Socio-economic implications of cancer survivorship: Results from the PROFILES registry

Floortje Mols a,b,* , Melissa S.Y. Thong a,b , Pauline Vissers a,b , Tamar Nijsten c , Lonneke V. van de Poll-Franse a,b

a CoRPS – Center of Research on Psychology in Somatic diseases, Department of Medical Psychology and Neuropsychology, Tilburg University, The Netherlands
b Comprehensive Cancer Centre South, Eindhoven Cancer Registry, Eindhoven, The Netherlands
c Department of Dermatology, Erasmus Medical Centre Rotterdam, Rotterdam, The Netherlands

ARTICLE INFO

Article history:
Available online 21 December 2011

Keywords:
Cancer
Life insurance
Mortgage
Health care insurance
Work

ABSTRACT

Introduction: The goal of this large population-based study was to examine the socio-economic implications of cancer survivorship.

Methods: Individuals alive and diagnosed with colorectal cancer and melanoma between 1998 and 2007 or Hodgkin lymphoma, non-Hodgkin lymphoma or multiple myeloma between 1999 and 2008 as registered in the Eindhoven Cancer Registry received a questionnaire on work changes and problems with obtaining a new (or extended) health care insurance, life insurance or a home loan; 70% (n = 2892) responded.

Results: Results showed that 28% of all cancer patients experienced changes in their work situation after cancer. Most of them switched to part-time work or stopped working entirely. Patients (3.4%) who tried to obtain a different or upgrade their health care insurance experienced problems and in most cases, these were eventually resolved. Problems with life insurance were somewhat more common with 18% of those who tried to obtain a life insurance experiencing problems. The majority of these patients was rejected by the insurance company (61%) or was accepted at a higher premium (22%). Of the 21% who tried to obtain a home loan, 9% experienced problems. However, 22.2% got accepted eventually, 27.8% got accepted but at a higher mortgage payment and 22.2% got rejected but were eventually accepted by another bank.

Conclusions: Almost a third of cancer survivors experienced changes in their work situation after cancer. Problems with obtaining health insurance, life insurance and home loans were also common.

© 2011 Elsevier Ltd. Open access under the Elsevier OA license.

1. Introduction

Advances in early diagnoses and effective treatment of cancer have led to an increasing number of cancer survivors.1,2 The effects of cancer and its treatment on the physical and mental health status of cancer survivors is an important research topic nowadays. Only a few studies take notice of more practical problems that cancer survivors might experience after diagnosis and treatment, like socio-economic implications of survivorship. A recent meta-analysis showed that cancer
survivors experience problems with respect to employment. In addition, to additional health care costs, cancer survivors may also experience financial problems like obtaining health care insurance, life insurance and home loans. Although these financial problems can have a major impact on the lives of cancer survivors, and these problems are often not justified according to patients’ current health status, research on these topics is still scarce and is most often done among small specific subgroups of survivors. Therefore, the goal of this large population-based study was to examine whether survivors of colorectal cancer, melanoma, Hodgkin lymphoma, non-Hodgkin lymphoma or multiple myeloma experienced changes in their work situation or experienced problems with obtaining a new (or extend an existing) health care insurance, life insurance or a home loan.

2. Materials and methods

2.1. Setting and participants

In this study, data from several large population-based surveys on survivors of colorectal cancer, melanoma, Hodgkin lymphoma, non-Hodgkin lymphoma and multiple myeloma from the PROFILES registry were used. These surveys were conducted to evaluate different patient reported outcomes often done among small specific subgroups of survivors. The Eindhoven Cancer Registry (ECR), which is part of the Comprehensive Cancer Centre South, compiles data of all individuals newly diagnosed with cancer in the southern part of the Netherlands, an area with 10 hospitals serving 2.3 million inhabitants. All individuals diagnosed with colorectal cancer and melanoma between 1998 and 2007 or Hodgkin lymphoma, non-Hodgkin lymphoma or multiple myeloma between 1999 and 2008 as registered in the ECR were eligible for participation. Due to the large number of colorectal cancer survivors (N = 5399) a weighted random selection of 2219 patients based on tumour, sex, and year of diagnosis was made. Due to the large number of melanoma survivors, we only selected patients diagnosed in 3 out of 10 regional hospitals. After excluding patients with cognitive impairment, who had unverifiable addresses, or had died prior to start of study (according to the ECR, hospital records, and the Central Bureau for Genealogy which collects information on all deceased Dutch citizens via the civil municipal registries), data collection started between 2008 and 2009. All surveys were approved by a local certified Medical Ethics Committee.

