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Taina Taskila
Marja-Liisa Lindbohm
Rami Martikainen
Ulla-Sisko Lehto
Jari Hakanen
Päivi Hietanen

Cancer survivors' received and needed social support from their work place and the occupational health services

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T. Taskila (✉) · M.-L. Lindbohm · R. Martikainen
Department of Epidemiology and Biostatistics, Finnish Institute of Occupational Health,
Topeliuksenkatu 41 a A,
00250 Helsinki, Finland
e-mail: taina.taskila@ttl.fi
Tel.: +358-30-4742388
Fax: +358-30-4742423

U.-S. Lehto
University of Tampere Medical School and Department of Health and Functional Capacity,
National Public Health Institute,
Mannerheimintie 166,
00300 Helsinki, Finland

J. Hakanen
Department of Psychology,
Finnish Institute of Occupational Health,
Topeliuksenkatu 41 a A,
00250 Helsinki, Finland

P. Hietanen
Finnish Medical Journal,
Mäkelänkatu 2 A, PL 49,
00501 Helsinki, Finland

Abstract *Goals of work:* Even though a lot of studies have been conducted concerning cancer patients' social support, the importance of social support from the work life is unclear. We examined the amount of emotional and practical support that cancer survivors needed and had actually received from their coworkers, supervisors, and the occupational health personnel. We also examined whether disease-related or sociodemographic background variables were associated with needed or received support. Finally, we investigated whether there were differences between various sources in received or needed support. *Patients and methods:* The data consisted of a total of 640 cancer survivors with breast cancer, lymphoma, testicular or prostate cancer, aged 25–57 years at the time of diagnosis. Information on social support was collected with a mailed questionnaire using an adapted version of the Structural-Functional Social Support Scale (SFSS). *Main results:* The cancer survivors had received most support from their coworkers and they hoped for more support especially from the occupational health care personnel (39% of women and 29% of men). The men who had lymphoma, had received chemotherapy, or had low education level needed more support. The need for practical support from the occupational health personnel was fivefold between the chemotherapy-treated and those not treated. The women both received and needed more support than the men did. *Conclusions:* There is a clear need for additional social support from work life among the cancer survivors especially from the occupational health personnel.

Keywords Cancer survivors · Social support · Chemotherapy · Work · Occupational health services

Introduction

Due to the improved prognosis of many forms of cancer, an increasing number of cancer patients return to work after their treatment, or continue to work during their treatment. This has increased interest to study changes in work life among people with cancer. Recent studies have indicated that cancer has little impact on people's employment and cancer survivors are often able to return to work [6, 8, 29, 36].

Even though people with cancer are usually able to continue working, they may experience mental and physical impairments in health as a result of cancer, which hinder their work career [1, 6, 20, 34]. It has also been indicated, for instance, that chronically ill people have

problems in finding adequate support from health care providers [33] and from the work place [41].

The effect of social support in 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 [11, 21, 23]. Social support has also been demonstrated to be associated with cancer patients' physical adaptation, progression of the illness and the quality of life [4, 5, 27]. In the general studies about social support and work life, it has been established that adequate social support is connected with better well-being and productivity at work, whereas inadequate support is connected with the increased risk of burnout [2, 31]. Moreover, limited support has been related to early retirement [15] and long sick leaves [39].

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) [24, 32]. Different types of social support have been claimed to be connected to different matters. For example, Bloom et al. [5] found a connection between social networks and emotional and practical support, whereas only emotional support was connected with well-being. De Leeuw et al. [11] found available support to be connected with less depressive symptoms, whereas received support was found to be associated with more depressive symptomatology. In addition, earlier studies have indicated that the need of social support may vary by gender, age, and socioeconomic status [12, 24, 40].

Previous research has usually presented family and friends as the cancer survivors' main sources of support, even though in some studies, colleagues and supervisors have been mentioned as possible sources of support [7, 24]. Family and friends can be an important source of emotional support, but they rarely have a possibility to offer practical support the cancer survivors may need in work life [9]. As Lehto-Järnstedt et al. (2004) [26] point out, it would be beneficial to measure support beyond the closest relationships.

Even though a lot of studies have been conducted concerning cancer patients' social support, the importance of support from work life is unclear. Because social support has been identified to have an important role in the lives of cancer survivors, it is important to know whether there are unmet needs of social support from work. Moreover, it is important to identify those people who have the biggest need for more support. Thus, the aim of this study was to examine first the amount of social support that cancer survivors received from their work place (coworkers, supervisors) and the occupational health services (occupational health nurse and doctor), and secondly, whether more emotional or practical support was needed. Thirdly, we examined whether disease-related (cancer-type, treatment) or sociodemographic background variables (gender, age at the time of diagnosis, marital status, education or occupation) were associated with received or needed support. Finally, we investigated whether there were differences between various sources of support in the amount of received or needed support. The occupational health personnel were selected as one potential source of support because in Finland, for several reasons (legislation, compensation system, development goals and programs), the coverage of occupational health services is high, about 90% of the employees. The aim of the services is to provide preventive, promotive, and curative activities for workers [37].

