus moderate, minutes <sup>e</sup>	201.4 (140.3)	98.0 (76.3)	0.06
Meeting public health guidelines (%) <sup>b</sup>	15 (58)	2 (25)	0.11
Fatigue <sup>e</sup>			
Total fatigue ( <i>n</i> =66)	16.1 (4.8)	18.8 (4.2)	0.05
Physical fatigue ( <i>n</i> =67)	11.0 (3.9)	12.9 (3.4)	0.09
Mental fatigue ( <i>n</i> =66)	5.0 (1.5)	5.9 (2.1)	0.08
Mental distress <sup>e</sup>			
MAX-PC			
Total MAX-PC ( <i>n</i> =65)	14.9 (10.1)	14.4 (8.9)	0.84
Prostate cancer anxiety ( <i>n</i> =66)	9.7 (7.3)	8.1 (6.4)	0.41
PSA anxiety ( <i>n</i> =66)	0.8 (1.3)	0.6 (1.6)	0.61
Fear of recurrence ( <i>n</i> =67)	4.6 (2.9)	5.8 (2.6)	0.17
HADS			
HADS-T ( <i>n</i> =66)	7.3 (5.9)	10.6 (3.7)	0.04
HADS-A ( <i>n</i> =66)	3.8 (3.6)	5.4 (3.2)	0.12
HADS-D ( <i>n</i> =65)	3.6 (3.0)	5.3 (1.8)	0.04
Global QoL <sup>e</sup>	68.6 (19.4)	64.1 (17.4)	0.40

*SD* standard deviation, *HADS* Hospital Anxiety and Depression Scale, *HADS-T* Hospital Anxiety and Depression Scale—total, *HADS-A* Hospital Anxiety and Depression Scale—anxiety, *HADS-D* Hospital Anxiety and Depression Scale—depression, *MAX-PC* Memorial Anxiety Scale for Prostate Cancer, *GLTEQ* Godin Leisure Time Exercise Questionnaire, *QoL* quality of life

<sup>a</sup>Median (range)/Mann-Whitney

<sup>b</sup>Number of patients (in percent)/chi-square test

<sup>c</sup>Living alone includes divorced, widowed, and single

<sup>d</sup>Physical comorbidity includes cardiovascular diseases, diabetes, asthma, or allergy

<sup>e</sup>Mean (SD)/independent sample *t* tests

**Table 2** Changes in physical activity, fatigue, mental distress and quality of life from T0 to T1 (n=51)

Variables	T0	T1	Change in score T0 to T1	95% CI of change score	p
Physical activity, GLTEQ (n=24)					
Weekly exercise					
Strenuous plus moderate minutes <sup>a</sup>	215.4 (136.5)	201.8 (115.1)	-13.6	-28.8 to 56.1	0.51
Meeting public health guidelines (%) <sup>b</sup>	15 (63)	17 (71)			0.73
Fatigue (n=49) <sup>a</sup>					
Total fatigue	16.1 (4.8)	14.0 (4.4)	-2.1	0.90 to 3.47	0.001
Physical fatigue	11.1 (4.0)	9.2 (3.4)	-1.9	0.76 to 2.91	0.001
Mental fatigue	5.1 (1.5)	4.7 (1.5)	-0.4	-0.04 to 0.73	0.07
Mental distress					
MAX-PC (n=49) <sup>a</sup>					
Total MAX-PC	14.9 (10.1)	13.0 (8.7)	-1.9	-0.13 to 3.97	0.07
Prostate cancer anxiety	9.7 (7.3)	8.5 (6.1)	-1.2	-0.32 to 2.81	0.12
PSA anxiety	0.8 (1.3)	0.3 (0.9)	-0.5	0.21 to 0.81	0.001
Fear of recurrence	4.4 (2.8)	4.3 (2.8)	-0.1	-0.41 to 0.73	0.57
HADS (n=49) <sup>a</sup>					
HADS-T	7.4 (5.9)	6.8 (5.0)	-0.6	-0.47 to 1.58	0.29
HADS-A	3.8 (3.6)	3.5 (3.0)	-0.3	-0.35 to 0.89	0.39
HADS-D	3.6 (3.0)	3.3 (2.7)	-0.3	-0.32 to 0.90	0.35
Global QoL (n=50) <sup>a</sup>	69.3 (18.9)	70.8 (22.7)	1.5	-7.8 to 4.8	0.63

SD standard deviation, HADS Hospital Anxiety and Depression Scale, HADS-T Hospital Anxiety and Depression Scale—total, HADS-A Hospital Anxiety and Depression Scale—anxiety, HADS-D Hospital Anxiety and Depression Scale—depression, MAX-PC Memorial Anxiety Scale for Prostate Cancer, GLTEQ Godin Leisure Time Exercise Questionnaire, QoL quality of life

<sup>a</sup> Mean (SD)/paired sample t test

<sup>b</sup> Number of patients (in percent)/McNemar’s test for paired samples

Satisfaction with the Course

Concerning satisfaction with the course, the respondents provided the following ratings at T1: 56% stated that the course had changed their everyday life expectations (to a high extent/fair extent) and 60% reported that the course had helped them to cope better with their PC and/or the side-effects associated with the treatment (to a high extent/fair extent) (data not shown).

