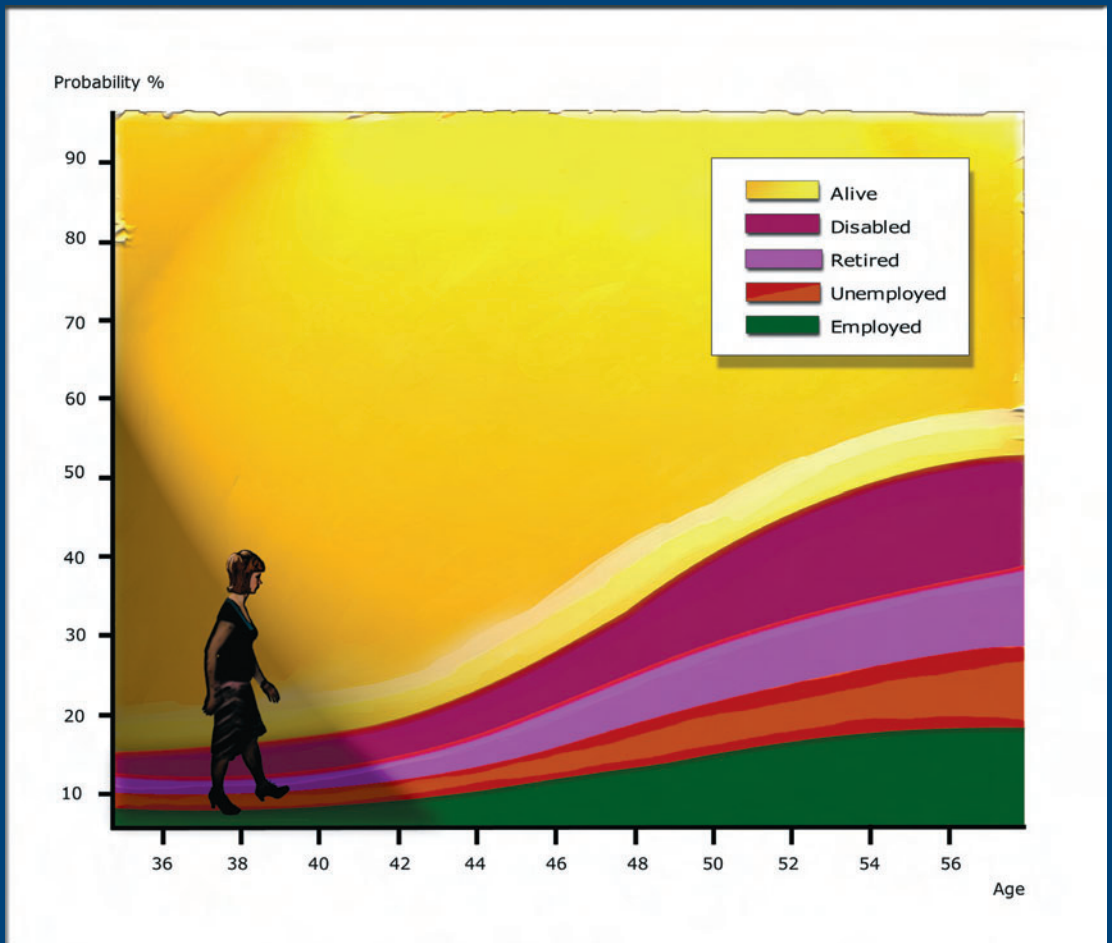


Taina Taskila

## Cancer survivors at work

– Work-related problems and factors associated with their employment, work ability and social support from the work community



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## **CANCER SURVIVORS AT WORK**

– Work-related problems and factors associated with their employment, work ability and social support from the work community

**Taina Taskila**

**People and Work Research Reports 80**

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## **KIITOKSET**

Aloitin väitöskirjatyöni heinäkuussa 2001 Työterveyslaitoksella tutkimusprojektissa ”Syöpään sairastunut työelämässä”. Työ toteutettiin suurimmalta osaltaan Epidemiologian ja biostatistiikan osastolla, joka organisaatiomuutoksen seurauksena lakkautettiin tammikuussa 2006. Haluan esittää lämpimät kiitokseni mukaville työtovereille ja kollegoille, jotka näiden vuosien aikana monella tavalla tukivat minua työssäni tällä osastolla. Erityisesti haluan kiittää professori Hilikka Riihimäkeä, joka osastonjohtajana käynnisti tutkimusprojektin ja tarjosi minulle mahdollisuuden tehdä väitöskirja mielenkiintoisessa ja aiheeltaan tärkeässä projektissa. Tutkimustyötä ovat taloudellisesti tukeneet Nordiska Cancer Union (NCU), Suomen Syöpäyhdistys, Suomen Syöpäjärjestöt ja Työsuojelurahasto (TSR). Olen lisäksi useiden kuukausien ajan saanut palkkaa väitöskirjaa varten Kansanterveystieteen tutkijakoululta (DPPH-koulu). Haluan mitä kunnioittavammin kiittää näitä tukijoitani korvaamattomasta taloudellisesta avusta, jota ilman tutkimusprojekti ei olisi ollut mahdollista toteuttaa.

Tutkimusprojektia ei myöskään olisi voitu toteuttaa ilman laadulliseen haastattelututkimukseen osallistuneita syövän itse kokeneita henkilöitä eikä ilman kyselylomaketutkimukseen osallistuneita syöpää sairastaneita ja heidän vertailuhenkilöitään. Osoitan lämpimät kiitokseni myös näille henkilöille, jotka osoittivat suurta luottamusta tutkimustamme kohtaan jakamalla kanssani kipeitäkin kokemuksia syöpään sairastumisesta ja työelämään paluusta, joka ei suinkaan aina suju ongelmitta.

Haluan kiittää työni ohjaajia, dosentti Marja-Liisa Lindbohmia ja dosentti Ossi Rahkosta korvaamattomista ja asiantuntevista kommentteista väitöskirjatyössäni sekä luottamuksesta, jota he ovat osoittaneet minua kohtaan antamalla minun toteuttaa väitöskirjatyöni mahdollisim-

man itsenäisesti. Dosentti Päivi Hietanen sai minut ymmärtämään, ettei syövässä ole kysymys ainoastaan biologisesta sairaudesta vaan sillä on lähestulkoon aina myös psykososiaalista merkitystä sairastuneen elämään. Haluan kiittää Päiviä mielenkiintoisista keskusteluista ja arvokkaasta yhteistyöstä koko tutkimusprojektin ajan. Dosentti Jari Hakasta kiitän lämpimästi tarttuvasta innostuksesta ja innovatiivisuudesta. Jarin arvokkaiden kommenttien avulla syöpään sairastuneiden työhyvinvointiin vaikuttavia tekijöitä otettiin tarpeeksi laajasti huomioon tutkimuksen kyselylomakeosuudessa. VTM Rami Martikaista kiitän tilastollisten analyysien asiantuntevasta toteuttamisesta. Kiitän myös väitöskirjani esitarkastajia, professori Markku Koskenvuota ja dosentti Anna-Mari Aaltoa, hyödyllisistä käsikirjoitukseen liittyvistä kommentteista ja parannusehdotuksista. Lausun myös mitä parhaimmat kiitokseni muille tutkimusprojektiin osallistuneille. FM Terttu Kaustiaa kiitän ansiokkaasta käsikirjoituksen oikoluvusta ja kielenhuollosta.

Olen ollut onnekas tavattuani monta upeaa ihmistä muutettuani Helsinkiin opiskelemaan vuosia sitten. Ilman ystävien tarjoamaa sosiaalista tukea ei mikään olisi mahdollista. Haluan kiittää ystäviäni niistä lukemattomista elämää täynnä olevista hetkistä, joita olen saanut heidän kanssaan kokea. Kiitän myös vanhempiani, Sirkka ja Erkki Taskilaa, tuesta jota he ovat minulle antaneet saavuttaakseni yhden suurimmista unelmistani. Viimeisenä, muttei vähäisimpänä, kiitän puolisoani ja parasta ystävääni Virpi Kiiskiä rakkaudesta ja vuosista yhdessä – menneistä ja tulevista.

*Amor Vincit Omnia*

Helsingissä 12. päivänä kesäkuuta 2007

*Taina Taskila*

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## TIIVISTELMÄ

Useat syöpään sairastuneet ovat halukkaita palaamaan työelämään sairautensa jälkeen, mutta on mahdollista, että he kohtaavat sairautensa seurauksena useita fyysisiä ja sosiaalisia ongelmia työelämässä. Syövän merkitystä työelämään ja työkykyyn tunnetaan huonosti. Tämän tutkimuksen tarkoituksena oli selvittää syövän vaikutusta työllisyyteen, työkykyyn ja työelämästä saatuun tukeen ja sen tarpeeseen.

Tutkimusongelmaa selvitettiin rekisteri- ja kyselytutkimuksen avulla. Rekisteritutkimus sisälsi kaksi aineistoa, joista ensimmäisessä oli 46 312 ja toisessa 12 542 työikäistä syöpään sairastunutta. Kullekin syöpään sairastuneelle valittiin sukupuolen ja syntymävuoden suhteen kaltaistettu verrokki, joka ei ollut sairastanut syöpää. Kyselytutkimuksen kaksi aineistoa käsitti 640 syöpään sairastunutta ensimmäisessä ja 591 syöpään sairastunutta ja 757 vertailuhenkilöä toisessa aineistossa.

Rekisteritutkimuksen tulosten mukaan syövällä on jonkin verran vaikutusta työllisyyteen. Työllisyys oli 2–3 vuotta sairastumisen jälkeen 64 %, kun se syöpää sairastamattoman vertailuryhmän keskuudessa oli 73 %. Työllisyysprosentti oli ennen sairastumista kummassakin ryhmässä yhtä suuri (78 %). Eri syöpätyyppejä sairastavien työllisyydessä oli selviä eroja. Syövän vaikutus työllisyyteen vaihteli myös koulutuksen mukaan erityisesti niillä, jotka sairastivat keskushermosto-, keuhko-, maha-, kohdunkaula- tai peräsuolen syöpää. Syöpään sairastuneet olivat useammin eläkkeellä kuin vertailuhenkilöt (34 % syöpään sairastuneilla ja 27 % vertailuhenkilöillä). Eri syöpää sairastavien väliset erot eläköitymisessä olivat kuitenkin suuret. Leukemiaan ja keskushermostosyöpään sairastuneilla oli kaksinkertainen riski jäädä eläkkeelle vertailuhenkilöihin nähden, kun esimerkiksi melanoomaa sairastaneiden ja heidän vertailuhenkilöidensä välillä ei havaittu eroja eläkkeelle siirtymisessä.

Ensimmäisessä kyselytutkimuksessa selvitettiin syöpään sairastuneiden saamaa ja toivomaa emotionaalista ja käytännön tukea työpaikalta ja työterveyshuollosta. Eniten tukea syöpään sairastuneet olivat saaneet työtovereilta, mutta he toivoivat myös enemmän lisätukea erityisesti työterveyshuollosta (39 % naisista ja 29 % miehistä). Naiset saivat enemmän tukea kuin miehet, mutta he myös toivoivat miehiä enemmän lisää tukea. Miehistä eniten lisätukea toivoivat 40–49-vuotiaat, lymfoomaa sairastaneet tai kemoterapiaa saaneet sekä vain peruskoulun käyneet henkilöt.

Toisessa kyselyaineistoon perustuvassa tutkimuksessa selvitettiin syövän vaikutusta työkykyyn vertaamalla työssä olevien syöpään sairastuneiden yleistä työkykyä vertailuhenkilöiden työkykyyn. Lisäksi tutkittiin, oliko työkyky huonontunut syövän vuoksi. Syöpään sairastuneiden yleinen työkyky ei poikennut syöpää sairastamattomien työkyvystä. Kuitenkin vastanneista 26 % raportoi fyysisen työkykynsä ja 19 % henkisen työkykynsä huonontuneen syövän vuoksi. Syöpään sairastuneet, joilla oli useita muita sairauksia tai jotka olivat saaneet kemoterapiaa, kokivat useimmin työkykynsä huonontuneen, kun taas sairastuneet, jotka olivat sitoutuneita työpaikkaansa ja jotka kokivat työilmapiirinsä hyväksi, harvemmin raportoivat huonontumista.

Tutkimuksen tulokset osoittavat, että varhainen työelämästä poistuminen, huonontunut työkyky ja sosiaalisen tuen riittämättömyys ovat yleisiä syöpään sairastuneiden kokemia ongelmia työelämässä. Sairauteen liittyvät tekijät, kuten syöpätyyppi, samoin kuin sosiodemograafiset tekijät, kuten esimerkiksi koulutus ja ammatti, ovat merkittävimpiä sairastuneiden työllisyyteen vaikuttavia tekijöitä. Syöpään sairastuneille työelämän sosiaalinen tuki on tärkeä voimavaratekijä, mutta muiden työpaikan voimavaratekijöiden vaikutus on kuitenkin epäselvä. Hoitoihin liittyviin tekijöihin, samoin kuin työpaikan voimavaratekijöiden vaikutukseen syöpään sairastuneiden työhön paluussa olisi tulevaisuudessa kiinnitettävä enemmän huomiota.

## **ABSTRACT**

Many people with cancer are willing and able to continue working after their illness. However, they may face several physical and social problems as a result of their illness. The consequences of cancer for work life and work ability are largely unknown. The aim of the study was therefore to examine the impact of cancer on employment, and to see what kind of sociodemographic factors, disease-related factors, and social factors at work are associated with cancer survivors' employment, work ability, and social support from work.

A registry-based study and a questionnaire survey were conducted to examine the above-mentioned questions. The registry-based study contained two data sets with 46,312 working-aged cancer patients in the first set and 12,542 in the second one. The same number of gender – and age-matched referents were used in both studies. The questionnaire survey included 640 cancer survivors in the first study, and 591 cancer survivors and 757 referents without cancer in the second one.

The results of the registry-based study showed that people with cancer were slightly less often employed than their referents. Two to three years after the diagnosis the employment rate of the cancer survivors was 9% lower than that of their referents (64% vs. 73%), whereas the employment rate was the same before the diagnosis (78%). The employment rate varied greatly according to the cancer type. Education was found to modify the effect of cancer on the employment, i.e. the difference between the cancer survivors and their referents regarding the probability of being employed was greater in the lower than in the higher educational groups. The modifying effect of education on the probability of employment was found among people with cancer of the lung, stomach, rectum, cervix uteri, and those with cancer of the nervous system. People with cancer

## ABSTRACT

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were less often employed than people without cancer mainly because of their higher retirement rate (34% vs. 27%). In addition, retirement varied greatly between the cancer types. The risk of retirement was twofold for people having cancer of the nervous system or people with leukaemia compared to their referents, whereas people with skin cancer, for example, did not have an increased risk of retirement.