The data of this study have been collected in connection with a Nordic questionnaire study on cancer and work life. The results presented in this article are based on the Finnish data.

Materials and methods

Participants

Altogether, 1,000 patients diagnosed with breast cancer, lymphoma, testicular or prostate cancer during the years 1997–2001 were selected from the list of patients of the 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 and had 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, must speak the native language Finnish or Swedish, and must be a resident of the Hospital District of Helsinki and Uusimaa, Finland. A questionnaire was sent to the patients, and a total of 825 persons (82.5%) returned the questionnaire. The response rate for women was 85% (605 persons) and for men 76% (220 persons).

People who had not been in paid work during the past 6 years (1997–2003) and those who had not been working after their cancer diagnosis, were excluded from the analysis (146 persons). Moreover, people who were either working alone or who had not told anyone at work about their illness (39 persons) were excluded. Finally, there was a total of 640 persons, of which 75% were women and 25% men.

In the final data, 89% of the women had breast cancer and 12% had lymphoma. Among the men, 41% had lymphoma, 30% prostate cancer, and 29% testicular cancer. The women who participated in the study were slightly older than the men: 83% of the women and 65% of the men were over 40 years old of age (Table 1).

Background variables

Information about the disease-related variables (diagnosis, age at the time of diagnosis, and treatment) were obtained

Table 1 Participants by age, diagnosis and type of treatment

Variable	Men		Women	
	N	%	N	%
Age, years				
25–39	56	34.6	81	16.9
40–49	41	25.3	180	37.7
≥50	65	40.1	217	45.4
Diagnosis				
Lymphoma	66	40.7	55	11.5
Breast cancer	–	–	423	88.5
Prostate cancer	49	30.3	–	–
Testicular cancer	47	29.0	–	–
Treatment				
No chemotherapy	91	56.2	238	49.8
Chemotherapy	71	43.8	240	50.2
Total	162	100	478	100

from the hospital files. Treatment was classified into two categories: chemotherapy or other type of treatment (endocrine therapy, radiotherapy, and/or surgery) (Table 1).

Sociodemographic variables including marital status (married, cohabitation, or others), education, and occupation were collected by the questionnaire. The participants were classified into four educational categories [14], as follows: 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 [38].

Measuring social support

The measurement of social support was based on the Structural-Functional Social Support Scale (SFSS), which has been developed especially for measuring disease-specific social networks and social support received by people having a serious somatic disorder or chronic disease [27]. 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. In this study we focused on the last two aspects.

The items were constructed from the issues brought up by 26 individuals who participated in a qualitative pilot study in the autumn of 2001. In the questionnaire, the participants 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 (coworkers, 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 to a lot). 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). This needed support had two items for both practical and emotional support. For example, the following item measuring emotional support was presented separately on each source: My coworkers/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 supervisor was as follows: "took my illness into consideration when planning/managing work tasks," was replaced in the case of occupational health personnel with the item: "evaluated my working conditions as regards coping at work".

For the analysis, the participants were divided into two groups: persons who would have needed more support and others. All those who had answered at least one of the questions "I hoped for more" were categorized 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.

Statistical analysis

At first, the three sources of support, i.e., coworker, 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 [13] were used to estimate the differences between the sources of support concerning both continuous and dichotomous response variables. Men and women were analyzed separately, because they had mainly different types of cancer. Significant background variables were included into the models. The interaction between the sources of support and background variables was also tested to assess whether the differences between the three sources of support were unequal according to the background variables, or if the effect of background variables on the responses differed between the sources of support. SAS 8.2 software was used in the statistical analyses.