Discussion

This explorative study on the effects of a 1-week course showed that the levels of total and physical fatigue were significantly reduced from T0 to T1. A significant reduction in the PSA anxiety subscale was also found, while no significant changes were observed concerning the general PCa anxiety and fear of recurrence subscales. The course did not significantly change the levels of PA, anxiety/depression, or Global QoL. The majority of the respondents stated that the course had helped them to meet everyday’s requirements.

During the 1990s, institutions similar to MBC were established in Sweden (e.g., Lydiagården) and Denmark (e.g., Dallund) based on the assumption that PA, lectures, and

group sessions were important elements in the rehabilitation of cancer patients. PA seems to have promising effects in PCa patients resulting in improved muscular fitness, physical function, QoL, and reduced fatigue [19]. General informational and educational programs for cancer patients have been found to have beneficial effects on emotional and functional adjustment, and treatment- and disease-related symptoms [20]. Group sessions focusing on sharing of experiences based on the importance of support from fellow patients have shown to improve coping in cancer patients [6, 20]. Such effects could not be detected in the present sample. This implies that the intervention could be ‘too weak’ or the sample did not fit the intervention.

Overall, in spite of some positive results such as reduction in fatigue and PSA anxiety, the 3-month effect of MBC’s prostate cancer-specific courses must be considered as negative. Similarly, Jorgensen et al. did not find any changes in QoL and mental distress at 1- and 6-months follow-up of Danish breast cancer patients attending a 1-week similar intervention at Dallund that was also compared to a control group. Jorgensen et al. suggest that the intervention could have been useful if the patients had attended the program closer to the end of treatment [21]. Courses starting as long as 2 years after the end of treatment may have limited effects due to the patients’ capacity for improvement actually are limited (a ceiling

effect). This could also be the case in our study, since half of our sample was participating more than 1.5 years after diagnosis, when their health condition probably is relatively stable.

Our findings are in contrast to a Dutch randomized study comparing groups getting PA and PA + cognitive-behavioral training compared to a control group in a 12-week outpatient program starting  $\geq 3$  months (average 1.3 years) after treatment. That study found an improved QoL in both intervention groups immediately after the intervention and at 3- and 9-month follow-up [22, 23]. Interestingly, the participants in that study should have three or more physical or psychological complaints in order to be included, thereby documenting morbidity and thus avoiding a major ceiling effect. The MBC PCa courses did not use such an inclusion criterion. This interpretation is supported by the fact that the mean Global QoL score at T0 was approximately 10 points higher than in the above-mentioned Dutch sample [23].

The ceiling effect and the patients' potential for improvement are issues to consider in future studies of information/exercise and rehabilitation programs. Heterogeneity of the study sample as to age and treatment is another issue to be considered in relation to rehabilitation of cancer patients. For example, the rehabilitation needs among young professionally active men who have undergone curative treatment of localized prostate cancer probably differ from the needs of older men with life-long androgen-suppressive therapy due to metastatic disease. Unselected inclusion of cancer patients will easily reduce the chance of improvement. Another strategy could be to include only those who report specific problems or in other ways have reduced health and thereby aiming the intervention group more homogeneous. The duration of the interventions might also be of importance since the intervention tested by May et al. [23] lasted for 12 weeks (once to twice weekly) compared to our intensive 1-week course.

In line with May et al. [23], we found a positive effect on fatigue. Due to the lack of a control group in our study, we cannot state whether the positive changes in fatigue at T1 are due to the course. The significant improvements observed could be due to 'regression toward the mean' rather than the intervention. The statistically documented improvement at T1 could in line with this, represents a spontaneous transition to their habitual level of fatigue [24]. On the other hand, fatigue was a central topic in the lectures which in combination with the PA could have influenced upon both the participants' cognition and level of activity and thus contributed to the reduced level of fatigue. The lack of a control group limits further elaboration on this point.

We believe the improvement in PSA anxiety is related to the information on this particular issue presented in the

lectures and discussed in the group sessions. Factual knowledge about PSA's significance for the clinical course of PCa is of relevance and will presumably reduce anxiety about PSA tests results.