In the first questionnaire study we investigated the extent of emotional and practical support that cancer survivors needed, and had actually received from their co-workers, supervisors and the occupational health personnel. The cancer survivors had received most support from their co-workers, and they hoped for more support especially from the occupational health care personnel (39% of women and 29% of men). The women both received and needed more support than did the men. More support was especially needed by those men who had lymphoma, had received chemotherapy or had a low education level.

In the second questionnaire study, we compared the self-assessed current work ability of employed cancer survivors with their referents without a history of cancer. Moreover, we investigated whether cancer had impaired their work ability. We found no difference in current work ability between the survivors and their referents. However, 26% of cancer survivors reported that their physical work ability, and 19% that their mental work ability had deteriorated due to cancer. The survivors who had other diseases or had had chemotherapy, most often reported impaired work ability, whereas survivors with a strong commitment to their work organization, or a good social climate at work, reported impairment less frequently.

The results of this study suggest that early departure from work life, impaired work ability, and lack of social support are the most common problems that cancer survivors face in work life. Disease-related factors, such as cancer type and type of treatment, as well as some sociodemographic factors, such as education and occupation, are the most important variables associated with these problems. Social support from work life is important for cancer survivors, the importance of other social factors at work, however, remains unclear. In the future, more attention should be paid to treatment-related factors, as well social factors at work, as these seem to play an important role in the cancer survivors' possibilities to continue working.

## **LIST OF ORIGINAL PUBLICATIONS**

- I Taskila-Åbrandt T, Martikainen R, Virtanen SV, Pukkala E, Hietanen P, Lindbohm ML. The impact of education and occupation on the employment status of cancer survivors. *European Journal of Cancer* 2004; 40(16):2488–93
- II Taskila-Åbrandt T, Pukkala E, Martikainen R, Karjalainen A, Hietanen P. Employment status of Finnish cancer patients in 1997. *Psycho-Oncology* 2005; 14: 221–226.
- III Taskila T, Lindbohm M-L, Martikainen R, Lehto U-S, Hakanen J, Hietanen P. Cancer survivors' received and needed social support from their work place and the occupational health services, *Supportive Care in Cancer* 2006; 14 (5): 427–435.
- IV Taskila T, Martikainen R, Hietanen P, Lindbohm M-L. Comparative study of work ability between cancer survivors and their referents, *European Journal of Cancer* 2007; 43: 914–920.



# 1 INTRODUCTION

*"I would gladly have given my job to someone younger. It scares me to return to work, because I've been absent for over a year. What frightens me most is how my colleagues are going to take my return. I guess they never expected me to return to work. Too much has happened over the past year. Mentally I haven't been able to keep track of things. First I prepared myself for dying – now I have to re-orientate myself in work life..."*

*A cancer survivor*

(Kivistö 2005)

All of us experience transitions in life. Some are broad transitions from a life-cycle perspective while others may be specific changes in some aspect of one's work. Among the major transitions are those from schooling to one's initial job, from working to being unemployed, and from working to retiring (Kasl and Jones 2000). The termination of work may be voluntary, involuntary, or involve self-imposed limitations. It may reflect a discriminatory event or a disability. It can lead to taking on a new role (a new job, unemployment, or retirement), or changes in one's current job (work assignments, hours etc.) (Barofsky 1989). Becoming seriously ill impacts work life in numerous ways.

Undoubtedly cancer is a life-threatening disease, but because of the improved treatment and prognosis of many forms of cancer, the majority of cancer survivors are able to continue living normal lives after their treatment. Nearly 60% of people with cancer live more than 5 years beyond their diagnosis in westernized countries (Berrino et al. 2003). As a result, the interest to study psychosocial aspects of cancer has increased during the past 20 years. A lot of attention has been paid, e.g., to cancer survivors' quality of life and long-term adjustment to illness.

## 1 INTRODUCTION

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Furthermore, researchers have increasingly examined the role that social support plays in recovery and stress, the impact of medical treatment on long-term adjustment of cancer survivors and many other issues (Baum and Andersen 2001).

Even though medical understanding of cancer has increased dramatically during the past decades, we have only now started to understand the social aspects of cancer. Cancer evokes a high level of anxiety and uncertainty in the patients, as well as in the people who are close to them (Koller et al. 1996). Furthermore, cancer is frequently cited as the most feared of all illnesses (Aro et al. 1999), and social interaction is often problematic for cancer survivors (Carter 1994; Fife and Wright 2000; Vickers 2001). Cancer has, therefore, long-term mental as well as social effects on the lives of individuals.

Even though more attention has lately been paid to the psychosocial aspects of cancer, only a few recent studies have concentrated on work-related issues of the disease. There is not much social epidemiological research on the impact of cancer diagnosis on employment and work ability. In fact, only few studies have used large data sets to examine the issue. It can be assumed, however, that at society level, there are several aspects which affect the employment and work ability of cancer survivors.

A person's return to work especially after a long sick leave is a critical phase (Kivistö et al. 2001). Continuance in work life depends on the individual's characteristics, such as capability to cope with crises. The coping process nevertheless depends on several social aspects of work, such as the work environment and the amount of social support one gets at the work place. When looking at the cancer survivors' return to work, the role of the work community and of health care services, and their role in rehabilitation remains unclear. In society, as well as at the work place, there are several components which affect an individual's capability to return to work after cancer.

The overall aim of the study was to examine the impact of cancer on employment and, furthermore, to study the problems cancer survivors experience in work life. The study problem was approached through a variety of explications widely used in work-related health research, psycho-oncology and social epidemiology.



## **2 LITERATURE REVIEW**

### **2.1 Conceptual background of the study**

#### **Work ability**

In the 1970s lot of effort was invested in developing appropriate measures to cope with chronic illness and disability as a result of big changes in society. The emphasis of chronic illness in the research reflects the fact that chronic disorders, rather than acute infectious diseases, became the major cause of disability and mortality in industrialized societies after the Second World War, and presented a huge challenge to the healthcare system.

A systematic approach to chronic illnesses is to understand the consequences of such conditions. To estimate the severity of the condition, three concepts have been used: impairment, disability, and handicap. Impairment is concerned with abnormalities in the structure or functioning of the body or its parts, disability with the person's ability to cope with daily activities, and handicap with the broader social and psychological consequences of living with impairment and disability. People with chronic conditions may face several problems in everyday life, such as unemployment or reduced career prospects, social isolation from one's family and friends, loss of important roles, and problems with identity, and many others (Locker 2001).

Sometimes cancer and its treatment have a serious impact on people's ability to resume their normal life. Surgical procedures often create considerable defects accompanied by dysfunction and even disfigurement, and radiation therapy can cause significant morbidity and unique tissue management problems. Speech, motor and cognitive functioning, for

## 2 LITERATURE REVIEW

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example, can all be adversely affected (Elomaa et al. 1999). In addition, cancer as a life-threatening disease increases people's stress level, and they may need more social support. Therefore, the primary objective of survivors' rehabilitation has been the restoration of the patient's mental and physical capacity. How successful this is, depends on both the judgment and skill of the therapist, and the post-treatment anatomic, physiologic, and personal characteristics of the patient (Rissanen 2001).

Maintaining economic growth at the same time as the population ages rapidly has become one of the major challenges in westernized countries. As a result, there has been increased interest in examining health-related factors associated with people's ability to work. New policies were needed to find expedients for lengthening people's work career (Ilmarinen 2006). In Finland, the result of the methodological development was the Work Ability Index. The Index has been defined as: "how able is the worker at present, and in the near future, and how able is he or she to do his or her work in respect to the work demands, health and mental resources?" The validity of the Index was assessed by clinical examinations and by follow-up inquiries. The Index was found to predict very significantly retirement due to disability and mortality (Ilmarinen and Tuomi 2004).

Work ability has most commonly been examined by measuring separately the physical and mental work ability. Poor subjective work ability and physical work load have been found to be associated with, e.g., early departure from work life (Salonen et al. 2003). It has also been popular to study factors affecting work ability (or work capacity). Reduced work ability has been reported to be associated with particularly with older age, physically demanding occupations, and lower socioeconomic status (Aittomaki et al. 2003; Carbone et al. 2004; Ilmarinen et al. 1997; Tuomi et al. 1991). In addition, some studies have examined the association between work ability and various exposures in the physical work environment, such as noise and vibration (Ilmarinen 2006). The Work Ability Index has also been used to evaluate work-related problems and to assess the work ability of different occupational groups, especially among elderly workers.

Lately the research on work ability has emphasized the role of interventions to improve the employees' work ability and thus to lengthen their work career by making work life more sustainable (Ilmarinen et al. 2004).

### **Social Support**

The effect of social support on the lives of cancer patients has been one of the main research targets in psycho-oncology. Social support has been claimed to have a buffering effect especially on cancer patients' depression and stress (De Leeuw et al. 2000; Kornblith et al. 2001; Ihlebaek and Eriksen 2003). Social support has also been demonstrated to be associated with cancer patients' physical adaptation, progression of the illness and quality of life (Blanchard et al. 1995; Bloom et al. 2001; Ganz et al. 2003a; Lehto-Järnstedt et al. 2004a).

In the general studies on social support and work life, social support has been found to be associated with better well-being and productivity at work (Baruch-Feldman et al. 2002), whereas inadequate support is connected with increased risk of burnout (Peeters and Blanc 2001) and stress (van der Doef et al. 1999). Limited support has also been related to premature retirement (Elovainio et al. 2003) and long sick leaves (Väänänen et al. 2003).

In earlier studies, three major types of social support have been applied: emotional (expressing positive feelings such as empathy), instrumental/tangible or practical (provision of material aid) and informational (giving advice/guidance) (Krishnasamy 1995; Schaefer et al. 1981). Different types of social support have been claimed to be related to different matters. For example, Bloom et al. (2001) found a connection between social networks and emotional and practical support, whereas only emotional support was connected with well-being. De Leeuw et al. (2000) found available support to be connected with less depressive symptoms, whereas received support was found to be associated with more depressive symptoms. In addition, previous studies have indicated that the need for social support may vary by gender, age, and socioeconomic status (Deimling et al. 2006; Krishnasamy 1995; Wardle et al. 2004).

### **Other social factors at work**

The relationship between the psychological work environment and health has received considerable attention in workplace health research. The focus seems logical in westernized societies where the workplace has gone through many changes during the past twenty years. Physical

## 2 LITERATURE REVIEW

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exerting conditions have become less frequent at workplaces and the complexity of modern society has increased work-related psychosocial demands (Theorell 2000).

Social factors at work, such as job demands, social support, social climate at work and commitment to the work organization have been some of the factors defining well-being at work, work-related stress, and burnout. Social factors at work have been found to be strongly associated with the incidence and symptoms of illnesses (van Vegchel et al. 2005). In her dissertation, Appelberg (1996) found that interpersonal conflicts at work were associated with increased risk of psychiatric morbidity among previously healthy and mentally stable persons of both genders, and with an elevated risk for work disability among women. Commitment to the work organization has been observed to correlate negatively with burnout (Schaufeli and Enzmann 1998) and stress (Mathieu and Zajac 1990). A poor social climate at work has been found to be associated with increased absenteeism, especially in female-dominant sectors (Piirainen et al. 2003).

The focus of research has traditionally been on work-related "un-well-being", i.e., in the study of various symptoms, such as stress and burnout. Recently, in line with the positive psychology movement, interest has been directed at positive work-related well-being, and what it consists of, other than lack of stress or burnout symptoms (Hakanen 2004).

### **Discrimination**

Discrimination has been one of the key terms in medical sociology. It has been defined as the process by which a member or members of a socially defined group is/are treated differently because of their membership in that group (Jary and Jary 1991). Discrimination can be based on, e.g., gender, ethnical background, illness, sexuality, disability, and social status. Discrimination can occur in just about every facet of public and private life: at school or work, when attending a public event or in a restaurant, and when applying for a job. When some experiences of discrimination are interpersonal and obvious, they are also likely to be institutional and invisible (Krieger 2000).

An important question in public health is: how can discrimination harm health? Recognizing that discrimination may be difficult to meas-

ure, researchers instead compare health outcomes of subordinate and dominant groups. The a priori assumption is that disparate social and economic conditions of subordinate and dominant groups will create differences in their physiological and health status (Krieger 2000). For example, it has been demonstrated that racial/ethnic economic disparities often explain U.S. racial/ethnic inequalities in health (Krieger et al. 1993).

The term "stigma" has most commonly been used, especially in medical sociology, to define personal discriminatory experiences. Stigma can be defined as "a mark or characteristic indicative of a history of a disease or abnormality" (Jary and Jary 1991). Perceived stigma has often been studied among people living with a chronic illness, such as HIV/AIDS (Emlet 2006) schizophrenia (Chan et al. 2004), and cancer (Fife and Wright 2000; Koller et al. 1996). It has been found, e.g., that people who have stigmatizing experiences have a poorer quality of life (Chan et al. 2004; Koller et al. 1996), are more often unemployed (Chan et al. 2004; Emlet 2006), are more likely to be never married/partnered (Emlet 2006), and have somatic symptoms more often (Fife and Wright 2000; Koller et al. 1996) than the general population or people without stigmatizing experiences.

A key a priori assumption explaining the differences in health status is the variation in social and economic conditions between dominant and subordinate groups. Poorer health among people with stigmatizing experiences can also be explained by the fact that people literally embody and biologically express their experiences of oppression and resistance (Krieger 2000). Thus, studying discrimination in social epidemiology involves studying biological as well as mental expressions of discrimination, and not only the economic and social disparities between these groups.

## **2.2 Focus of early research on cancer and work life**

The interest to study cancer patients' work-related issues goes back to 1973 when Robert McKenna requested research proposals by the Ameri-

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can Cancer Institute to examine the magnitude of discrimination against cancer patients who were able to work. According to McKenna's report, if discrimination was found to be a problem among cancer patients, then an action program designed to modify discriminatory hiring practices was to be established and furthermore, an evaluation of this effort was needed (Barofsky 1989). As a result, job discrimination was to become the focus of the research on cancer and work for the next 20 years.

