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ORIGINAL ARTICLE

Sick leave of spouses to cancer patients before and after diagnosis

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Abstract

Background. The impact of cancer on spouses of cancer patients may be considerable in many aspects. Our objective was to evaluate sick leave in spouses of cancer patients before and after the diagnosis. *Material and methods.* Using Swedish population-based registries, we studied sick leave of spouses to patients with newly diagnosed colon, rectal, lung, prostate, or breast cancer. We identified the cancer patients via the Swedish Cancer Registry and obtained information of their spouse through linkage with the population register. We assessed the number of sick leave episodes and sick days one year before until one year after the spouses' cancer diagnosis by cross-referencing with Swedish Social Insurance Agency data. We also compared the number of sick days of spouses with the general population adjusted for age, sex and partner status. *Results.* In general, spouses (N=1 923) to cancer patients had an increase in the frequency of new episodes of sick leave in the months before and after the cancer diagnosis. Spouses of lung cancer patients had most sick leave episodes, and the largest number of sick days per person. In comparison to the general population, spouses in the lung cancer group also had the highest standardised sick day ratio 1.76; 95% confidence interval 1.24, 2.40. The corresponding risk for spouses in other groups of cancer was not significantly increased. *Discussion.* In Sweden there is often increased sick leave of spouses to cancer patients. It may be due to emotional stress and physical reactions that follow with cancer which needs to be further explored in order to provide adequate support and care.

Both the patient and their family are affected by the disease and the treatment experience after a diagnosis of cancer. The spouse of a person affected by cancer is often the most important person in providing both emotional and practical support during the time of disease and treatment [1-3]. The significance of this support increases as a growing number of cancer treatments are delivered in open care.

To be a spouse to a cancer patient is often associated with a substantial impact in daily life. Besides worries about the disease and treatment outcome, practical duties often increase the burden. For example providing transport, accompanying to medical appointments, coordinating between different care settings, helping in medication, and also taking a great deal of household responsibilities may be additional demands on the partner. Furthermore, many spouses undertake major care giving tasks [4,5]. Time and costs associated with informal care giving for cancer survivors can be substantial. The burden of care giving may include not being able to perform employment work as usual, leading to both psychosocial as well as financial consequences [6]. Consequently, spouses provide support, but also need support for themselves many years after the cancer diagnosis [3]. Previous studies have demonstrated that mental health is negatively affected [7] and that psychological morbidity such as anxiety and depression are common among spouses of cancer patients [8-12]. Sometimes the partner experience even more anxiety than the cancer patient [13]. In a former study on health care utilisation by partners of cancer patients, we found that spouses of patients with

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colon, lung and prostate cancer have a two to three times increased rate of psychiatric diagnosis. We also found that circulatory, respiratory, and gastrointestinal diagnoses increased by 25% the first year after the cancer diagnosis. The same study showed that health care costs increased among spouses of patients with colon, lung and prostate cancer, due to an increase in their health care utilisation the first and second year after the cancer diagnosis [14].

The impact of cancer on spouses of cancer patients is considerable and complex [7-14]. With an increasing number of cancer patients living with the disease for a longer period of time, we can expect more spouses to be involved and affected. We hypothesized that spouses to cancer patients have an increase in sick leave. If so, it is of interest out of a health economical point of view as it might affect both the household economical level and the public payer level. However, no previous studies have been found with the focus of sick leave by spouses of cancer patients. The present observational study was conducted to fill the gap of knowledge in the literature, hence we investigated sick leave in spouses of cancer patients in Sweden before and after the cancer diagnosis using population-based prospectively ascertained registry data.

Materials and methods

This study is a part of a survey with the aim of mapping and analyzing cancer and its consequences in the county of Skåne. We selected five major forms of cancer: colon, rectal, lung, breast and prostate cancer, which are all included in the Swedish Cancer Registry [15].

Definitions

A spouse was defined as the adult husband/wife/legal partner living at the same address as the patient at the year of the cancer diagnosis. The age of the spouse was set on the 1st of January in the year of the cancer diagnosis.

Sickness benefit is an income related benefit from the Swedish Social Insurance Agency, and is a compensation for loss of income due to illness that reduces work capacity. All residents aged 16–64 years can be granted this economic security according to the Swedish legislation.