At several places in Europe, both outpatient- and inpatient-based programs, including information, PA, and group sessions, for cancer patients with different duration are currently running. So far, there is no conclusive evidence that longer programs are more beneficial than short ones. Further, the effects of an inpatient 1-week program like ours as compared to less intensive programs administered over weeks while the patients stay at home are unknown. Factors like employment status, family situation, social network, health status, and specific problems will probably determine the patients' preference for the type of program. For example, PA might have better effects in a program lasting for several weeks while information and group sessions might be more efficiently administered in an intensive program outside the routines of daily life. We believe that a follow-up or a booster procedure on PA and perhaps other elements could be relevant supplements to the 1-week course. Probably a 1-week course alone is too short to influence the patients' exercise behavior over time. It is therefore reasonable to speculate that a follow-up course would increase the chance to obtain positive results. Also, the use of objective measurements of PA or physical performance would improve the program.

Behavior change is a complex process and there are several levels in motivation for changes. A well-known model is 'the transtheoretical model' [25] with five stages of change and it can be used in a variety of behaviors. Most probably, the PCa patients in the present study were in different motivation stages in terms of their wishes/desires to change their exercise behaviors. For future studies in the field, it would be interesting to include the model, so even if the participants did not change their level of PA, it would be possible to see if they had changed in stage to become an exerciser.

There are some major limitations of the present study. The heterogeneity of the sample in terms of a relatively wide span between the participants' health status is related to referral patterns of the MBC. These could not be changed when the study was designed. The relatively high mean scores on the outcome variables at T0 limit the possibility to improve and detect improvements of the participants' health. The lack of a control group is another limitation specifically affecting the implications of the finding of a lowered fatigue level at T1. Since the study was based upon a convenience sample, further elaboration on this point is not possible except stating that a control group is needed in order to verify such an effect of the course on fatigue.

In conclusion, the intensive 1-week inpatient course was followed by minor reductions in fatigue and PSA anxiety and satisfied patients. Still, the overall findings indicate that



an intensive 1-week course does not influence substantially on most of the health-related outcomes in PCa patients after 3 months. Controlled trials directed towards a more homogenous group of patients with anticipated recovery capacity are needed for documentation of efficacy rehabilitation efforts among cancer patients.

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**Conflicts of Interest** We state that there are no potential conflicts of interest in this study.