In the introduction to his book *Work & Illness – The Cancer Patient*, Ivan Barofsky (1989) listed three ways in which the cancer patient may become a victim of job discrimination in the United States. First, the wage/benefit system in the society couples the usefulness of the employee to the benefits he or she receives. Consequently, the least valued worker is least likely to continue to be employed and to receive medical benefits. Second, the social insurance system is built in such a way that by eliminating a cancer patient, it protects the larger group from the risk of increased costs. Third, some patients require more costly medical care than others. According to Barofsky, these differences may affect decisions about the patient as an employee, his or her present insurability, and the future risk of disease recurrence. While these possibilities may exist, Barofsky pointed out that there are also social factors which could mitigate the occurrence of job discrimination.

Thus, the focus of the earliest research was on explaining the discrimination experiences of cancer patients and estimating the magnitude of these experiences among people with cancer. The majority of the studies at that time were conducted in the United States. Frances Feldman carried out three studies: *Work and Cancer Health Histories* (1976, 1978, and 1980, no original publications), and published several articles and book chapters on the topic (Feldman 1989). For example, in her study published in Barofsky's book, Feldman investigated 344 cancer patients, aged 23–50 years. She reported that nearly 70% of all the respondents perceived that their attempts to change jobs or occupations because of unpleasant or unfair conditions at work were associated with attitudes about cancer. According to Feldman, a new job was hard to find for many of them; 22% of the respondents reported at least one job rejection due to cancer. Some people had given up to changing jobs, because they were discouraged by rejections or because of prospective loss or reduction in health or other job benefits (Feldman 1989). Furthermore, 101 cured

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cancer patients reported having had the following problems in work life: fatigue (30%), absenteeism (14%), psychological problems (12%), social stigma (12%) and discrimination by an employer (10%) (Ehrmann-Feldmann et al. 1987). In addition, many studies have reported cancer patients having difficulties in obtaining health or life insurance because of health reasons (Bednarek et al. 2005; Clark and Landis 1989; Holmes et al. 1989; Mellette 1985).

Some studies on cancer patients and work were published in the end of the 1980s and in 1990s. Hoffman (1989 and 1991) reviewed the earlier studies and concluded that even though cancer patients are able to return to work, they may face discrimination as a result of their illness. She called for action by health professionals as well as cancer patients themselves to combat cancer-based discrimination through public and professional education, individual and group advocacy, and appropriate use of legal remedies. Similarly, Carter (1994) concluded that returning to work is often problematic for cancer survivors, because of the social stigma which is often attached to cancer. As a result, survivors find it difficult to talk about their disease with colleagues and others. According to Carter, clinicians are in key role in promoting the development of work re-entry programs for people with cancer. Clark and Landis (1989) described three ways in which discrimination may be perceived among breast cancer patients (first, facing co-workers, subordinates, and employers: second, rejection and third: insurance benefits). They recommended a work re-entry program, and were thus the first to suggest a comprehensive rehabilitation program for working-aged cancer patients.

Interestingly, Spelten et al. (2002) concluded in their review article covering of the years 1985–1999, that discrimination at work was not significantly related to return to work, and did not seem to be a more relevant problem among cancer survivors than in a control group of persons who did not have cancer. At the end of 1990s and beginning of the 2000s there have been only few studies on cancer and work, in which discrimination was included in the analyses. Langeveld et al. (2002) studied the employment of 500 young adult survivors of childhood cancer and 1092 referents in the Netherlands, and found that the survivors had experienced some form of job discrimination as a result of their health history. Bouknight et al. (2006) suggested that perceived employer discrimination because of cancer was negatively associated

with return to work. Among other issues, Schultz et al. (2002) studied discrimination experiences of 4364 people with cancer, and reported that only 7.3% had experienced discrimination in work life.

Maunsell et al. (2004) concluded in their study of 646 breast cancer survivors and 890 referents, that no deterioration in working conditions was observed in either group, suggesting that it is rare for women diagnosed with breast cancer to experience discrimination at work. Hoffman (2005) equally pointed out that because of improved medical, social and legal progress, cancer survivors can often minimize the effect of discrimination on their careers.

### **2.3 Employment of cancer survivors**

Spelten et al. (2002) reviewed 14 studies on the return to work among people with cancer. Both the rate of returning to work and factors affecting the return were examined. Spelten focused on several issues which had received too little attention in previous research. According to Spelten, the biggest problem was the lack of systematic research into the return to work of cancer survivors. For example, very little attention had been paid to the effect of the site of the cancer and the treatment. Additionally, the sample sizes were relatively small, and there was no overall information on the prevalence of cancer in the working population. Furthermore, differences in job type were not addressed beyond a distinction between manual and non-manual labor. Finally, most studies did not compare the employment status of the cancer patients to that of the general population, and it was impossible to differentiate the impact of cancer as such, and the impact of the overall situation on the labor market.

The reviews by both Spelten et al. (2002) and by Steiner et al. (2004) suggest that the focus of future research should be on cancer survivors' mental and physical coping in work life. Furthermore, they propose that those work-related, disease-related, and person-related factors which may have an effect on work life and return to work should be identified.

As a result, in recent years the interest to study work and cancer has increased, and several articles on this topic have been published. In addition, the focus of research has changed. Rather than studying job



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discrimination, new studies have focused on the employment of cancer survivors, examining the impact of cancer diagnosis on employment and work ability, and defining factors which might be associated with cancer survivors' employment and return to work (Tables 1a and 1b).

Some studies have also looked for factors which make people either to leave or stay in work life. In an article about cancer survivors' retirement and work decisions, Bednarek and Bradley (2005) established internal and external factors for cancer survivors' decision either to retire or to work. According to the authors, cancer diagnosis and disease stage, treatment-related symptoms, comorbidities, race/ethnicity, age, institutional structure of benefits, and family/caregiver responsibilities were external factors, whereas marital status, education, changes in preference for work versus leisure, potential shorter life expectancy, cultural norms and concern for future medical expenses were internal factors.

The earlier studies conducted in the 1970s–1990s also dealt with other issues besides discrimination experiences; it was common to report employment status of cancer patients and to list factors that were associated with employment. For example, Whetley et al. (Wheatley et al. 1974) studied the employment status of 74 people with a history of cancer. They found that 55% were working, 3% were on disability pension, and 42% had stopped working as a result of cancer. Moreover, Winick and Robbins (Winick et al. 1977) reported that 74% of 790 breast cancer patients returned to work within three months of their mastectomies.

Ganz et al. (1989) reported that about 30% of 320 cancer patients were working compared to nearly 71% who were not working. In addition, major differences were found between the working and nonworking subjects regarding to education, occupation and the malignancy of their disease. The nonworking subjects had a higher incidence of disease with metastasis (29%) than the working subjects (19%). The nonworking subjects were older, had more chronic disease, and had stopped working more than a year before their cancer diagnosis, thus suggesting that the termination of work was independent of the symptoms or problems related to cancer diagnosis and treatment.

In the 1990s, the victimized term "cancer patient" was universally replaced by the term "cancer survivor" in the research on cancer and work. Van der Wouden et al. (1992) studied the occupational re-integration

**Table 1a: Focus of studies on cancer survivors' employment, published in 2002–2006**

Authors and year of publication	Study design	Study population	Year(s) of diagnosis	Time of follow-up	Controlled confounders
Bradley et al. 2005 USA	population-based follow-up study	267 men with prostate cancer and 539 referents	2001–2002	12 months	age, marital status, education, number of children, income, job type
Bradley and Bednarek 2002, USA	population-based follow-up study	253 people with lung, colorectal, breast, and prostate cancer	1992–1994	5–7 years	–
Bouknight et al. 2006 USA	population-based follow-up study	416 women with breast cancer	2001–2002	18 months	–
Drolet et al. 2005 Canada	population-based retrospective follow-up study	646 women with breast cancer and 890 referents	1996–1997	3 years	age, co-morbidity, living with a partner, income, job experience, job type, hours worked, belonging to a union, sampling time
Hewitt et al. 2003 USA	population-based cross-sectional study	4878 people with all cancer types and 90737 people without history of cancer	1998–2000	–	sociodemographic characteristics and the presence of comorbid conditions
Langeveld et al. 2003 Netherlands	hospital-based cross-sectional study	500 people with different types of childhood cancer (e.g. sarcomas, leukemia, brain tumour or Hodgkin disease) and 1092 referents	1963–1992	–	none
Nagarajan et al. 2003 USA	population based cohort study	694 people with childhood cancer (sarcomas)	1970–1986	16 (median year from the diagnosis)	Age at the questionnaire completion, time since diagnosis
Short et al. 2005 USA	population based cohort study	1433 people with 11 different cancer types	1997–1999	1–5 years	time since diagnosis
Spelten et al. 2003 Netherlands	hospital based prospective cohort study	235 people with breast carcinoma, gastro-intestinal cancer, and cancer of the genitals, and haematology	no information available	6, 12 and 18 months	time since diagnosis, age, gender
Yabroff et al. 2004 USA	cross-sectional population based study	1823 people with all cancer types (except melanomas) and 5469 referents	no information available	–	age, gender, and educational level

**Table 1b: Summary of the results of studies on cancer survivors' employment, and factors affecting employment and work ability**

Authors and publication year	Employment of cancer patients vs. referents (%)	Factors affecting employment and work ability		
		disease-related factors	sociodemographic factors	work-related factors
Bradley et al. 2005	81 vs. 86	treatment, stage of disease	age, education, occupation	physical workload, heavy lifting, stooping, keeping up with others, learning new things
Bradley and Bednarek 2002	67	cancer type	age, ethnical background, education	heavy lifting, keep pace with others
Bouknight et al. 2006	83	health status, stage of the disease	age, race, education	heavy lifting, employer accommodation for the illness, perceived discrimination at work
Drolet et al. 2005	80 vs. 85	recurrence of disease	age, union membership, income	–
Hewitt et al. 2003	–	cancer type, other diseases	age, education	–
Langeveld et al. 2003	53 vs. 75	–	–	–
Nagarajan et al. 2003	83	–	education, gender, having health insurance, marital status	–
Short et al. 2005	84	cancer type, stage, other diseases, recurrence of the disease	age, gender	–
Spelten et al. 2003	64	cancer type, treatment, fatigue, depression, physical complaints	age	physical workload
Yabroff et al. 2004	41 vs. 46	cancer type, health status, other diseases, stage of the disease, time since diagnosis	–	–

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of 849 long-term cancer survivors in the Netherlands; this was the first European study conducted in the field. They reported that 44% of the people who worked at the time of the diagnosis returned to their job, 24% of them part time. Moreover, they found that respondents who had been treated for head or neck tumours had more difficulties remaining employed than did people with other diagnosis.

Bradley and Bednarek (2002a) studied the employment patterns of 253 long-term cancer survivors, of whom 67% were employed 5–7 years after their diagnosis. In a follow-up study of 1763 cancer survivors, 84% were employed 4 years after their diagnosis (Short et al. 2005). Schultz et al. (2002) studied the employment of 4364 cancer survivors, and found that 56% of the survivors (nearly 64% of men and 49% of women) were working, whereas 8.5% considered themselves unable to work. Age, gender, ethnic group, and cancer type were associated with the employment status of the survivors. Furthermore, a study of 416 employed women with breast cancer suggest that health status, cancer stage, treatment, and job type were independently associated with return to work (Bouknight et al. 2006). Maunsell et al. (2004) concluded in their study of 646 breast cancer survivors and 890 referents that three years after the diagnosis, slightly more survivors (21%) were unemployed than women in the comparison group (15%). However, almost all women in both groups said that the decision to stop working was their own. Spelten et al. (2003) studied predictors of returning to work and the duration of sick leave among cancer survivors. They found that diagnosis, treatment, age and workload predicted significantly the duration of the sick leave, whereas fatigue levels predicted the return to work.

Bradley and colleagues have also published two studies on the effect of cancer diagnosis on income (Bradley et al. 2002b and 2002c). The data consists of 156 women with breast cancer and 5818 cancer-free controls. They concluded that breast cancer has a negative impact on employment; the probability of cancer survivors working was 10% less than for women without cancer. However, among those survivors who worked, the hours of work, wages, and earnings were higher than in the control group. Similarly, Maunsell et al. (2004) reported that survivors worked more hours per week than their referents. Furthermore, a study of 105 breast cancer survivors and the same number of cancer-free controls came up with findings similar to those of Bradley, suggesting that

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cancer diagnosis did not have a great impact on total income (Chirikos et al. 2002). Contrary results were published before the beginning of the 2000s in Van der Wouden's study (1992), stating that the mean income of cancer survivors had increased less than that of the average Dutch population. A Canadian study of 646 breast cancer survivors and 890 referents showed that income less than \$20,000 compared with  $\geq$  \$50,000 was associated with not working only among the survivors. In addition, older age and union membership increased the likelihood of not working among both the survivors and the referents (Drolet et al. 2005).

Some studies on childhood cancer survivors have examined the effect of diagnosis on employment. The socioeconomic status of 2,283 people with childhood cancer and 3,261 of their siblings was studied. Almost twice as many male survivors were found to be unemployed compared to their controls. A large proportion of male survivors, as compared to their controls, also appeared to be in the lower income categories, as well as lower occupational positions. The differences between the women were not so significant (Teta 1989). The employment situation of people with a history of childhood cancer has not changed drastically in the past few years. Langeveld et al. (2003) found that the percentage of employed survivors was significantly lower than of their controls, the survivors being more often students or homemakers. A study of 694 people with bone tumours revealed that education, having health insurance, and being married, were significant positive predictors of employment (Nagarajan et al. 2003).

The mean rate of returning to work in the studies reviewed by Spelten (2002) was 62% (range 30%–93%). The studies conducted in the years 2000–2006 suggest that the employment rate of people with cancer has slightly increased in recent years. The mean rate of employment of the 10 studies reviewed in this work was nearly 71% (range 41%–84%). Furthermore, the employment rate of the referents was 73% in the four studies which included a reference group (Table 1b). The employment of cancer survivors has most commonly been found to be associated with age, cancer type, socioeconomic status (education and occupation), and work load.

### **2.4 Work ability of people with cancer**

A review of 18 studies concerning the need for further research in cancer and work was published in 2004. According to the authors, the research focus should be on observational studies of the impact of cancer on work and on interventions to improve the functioning of cancer survivors at work (Steiner et al. 2004). In recent years there has been increased interest to study the factors which might be related to cancer survivors' disability or decreased ability to work.

The first research article on the work disability of cancer patients was published in 1989, when one was more likely than before to survive from cancer, and more survivors were able and willing to return to work. The study covering 247 people with cancer concluded that physical factors at work and disease-related factors were the strongest predictors of work disability (Greenwald et al. 1989). Several years later, a study of 4878 cancer survivors and 90737 controls indicated that cancer survivors were more likely to report being in fair or poor health than people without cancer or people with some other chronic disease (Hewitt et al. 2003). Similarly, Yabroff et al. (2004) in their study of 1823 people with cancer and 5469 matched controls noted that 31% of the cancer survivors versus 18% of the controls perceived their health as fair or poor.