On the first day of illness no benefit is paid, and the following 13 days are directly paid by the employer. Sick periods shorter than 14 days of employees are not registered by the Swedish Social Insurance Agency, and were consequently not available for this study. The sickness benefit from the Social Insurance Agency may be approved from the 15th day of sick leave, for this approval a certificate of sick leave issued by a doctor is required. We defined an *episode of sick leave* as one coherent registered period of absence from work due to sickness. Sickness benefit can be approved with different extent; for a quarter of day, half day or three quarter of a day or a full working day (normally eight hours). Hence, it is possible to work part of a day and thereby receive partial sickness benefit. The term *gross sick days* are the total number of sick days irrespective of the extent. *Net sick days* are the number of gross sick days multiplied with the extent (e.g., two gross sick days with half-time sickness benefit becomes one net sick day).

Data resources

We linked data from the Swedish Cancer Registry, population register and the Swedish Social Insurance Agency via the individual's unique 10-digit personal identification number which is carried by all Swedish residents.

The Swedish Cancer Registry covers the whole Swedish population. A report has to be sent for every cancer case diagnosed at clinical-, morphological-, other laboratory examinations as well as cases diagnosed at autopsy.

The *population registry* is a national register containing vital statistics of e.g., date of birth, gender, place of residence, marital status and the spouses' identification number on all Swedish residents.

The Swedish Social Insurance Agency administers social insurances for all Swedish residents including sick pay and disability pension. The registry is linked to the actual reimbursement system. Sick periods shorter than 14 days are paid by the employer and are not registered by the Social Insurance Agency. Consequently these periods were not available to be included in this study.

Study subjects

First, we identified all patients living in the county of Skåne, Sweden diagnosed with colon, rectal, breast, prostate and lung cancer during the period of 2004 to 2005 (irrespective of first time cancer diagnosis or not) via the Swedish Cancer Registry. Second, we obtained information of the partner status and their spouses' personal identification number via the population register, and finally we cross-referenced their identities with data on sick leave from the Social Insurance Agency. For this study purpose we only included spouses in the age of 17–64 years, as the general age for retirement in Sweden is 65 years.

Study measures and statistical methods

Outcome measures for this study were episodes of sick leave and sick days. Sick days were calculated in

terms of gross and net number of days (see definitions). This calculation also included sick days after the study period if the period of sick leave had started during the study period.

- 1. We compared the total number of episodes of sick leave and sick days for the whole measure period between spouses for the different types of cancers.
- 2. We calculated new episodes of sick leave for the period of 12 months before and compared those with the period of 12 months after the date of the cancer diagnosis.
- 3. The number of new episodes of sick leave that started during the 2-year period was calculated in order to study development over time. In addition we calculated point prevalence estimates of spouses with ongoing sick leave in 30-days intervals from 360 days before until 360 days after the date of the cancer diagnosis.
- 4. For each separate calendar year, we calculated a standardized sick day ratio, i.e., the ratio between the observed and expected number of sick days generated by spouses. The expected number of sick days is based on the observed frequency of sick days in the general population of Skåne standardized for age, sex and marital status (direct standardization).
- 5. We also assessed the International Classification of Diseases (ICD 10) diagnosis codes as provided by the sick-listing doctor on the certificate of sick leave to compare the relative frequency of different diagnoses within the study subgroups. The diagnosis codes are required on the certificate of sick leave, and are used by the Social Insurance Agency in the assessment of the individuals working capacity.

Ethical approval

The design of the study was approved by the Committee for Research and Ethics by the University Hospital of Lund.

Results

Sample description

In 2004 and 2005, 7 143 patients were diagnosed with colon, rectal, lung, breast and prostate cancer in the county of Skåne. According to the population register 4 088 of them lived together with a spouse the year of the cancer diagnosis. Of the 4 088 partners, 1 923 spouses were aged 17–64 years, i.e. eligible to enter the study (Table I, no spouse was younger than 25 years old).

Episodes of sick leave

Spouses to patients with colon, rectal and lung cancer had the highest relative frequency of one or more new episodes of sick leave for the full 2-year period (one year before until one year after the date of diagnosis). However, no statistically significant differences were found between spouses in the different diagnosis groups (Table II). We did not observe any essential differences in sick leave with respect to age and sex of the spouses.

Most spouses with sick leave had only one or two new episodes during this period. Spouses to patients with breast cancer had the lowest relative frequency of new episodes (Table II).

The number of new episodes of sick leaves increased in the colon, rectal and lung cancer group, while there was only a minor increase for spouses to patients with breast cancer and no increase at all for spouses to patients with prostate cancer (Figure 1). In general the increase in the frequency of sick listing occurred about one month before the date of the cancer diagnosis and remained elevated for the two following months before returning to the "baseline" level (Figure 2).

A peak in the number of persons with ongoing episodes (point prevalence) of sick leave was seen after the cancer diagnosis for spouses to patients with lung, colon and rectal cancer (Figure 3).