Results

Received social support

The mean values of received support by each source are presented according to the background variables in Table 2. The men received less support from their coworkers and supervisors than the women, whereas both genders received an equal amount of support from the occupational health personnel. In both genders, neither age nor marital status was associated with received support from any source. People with different diagnoses have received an unequal amount of support from coworkers and supervisors, and the people whose cancer was treated with chemotherapy received more support than people who had other treatments. Persons with more education have received more support from the occupational health personnel compared to persons with less education. Service and

Table 2 Mean values and standard deviations of received support from different sources by background variables

Variable	Coworkers Mean value (SD)	Supervisor Mean value (SD)	Occupational health personnel Mean value (SD)
Gender			
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	$p<0.0001$	$p=0.03$	$p=0.73$
Age, years			
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	$p=0.40$	$p=0.10$	$p=0.11$
Marital status			
Married, cohabiting	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	$p=0.41$	$p=0.26$	$p=0.63$
Diagnosis			
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	$p<0.0001$	$p=0.005$	$p=0.41$
Treatment			
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	$p=0.0004$	$p<0.0001$	$p=0.25$
Education			
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	$p=0.64$	$p=0.56$	$p=0.004$
Occupation			
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	$p=0.02$	$p=0.10$	$p=0.05$
Total	11.4	10.1	6.8

Table 3 Differences in means (95% confidence interval) of received support between sources in treatment groups among men and women

Compared sources of support	Men		Women	
	No chemotherapy	Chemotherapy	No chemotherapy	Chemotherapy
Coworker 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)
Coworker 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

care workers and shop and market sales workers have received more support from all sources than those in other occupations have.

The effects of background variables and the differences between the sources of support were estimated by multivariate model. The multivariate analysis of background variables indicated that the differences between the sources of received support were dependent on a treatment, both among men and among women. People received significantly more support from their coworkers and supervisors than from the occupational health personnel, and these differences were greater among those whose cancer had been treated with chemotherapy than among those who have undergone other treatments (Table 3). Women received more support from their coworkers than from their supervisors. Both men and women who were treated with chemotherapy received more support from their coworkers and supervisors than those not treated in this way, whereas there was no difference between the treatment groups as regards the support from occupational health personnel. Other background variables were not associated with received support.

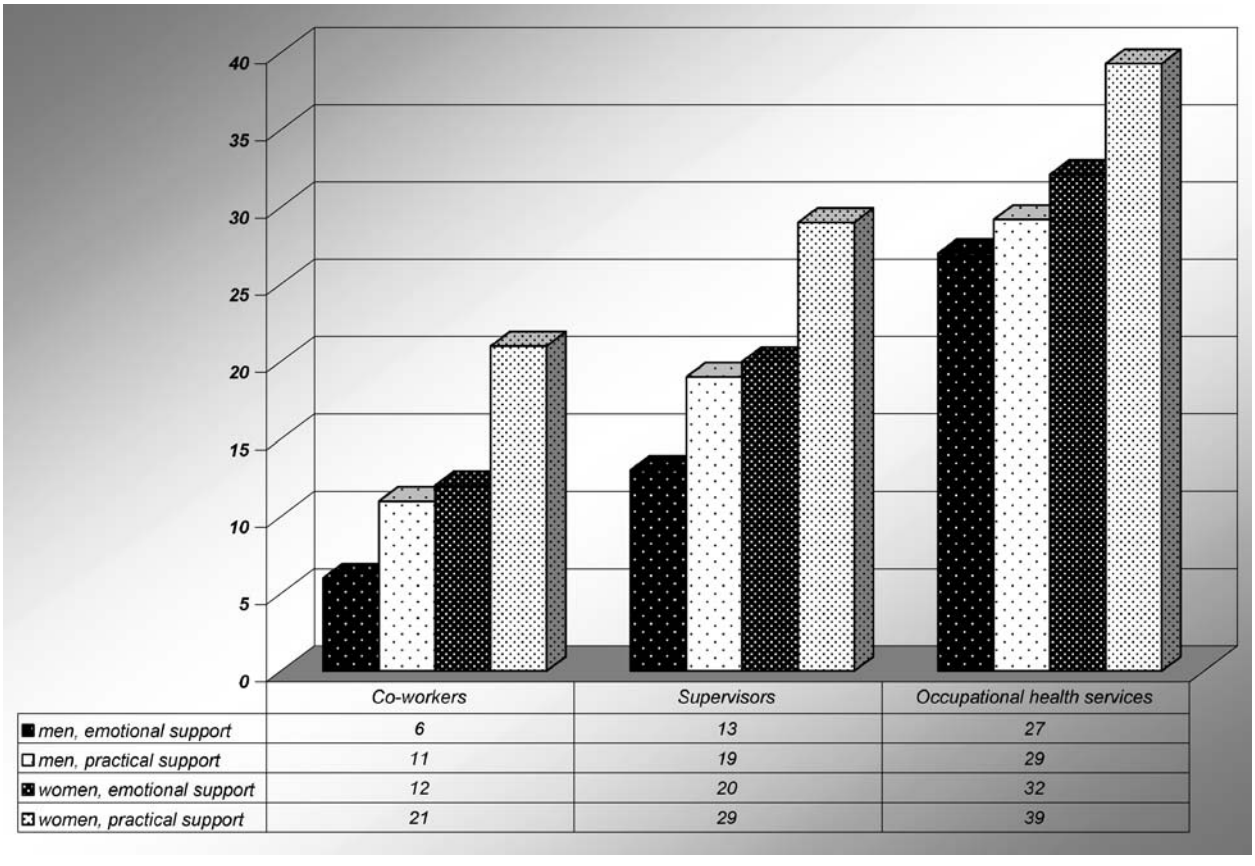

Fig. 1 Percentages of those who needed more emotional and practical support from various sources