In a study of 267 men with prostate cancer, 26% of them reported impairment in their ability to perform physical and cognitive tasks at work a year after the diagnosis (Bradley et al. 2005). Similar results were obtained in a Norwegian follow-up study of 459 people with Hodgkin's disease: at diagnosis 2% of the survivors were permanently disabled and 19% at follow-up. The study also pointed out that age, psychosocial distress and fatigue predicted permanent disability among the cancer survivors (Abrahamsen et al. 1998). In another recent Norwegian study of 852 cancer survivors and 1548 referents, people with cancer reported significantly poorer physical and mental work capacity than the referents (Gudbergsson et al. 2006).

In the follow-up study reviewed earlier (Short et al. 2005), one of five survivors reported cancer-related disability. Furthermore, 13% of all survivors had quit working due to cancer-related reasons within 4 years of diagnosis. Recurrence of the disease increased the likelihood of leaving one's job. Work disability was related to gender, cancer type,

and having other chronic health conditions. In a study of Bradley and Bednarek (2002a) the majority of the survivors who stopped working did so because they retired (54%), or were in poor health or were disabled (24%). In addition, the side effects of cancer therapies on work ability were examined in a study of 224 people with cancer. Nearly 40% of the respondents reported that chemotherapy had affected their work duties "quite a bit" or "very much" (Lindley et al. 1999). The importance of the capability to continue working for cancer survivors' mental health has also been demonstrated. A Norwegian study pointed out that cancer patients' impaired ability to continue professional work and/or daily life activities correlated significantly with anxiety and depression (Aass et al. 1997).

### **2.5 The role of psychosocial factors at work**

Even though psychosocial factors, such as discrimination and social support, have been one of the main research targets in psycho-oncology, very few recent studies have taken into account the importance of psychosocial factors on the work-related issues of cancer patients.

Feldman (1984) reviewed several studies on work and cancer, and concluded that married respondents and those with close relationships were better able to cope with their illness and work life. In her other study she paid attention to the psychosocial stress that people may face at their work place. She noted that stress-related work problems were connected with age and diagnosis, suggesting that cancer patients over 45 years of age reported more stress-related work problems connected with cancer than did younger patients. In addition, people with colon or rectal cancer suffered more from work-related stress than people with head or neck cancer. According to Feldman, the differences in stress levels could be related to the tendency to secrecy of those with rectal or colon cancer, because they experienced a level of stress that people with head/neck cancer did not due to the fact that the conditions of the latter rarely permitted secrecy; instead they had to deal with obvious voice or facial impairments. Mellette (1985) pointed out that the health insur-

ance problems of cancer patients in the USA may decrease potential productivity, as well as jeopardize the quality of life of the cancer patient when she or he feels unable to change jobs because of fear of losing of insurance coverage or other benefits.

Berry (1993) interviewed 19 persons with a history of cancer. She found that mobilizing social support in the work environment was crucial for the coping process. The positive attitude of co-workers has also been detected to be positively associated with cancer survivors' return to work (Lehto-Jarnstedt et al. 2004a). Maunsell et al. (1999) conducted 13 unstructured interviews among breast cancer survivors. The participants reported lack of discussion with health professionals about return to work issues. Maunsell suggested that the behaviour of health professionals may influence women's work experiences from the very beginning.

Some recent studies have examined whether practical support given by the employer or colleagues has an impact on cancer survivors' return to work. For example, Bouknight in his study (2006) reviewed previously, reported that not only cancer-related variables but also work place accommodations for illness, such as flexibility of working hours, etc., were positively associated with return to work. In addition, a Dutch study of 100 occupational physicians showed that a physician's performance and continuity of care were related to cancer survivors' return to work (Verbeek et al. 2003). The studies suggest that work place accommodations and occupational rehabilitation may play an important role in the survivors' decisions to either continue or quit working.

### **2.6 Limitations in previous studies**

Even though recent studies have taken into account some of the methodological problems Spelten et al. (2002) brought into the light, such as using people with no history of cancer as referents and conducting follow-up studies, many questions still remain unanswered.

The studies conducted thus far in the 2000s suggest that cancer has less impact on survivors' employment than anticipated, and the majority of cancer survivors are in fact able to continue working. However, the variation in reported employment rates has remained relatively wide. For



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example, the employment rate in 10 reviews published in 2000s, (which reported the employment rate, and investigated factors affecting to employment), the employment rate ranged from 41%–81% (Table 1b).

Rather great differences in employment rate could be explained by the fact that different types of cancer were studied, and in many studies the data have been relatively limited covering only some hundreds of subjects. Moreover, the data mainly include people with the most common cancer diagnoses, such as women with breast cancer and men with prostate cancer. Furthermore, no prevalence of cancer in the working population has been reported nor enough attention has been paid to the effect of disease-related or sociodemographic factors on employment.

In addition, despite of the fact that many studies in psycho-oncology have detected the importance of psychosocial determinants, such as social support, on cancer survivors' physical and mental well-being, only few studies about work and cancer have taken into account social factors in work life. The role of psychosocial factors on the return to work of cancer survivors has been noted in some studies, and also some potential social problems that people with cancer may face in work life have been described (Berry 1993; Feldman 1984; Maunsell et al. 1999; Mellette 1985). However, because of the qualitative nature of most studies in this field, the data have usually been quite small, consisting of only a few dozen subjects. Thus, even though potential problems may have been identified in these studies, no prevalence of these problems could have been established. Neither has the effect of external factors, such as social support from the work place been reported on cancer survivors' well-being at work.

Some recent studies have also pointed out that cancer survivors experience limitations in their ability to work, or even disability. Some socio-economic factors which may be related to impaired work ability have also been reported. There are, without doubt, many cancer survivors who suffer from impaired mental and physical health as a result of their illness. Nevertheless, little is known about the association of social and disease-related factors with cancer survivors' experiences of impaired work ability.

As long as such questions remain unanswered, it is impossible to identify those cancer survivors who experience most difficulties in work life. Likewise, one cannot make further suggestions for bettering working conditions of people with cancer.

### **3 AIMS OF THE STUDY**

The general aim of the study was to examine the impact of cancer on employment and work ability, as well as to investigate the importance of social support from the work life for people with cancer.

The specific aims of this study were:

- 1) To investigate in a whole population setting whether cancer diagnosis has an impact on employment or retirement by comparing the employment of cancer survivors to that of the cancer-free population. Moreover, to investigate whether this impact varies by cancer type or by some sociodemographic factors (Studies I and II)
- 2) To examine the extent of practical and emotional support that cancer survivors had received, and how much support they would have needed from their work place and the occupational health services, and whether received and needed support varied by socio-demographic or disease related background variables. Furthermore, to study whether there are differences between various sources of received and needed support (Study III)
- 3) To study whether the self-assessed work ability of cancer survivors differs from that of people without cancer, and whether the survivors perceive that cancer has impaired their work ability, and whether some disease-related factors, or sociodemographic factors or social factors at work are related to impaired work ability (Study IV)

## **4 MATERIALS AND METHODS**

### **4.1 Registry-based studies**

#### **Subjects**

There were two separate data sets in the registry based studies (Studies I and II). The first data consisted 90% of all cancer patients, aged 15–64 years and alive on December 31, 1997. For the second data, all new cancer cases diagnosed in 1987–88 or 1992–93 and aged 15–60 years at the time of the diagnosis were included. Cases were identified from the Finnish Cancer Registry in both data sets. The reason why persons as young as 15 years of age were included into the studies is that the data sets in the Finnish Cancer Registry are arranged in 5-year age periods (e.g. age 15–19, age 20–24, etc.).

In the first final data, there were 46,312 cancer patients, and in the second one 12,542 people with cancer. In both data sets, an equal number of age and gender matched referents was selected for all cancer survivors from the Finnish population free of cancer and alive on December 31, 1997 (Study I), and on December 31, 1990 or 1995 (Study II). People who had more than one type of malignant tumor were excluded from the data in both files and people who had a previous cancer diagnosis were excluded from the data of 12,542 survivors.

#### **Employment status and construction of the data files**

Data on the individual's employment status in 1997 was obtained from the employment statistics of Statistics Finland, and employment status in 1990 and 1995 was obtained from the population census files of

Statistics Finland. In both data sets, the linkage failed in 0.5% of the cases. Employment status refers to the main activity of people with cancer in 1997 (Study I) and in 1990 of people diagnosed with cancer in 1987–88, and in 1995 of people diagnosed in 1992–1993 (Study II). After the linkage, the personal identifiers were deleted, but a code was included to match each cancer patient to his/her referent. Because of legal confidentiality requirements, a 90% random sample of 46,312 and 12,542 cancer survivors and an equal number of referents, was generated and analyzed.

In both studies, employment status was divided into "employed" and "not employed". The latter group includes unemployed persons, homemakers, students, military conscripts, and those on disability pension, retired, or unknown. In the first study, employment status was divided also described by retirement ("retired" and "not retired").

### **Sociodemographic factors**

We studied whether impact of cancer diagnosis on employment varies by education, occupation, calendar time, hospital district (21 regions), age, gender, or mother tongue (Swedish or Finnish). Mother tongue was included because it has been reported earlier that Swedish-speaking minority has longer life expectancy than Finnish-speaking population (Hyypä and Mäki 2001).

In the study of 12,542 cancer survivors, data on occupation and education were based on the census data of the year prior to the diagnosis, i.e. 1985 or 1990 censuses. The occupational and educational categories used in the studies are based on the official classifications of Statistics Finland. Occupational categorization is based on the classification in the census files 1970–1985 (Tilastokeskus 1991). The educational categorization is based on Educational classification in 1981 (Tilastokeskus 1982).

### **Statistical analyses for the registry-based studies**

In Studies I and II the outcome variables, employment or retirement, were dichotomous (either "employed" or "not employed" and "retired"

or "not retired"). The effect of cancer status on these outcomes was assessed using cross tabulations (Study I) and generalized linear models (Study II). Interaction between cancer status and the sociodemographic variables was also tested in the second study. Because the referents had the same age and gender distributions as the cancer patients, further adjustments were not used.

Relative risk was chosen instead of odds ratio in order to avoid overestimating the effect of cancer, because our outcomes (employment and retirement) were common in our data. SAS software was used for the statistical analyses in both studies.

## 4.2 Questionnaire study

### Participants

Altogether 1000 patients diagnosed with breast cancer, lymphoma, testicular or prostate cancer, during the years 1997–2001 were selected from the patient Register of the Department of Oncology of the Helsinki University Hospital in the spring of 2003. The selected patients had to have a good prognosis (no distant metastasis) and to be 25–57 years of age at the time of diagnosis. Other inclusion criteria were: no previous cancer, no ongoing treatment with cytostatic drugs, native language Finnish or Swedish, resident of the Hospital District of Helsinki and Uusimaa, Finland. In addition, a reference group of 1500 persons was selected from the files of the Population Register Centre. The referents were selected randomly from the general population living in the same district and having the same age and gender distribution as the group of cancer survivors. The questionnaire forms were mailed to the patients and the referents, and two reminders were sent later. A total of 825 cancer survivors (82.5%) and 1026 referents (68%) returned the questionnaire.

The referents who reported having had cancer were excluded from all the analyses (31 persons). In the study on social support (Study III) people who had not been in paid work during the past six years (1997–2003) and those who had not been working after their cancer diagnosis (146

persons) were excluded from the analyses. In addition, people who were either working alone or who had not told anyone at work about their illness (39 persons) were excluded. In the study on work ability (Study IV) further analyses were restricted to those who were either employed full-time or part-time, worked as freelancers, or were entrepreneurs at the time of the survey.

The final data of the third study consisted of a total of 640 persons, of whom 75% were women and 25% men; the fourth study consisted of 591 cancer survivors (74% women and 26% men) and 757 referents (73% women and 27% men). 89% of the women had breast cancer and 12% had lymphoma. Among the men, 41% had lymphoma, 30% had prostate cancer and 29% testicular cancer. The women who participated in the study were slightly older than the men: 83% of the women were over 40 years old of age, and 65% of the men, respectively. 50% of the women and about 40% of the men had had chemotherapy.

### **Disease-related and sociodemographic factors**

Information about the disease-related variables (diagnosis, age at the time of diagnosis and treatment) were obtained from the hospital files, and were included in both studies. Treatment was classified into two categories: chemotherapy or some other type of treatment (endocrine therapy, radiotherapy and/or surgery).

In addition, a variable about the number of other diseases was included in the study on work ability (Study IV). In the questionnaire, a list was presented to the participants and they were asked to mark their current chronic diseases or injuries that had been diagnosed by a physician. The conditions included injury or accident, musculoskeletal disease, cardiovascular disease, respiratory disease, mental disorder, neurological or sensory diseases, digestive disease, genitourinary disease, skin disease, tumour (asked only from the referents), endocrine and metabolic diseases, blood diseases, or other disorder or disease. Anyone marking "other" was asked to specify the disorder or disease (Tuomi et al. 1998).

Socio-demographic variables including marital status (married, cohabitating, or other), education and occupation were collected by the questionnaire and were used in both studies. The participants were clas-

sified into four educational categories (Elo et al. 2001): comprehensive school (approximate length 1–9 years), secondary school / vocational school (10–12 years), college degree (13–16 years) and higher university degree (more than 16 years). Furthermore, the occupations were coded based on the International Standard Classification of Occupations ISCO-88 (Tilastokeskus 2001).

### **Received and needed social support**

The social support that the cancer survivors received and needed social support from their work place and the occupational health services (Study III) was measured by using the Structural-Functional Social Support Scale (SFSS). This validated scale has been developed especially for measuring disease-specific social networks and social support received by people with a serious somatic disorder or chronic disease (Lehto-Järnstedt et al. 2004b). The SFSS focuses on three aspects of social relationships: 1) the existence and number of cancer-specific sources of social support, 2) the amount of support received from these sources and 3) whether this support corresponds to the expectations of the patient. We focused on the two last-mentioned aspects. Because the Scale was disease-specific, it was not included in the questionnaire of the referents.

The items of received support were constructed from the issues brought up by 26 cancer survivors who participated in a qualitative pilot study in autumn 2001. In the questionnaire the cancer survivors were asked to evaluate their received and needed support at the work place or from the occupational health services according to the situation at their first work place after the cancer diagnosis.