Number of sick days

The mean number of gross sick days per person for the whole sample created by new episodes was 41

Cancer of patient	Spouses, N	Women, N (%)	Men, N (%)	Age 25-44 years*, N (%)	Age 45-64 years, N (%)
Colon cancer	162	113 (70)	49 (30)	16 (10)	146 (90)
Rectal cancer	106	78 (66)	28 (34)	8 (8)	98 (92)
Lung cancer	230	144 (63)	86 (37)	16 (7)	214 (93)
Breast cancer	548	2 (<1)	546 (>99)	84 (15)	464 (85)
Prostate cancer	877	873 (>99)	4 (<1)	27 (3)	850 (97)
Total	1923	1210 (63)	713 (37)	151 (8)	1772 (92)

*No partner below the age of 25 years was identified.

	Cancer of patient					
Number of sick leave episodes by spouses	Colon cancer N=162 %	Rectal cancer N=106 %	Lung cancer N=230 %	Breast cancer N=548 %	Prostate cancer N=877 %	Total N=1923 %
One episode	12	17	13	10	12	12
Two episodes	5	8	7	2	2	3
Three episodes	2	1	3	<1	<1	<1
Four episodes	<1	-	<1	<1	<1	<1
Five episodes	-	_	<1	<1	<1	<1
One or more episodes	20	26	24	13	15	16

Table II. Percent of spouses to cancer patients with sick leave episodes over the period of two years (one year before until one year after the cancer diagnosis).

days (range 29–58). The corresponding number of net sick days per person was 26 days (range 18–39). The smallest number of both net and gross sick days per person was found among spouses of patients with breast cancer while partners in the lung cancer group had the highest number of both net and gross sick days (together with spouses in the colon cancer group for gross sick days) (Figure 4).

The standardized sick day ratio (comparing the observed to the expected number of sick days) was significantly increased in spouses to lung cancer patients with a ratio of 1.70 (95% confidence interval 1.21, 2.28) for the calendar year 2004 and ratio 1.76 (95% confidence interval 1.24, 2.40) for 2005 (Table III). The ratios for men and women were essentially the same, and spouses to other types of cancer patients did not have significantly increased sick day ratios.

Diagnosis of new episodes of sick leave

Psychiatric diagnoses (30%) accounted for the single largest group of diagnoses generating new episodes



Figure 1. The mean numbers of new episodes of sick leave per spouse one year prior and one year after the diagnosis of the cancer patient (data is standardised for age and sex). of sick leave. The proportion of psychiatric diagnoses was highest in spouses of patients with rectal cancer (49%), lung cancer (44%) and colon cancer (37%).

Discussion

To our knowledge, this is the first study systematically investigating sick leave generated by spouses of persons with cancer. In general, the spouses were more frequently on sick leave in the months before and after the cancer diagnosis which may indicate that the time around the diagnosis is experienced as very difficult. However, we also found a difference in the pattern of sick leave depending on the diagnosis. Spouses to patients with colon, rectal and lung cancer generated the highest burden of sick leave in terms of ongoing and new episodes but also in numbers of sick days. The same groups of spouses have been shown to be negatively affected in terms of health, with a negative impact on health and consequently an increase in health care utilization in the years following the diagnosis of the cancer patient [14]. This is also consistent with a recent study showing that lung and colorectal cancer produced the most adverse effects on spouses' earnings [16]. In our study, spouses to patients with lung cancer had a substantial increase of new episodes of sick leave around the time for diagnosis, and they were also the group that generated the highest number of sick days. A likely explanation may be the stage and prognosis of the different types of cancer. Breast and prostate cancer are often diagnosed at an early stage, were there are few or none symptoms present. Patients with colon, rectal and lung cancer often present with more notable symptoms at the time of diagnosis, and the cancers are often in a more advanced stage. There are also well established differences in survival rates, where breast and prostate cancer have the best survival rates and lung cancer the worst. Studies with spouses of lung cancer patients have shown that they have lower health related quality of life [17], and that they are negatively affected in terms of mental



Figure 2. The percentage of new sick listing episodes per month for spouses to lung, colon, prostate, rectal and breast cancer patients, 12 months before until 12 months after the cancer diagnosis.

health with depression, exhaustion and lower emotional well being [7]. Thus, the diagnosis, stage, and prognosis of the cancer patient must be considered as significant factors influencing the situation of the spouse.