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## References

1. Horner MJ, Ries LAG, Krapcho M, Neyman N, Aminou R, Howlader N, Altekruse SF, Feuer EJ, Huang L et al. (2009) SEER Cancer Statistics Review. National Cancer Institute. [http://seer.cancer.gov/csr/1975\\_2006/](http://seer.cancer.gov/csr/1975_2006/). Accessed 25 October 2009
2. Heidenreich A, Aus G, Bolla M, Joniau S, Matveev V, Schmid H-P, Zattoni F (2007) Guidelines on prostate cancer. European Association of Urology. Type ref: report
3. Galvao DA, Taaffe DR, Spry N, Joseph D, Turner D, Newton RU (2009) Reduced muscle strength and functional performance in men with prostate cancer undergoing androgen suppression: a comprehensive cross-sectional investigation. *Prostate Cancer Prostatic Dis* 12:198–203
4. Potosky AL, Davis WW, Hoffman RM, Stanford JL, Stephenson RA, Penson DF, Harlan LC (2004) Five-year outcomes after prostatectomy or radiotherapy for prostate cancer: the prostate cancer outcomes study. *J Natl Cancer Inst* 96:1358–1367
5. Roth AJ, Weinberger MI, Nelson CJ (2008) Prostate cancer: psychosocial implications and management. *Future Oncol* 4:561–568
6. Gregoire I, Kalogeropoulos D, Corcos J (1997) The effectiveness of a professionally led support group for men with prostate cancer. *Urol Nurs* 17:58–66
7. Fossa SD, Kvaloy J, Kvaloy S, Loge JH, Dahl AA (2008) [Courses for cancer patients-15 years' experience at The Montebello Centre in Norway]. *Tidsskr Nor Laegeforen* 128:2554–2557
8. Godin G, Jobin J, Bouillon J (1986) Assessment of leisure time exercise behavior by self-report: a concurrent validity study. *Can J Public Health* 77:359–362
9. Jacobs DR, Ainsworth BE, Hartman TJ, Leon AS (1993) A simultaneous evaluation of 10 commonly used physical activity questionnaires. *Med Sci Sports Exerc* 25:81–91
10. Guillemin F, Bombardier C, Beaton D (1993) Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol* 46:1417–1432
11. US Department of Health and Human Services (2008) 2008 Physical Activity Guidelines for Americans. Be active, healthy, and happy! Ref type: report
12. Chalder T, Berelowitz G, Pawlikowska T, Watts L, Wessely S, Wright D, Wallace EP (1993) Development of a fatigue scale. *J Psychosom Res* 37:147–153
13. Minton O, Stone P (2009) A systematic review of the scales used for the measurement of cancer-related fatigue (CRF). *Ann Oncol* 20:17–25
14. Roth AJ, Rosenfeld B, Kornblith AB, Gibson C, Scher HI, Curley-Smart T, Holland JC, Breitbart W (2003) The memorial anxiety scale for prostate cancer: validation of a new scale to measure anxiety in men with prostate cancer. *Cancer* 97:2910–2918
15. Zigmond AS, Snaith RP (1983) The hospital anxiety and depression scale. *Acta Psychiatr Scand* 67:361–370
16. Bjelland I, Dahl AA, Haug TT, Neckelmann D (2002) The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosom Res* 52:69–77
17. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, Filiberti A, Flechtner H, Fleishman SB, de Haes JC et al (1993) The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 85:365–376
18. Hjermstad MJ, Fossa SD, Bjordal K, Kaasa S (1995) Test/retest study of the European Organization for Research and Treatment of Cancer Core Quality-of-Life Questionnaire. *J Clin Oncol* 13:1249–1254
19. Thorsen L, Courneya KS, Stevinson C, Fossa SD (2008) A systematic review of physical activity in prostate cancer survivors: outcomes, prevalence, and determinants. *Support Care Cancer* 16:987–997
20. Meyer TJ, Mark MM (1995) Effects of psychosocial interventions with adult cancer patients: a meta-analysis of randomized experiments. *Health Psychol* 14:101–108
21. Jorgensen IL, Frederiksen K, Boesen E, Elsass P, Johansen C (2009) An exploratory study of associations between illness perceptions and adjustment and changes after psychosocial rehabilitation in survivors of breast cancer. *Acta Oncol* 48:1119–1127
22. Korstjens I, May AM, van Weert E, Mesters I, Tan F, Ros WJ, Hoekstra-Weebers JE, van der Schans CP, van den Borne B (2008) Quality of life after self-management cancer rehabilitation: a randomized controlled trial comparing physical and cognitive-behavioral training versus physical training. *Psychosom Med* 70:422–429
23. May AM, Korstjens I, van Weert E, van den Borne B, Hoekstra-Weebers JE, van der Schans CP, Mesters I, Passchier J, Grobbee DE, Ros WJ (2009) Long-term effects on cancer survivors' quality of life of physical training versus physical training combined with cognitive-behavioral therapy: results from a randomized trial. *Support Care Cancer* 17:653–663
24. Chernick MR, Friis RH (2003) Introductory biostatistics for the health sciences. Modern applications including bootstrap. Wiley, Hoboken
25. Prochaska JO, DiClemente CC (1983) Stages and processes of self-change of smoking: toward an integrative model of change. *J Consult Clin Psychol* 51:390–395



# Appendix



## Appendix A: Questions about needs for rehabilitation services and rehabilitation services offered/used

*Hvor stort behov har du hatt for følgende typer rehabilitering i forbindelse med kreftsykdommen?*

	Har ikke hatt behov	Har hatt noe behov	Har hatt stort behov
Fysioterapi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rekreasjonsopphold eller lignende	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psykologisk rådgiving/behandling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ergoterapi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gruppemøter for pasientstøtte	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fysisk opptrening (ikke fysioterapi)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Samtale med sosionom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*I hvor stor grad har du benyttet deg av følgende typer rehabilitering i forbindelse med kreftsykdommen?*

	Har ikke fått tilbud	Har fått tilbud, men ikke benyttet	Benyttet i liten grad	Benyttet i stor grad
Fysioterapi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rekreasjonsopphold eller lignende	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psykologisk rådgiving/behandling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ergoterapi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gruppemøter for pasientstøtte	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fysisk opptrening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Samtale med sosionom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opphold på Montebellosenteret	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix B: Questions about interest and preferences for exercise counselling and programming



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### ØNSKER KNYTTET TIL TRENINGSVEILEDNING

På de neste fem spørsmålene skal du krysse av på kun et svaralternativ per spørsmål. Svarene du gir skal være basert på hva du har foretrukket, ikke nødvendigvis hva du faktisk har fått.

32. Ville du ønsket å få treningsveiledning på et eller annet tidspunkt etter kreftdiagnosen (under og/ eller etter behandling)?