The people were asked to evaluate how much support they had received from each source (co-workers, supervisor and occupational health personnel). There were four items for each source of received support. The scale of received support ranged from 1 to 5 (not at all – very much). The total amount of received support was measured by summing up the values of each item by the source. The score ranged from 4 to 20.

In addition, the participants were asked how satisfied they were with the support they had received. The needed support had three categories (I hope for more – I am satisfied – I hope for less) and two items for

both practical and emotional support. Both received and needed support were measured by the same items.

For example, the following item measuring emotional support was presented separately on each source: My co-workers/superior/occupational health nurse or doctor "showed compassion and understanding". Moreover, the items differed from each other depending on what type of support was possible for a source to offer. For example, the item evaluating practical support offered by a superior was as follows: "took my illness into consideration when planning/managing work tasks", and was replaced in the case of occupational health personnel with the item: "evaluated my working conditions as regards coping at work" (Appendix). Emotional and practical support were measured separately only in the category of needed support, because there was no statistical difference between emotional and practical support in received support.

For the analysis, the participants were divided into two groups: persons who would have needed more support, and the others. All those who had answered at least one of the questions "I hoped for more" were placed into the first group. "Others" were people who had answered all the questions by "I am satisfied" or "hoped for less support". The latter group was combined with those who were satisfied because there were only six persons who hoped for less support.

### **Work ability**

To assess work ability in Study IV, the participants were asked to estimate their current work ability in comparison with their lifetime best by answering the following question: "Assume that your work ability at its best has a value of 10 points. How many points would you give your current work ability? (0 means that you cannot currently work at all)." The item is included in the Work Ability Index (WAI), which is a validated tool for measuring self-assessed work ability (Tuomi et al. 1998). The item has found to have the strongest effect on the rate of reliability on the scale (Ilmarinen and Tuomi 2004).

In addition, we asked the cancer survivors to evaluate whether the cancer diagnosis had impaired their physical or mental work ability on a scale of 1 (not at all) to 5 (very much). For the analysis, the partici-



pants were divided into the following three groups: people whose work ability was not impaired at all as a result of cancer, those who reported that cancer had little impact on their work ability, and finally, those who answered that cancer had impaired their work ability to some extent, quite a lot, or very much.

### **Social factors at work**

Other social factors at work were included in the study of work ability (Study IV). The items measuring support from supervisors and co-workers, social climate at work, and commitment to the work organization were taken from the general Nordic Questionnaire (QPSNordic). It is a validated tool for measuring psychological and social factors at work, including job organization characteristics, and individual work-related attitudes (Elo et al. 2001). Social climate, commitment to the work organization and support from supervisors were measured by three items, and support from co-workers was determined from two items. The scale ranked from 1 (very seldom – little or not at all –disagree totally) to 5 (very often or always – very much – agree totally) for all the questions. The individual values of the items measuring the same social factor were summed.

### **Statistical analyses for the questionnaire study**

In Study III, the three sources of support (co-worker, supervisor and occupational health personnel) were studied separately. Differences in received support were assessed by comparing the mean values between the categories of each background variable. The association between these variables and both dichotomous needed support, emotional and practical, was estimated by cross-tabulations.

Generalized linear models for correlated data (Diggle et al. 1994) were used to estimate the differences between the sources of support concerning both continuous and dichotomous response variables. Statistically significant background variables were included in the models. The interaction between the sources of support and background vari-

ables was also tested to assess whether the differences between the three sources of support were unequal according to the background variables or whether the effect of background variables on the responses differed between the sources of support.

In Study IV, one of the main interests was to assess the effect of the explanatory variables on current work ability, and to see whether the effect differed between the cancer survivors and their referents. The general linear model was used to assess the effects of both categorical and continuous explanatory variables on current work ability. The differences in the mean values of current work ability between the categories of the explanatory variables were tested. Furthermore, the effect of an increase of one unit in the continuous variables on the mean of the outcome variable was evaluated.

The scale for outcome variables was ordinal. Thus, we fit the proportional odds model (McCullagh et al. 1989) with the cumulative link function to assess the effects of the explanatory variables on the two ordinal categorical outcome variables representing impaired physical and mental work ability among the cancer survivors. The homogeneity of the odds ratios across all possible cut-off points of the outcome was confirmed.

In both studies, men and women were analysed separately, because they had mainly different types of cancer. SAS software was used in the statistical analyses.

## **5 RESULTS**

### **5.1 Employment of cancer survivors (Studies I–II)**

#### **The impact of cancer on employment and retirement**

In the population of 46,312 people with cancer in 1997 and the same number of age- and gender-matched referents, the survivors were slightly less often employed than their referents: 50% were employed, in comparison to 55% of people without cancer.

The differences in the employment rate of 12,542 people with cancer and their referents were also examined (Table 2). The employment rate of the cancer survivors before diagnosis (either in 1985 or 1990) was 78%, being equal to that of their referents. Two to three years after the diagnosis the employment rate of the cancer survivors was slightly lower (64%) than that of their referents (73%).

In addition, almost all survivors of different cancer types were retired more commonly than their referents (Table 3). On average, 34% of cancer patients had retired, in comparison to 27% of their referents in 1997 (RR 1.27, CI 1.24–1.30).

#### **The impact of cancer type on employment and retirement**

Looking at the other variables, we explored the effect of cancer diagnosis on employment according to cancer type. The strong variation in the employment rate was found between people with different cancer types. The cancer sites of young persons at diagnosis (e.g. testis) showed a high employment rate, while the sites prevalent at high age (e.g. prostate) showed a low rate. People with lung cancer were least likely to be employed (RR 0.45, CI 0.34–0.59) On the other hand, people diagnosed

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**Table 2. Employment rate of cancer survivors and RR by cancer type 2–3 years after diagnosis compared with referents matched for sex and year of birth**

Cancer type	N	Employed %		RR (95 % CI)
		Cancer survivors	Referents	
Stomach	284	38	54	0.71 (0.59-0.85)
Colon	538	53	59	0.90 (0.81-0.99)
Rectum	331	43	54	0.79 (0.68-0.93)
Cervix uteri	183	58	75	0.77 (0.67-0.90)
Corpus uteri	548	42	51	0.84 (0.74-0.95)
Ovary	534	54	65	0.83 (0.75-0.92)
Prostate	240	30	34	0.87 (0.67-1.13)
Testis	206	72	69	1.02 (0.93-1.19)
Kidney	404	50	55	0.91 (0.80-1.04)
Bladder	364	47	57	0.82 (0.72-0.95)
Melanoma of the skin	853	68	66	1.03 (0.97-1.11)
Non-melanoma of the skin	203	56	53	1.06 (0.88-1.26)
Leukemia	222	45	64	0.70 (0.59-0.84)
Non-Hodgkin's lymphoma	411	49	66	0.75 (0.66-0.84)
Hodgkin's disease	269	64	65	0.98 (0.87-1.11)
Lung	279	19	43	0.45 (0.34-0.59)
Breast	4098	61	65	0.95 (0.92-0.98)
Nervous system	878	45	69	0.66 (0.61-0.71)
Thyroid gland	629	70	70	1.01 (0.94-1.08)

with melanoma of the skin (RR 1.03, CI 0.97–1.11), non-melanoma of the skin (RR 1.06, CI 0.88–1.26), testis (RR 1.02, CI 0.93–1.19), and thyroid gland (RR 1.01, CI 0.94–1.08) did not differ statistically significantly from their referents in regard to employed (Table 2).

Retirement was also strongly dependent on cancer type. For example, the risk of retirement was twofold for people with cancer of the nervous system (RR 2.22, CI 2.05–2.41) and people with leukaemia (RR 2.04, CI 1.69–2.46) compared to their referents, whereas people with melanoma of the skin did not have an increased risk of retirement (RR 0.94, CI 0.85–1.03) (Table 3).

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**Table 3. Retirement of cancer patients in 1997 in comparison to referents matched for sex and year of birth**

	N	Retired (%)		Risk of retirement (RR) 95% CI
		Cancer survivors	References	
<i>All cancer sites</i>	46312	34	27	1.27 (1.24–1.30)
<u>HEAD AND NECK CANCERS</u>	<u>1823</u>	<u>42</u>	<u>32</u>	<u>1.34 (1.23–1.46)</u>
Eye	352	29	25	1.16 (0.90–1.48)
Lip	232	57	52	1.11 (0.94–1.31)
Tongue	224	43	23	1.88 (1.42–2.50)
Salivary gland	259	29	25	1.41 (1.09–1.83)
Mouth, other	207	43	30	1.12 (0.84–1.06)
Pharynx	268	38	23	1.66 (1.27–2.17)
Larynx	281	60	43	1.39 (1.18–1.64)
<u>DIGESTIVE ORGANS</u>	<u>4051</u>	<u>40</u>	<u>33</u>	<u>1.22 (1.15–1.29)</u>
Stomach	912	48	35	1.35 (1.21–1.51)
Small intestine	183	37	28	1.31 (0.97–1.78)
Colon	1902	35	30	1.17 (1.07–1.28)
Rectum	1054	44	38	1.17 (1.05–1.29)
<u>FEMALE GENITAL ORGANS</u>	<u>5105</u>	<u>35</u>	<u>31</u>	<u>1.13 (1.07–1.19)</u>
Cervix uteri	914	28	25	1.13 (0.96–1.31)
Corpus uteri	1740	51	43	1.17 (1.09–1.26)
Ovary	2231	27	25	1.07 (0.97–1.18)
Other female genital	220	33	28	1.18 (0.89–1.56)
<u>URINARY AND MALE GENITAL ORGANS</u>	<u>4558</u>	<u>44</u>	<u>37</u>	<u>1.18 (1.12–1.24)</u>
Prostate	1157	65	61	1.06 (1.00–1.13)
Testis	912	16	13	1.23 (0.98–1.55)
Kidney	1379	43	32	1.34 (1.22–1.48)
Bladder	1110	44	37	1.20 (1.08–1.33)
<u>SKIN</u>	<u>3997</u>	<u>25</u>	<u>25</u>	<u>1.00 (0.93–1.08)</u>
Melanoma of the skin	3049	23	24	0.94 (0.85–1.03)
Non-melanoma of the skin	948	34	29	1.17 (1.02–1.33)
<u>SARCOMAS</u>	<u>1122</u>	<u>29</u>	<u>19</u>	<u>1.50 81.30–1.76)</u>
Bone	488	29	15	1.88 81.46–2.42)
Soft tissue	634	29	23	1.31 (1.08–1.59)
<u>LYMPHOID TISSUES</u>	<u>3791</u>	<u>26</u>	<u>16</u>	<u>1.62 (1.48–1.77)</u>
Leukemia	1017	27	13	2.04 (1.69–2.46)
Non-Hodgkin's lymphoma	1452	34	23	1.56 (1.28–1.92)
Hodgkin's disease	1322	16	10	1.47 (1.31–1.66)
<u>OTHER CANCER TYPES</u>				
Lung	934	60	39	1.53 (1.39–1.69)
Breast	13086	33	28	1.18 (1.14–1.23)
Nervous system	3667	39	18	2.22 (2.05–2.41)
Thyroid gland	2840	19	17	1.14 (1.02–1.27)
Multiple myeloma	269	59	36	1.64 (1.36–1.98)

### **The impact of education and occupation on employment**

In the first study, we examined the effect of cancer diagnosis on employment and whether the effect varies according to education, occupation, age, gender, hospital district, mother tongue (Swedish or Finnish), and calendar time. We found that education and occupation modified the effect of cancer on employment. Other variables did not have such modifying effects.

In agricultural, forestry, and fishery work and in transport and communication, manufacturing and services, cancer survivors had an 18–20% lower statistically significant probability of being employed (RR) than their referents. In technical, physical, social sciences, humanistic and artistic work, as well as administrative, managerial, and clerical work the probability of employment was only 7% lower among the cancer survivors than among their referents.

The probability of being employed was lowest among those cancer survivors who had only primary education. The survivors were 19% less likely to be employed than their referents. Among people who had completed vocational or professional school, the probability of being employed was 12% lower in the group of cancer survivors than in the reference group. Finally, there was no statistically significant difference in the employment among people who had university education.

Moreover, we found that education modified the effect in people with cancer of the nervous system ( $P = .0014$ ), lung, stomach, rectum, or cervix uteri ( $P < .0001$  in all) (Table 4). In other cancer types there was no interaction between cancer diagnosis and education. People with only primary school education had lower probability of being employed compared to their referents, whereas in the higher educational groups there was no statistically significant difference in employment between the cancer survivors and their referents, except for cancer of the nervous system (RR 0.84, CI 0.71–0.99).