Table 4 Odds ratios (95% confidence interval) for needed emotional support: comparison between occupational health services, supervisors, and coworkers

Compared sources of support	Men	Women
Occupational health services vs coworker	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 coworker	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; variable in the model of women: source

Needed emotional and practical support

Depending on the source of support, 11–29% of the men needed more practical support and 21–39% of the women, respectively (Fig. 1). The corresponding percentages for emotional support were 6–27% for men and 12–32% for women. Women needed additional support from all sources more often than men did. For example, 29% of the women wished for more practical support from their supervisors, whereas the corresponding percentage for men was 19% (p=0.02).

We explored whether any of the background variables was associated with the needed support. Among the men, there were differences in needed support from the occupational health personnel, but not in needed support from other sources. More support was especially hoped by men who had received chemotherapy: 44% of them needed more practical support, whereas the corresponding percent age for men who had some other treatment was 16% (p=0.0003). Moreover, there were differences in needed practical support between the cancer types: 43% of the men with lymphoma needed more support from occupational health personnel, whereas the corresponding percentage for men with testicular or prostate cancer was 23 and 15%, respectively (p=0.007). The higher the education level, the lesser was the need for additional support (p=0.05). There was also a clear need for more support among men who were craft workers, plant or machine operators or assemblers, or in elementary occupations as compared to the professionals (p=0.003). Among the women, there were no such differences between the background variables in any sources of support.

The differences between the sources of support in the amount of needed emotional and practical support were estimated by the multivariate model. Men hoped for more emotional support from the occupational health personnel almost six times and from their supervisors over two times more than from their coworkers (Table 4). 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 [odds ratios (OR) 2.27; 95% confidence interval (CI) 1.08–4.81]. Women hoped also for more emotional support from occupational health services, although the odds ratios between the sources were slightly lower among them. Other statistically significant associations between background variables and needed emotional support were not found.

Men's need for practical support from different sources was dependent on the type of treatment. Those treated with chemotherapy needed 5.60 times more practical support from the occupational health personnel than from their coworkers, whereas among those not treated with chemotherapy, the respective odds ratio was 2.19 (Table 5). On the contrary, the need from supervisors was greater among those not treated with chemotherapy than among those who were treated with chemotherapy.

The need for practical support from the occupational health personnel was fivefold between the chemotherapy-treated men and those not treated (OR 5.00; 95% CI 2.19–11.43), whereas from the other sources there were no significant differences between the two treatment groups. Among the men, education was also associated with the need for practical support. The odds ratios for the need for additional support according to education level were as follows: college (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.

Women also needed more practical support from occupational health personnel and their supervisor than from their coworkers (Table 5). None of the background

Table 5 Odds ratios (95% confidence interval) for needed practical social support: comparison between occupational health services, supervisors, and coworkers

Compared sources of support	Men		Women
	No chemotherapy	Chemotherapy	
Occupational health services vs coworker	2.19 (1.01–4.74)	5.60 (2.55–12.31)	2.34 (1.83–2.99)
Occupational health services vs supervisor	0.80 (0.35–1.81)	3.42 (1.66–7.03)	1.51 (1.21–1.88)
Supervisor vs coworker	2.74 (1.30–5.79)	1.64 (0.73–3.66)	1.55 (1.27–1.90)

Multivariate logistic regression models for correlated data; variables in the model of men: source, treatment, source X treatment, education; variable in the model of women: source

variables were, however, related to needed practical support among them.

Discussion

The cancer survivors received most support from their coworkers, and they were most satisfied with their support. The survivors received least support from the occupational health personnel, and notable proportion of the participants also needed more support from them (39% of the women and 32% of the men). Those treated with chemotherapy needed more support especially from the occupational health personnel than from the other sources of support (coworkers or supervisors) compared to people with other treatments. More support was especially hoped by the men who have had lymphoma or who were less educated. There were no such differences in the disease-related or socio-demographic background variables among the women, who both received and needed more support than the men did.