Ja  Nei  Kanskje

Selv om du svarte nei på spørsmålet over, ber vi deg allikevel å svare på de neste spørsmålene

33. Hvem ville du foretrekke å få treningsveiledning av?

- Kreftlege
- Sykepleier
- Kreftpasient/ tidlig kreftpasient
- Treningsveileder på en kreftklinikk
- Treningsveileder på et lokalt treningsstudio

34. Når ville du foretrekke å få treningsveiledning?

- Før behandling
- Under behandling
- Umiddelbart etter behandling
- 3-6 måneder etter behandling
- Minst 1 år etter behandling

35. Hvor ville du foretrekke at veiledningen fant sted?

- Sykehus
- Lokalt treningsstudio
- Hjemme hos meg selv
- Annet sted    Hvor:

36. Hvordan ville du foretrekke å bli veiledet?

- Ansikt til ansikt
- Telefon
- Brosjyre
- Video
- Via Internett
- Andre måter    Hvordan:

### ØNSKER KNYTTET TIL TRENINGSPROGRAMMER

På de neste 14 spørsmålene skal du krysse av på kun et svaralternativ per spørsmål. Svarene du gir skal være basert på hva du har vært i stand til/ interessert i/ foretrukket, ikke nødvendigvis hva du faktisk har gjort.

37. Ville du vært istand til å gjennomføre et treningsprogram laget for personer som har eller har hatt kreft, på et eller annet tidspunkt etter kreftdiagnosen (under og/eller etter behandling)?

Ja  Nei  Kanskje

38. Ville du vært interessert i å gjennomføre et treningsprogram laget for personer som har eller har hatt kreft, på et eller annet tidspunkt etter kreftdiagnosen (under og/eller etter behandling)?

Ja  Nei  Kanskje

### Hvis du skulle begynne med et treningsprogram:

39. Hvilken type trening ville du foretrekke mest?

- Gå
- Danse
- Svømme
- Sykle
- Gå på skøyter
- Jogge
- Styrketrening
- Aerobic - gym etter musikk
- Gå på ski
- Bevegelighetstrening
- Annet

40. Når ville du foretrekke å starte?

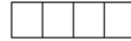
- Før behandling
- Under behandling
- Straks etter behandling
- 3-6 måneder etter behandling
- Minst 1 år etter behandling

41. Hvem ville du foretrekke å trene sammen med?

- Alene
- Med andre som har eller har hatt kreft
- Med venner
- Med familie
- Det er det samme for meg



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42. Hvor ville du foretrekke å trene?
- Hjemme
  - På et lokalt treningsstudio
  - På et treningssenter for kreftpasienter
  - Det er det samme for meg
43. Når på dagen ville du foretrekke å trene?
- Om morgenen
  - Om ettermiddagen
  - Om kvelden
  - Det er det samme for meg
44. Hvor intensivt ville du foretrekke at treningsprogrammet var?
- Lav intensitet
  - Moderat intensitet
  - Høy intensitet
  - Det er det samme for meg
45. Hvilken type aktivitet ville du foretrekke?
- Samme aktiviteter hver gang
  - Ulike aktiviteter hver gang
46. Hvordan ville du foretrekke å gjennomføre øvelsene?
- Med tilsyn/veiledning
  - Uten tilsyn/i eget tempo
47. Hvordan ville du foretrekke å strukturere treningsprogrammet?
- Spontan/fleksibelt
  - Planlagt (dvs. oppsatte dager/tidspunkter)
48. Hva slags aktiviteter ville du foretrekke?
- Rekreasjonsbaserte
  - Konkurransbaserte
49. Ville du være interessert i å lære en avspenningsteknikk?
- Ja
  - Nei
  - Vet ikke
50. Hvis du ikke orker/ liker fysisk aktivitet, er det andre former for aktiviteter (f.eks tening, maling, snekring) som kunne hjelpe deg?
- Ja, hvilke:
  - Nei
  - Vet ikke



## Appendix C: Godin Leisure Time Exercise Questionnaire



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### TRENING I FRITIDEN

Når du skal svare på de neste tre spørsmålene, ber vi deg tenke på din gjennomsnittlige ukentlige trening i månedene før du fikk din kreftdiagnose, i den tiden du fikk behandling og i løpet av den siste måneden.

Når du svarer på spørsmålene under skal du merke deg følgende:

- Ta bare med treningsøkter som varte 10 minutter eller lenger
- Ta bare med trening du har gjort i løpet av fritiden (altså ikke i arbeidstiden eller husarbeid)
- Merk deg at hovedforskjellen mellom de tre treningskategoriene er intensiteten
- Skriv ned hvor mange ganger per uke i gjennomsnitt du gjorde en aktivitet i første kolonne, og hvor lenge du holdt på per gang i gjennomsnitt på andre kolonne.