**Table 4. Number of people with cancer and RR of being employed by level education among people with cancer of the nervous system, lung, stomach, rectum and cervix uteri, compared with their referents**

	Cancer of the nervous system		Lung cancer		Stomach		Rectum		Cervix uteri	
	N	RR (95% CI)	N	RR (95% CI)	N	RR (95% CI)	N	RR (95% CI)	N	RR (95% CI)
Education										
Primary school (1–9 years)	398	0.55 (0.47–0.65)	210	0.48 (0.34–0.68)	177	0.56 (0.42–0.75)	182	0.64 (0.48–0.84)	87	0.64 (0.48–0.86)
Vocational and professional (10–12 years)	296	0.66 (0.58–0.76)	46	0.59 (0.36–0.98)	75	0.87 (0.65–1.17)	88	0.78 (0.59–1.03)	68	0.82 (0.66–1.02)
Polytechnic (13–16 years)	108	0.79 (0.68–0.92)	13	0.64 (0.26–1.57)	15	0.99 (0.66–1.50)	33	1.17 (0.82–1.68)	19	1.09 (0.86–1.39)
University (over 16 years)	76	0.84 (0.71–0.99)	10	0.88 (0.57–1.36)	17	1.11 (0.78–1.59)	28	1.02 (0.78–1.35)	9	1.04 (0.76–1.42)

## 5.2 Cancer survivors' social support from the work place and occupational health services (Study III)

### Received and needed support

The mean values of received support by each source are presented according to background variables in Table 5. People with cancer had received most support from their co-workers, and least support from the occupational health personnel. The mean value for received support from co-workers was 11.4, from supervisors 10.1 and from occupational health personnel 6.8 (on a scale from 4.0 to 20.0)

The survivors needed more practical support than emotional support from all sources (Figure 1). The cancer patients needed practical support from their supervisors most of all in the form of taking the illness into consideration when planning and managing their work tasks. Support

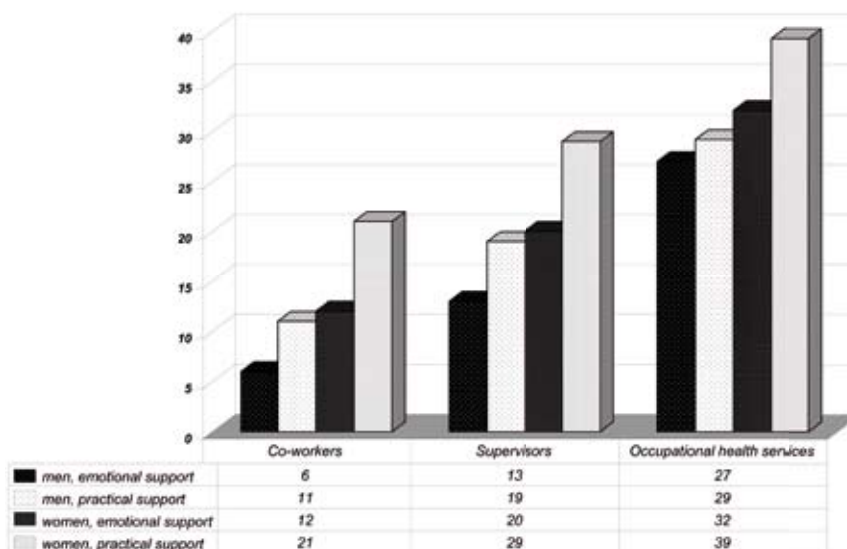


FIGURE 1. Percentages of those who reported to need more support emotional and practical support from various sources



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**Table 5: Mean values and standard deviations of received support from different sources by background variables**

Variable	Co-workers mean value (SD)	Supervisor mean value (SD)	Occupational health personnel mean value (SD)
<u>GENDER</u>			
men	9.6 (4.2)	9.4 (4.0)	6.7 (3.6)
women	12.0 (4.1)	10.3 (4.3)	6.8 (3.8)
p-value	p<0.0001	p=0.03	p=0.73
<u>AGE, years</u>			
25–39	11.3 (3.9)	10.7 (3.8)	6.2 (3.3)
40–49	11.7 (4.4)	10.2 (4.1)	7.1 (3.7)
≥50	11.2 (4.4)	9.7 (4.6)	6.8 (3.9)
p-value	p=0.40	p=0.10	p=0.11
<u>MARITAL STATUS</u>			
married, co-habiting	11.3 (4.3)	10.2 (4.2)	6.7 (3.7)
other	11.7 (4.2)	9.9 (4.3)	6.9 (3.8)
p-value	p=0.41	p=0.26	p=0.63
<u>DIAGNOSIS</u>			
lymphoma	10.9 (4.2)	10.5 (4.1)	6.3 (3.5)
breast cancer	12.0 (4.1)	10.3 (4.3)	6.9 (3.8)
prostate cancer	9.1 (4.5)	7.9 (4.0)	7.0 (3.9)
testicular cancer	9.3 (4.0)	9.3 (3.5)	6.5 (3.4)
p-value	p<0.0001	p=0.005	p=0.41
<u>TREATMENT</u>			
no chemotherapy	10.8 (4.4)	9.4 (4.2)	7.0 (3.8)
chemotherapy	12.0 (4.0)	10.8 (4.2)	6.6 (3.6)
p-value	p=0.0004	p<0.0001	p=0.25
<u>EDUCATION</u>			
higher university degree (over 16 years)	11.8 (4.3)	9.7 (4.4)	7.9 (4.3)
college degree (13–16 years)	11.4 (4.7)	10.2 (4.7)	6.7 (3.6)
secondary /vocational school (10–12 years)	11.3 (4.1)	10.4 (4.1)	6.6 (3.7)
comprehensive school (1–9 years)	11.2 (4.2)	10.0 (4.0)	6.3 (3.3)
p-value	p=0.64	p=0.56	p=0.004
<u>OCCUPATION</u>			
legislators, professionals, senior officials and managers	11.1 (4.3)	10.2 (4.1)	6.2 (3.2)
technicians and associate professionals	11.4 (4.2)	9.8 (4.2)	6.7 (4.0)
clerks	11.7 (4.1)	9.9 (4.2)	7.1 (3.7)
service and care workers, and sales personnel	12.8 (4.2)	11.4 (4.7)	7.6 (4.2)
craft workers, plant and machine operators, assemblers and elementary occupations	10.5 (4.5)	9.6 (4.4)	7.3 (3.6)
p-value	p=0.02	p=0.10	p=0.05
<b>TOTAL</b>	<b>11.4</b>	<b>10.1</b>	<b>6.8</b>

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was also needed when the occupational health personnel were evaluating the patients' working conditions as regards their ability to cope at work.

Depending on the source of support, 11–29% of the men needed more practical support and 21–39% of the women, respectively. The corresponding percentages for emotional support were 6–27% for men and 12–32% for women. People needed more support especially from the occupational health services: 39% of women and 29% of men needed more practical support from that source.

The differences in the needed support between the sources were assessed by the multivariate model. Men hoped for almost six times more emotional support from the occupational health personnel, and over two times more from their supervisors than from their co-workers (OR 5.92, CI 2.70–12.99). Women hoped also for more emotional support from the occupational health services, although the odds ratios between the sources were slightly lower among them (Table 6).

### **Sociodemographic factors associated with received and needed support**

Gender was associated with received and needed support. Women needed more support from all sources than did men. However, there were differences between the men's background variables in the needed support from occupational health services, whereas such differences were not

**Table 6: Odds ratios (95% confidence interval) for needed emotional support: comparison between occupational health services, supervisors and co-workers\***

Compared sources of support	Men	Women
Occupational health services vs. co-worker	5.93 (2.70–12.99)	3.63 (2.65–4.96)
Occupational health services vs. supervisor	2.57 (1.48–4.49)	1.91 (1.48–2.46)
Supervisor vs. co-worker	2.30 (1.13–4.70)	1.90 (1.43–2.52)

\*Multivariate logistic regression models for correlated data; variables in the model of men: source and age, and in the model of women: source

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found among the women. Age was associated with the need for emotional support among the men, but not among the women. Men who were 40–49-years needed more support than those under 40 years old (OR 2.27; 95% CI 1.08–4.81).

The support received and needed by the men depended on their education. Men with a higher education had received more support from the occupational health personnel than had those with less education. In addition, the higher the education level, the lesser was the need for additional support from the occupational health personnel ( $p=0.05$ ). The odds ratios for the need for additional practical support according to education level were as follows: college education (3.59; 1.43–8.98), secondary/vocational school (2.94; 1.21–7.16) and comprehensive school (6.63; 2.39–18.39) in contrast to people with a university degree.

Occupation was associated with received support among both genders. Service and care workers and shop and market sales personnel had got more support from all sources, than those in other occupations (Table 5). In addition, among the men, the needed support was associated with occupation. There was clear need for more support from occupational health services among the men who were craft workers, plant or machine operators or assemblers, or in elementary occupations as compared with the professionals ( $p=0.003$ ).

### **Disease-related factors associated with received and needed support**

The differences between the sources of received support were greater among those whose cancer had been treated with chemotherapy than among those who had been treated in other ways (Table 7). Both men and women who had been treated with chemotherapy had received more support from their co-workers and supervisors than those not treated in this way. There was no difference between the treatment groups as regards the support from the occupational health personnel.

More support from the occupational health personnel was especially hoped by men who had received chemotherapy: 44% of them needed more practical support, whereas the corresponding percentage for men who had some other treatment was 16% ( $p=0.0003$ ). The need for

**Table 7: Differences in means (95% confidence interval) of received support between sources in the treatment groups of men and women \***

Compared sources of support	Men		Women	
	No chemotherapy	Chemotherapy	No chemotherapy	Chemotherapy
Co-worker vs. occupational health services	1.91 (0.88–2.94)	4.16 (3.0–5.31)	4.48 (3.88–5.08)	5.80 (5.20–6.39)
Supervisor vs. occupational health services	1.91 (0.85–2.98)	3.80 (2.64–4.95)	2.63 (2.03–3.24)	4.28 (3.68–4.87)
Co-worker vs. supervisor	–0.01 (–1.05–1.03)	0.36 (–0.76–1.49)	1.84 (1.25–2.43)	1.52 (0.93–2.10)

\* Multivariate general linear models for correlated data

practical support from the occupational health personnel was five-fold between the chemotherapy-treated men and those not treated in this way (OR 5.00; 95% CI 2.19–11.43), whereas from the other sources there were no significant differences between the two treatment groups. Moreover, there were differences in the practical support needed by the men, depending on their cancer type: 43% of men with lymphoma needed more support from the occupational health personnel whereas the corresponding percentage for men with testicular or prostate cancer was 23% and 15%, respectively ( $p=0.007$ ).

### **5.3 Work ability of cancer survivors (Study IV)**

#### **Current work ability of cancer survivors and their referents and impact factors**

The mean values for the perceived current work ability of the cancer survivors and their referents were nearly the same. The mean value for current work ability for men with cancer was 8.37 and for those without cancer 8.23. The corresponding values for women were 8.25 and 8.37 (on a scale from 0 to 10).

Neither did a multivariate analysis reveal any difference in the mean work ability between the employed cancer survivors and their referents. Age and education were associated with current work ability. Better educated men had a higher mean work ability than the less educated ones ( $p<0.001$ ). The more diseases that people had, the poorer was their work ability. A better social climate at work and greater commitment to the work organization were related to better work ability among both genders. Other disease-related, sociodemographic, or social factors at work were not significantly associated with current work ability.

We also studied whether there were differences in the relationship of the explanatory variables with work ability between the cancer survivors and their referents. Among the men, an interaction was noted between cancer survivors and their referents in social support from one's supervisor ( $p=0.003$ ). The male referents who got more support had better work ability than the other referents, whereas such an association was not found

among the male survivors. Among the women, getting support from a supervisor increased the level of work ability equally in both groups.

### **Impairments in physical and mental work ability among the cancer survivors**

We investigated whether the survivors perceived that cancer had impaired their work ability. A total of 20% (n=31) of the men and 28% (n=121) of the women reported that cancer had impaired their physical work ability to some extent, quite a lot, or very much. Impaired mental work ability was reported by 23% (n=35) of the men and 18% (n=79) of the women. Men with testicular cancer reported less impairment than men with other cancer types. Only 4% (n=2) and 13% (n=6) of this group reported impaired physical and mental work ability, respectively.

All in all, 26% of the survivors reported that their physical work ability and 19% that their mental work ability was impaired due to cancer. Those cancer survivors who reported impaired ability to work also had lower current work ability than survivors who did not report impairment. The mean values of current work ability for those reporting impaired physical work ability was 6.58 and 8.96 for those who did not report physical impairment. The corresponding mean values of current work ability in mental work ability were 7.23 and 8.8, respectively.

### **Factors affecting impaired work ability**

We investigated factors that were associated with impairments in physical and mental work ability among the cancer survivors using a multivariate model (Tables 8 and 9). Impaired work ability was dependent on some sociodemographic and disease related factors and social factors at work.

**Sociodemographic factors** Among the women, age was associated with impaired physical work ability, the oldest age group (55–64 years) having almost a fivefold risk of impairment compared with the youngest group (25–34 years), as a result of cancer. Among the men, age did not increase the risk of impaired work ability. The men with a higher university de-

## 5 RESULTS

**Table 8. Odds ratios (with 95% confidence intervals) for impaired physical work ability among the cancer survivors estimated by the multivariate proportional odds model**

	Men	Women
<i>Treatment</i>		
No chemotherapy	1.00	1.00
Chemotherapy	2.79 (1.24–6.32)	2.16 (1.45–3.21)
<i>Other diseases or injuries</i>		
None	1.00	1.00
One	0.87 (0.35–2.16)	2.02 (1.33–3.08)
Two or more	5.08 (1.49–17.29)	3.82 (2.11–6.92)
<i>Age, years</i>		
25–34	–	1.00
35–44	–	2.90 (0.83–10.20)
45–54	–	2.77 (0.83–9.21)
55–64	–	4.56 (1.36–15.34)
<i>Education</i>		
Comprehensive school (1–9 years)	1.00	–
Secondary /vocational school (10–12 years)	0.46 (0.14–1.53)	–
College degree (13–16 years)	0.61 (0.20–1.89)	–
Higher university degree (> 16 years)	0.10 (0.03–0.38)	–
<i>Commitment to the work organization</i>	0.79 (0.69–0.91)	0.90 (0.83–0.97)
<i>Social support from co-workers</i>	–	0.83 (0.73–0.94)

**Table 9. Odds ratios (with 95% confidence intervals) for impaired mental work ability among the cancer survivors estimated by the multivariate proportional odds model**

	Men	Women
<i>Other diseases or injuries</i>		
None	1.00	1.00
One	1.85 (0.84–4.09)	1.38 (0.88–2.18)
Two or more	8.34 (2.41–28.83)	2.86 (1.54–5.30)
<i>Age, years</i>		
25–34	–	1.00
35–44	–	1.12 (0.34–3.69)
45–54	–	0.50 (0.16–1.53)
55–64	–	0.84 (0.27–2.57)
<i>Good social climate at work</i>	0.80 (0.70–0.91)	0.84 (0.76–0.94)
<i>Commitment to the work organization</i>	–	0.87 (0.79–0.96)
<i>Social support from co-workers</i>	–	0.84 (0.73–0.96)

## 5 RESULTS

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gree were 10 times less likely to report impairment than those who had the least amount of education. However, such an education-dependent difference was not found among the women (Table 8).

**Disease-related factors** The men and the women who had other diseases or injuries had an increased risk of physical and mental impairment in work ability than those who did not have any other disease in addition to cancer. Moreover, both the men and the women who had had chemotherapy had an increased risk of impaired physical work ability.

**Social factors at work** The higher that the commitment to the work organization was, the lesser was the risk of impaired physical work ability among both genders. Among the women, commitment to the work organization was also related to a lesser likelihood of impairment in mental work ability. In addition, among the women co-workers' support was associated with a reduced risk of impaired mental and physical work ability. Both the men and the women who reported a good social climate at work were least likely to have impaired mental work ability.



## **6 DISCUSSION**

### **6.1 Cancer survivors' problems in work life**

#### **Early departure from work life**

In the first few years of the 2000s most of the cancer survivors have been able to continue working after their treatment. There is, however, a group of cancer survivors who do not return to work as a result of their illness. In our registry-based study, we found that the employment rate of cancer survivors was 9 percentage points lower than that of their gender- and age-matched referents 2–3 years after the diagnosis (64% vs. 73%). Our results indicate that Finnish people with cancer are slightly less often employed than their referents, mainly because of their higher retirement rate. On average, 34% of the cancer patients in our study had retired, in comparison to 27% of the referents.