We collected the data by the postal questionnaire and a relatively high response rate of 82.5% was achieved. Social support was measured using an adapted version of the Structural–Functional Social Support Scale (SFSS), which has been shown to have good or sufficient psychometric properties [26]. A limitation of our study was a cross-sectional design. The questions on support concerned the time of return to work that had occurred 2–6 years (depending on the time of diagnosis) before the date of the questionnaire. However, received and needed support did not vary by the year of diagnosis. This suggests that different time lapses of recall have not affected our findings.

The restriction of the study to those who were working after their cancer diagnosis may have affected our findings. On the other hand, those who were excluded from the final study population did not differ with respect to sex or education from those who were included. If also those who did not return to work after the cancer diagnosis had been included in our data, proportion of those, who needed more support might have been even bigger.

There was a clear difference between the people who needed more support and those who did not. Our results show that the type of treatment was related to both the received and the needed support. People treated with chemotherapy received more support from their supervisors and coworkers than people who had other treatments did. However, the men with chemotherapy would have needed more practical support, especially from the occupational health personnel. Earlier studies have indicated that cancer treated with chemotherapy, along with its side effects, (especially fatigue) has a negative impact on returning to work [28, 35]. It has been shown in several studies that people who have had chemotherapy suffer more from, e.g., depression [10]. This can partly explain the greater need for social support among these people.

There are only a few comparative studies about the impact of the cancer type on social support, and the results have been contradictory. For example, in a recent study of Deimling et al. (2005) [12], cancer type was not associated with the activity of seeking social support. Similarly, Harrison et al. (1995) [19] found no differences between lymphoma patients and bone sarcoma patients in seeking support. On the other hand, Lehto-Järnstedt et al. (2004) [26] discovered that women with breast cancer got more support than people with melanoma. We found no clear differences in received support between women with breast cancer and lymphoma. Instead, men with lymphoma were in greater need of support from occupational health personnel compared to men with prostate or testicular cancer. Lymphoma patients' higher need for support was not dependent on the type of treatment. In both treatment groups (chemotherapy or not chemotherapy), they hoped for more support than testicular cancer patients.

The gender differences can be partly explained by the cancer type, because there were no differences in needed support between the men and the women who had lymphoma. Thus, making conclusions about the gender differences in this study is difficult, because the men and the women had mainly different cancer types. On the other hand, it has been noted that the experience of social support might be different for men and women [16, 24]. According to previous research, women often seek for support more actively and also have wider social network than men, whereas men usually lean on one person, a spouse in most cases [18, 19, 25]. In addition, women seem to benefit from a wide social network more than men. Hann et al. (2002) [18] observed that a wide social network was connected to less depressive symptoms among women, whereas this effect was not found among men. Similarly, Bildt and Michelsen (2002) [3] noted that deficient support from work was related to problems in mental health among women, but a similar connection was not found among men.

It has been found in several studies that social support obtained from family and friends is important for cancer patients [4, 5, 7]. We had no information about social support outside of the work place. However, we included marital status ("married, cohabitation" and "others") into our multivariate models on social support, but it was not associated with needed or received social support from work place or occupational health services.

Our results indicate that men with less education and a lower occupational status had a greater need for support than those with a higher status. 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 who hold lower positions [30]. Moreover, it has been shown that people with lower education and occupational status have more sick leaves than people in

higher positions [22]. In addition, it has been noted that access barriers to cancer treatment are greater to patients with lower socioeconomic status [17, 40].

There is no previous research on the role of occupational health services in supporting cancer patients' return to work. Our results indicate that the cancer survivors' social support from their work place and especially from the occupational health personnel was inadequate. Nearly 30% of the men and 40% of the women reported that they needed more practical support from the occupational health services. The possibilities of 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 the cost restrains, it is difficult for most occupational health units to establish an occupational health service team that is multidisciplinary enough [37]. In some cases occupational health service provided by an employer includes variety of services, but sometimes it covers only the minimum (medical check-ups). Thus, the quality and quantity of occupational health services may vary remarkably by a work place.

Practical support was most needed from the supervisors by taking illness into consideration when planning and managing the work tasks of a cancer patient, and when the occupational health personnel were evaluating the working conditions as regards the cancer patient's coping at work. The fact that more support was hoped for, particularly from the occupational health personnel, suggests that cancer survivors' need a more systematic return to work support scheme. Occupational health services may have important role to play in management of the return to work of cancer survivors by early assessment and intervention, such as arranging rehabilitation.

More research is needed on the importance of social support to cancer survivors returning to work and on the role of personal characteristics and work environment aspects, which have impacts on the cancer survivors' possibilities to return to work.

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