25. Tenk tilbake på din gjennomsnittlige ukentlige trening i **månedene før du fikk din kreftdiagnose**. Hvor mange ganger i løpet av en vanlig syvdagersuke gjennomførte du følgende trening:

a) **HARD TRENING**  
(VELDIG ANSTRENGENDE, HJERTE SLÅR FORT)  
(f.eks. løping, jobbing, ishockey, fotball, squash, basketball, skigåing, judo, rulleskøyter, rask svømming, rask sykling over lange avstander)

a1) Ganger per uke i gjennomsnitt

--	--	--	--

a2) Hvor lenge per gang i gjennomsnitt (antall min.)

--	--	--	--

b) **MODERAT TRENING**  
(MODERAT ANSTRENGENDE)  
(f.eks. rask gange, tennis, lett sykling, volleyball, badminton, rolig svømming, slalåm, folkedans)

b1) Ganger per uke i gjennomsnitt

--	--	--	--

b2) Hvor lenge per gang i gjennomsnitt (antall min.)

--	--	--	--

c) **LETT TRENING**  
(MINIMALT ANSTRENGENDE)  
(f.eks. lett gange, yoga, bueskytting, fiske, bowling, golf, snøscooterkjøring)

c1) Ganger per uke i gjennomsnitt

--	--	--	--

c2) Hvor lenge per gang i gjennomsnitt (antall min.)

--	--	--	--





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27. Tenk tilbake på din gjennomsnittlige ukentlige trening **den siste måneden**. Hvor mange ganger i løpet av en vanlig syvdagersuke gjennomførte du følgende trening:

a) **HARD TRENING**  
(VELDIG ANSTRENGENDE, HJERTE SLÅR FORT)  
(f.eks. løping, jobbing, ishockey, fotball, squash, basketball, skigåing, judo, rulleskøyter, rask svømming, rask sykling over lange avstander)

a1) Ganger per uke i gjennomsnitt

--	--	--	--

a2) Hvor lenge per gang i gjennomsnitt (antall min.)

--	--	--	--

b) **MODERAT TRENING**  
(MODERAT ANSTRENGENDE)  
(f.eks. rask gange, tennis, lett sykling, volleyball, badminton, rolig svømming, slalåm, folkedans)

b1) Ganger per uke i gjennomsnitt

--	--	--	--

b2) Hvor lenge per gang i gjennomsnitt (antall min.)

--	--	--	--

c) **LETT TRENING**  
(MINIMALT ANSTRENGENDE)  
(f.eks. lett gange, yoga, bueskytting, fiske, bowling, golf, snøscooterkjøring)

c1) Ganger per uke i gjennomsnitt

--	--	--	--

c2) Hvor lenge per gang i gjennomsnitt (antall min.)

--	--	--	--

## Appendix D: The Fatigue Questionnaire

### Fatigue (tretthet)

Vi vil gjerne vite om du har følt deg sliten, svak eller i mangel av overskudd den siste måneden. Vennligst besvar ALLE spørsmålene ved å krysse av x for det svaret du synes passer best for deg. Vi ønsker at du besvarer alle spørsmålene selv om du ikke har hatt slike problemer. Vi spør om hvordan du har følt deg i det siste og ikke om hvordan du følte deg for lenge siden. Hvis du har følt deg sliten lenge, ber vi om at du sammenlikner deg med hvordan du følte deg sist du var bra. (Ett kryss på hver linje)