Even though the cancer survivors' employment rate has risen since the 1970s and 1980s, our results and the latest studies in this field suggest that cancer survivors are still more often outside of the work force than people without cancer (Bradley and Bendarek 2002a; Langeveld et al. 2003; Maunsell et al. 2004; Yabroff et al. 2004; Schultz et al. 2002; Short et al. 2005).

Although cancer survivors seldom face blatant employment discrimination, many survivors still fear that they may be unable to obtain and keep a job. According to Hoffman (2005) one reason for these fears at work arises from the fact that many supervisors and coworkers have misconceptions about cancer survivors' ability to work during and after their treatment. Furthermore, Bouknight and Bradley (2006) reported

recently that perceived employer discrimination because of cancer was negatively associated with return to work for breast cancer survivors. However, because studies on the effects of discrimination are very scarce, one cannot draw conclusions about the role that discrimination plays today on cancer survivors' employment and return to work.

Even though most cancer survivors are willing to continue working, there are also some people who may voluntarily leave work life after cancer. Drolet et al. (2005) reported that female cancer survivors were more likely than women in the control group to report that they valued work less than before. On the other hand, it has been claimed that cancer survivors are more motivated, or compelled to remain at work to maintain their health insurance coverage (Bradley et al 2002, Madrian 1994, Mock 1998). It has also been suggested that returning to work after a disabling illness is related less to the actual illness than to having alternative resources for financial support (Abrahamsen et al 1998, Chirikos et al 2002). On the contrary, individuals who retire early may experience long-term economic consequences such as reduced income. According to Bednarek and Bradley (2005) those cancer survivors who were employed 5–7 years after their diagnosis had greater household incomes in relation to the retirees. Thus the employment status of individuals after cancer diagnosis may vary from one country to another, depending on the financial support that a state offers for people with a chronic illness.

### **Impaired work ability due to cancer**

It has been suggested that the main reason for cancer survivors' early departure from work life is related to the difficulties to maintain their work ability to as a result of their illness (Hewitt et al. 2003; Short et al. 2005; Yabroff et al. 2004). In our questionnaire study, the current work ability of the cancer survivors and their referents did not differ significantly. However, 26% of the survivors reported that their physical work ability and 19% that their mental work ability had been impaired due to cancer.

The number of cancer survivors who reported impairments in our study is in line with the figures presented in other studies. For example, five recently published studies investigating working impairment due to

cancer (Bradley et al. 2005; Bradley and Bednarek 2002a; Gudbergsson et al. 2006; Short et al. 2005; Yabroff et al. 2004) reported that perceived percentages work-related impairment varied from 21% (Short et al. 2005) to 31% (Yabroff et al. 2004). Moreover, it has recently been shown that cancer survivors are more likely to report being in poor health than people without cancer or people with other chronic conditions (Hewitt et al. 2003; Yabroff et al. 2004).

It has been noted earlier that cancer has a greater impact on the survivors' physical than mental capabilities. Some studies have indicated that physical work load is associated with reduced work ability (Bradley and Bednarek 2002a; Bouknight et al. 2006; Spelten et al. 2003). However, many studies have reported that cancer survivors experience neurocognitive changes as a results of the treatment they undergo, especially after chemotherapy (Ahles et al. 2002; Heflin et al. 2005). These changes include, e.g., loss of short- and long-term memory, speed of processing things, and impairments in motor function. These symptoms have been found to be associated with, for example, the cancer survivors' quality of life (Rugo et al. 2003; Stewart et al. 2006). It can thus be assumed that problems in cognitive function may affect cancer survivors' work ability.

Interestingly, even though cancer survivors' often report impairments in their work ability, other essential differences in work-related issues, such as hours of work and wages, have rarely been reported between cancer survivors and people without cancer. It has been noted earlier that cancer has only little impact on people who remain in work life (Gudbergsson et al. 2006; Maunsell et al. 2004; Schultz et al. 2002). For instance, the hours of work and wages of breast cancer survivors who remained employed, were even higher than those of the women in the control group, although, in general, cancer had a negative impact on employment (Bradley et al. 2002c).

### **Lack of social support from work life**

Most survivors stay at work not only for the obvious financial benefit, but also for the self-esteem and social support they get from work (Hoffman 2005). Our results indicate that cancer survivors' social support from their work place, and especially from the occupational health personnel

is inadequate. Nearly 30% of the men and 40% of the women reported that they needed more practical support from the occupational health services.

There is no previous research on the role of occupational health services in supporting cancer patients' return to work. Previous research has usually presented the family and friends as cancer survivors' main sources of support even though in some studies colleagues and supervisors have been mentioned as possible sources of support (Krishnasamy 1995). It has also been reported earlier that chronically ill people have problems in finding adequate support from health care providers (Maunsell et al. 1999; Sharpe et al. 2005) as well as from their work place (Vickers 2001).

Our results indicate that cancer survivors needed more practical support especially from the supervisors and occupational health personnel. Similarly, Bouknight and Bradley (2006) reported that practical support, such as perceived employer accommodation for illness and treatment was independently associated with return to work at 12 months after breast cancer diagnosis. In addition, oncology care providers reported their patients' demands for greater flexibility in scheduling medical care to accommodate cancer survivors' work schedules (Clark and Stovall 1996). More recently, Hewitt et al. (2003) reported that the use of supportive care services, such as occupational therapy, was greater among cancer survivors than those without a history of cancer.

The results of a Dutch study indicated that a physician's performance in occupational rehabilitation in meaning of interventions in relations to work and also, continuity of care in the meaning of seeing the same physician, were both related to return to work of cancer survivors (Verbeek et al. 2003). The results of a recently published intervention study suggests that possibility to have consultation by an occupational physician as regards of return to work -issues was found helpful among employed cancer survivors (Nieuwenhuijsen et al. 2006).

The possibilities of the occupational health personnel to give support and contribute to the cancer survivor's return to work depend on how the health services have been organized at the work place. Due to cost restrains, it is difficult for most occupational health units to establish an occupational health service team that is multidisciplinary enough (Taskinen 2004). In some cases the occupational health service arranged

by an employer includes a variety of services, but sometimes it covers only the minimum (medical check-ups). Thus the quality and quantity of Finnish occupational health services may vary considerably according to a work place. This naturally has a great impact on the social support that the occupational health personnel are able to offer for people with cancer.

### **6.2 The role of different factors in the work-related problems of cancer survivors**

Whether a survivor continues to work during his/her treatment or returns to work after treatment, and if so, whether the survivor's condition will lead to impaired work ability or early departure from work life, depends on many factors. These are, for instance, age, cancer type, gender, type of treatment, the presence of other chronic diseases, occupation, education, as well as the extent of social support from the work place, and the social climate at work. I have divided these factors into three categories depending on the type of factor, i.e., disease-related and sociodemographic factors, and social factors at work.

#### **Disease-related factors**

Our study revealed considerable differences in the likelihood of being employed and the risk of retirement between people with different cancer types. The retirement risk was very high among people with cancer of the nervous system and leukemia, whereas people with melanoma did not have an increased risk of retirement. This might be due to the character of melanoma; in many cases melanoma spreads superficially, and a nevus can be removed in a simple operation. In most of the cases no other treatment is necessary (Brash 1997). In the case of cancer of the nervous system and leukemia, the fatiguing effects of the treatment, together with the high recurrence rate (Jääskeläinen et al. 1999; Ruutu 1999), may be the main reasons for the high retirement rates of people with these cancers.

## 6 DISCUSSION

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People with lung cancer were the least likely to be employed, but they did not have the highest risk of being retired. This can naturally be explained by the low life expectancy of people with lung cancer: the relative five- year life expectancy is 10% among men and 13% among women (Mattson 1999). Thus people with lung cancer often do not live long enough to retire.

The employment rate of cancer survivors has varied considerably in different studies. The employment rate in 10 studies published in the early 2000s and reviewed in this study (Table 1) ranged from 41% (Yabroff et al. 2004) to 84% (Short et al. 2005). Most of the variation can be explained by the different pattern of the cancer types examined. Not only cancer type, but also related factors, such as prognosis and side effects of the treatment are strongly associated with the employment of cancer survivors (Bradley et al. 2005; Bouknight et al. 2006; Langeveld et al. 2003; Schultz et al. 2002; Short et al. 2005; Yabroff et al. 2004). For example, fatigue is one of the most common side effects of cancer treatment, and it independently predicts how soon a person with cancer is able to return to work (Spelten et al. 2003).

In addition, cancer type and the type of treatment seem to play an important role, not only in employment, but also in the cancer survivors' received and needed social support. In our study, the people treated with chemotherapy had received more support from their supervisors and co-workers than people who had other treatments. However, the men with chemotherapy would have needed more practical support, especially from the occupational health personnel. It has been shown in several studies that people who have had chemotherapy suffer more from e.g. depression (de Jong et al. 2002). This can partly explain the greater need for social support among these people.

Treatment was also associated with impaired work ability. According to our results, people treated with chemotherapy had a greater likelihood to report impaired work ability than did those with other treatments. Moreover, the presence of other diseases or injuries seems to impair physical work ability significantly, especially among cancer survivors with two or more other diseases or injuries. It has also been reported earlier that cancer survivors with other chronic diseases are more likely to report being in fair or poor health (Hewitt et al. 2003; Yabroff et al. 2004) and are more likely to quit work as a result of cancer (Short et al. 2005).

There are only few comparative studies on the impact of cancer type on social support, and their results have been contradictory. For example, in a recent study of Deimling et al. (2006) cancer type was not associated with the person's activity in seeking for social support. Similarly, Harrison et al. (Harrison et al. 1995) found no differences between lymphoma patients and bone sarcoma patients in regard to seeking support. On the other hand, Lehto-Järnstedt et al. (2004a) discovered that women with breast cancer got more support than did people with melanoma. We found no clear differences in received support between women with breast cancer and those with lymphoma. Instead, men with lymphoma were in greater need of support from the occupational health personnel than men with prostate or testicular cancer.

Lack of social support and poorer outcomes in work ability among people with certain cancer types could also be related to the type of treatment. The prevalence of treatment-related symptoms, such as anaemia, fatigue, cognitive impairment and treatment-induced menopause is higher among people treated with chemotherapy than among people with other treatments (Birgegård et al. 2005; Leining et al. 2006; Stewart et al. 2006). Furthermore, quality of life has been suggested to be significantly poorer among those cancer patients who suffer from treatment-related symptoms (Ahles et al. 2002; Fan et al. 2005; Ganz et al. 2003b; Knight et al. 2004). Therefore, it is possible that these people also suffer more from lack of support and have poorer work ability than those with fewer symptoms. However, research on the impact of treatment-related symptoms on the employment of cancer survivors is scarce.

### **Sociodemographic factors**

We studied whether cancer survivors' employment, retirement, impaired work ability or received and needed social support were associated with any of the sociodemographic factors. We found that education, occupation, age, and gender were associated with all or some of the explanatory variables.

**Education and occupation.** We found that the effect of cancer on employment varied by education and occupation, which were the only sociodemographic factors that had an impact on the employment of cancer survivors in our registry-based study. Moreover, a lower educational

level was also found to be associated with impaired work ability. Men with a university degree were less likely to report impairments than those who had less education. Similarly, other recent studies suggest that cancer survivors with a low level of education are least likely to be employed (Bradley et al. 2005; Langeveld et al. 2003; Nagarajan et al. 2003).

The effect of cancer on employment varied notably by education among people with certain types of cancers. Earlier studies have indicated that some cancer sites are associated with lower socio-economic status, which in turn is closely related to educational attainment (Hewitt et al. 2003; Steenland et al. 2002). In our data, 70% of the people with lung cancer, and 62%, 55%, 48%, and 45% of those with cancer of the stomach, rectum, cervix uteri, and the nervous system had only primary education, respectively. It is more likely that less educated people work in more physically demanding jobs. Because cancer reduces a person's physical capacity, it was expected that cancer patients with a lower education might be more likely to terminate their work career than people with a higher education. In addition, in some occupations, such as construction work, employment is sensitive to economic fluctuations. In such occupations cancer diagnosis might have a stronger impact on one's employment possibilities: when there is an oversupply of workforce, it is less likely that people with a history of cancer will be employed.

We found that the received and needed social support was associated with education and occupation. Men with less education and a lower occupational status had a greater need for support than did those with a higher education and occupational status. In addition, our results show that male survivors with a higher level of education had a lower risk of impaired physical work ability than did men with less education. Previous studies have reported that people who hold better occupational positions and have a higher education are in better health and experience less work-related stress than people with less education and in lower positions (Mustard et al. 2003). Moreover, it has been shown that people with a lower education and occupational status have more sick leaves than people in higher positions (Ihlebaek et al. 2003; Vahtera et al. 2000). It has also been noted that access to cancer treatment is more difficult for patients with lower socioeconomic status (Guidry et al. 1996; Wardle et al. 2004).

All in all, it seems that cancer survivors with higher education manage better in work life; there may also be more flexibility for people in



higher positions to take long sick leaves or to work part time than for people in lower positions, and thus to have better possibilities to continue working.

**Gender and age.** Age and gender did not have modifying effects on employment of cancer survivors, but an association was found in received and needed social support and work ability. Women received more support than did the men, but they also needed more support. Furthermore, support from co-workers was related to a reduced risk of impaired work ability among the women, but not among the men.

The gender differences in needed support can partly be explained by the cancer type, because there were no differences in needed support between the men and the women who had lymphoma. It is therefore difficult to draw conclusions about the effect of gender on support in this study, because the men and the women had mainly different cancer types. On the other hand, it has been noted that men and women may experience social support differently (Krishnasamy 1995). According to previous research, women often seek for support more actively and also have wider social networks than men, who usually lean on one person, a spouse in most cases (Hann et al. 2002; Harrison et al. 1995; Lehto et al. 2005). In addition, women, more than men, seem to benefit from a wide social network. Hann et al. (2002) observed that a wide social network was connected with less depressive symptoms among women, whereas this effect was not found among men. Similarly, Bildt and Michelsen (2002) noted that deficient support from work was related to problems in mental health among women, but not among men.

Age was associated with impaired physical and mental work ability among the women, whereas among the men, age did not increase the risk of impairment. Among the women, the risk of reporting impaired mental work ability was more common in younger than in older age groups. The result is in line with a previous study that indicates, for example, a greater risk for psychological distress among younger than older women with breast cancer (Maunsell et al. 2004). Furthermore, treatment-induced menopause has been found to be associated with poorer perceived health among younger women but not among older women (Ganz et al. 2003a).