The considerable impact of the cancer diagnosis on the spouse appears to be through the whole trajectory of illness from time of diagnosis to survival after treatment or in some cases after cancer patients' death [7,12,14,17]. Apart from the psychological morbidity and impact on health related quality of life in significant others of cancer patients [17], economical and occupational burdens can also follow the cancer diagnosis [16,18,19]. Especially women's earnings are lower after their spouses' cancer illness, but men's earnings seems to be unaffected by their wives cancer disease [16]. Grunfeld et al. [18] reported that 70% of partners had some form of adverse impact on work, like missing work. Longo et al. [19] presented similar results indicating that one third of partners working days are lost time from work required by the needs of the partner with cancer. However, both studies used questionnaires, none of them focused on sick leave. These three studies together with the findings



Figure 3. The percentage of ongoing episodes of sick leave (point prevalence) by spouses to lung, colon, prostate, rectal and breast cancer patients. Day 0 is the day of cancer diagnosis.



Figure 4. The mean number of gross and net sick days (see methods for definition) of spouses to cancer patients during the study period of two years.

from our study indicate that the household economic situation might be more or less severe affected due to impact not only on the work situation by the cancer patient but also by the spouse. This must also be taken into consideration when calculating society's total costs of cancer.

In Sweden there is a general trend of decreased sick leave from 2004 to 2005 probably due to slight policy

Table III. Standardised sick day ratio (SSR)^{*} of spouses of cancer patients.

	Calendar year		
Cancer of patient	2004	2005	
Colon cancer			
SSR	1.30	1.03	
95% CI	0.89-1.81	0.64-1.55	
No. of cases	83	79	
Rectal cancer			
SSR	1.27	0.90	
95% CI	0.85 - 1.76	0.54-1.37	
No. of cases	52	54	
Lung cancer			
SSR	1.70	1.76	
95% CI	1.21 - 2.28	1.24 - 2.40	
No. of cases	118	112	
Breast cancer			
SSR	1.08	0.93	
95% CI	0.64 - 1.65	0.50-1.51	
No. of cases	298	250	
Prostate cancer			
SSR	1.06	0.88	
95% CI	0.71 - 1.50	0.54-1.31	
No. of cases	450	427	
Total			
SSR	1.17	1.01	
95% CI	0.77 - 1.67	0.62 - 1.51	
No. of cases	1001	922	

*The sick day ratio (SSR) is calculated by dividing the observed by the expected number of sick days generated by spouses. The expected number of sick days is based on the observed frequency of sick days in the general population, standardised for sex, age and marital status. changes, but this is accounted for in the calculation of the risk ratios per calendar year using data from the general population in the denominator. Notably, sick leave shorter than 14 days were not possible to capture within this study, which means that there are more episodes of sick leave both before and after the cancer diagnosis that we were not able to detect. We believe this have biased our study somewhat towards the null as it is possible that short sick listings at the time of the cancer diagnosis may be more frequent than elsewhere during the study period.

We do not see any obvious confounders of observed association, i.e. factors that cause increased sick leave of the spouses as well as causing the cancer of the patients, although e.g., environmental factors cannot be fully excluded. We find it most likely that the increase in sick leave is generated by the psychological distress surrounding the signs and symptoms of the patient, medical work-up, cancer diagnosis, and treatment of the cancer patient. The true reason for sick leave has not been possible to analyze to full extent. However, the relatively high number of psychiatric diagnosis on the certificates of sick leave support the view that circumstances around the cancer patients' situation is contributing to the spouses' sick leave. Further, it was not possible to identify partners who were retired from work early during the 2-year period, thus no longer at risk of being sick listed. In a sensitivity analysis we excluded persons 62-64 years of age, and found only marginal differences in the point prevalence estimates of sick leave (e.g. in the colon cancer group, the numbers of episodes of sick leave increased with 10%). Another source of bias also working in the direction of less sick leave the longer the followup is that partners who relocated outside Sweden, died or were transferred to disability pension consequently no longer could be sick listed. Still, we deem that the overall impact on results due to this would probably be close to negligible.

In conclusion we found increased sick leave by partners to cancer patients in the immediate period before and after their cancer diagnosis. This is of importance from a health economical perspective, where increased sick leave by partners should be a part of the estimation of indirect costs of cancer. Differences between the different diagnoses groups related to stage, prognosis, treatment and symptoms needs to be further explored in order to identify partners at risk of having impact on their health. This is also of importance in the development of improved cancer care. Knowledge is needed about the situation of the partner in relation to the person with cancer so that adequate support/care can be given to the partner in an early stage. It is also of importance to study if the outcome for the cancer patient is related to having a partner or not. Qualitative studies about experiences of living with cancer are planned with the aim of including both the partner and the person with cancer.

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

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