- 
- |   |   |   |   |   |
|---|---|---|---|---|
| 1. Har du problemer med at du føler deg sliten?                                   | <input type="checkbox"/> Mindre enn vanlig      | <input type="checkbox"/> Ikke mer enn vanlig    | <input type="checkbox"/> Mer enn vanlig             | <input type="checkbox"/> Mye mer enn vanlig     |
| 2. Trenger du mer hvile?  | <input type="checkbox"/> Nei, mindre enn vanlig | <input type="checkbox"/> Ikke mer enn vanlig    | <input type="checkbox"/> Mer enn vanlig             | <input type="checkbox"/> Mye mer enn vanlig     |
| 3. Føler du deg søvnnig eller døsig?  | <input type="checkbox"/> Mindre enn vanlig      | <input type="checkbox"/> Ikke mer enn vanlig    | <input type="checkbox"/> Mer enn vanlig             | <input type="checkbox"/> Mye mer enn vanlig     |
| 4. Har du problemer med å komme igang med ting?                                   | <input type="checkbox"/> Mindre enn vanlig      | <input type="checkbox"/> Ikke mer enn vanlig    | <input type="checkbox"/> Mer enn vanlig             | <input type="checkbox"/> Mye mer enn vanlig     |
| 5. Mangler du overskudd?  | <input type="checkbox"/> Ikke i det hele tatt   | <input type="checkbox"/> Ikke mer enn vanlig    | <input type="checkbox"/> Mer enn vanlig             | <input type="checkbox"/> Mye mer enn vanlig     |
| 6. Har du redusert styrke i musklene dine?  | <input type="checkbox"/> Ikke i det hele tatt   | <input type="checkbox"/> Ikke mer enn vanlig    | <input type="checkbox"/> Mer enn vanlig             | <input type="checkbox"/> Mye mer enn vanlig     |
| 7. Føler du deg svak?   | <input type="checkbox"/> Mindre enn vanlig      | <input type="checkbox"/> Som vanlig             | <input type="checkbox"/> Mer enn vanlig             | <input type="checkbox"/> Mye mer enn vanlig     |
| 8. Har du vansker med å konsentrere deg?  | <input type="checkbox"/> Mindre enn vanlig      | <input type="checkbox"/> Som vanlig             | <input type="checkbox"/> Mer enn vanlig             | <input type="checkbox"/> Mye mer enn vanlig     |
| 9. Forsnakker du deg i samtaler?  | <input type="checkbox"/> Mindre enn vanlig      | <input type="checkbox"/> Ikke mer enn vanlig    | <input type="checkbox"/> Mer enn vanlig             | <input type="checkbox"/> Mye mer enn vanlig     |
| 10. Er det vanskeligere å finne det rette ordet?                                  | <input type="checkbox"/> Mindre enn vanlig      | <input type="checkbox"/> Ikke mer enn vanlig    | <input type="checkbox"/> Mer enn vanlig             | <input type="checkbox"/> Mye mer enn vanlig     |
| 11. Hvordan er hukommelsen din?   | <input type="checkbox"/> Bedre enn vanlig       | <input type="checkbox"/> Ikke verre enn vanlig  | <input type="checkbox"/> Verre enn vanlig           | <input type="checkbox"/> Mye verre enn vanlig   |
| 12. Hvis du føler deg sliten for tiden, omtrent hvor lenge har det vart?          | <input type="checkbox"/> Mindre enn en uke      | <input type="checkbox"/> Mindre enn tre måneder | <input type="checkbox"/> Mellom tre og seks måneder | <input type="checkbox"/> Seks måneder eller mer |
| 13. Hvis du føler deg sliten for tiden, omtrent hvor mye av tiden kjenner du det? | <input type="checkbox"/> 25% av tiden           | <input type="checkbox"/> 50% av tiden           | <input type="checkbox"/> 75% av tiden               | <input type="checkbox"/> Hele tiden             |

## Appendix E: Memorial Anxiety Scale for Prostate Cancer

I. Nedenfor finner du en liste over utsagn fra menn om prostatakraft. Sett kryss ved det utsagnet som var mest sant for deg *i løpet av den siste uken*: Slett ikke, sjelden, noen ganger, ofte.

**55. Alt om prostatakraft vekker sterke følelser hos meg**

- Slett ikke
- Sjelden
- Noen ganger
- Ofte

**56. Selv om det er en god idé, blir jeg skremt av å ta en PSA-test**

- Slett ikke
- Sjelden
- Noen ganger
- Ofte

**57. Hver gang jeg hører om en venn eller en kjent person med prostatakraft, blir jeg mer engstelig for min egen prostatakraft**

- Slett ikke
- Sjelden
- Noen ganger
- Ofte

**58. Når jeg tenker på å ta en PSA-test, blir jeg mer engstelig for min prostatakraft**

- Slett ikke
- Sjelden
- Noen ganger
- Ofte

**59. Andre ting får meg til å tenke på prostatakraft**

- Slett ikke
- Sjelden
- Noen ganger
- Ofte

**60. Jeg føler meg nummen når jeg tenker på prostatakreft**

Slett ikke

Sjelden

Noen ganger

Ofte

**61. Jeg tenker på prostatakreft uten at det er meningen**

Slett ikke

Sjelden

Noen ganger

Ofte

**62. Jeg har masse følelser omkring prostatakreft, men jeg ønsker ikke å gå inn i dem**

Slett ikke

Sjelden

Noen ganger

Ofte

**63. Jeg får mer innsovningsvansker fordi jeg ikke kan få tankene på prostatakreft ut av hodet**

Slett ikke

Sjelden

Noen ganger

Ofte

**64. Jeg er redd for at resultatene av PSA-testen vil vise at sykdommen min er blitt verre**

Slett ikke

Sjelden

Noen ganger

Ofte

**65. Bare å høre ordet ”prostatkreft” skremmer meg**

Slett ikke

Sjelden

Noen ganger

Ofte

**II. Angi på de neste tre spørsmålene hvor ofte disse situasjonene NOEN GANG har vært riktige for deg.**

- 66. Jeg er så redd for PSA-testen min, at jeg har tenkt på å utsette den**
- Slett ikke
- Sjelden
- Noen ganger
- Ofte
- 67. Jeg er så bekymret for resultatene av PSA-testen at jeg har tenkt på å be legen min om å gjenta den**
- Slett ikke
- Sjelden
- Noen ganger
- Ofte
- 68. Jeg er så opptatt av PSA-testen min at jeg har tenkt på å få testen gjentatt ved et annet laboratorium for å være sikker på at den er riktig**
- Slett ikke
- Sjelden
- Noen ganger
- Ofte