Even though age did not have a modifying effect on employment in our study, the impact of increased age on the employment and work

ability of cancer survivors has been detected in several other studies (Bradley et al. 2005; Drolet et al. 2005; Schultz et al. 2002; Short et al. 2005; Spelten et al. 2003). The Finnish social security system enables people to retire due to a serious illness. This procedure has been prevailing practice especially in the case of persons approaching the statutory retirement age. Cancer is more common among middle-aged people, and retiring, rather than becoming unemployed, is probably seen as a better alternative among elderly people with cancer.

### **Social factors at work**

We studied whether social factors at work were associated with impaired work ability. Our results indicate that the survivors with enough social support from co-workers, a strong commitment to the work organization or those who reported a good social climate at work were least likely to report impairments in their work ability.

The studies on work ability conducted in the general population have mostly been focussed on the physical work environment, rather than mental loading factors at work. However, some attention has lately been paid to examining the effect of social factors at work on people's work ability. Väänänen (2005), for example, studied psychosocial determinants of sickness absence. Moreover, Elovainio et al. (2003) found an association between early retirement and limited support.

Work ability, however, has been found to affect people's subjective well-being (Sjögren-Rönkä et al. 2002; Tuomi et al. 2004). Furthermore, it has been found that work demands and the work environment, as well as the promotion of professional competence have a strong association with work ability (Tuomi et al. 2001). It has also been reported that if employees receive enough support from the supervisors, and if organizational practices are improved, their work ability, organizational commitment and mental well-being improve markedly (Tuomi et al. 2004).

A few studies have suggested an association between social support and cancer survivors' return to work (Berry et al. 1993; Bouknight et al. 2006; Clark et al. 1989; Maunsell et al. 1999). Two of these four of studies were based on qualitative data on only a few dozen subjects (Berry et al. 1993; Maunsell et al. 1999). One of the studies (Clark and Landis 1989) recommends a rehabilitation program for working-aged

cancer survivors and proposes social support as an important part of rehabilitation.

Because impaired work ability has been found to be associated with early departure from work life (Ilmarinen 2006) it can be concluded that social factors may affect both work ability and continuance in work life among people with cancer. On the other hand, because of the lack of referent groups in most of the studies, it cannot be assessed whether the survivors' well-being at work is based on the same kind of aspects as that of people without a history of cancer.

Results of our study on work ability suggest that social factors at work have an important role for well-being of cancer survivors and people without cancer. Because of the lack of the studies in this field, however, more specific conclusions about the issue cannot be made.

### **6.3 Methodological considerations**

#### **Registry-based study**

The existence of a comprehensive cancer registry in Finland made it possible for us to investigate in a whole population setting whether people's cancer diagnoses have an impact on employment, by comparing the employment status of all working-aged cancer survivors with that of the cancer-free population. This was the first study in which the impact of cancer diagnosis on employment was examined in a large population setting.

Because of legal confidentiality restrictions, we were able to analyze 90% of a random sample of the whole population in both data sets. The possibility of bias was minimal, because almost all cancer cases were included in the analyses, and age- and gender-matched referents were used in both studies.

Because of the cross-sectional design of the first study, it was impossible to investigate the impact of time on the employment of cancer survivors. In the second study, we found that cancer diagnosis affected employment. However, the time span examined was only two to three years after the cancer diagnosis. Cancer often has long-term effects on peoples lives, thus the time span could have been even longer. In addi-

tion, not only cancer type, but also treatment as an explanatory variable, could have been included in the analyses. The type of treatment has been reported to have long-term effects on cancer survivors' mental and physical well-being (de Jong et al. 2002; Ganz et al. 2003b; Kornblith et al. 2003; Lindley et al. 1999; Vistad et al. 2006). It can therefore be assumed to have an impact on cancer survivors' possibilities to continue in work life.

### **Questionnaire study**

We collected the data by a postal questionnaire which was sent to 1000 cancer survivors and 1500 referents. The response rate was relatively high: 82.5% for the cancer survivors and 68% for the referents. The first questionnaire study included 640 cancer survivors (Study III) and the second one 591 people with cancer and 757 referents (Study IV).

The outcome variable in the first questionnaire study (Study III) was the needed and received social support from the subject's work place and occupational health personnel. It was measured by the adapted version of Structural-Functional Social Support Scale (SFSS). The scale has been shown to have good psychometric properties (Lehto-Jarnstedt et al. 2004a). Moreover, in the second questionnaire study (Study IV) the outcome variable, work ability, was measured by using an item from the Work Ability Index (WAI), which has proven to be a good predictor of retirement due to work disability and mortality (Ilmarinen and Tuomi 2004).

Several studies have pointed out that social support obtained from one's family and friends is important for cancer patients (Blanchard et al. 1995; Bloom et al. 2001). We had no information about social support outside of the work place. However, we did include information on marital status ("married, cohabiting" and "other") into our multivariate models on social support, but it was not associated with needed or received social support from the work place or from occupational health services. In the light of this notion, it may be possible that the extent of support from other sources is not associated with the support needed from one's work place.

The cross-sectional design was a limiting factor in the studies. In addition, the survivors' capability to remember how much support they

## 6 DISCUSSION

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had received or needed several years prior to the study, may have affected our findings. However, the questions on support concerned the time of returning to work, i.e., 2–6 years (depending on the time of diagnosis) before the date of the questionnaire. Neither support nor work ability varied by the year of diagnosis. This suggests that the different time lapses of recall have not affected the findings.

The restriction of the study to those people only who were working after their cancer diagnosis may have affected the results. On the other hand, the cancer survivors who were excluded from the final study population in the study on received and needed social support, did not differ with respect to gender or education from those cancer survivors who were included. If also those who did not return to work after their cancer diagnosis had been included in the data, the amount of needed support might have been even greater.

In the study on work ability, selective participation may have played a role in not finding any difference in work ability between the survivors and their referents. The response rate of the survivors was clearly higher (82.5%) than that of the referents (68%). Moreover, the oldest age group of the referents (55–64 years) were more active responders (74%) than the younger age groups (65%), whereas the cancer survivors' response rate did not vary by age. Earlier studies have found an association between impaired work ability and increased age (Ilmarinen and Tuomi 2004). It is therefore possible that the difference in age distribution may have reduced the difference in work ability between these two groups.

There were clear differences, however, between the cancer survivors who needed more support and those who did not. In addition, the cancer survivors who reported impaired work ability due to cancer differed from those cancer survivors who did not experience impaired work ability.

## 7 CONCLUSIONS

Nowadays most cancer survivors are able to return to work. There is a group of cancer survivors who nevertheless experience problems when returning to work. Our results suggest that early departure from work life, as well as impaired work ability and the lack of social support are the most common problems encountered by many cancer survivors. People with disabling cancer or a poor prognosis and lower educational level were least likely to be employed. Educational level was also associated with impaired work ability and the need for more support. Moreover, impaired work ability was negatively associated with chemotherapy, presence of other diseases and increased age, whereas people who displayed a strong commitment to their work organization, had a good social climate at work, and got enough social support from their co-workers reported impairment less frequently. The associations between different factors on employment, work ability and social support are presented in Figure 2.

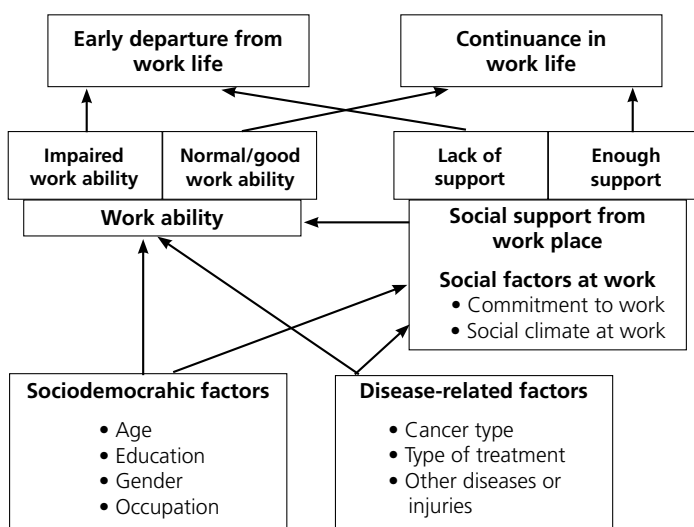


FIGURE 2. Factors associated with work ability, employment and social support of cancer survivors.

## 7 CONCLUSIONS

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Lack of social support and impaired work ability may lead to early departure from work life, whereas enough support and normal or good work ability are some of the factors which presumably keep people in work life.

We resorted to registries when examining the impact of cancer on employment. This is the first research in which all working-aged people with cancer have been included in one study. Most of the previous studies have included people with only the most common cancer types, such as breast cancer. Thus it has previously been difficult to compare the impact of cancer on employment between different cancer types, as was done in our study.

Even though the importance of social support for cancer survivors' physical and mental well-being has been detected in several studies, our study is the first one concentrating on support specifically from the work place. Moreover, there are no previous studies conducted on a sample which has been large enough to examine the importance of social support from work for people with cancer. Furthermore, this is the first study in which social factors at work, such as social climate at work and social support from the work place, have been included in the analyses of cancer survivors' work ability. Because of the lack of studies or the lack of evidence in the studies, it has previously been difficult to identify those cancer survivors who are at highest risk of early departure from work life.

In the studies published in the first years of the 2000s, the number of factors associated with cancer survivors' return to work has increased, and more evidence has been obtained especially about the importance of disease-related factors on cancer survivors' employment. Research in this field suggests that the employment of cancer survivors depends strongly on their cancer type as well as the type of treatment, recurrence of disease, and the presence of other diseases (Bradley et al. 2005; Hewitt et al. 2003; Langeveld et al. 2002; Schultz et al. 2002; Short et al. 2005; Yabroff et al. 2004). Some sociodemographic factors have also been found to be related to cancer survivors' return to work. Those with higher age, lower education, and working in blue-collar jobs have reported to be less likely to be employed (Bradley et al. 2005; Langeveld et al. 2002; Nagarajan et al. 2003; Schultz et al. 2002; Short et al. 2005;).

## 7 CONCLUSIONS

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Treatment-related symptoms, such as pain and fatigue, have been found to be associated with, e.g., survivors' cognitional functioning, level of depression, quality of life, anaemia, sexual functioning, and many more (Birgegard et al. 2005; Fan et al. 2005; Ganz et al. 2003b; Rugo et al. 2003; Vistad et al. 2006). Only few studies, however, have examined the impact of treatment-related symptoms on the return to work of cancer survivors. More research is needed on the long-term effects of treatment and its symptoms on survivors' continuance in work life.

Some studies have described potential social problems which cancer survivors may experience in work life. These problems include experiences of discrimination as a result of cancer, such as unwanted changes in work tasks, and the immense difficulty of changing jobs due to fear of losing one's insurance coverage. These problems may have a negative effect on cancer survivors' quality of life and productivity (Maunsell et al. 1999, Berry et al. 1993). Because of the qualitative nature of these studies, the data have been limited, covering only some dozens of subjects. Thus, even though some work-related problems have been identified in these studies, no prevalence of these problems has been established.

As it was noted before, not much information is available about the importance of social factors at work on either cancer survivors' work ability or the survivors' continuance in work life. Recent research suggests that social support from the work community and occupational health care, and the willingness of the employer to accommodate the cancer survivors' illness and treatment needs are important aspects of survivors' return to work. However, only one intervention study (Nieuwenhuijsen et al. 2006) designed to enhance return to work has been published in the field so far. More research is needed on interventions that facilitate returning to work and maintaining the employment of cancer survivors.

In the reviewed studies, about 20–30% of the cancer survivors reported impairment of their work ability due to cancer. In the future, it would be important to identify those survivors who have the highest risk of impaired work ability and are therefore more likely to leave work life early. By identifying these people, it would be possible to plan a more systematic 'return to work' support scheme for them. These services could play an important role in the management of cancer survivors' return



## 7 CONCLUSIONS

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to work, through early assessment and intervention, e.g. by arranging rehabilitation for them.

By developing such supportive services, the possibilities to help people to continue working would improve. Furthermore, cancer survivors should be offered opportunities to return to work more flexibly from retirement or unemployment. The decision to either work or quit working should be possible to make at individual level, regardless of a person's history of illness.

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## APPENDIX

### APPENDIX

Appendix: The following questions deal with your experience on received (Scale A) and needed (Scale B) support. Circle the alternative that most closely corresponds to your experiences. Use both scale A and B for each statement. Answer the questions according to the situation at your first workplace after your cancer diagnosis.

SCALE A	not at all	little	to some extent	rather much	very much	SCALE B		
						I hope for more	I am satisfied	I hope for less
<b>My supervisor</b>								
Kept in touch with me during my sick leave	1	2	3	4	5	1	2	3
Showed compassion and understanding	1	2	3	4	5	1	2	3
Gave me helpful advice on coping at work	1	2	3	4	5	1	2	3
Took my illness into consideration when planning or managing work tasks	1	2	3	4	5	1	2	3
<b>My colleagues</b>								
Kept in touch with me during my sick leave	1	2	3	4	5	1	2	3
Showed compassion and understanding	1	2	3	4	5	1	2	3
Gave me helpful advice on coping at work	1	2	3	4	5	1	2	3
Helped me in my work tasks	1	2	3	4	5	1	2	3
<b>Occupational health physician or nurse</b>								
Kept in touch with me during my sick leave	1	2	3	4	5	1	2	3
Showed compassion and understanding	1	2	3	4	5	1	2	3
Gave me helpful advice on coping at work	1	2	3	4	5	1	2	3
Evaluated my working conditions considering coping at work	1	2	3	4	5	1	2	3



Due to the improved prognosis of many forms of cancer, an increasing number of cancer survivors are able and willing to return to work after their treatment. It is generally believed, however, that people with cancer are either unemployed, stay at home, or retire more often than people without cancer. This study investigated the problems that cancer survivors experience on the labour market, as well as the disease-related, sociodemographic and psychosocial factors at work that are associated with the employment and work ability of cancer survivors.

The results of this study show that the majority of the survivors are able to return to work. There is, however, a group of cancer survivors who leave work life early, have impaired work ability due to their illness, and suffer from lack of support from their work place and the occupational health services.

The study sheds new light on the impact of serious illness on a person's employment and work ability. It also provides valuable information about the need of seriously ill persons for social support from work life. The study gives an overall picture of the role of various factors on cancer survivors' possibilities to continue working.

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