**III. Nedenfor finner du noen påstander angående hva en person kan tro om sin egen helse. Når du tenker på *den siste uken*, vær snill å angi hvor mye du er enig eller uenig i hver påstand: Helt enig, enig, uenig, helt uenig.**

- 69. Fordi kreft er uforutsigbar, føler jeg at jeg ikke kan planlegge for fremtiden**
- Helt enig
- Enig
- Uenig
- Helt uenig
- 70. Min frykt for at kreften skal bli verre, hindrer meg i å nyte livet**
- Helt enig
- Enig

Uenig

Helt uenig

**71. Jeg er redd for at kreften min skal bli verre**

Helt enig

Enig

Uenig

Helt uenig

**72. Jeg er mer nervøs etter at jeg fikk diagnosen prostatakraft**

Helt enig

Enig

Uenig

Helt uenig

## Appendix F: The Hospital Anxiety and Depression Scale

### HADS

Dette spørreskjemaet er utformet for å hjelpe oss til å forstå hvordan du føler deg. Les hvert utsagn og sett kryss x i ruten som best beskriver dine følelser den siste uka. Fundér ikke for lenge på ditt svar; din umiddelbare reaksjon på hvert spørsmål er sannsynligvis riktigere enn et svar som du har tenkt lenge på.

1. J eg er nervøs eller anspent

- For det meste
- Ofte
- Noen ganger
- Ikke i det hele tatt

2. J eg gleder meg fremdeles over ting jeg pleide å gleder meg over

- Avgjort like mye
- Ikke fullt så mye
- Bare lite grann
- Ikke i det hele tatt

3. J eg har en urofølelse som om noe forferdelig kommer til å skje

- Helt sikkert og svært ille
- J a, men ikke så veldig ille
- Litt ille, men det bekymrer meg ikke så mye
- Ikke i det hele tatt

4. J eg kan le og se det morsomme i situasjoner

- Like mye som jeg alltid har gjort
- Ikke like mye nå som før
- Avgjort ikke så mye nå som før
- Ikke i det hele tatt

5. J eg har hodet fullt av bekymringer

- Veldig ofte
- Ganske ofte
- Av og til
- En gang i blant

6. J eg er i godt humør

- Aldri
- Noen ganger
- Ganske ofte
- For det meste

7. J eg kan sitte i fred og ro og kjenne meg avslappet

- J a, helt klart
- Vanligvis
- Ikke så ofte
- Ikke i det hele tatt

8. J eg føler meg som om alt går langsommere

- Nesten hele tiden
- Svært ofte
- Fra tid til annen
- Ikke i det hele tatt

9. J eg føler meg urolig liksom jeg har sommerfugler i magen

- Ikke i det hele tatt
- Fra tid til annen
- Ganske ofte
- Svært ofte

10. J eg har sluttet å bry meg om hvordan jeg ser ut

- J a, helt klart
- J eg bryr meg ikke så mye som jeg burde
- Det kan nok hende jeg ikke bryr meg nok
- J eg bryr meg om utseendet like mye som jeg alltid har gjort

11. J eg føler meg rastløs som om jeg stadig må være i aktivitet

- Uten tvil svært mye
- Ganske mye
- Ikke så veldig mye
- Ikke i det hele tatt

12. J eg ser med glede frem til hendelser og ting

- Like mye som jeg alltid har gjort
- Heller mindre enn jeg pleier
- Avgjort mindre enn jeg pleier
- Nesten ikke i det hele tatt

13. J eg kan plutselig få en følelse av panikk

- Uten tvil svært ofte
- Svært ofte
- Ikke så veldig ofte
- Ikke i det hele tatt

14. J eg kan glede meg over en god bok eller et radio eller et TVprogram

- Ofte
- Fra tid til annen
- Ikke så ofte
- Svært sjelden

## Appendix G: Global quality of life-scale (from EORTC QIQ-C30)

### Livskvalitet

Som svar på de neste spørsmålene sett en ring rundt det tallet som best beskriver din tilstand siste uken.

#### 1. Hvordan har din helse vært den siste uken?

Svært dårlig 1      2      3      4      5      6      7      Helt utmerket

#### 2. Hvordan har livskvaliteten din vært den siste uken?

Svært dårlig 1      2      3      4      5      6      7      Helt utmerket