2.2. Data collection

Survivors were informed of the surveys via a letter from their (ex)-attending specialist. The letter explained that by completing and returning the enclosed questionnaire, patients consented to participate and agreed to the linkage of the questionnaire data with their disease history in the ECR. Patients were reassured that non-participation had no consequences on their follow-up care or treatment. Non-respondents were sent a reminder letter and the questionnaire within 2 months.

2.3. Measures

Survivors’ sociodemographic and clinical information were available from the ECR. The ECR routinely collects data on tumour characteristics, including date of diagnosis, tumour grade, clinical stage, primary treatment, and patient background characteristics including date of birth and comorbidity at the time of diagnosis. Socioeconomic status was determined by an indicator developed by Statistics Netherlands. Questions on current comorbidity, marital status, educational level, and current occupation were added to the questionnaire. We also added questions on problems with insurance and home loans. Data on if and how these problems were eventually solved were only available for patients with colorectal cancer, Hodgkin lymphoma, non-Hodgkin lymphoma, and multiple myeloma, and not for melanoma survivors.

2.4. Statistical analyses

Routinely collected data from the ECR on patient and tumour characteristics enabled us to compare the group of respondents, non-respondents and patients with unverifiable addresses, using t-tests for continuous variables and chi-square analyses for categorical variables. Percentages of patients experiencing changes in work situations were calculated among those younger than 65 at diagnosis since that is the age of retirement in the Netherlands. In addition, percentages of patients experiencing problems with insurance and home loans were calculated. All statistical test’s were two-sided and considered significant if p < 0.05. All statistical analyses were performed using SAS (version 9.2 for Windows, SAS Institute Inc., Cary, NC).

3. Results

3.1. Demographic and clinical characteristics

The response rate was high, with 70% of the 4123 cancer survivors returning a completed questionnaire. As described in a previous paper, patients with unverifiable addresses in general were younger, with more years since diagnosis, and they were less often treated with surgery, and less often diagnosed with colorectal cancer. Non-respondents were less often treated with radiotherapy or chemotherapy. In total, 2892 cancer survivors were included in the final analyses (mean age 64.3). The majority of those respondents was male (53.9), married (76%), had a medium educational level (60%), was not employed (75%), and had a medium or high socio-economic status (79%) (Table 1).

3.2. Work changes

The majority of patients younger than 65 at time of diagnosis (n = 913; 72.2%) stated that their work situation had not changed due to cancer. However, of those who did experience changes (n = 351; 27.8%), 76 (21.7%) patients chose to stop working themselves, 108 patients (30.8%) indicated that they...
were unable to work due to their cancer, 25 patients (7.1%) said that they had been fired due to cancer, and 23 (6.6%) patients retired early due to cancer. In addition, 97 (27.6%) patients switched to part-time work, six patients (1.7%) worked more hours after their diagnosis, and 16 patients (4.6%) followed occupational retraining due to cancer.

### 3.3. Problems with insurance and home loans

Demographic and clinical characteristics of those reporting socio-economic problems are described in Table 1. One third of patients did not try to obtain a different or more complementary health care insurance (e.g. an upgrade) ($n = 1014$; . . .).
36.7%) after their cancer diagnosis. However, 1748 patients did try and 60 (3.4%) of them experienced problems (Fig. 1). Regarding the resolution of these problems in these patients (excluding the melanoma patients), 19 (42.2%) survivors got accepted eventually, 13 (28.9%) got accepted at a higher premium, 7 (15.6%) got rejected by the insurance company, and 6 (13.3%) got rejected but were eventually accepted by another company.

On obtaining life insurance after cancer diagnosis, 586 (22.1%) survivors tried and of these, 119 patients (20.3%) experienced problems (Fig. 1). Of those patients who did experience problems with getting a life insurance, nine patients (11.1%) got accepted eventually, 18 (22.2%) got accepted at a higher premium, 49 (60.5%) got rejected by the insurance company and five (6.2%) got rejected but were eventually accepted by another company.

Of the 557 (21.2%) survivors who tried to get a home loan, 53 patients (9.5%) experienced problems (Fig. 1). Of these patients, eight patients (22.2%) got accepted eventually, 10 (27.8%) got accepted but they pay a higher premium, 10 (27.8%) got rejected by the bank and eight (22.2%) got rejected but were eventually accepted by another bank.

4. Discussion

The present study showed that of the 28% cancer patients experienced changes in their work situation after cancer. Most of them switched to part-time work or stopped working entirely.

These percentages were also found in two Dutch population-based studies among long-term Hodgkin and non-Hodgkin lymphoma survivors.17,18

No more than 3.4% of patients who tried to obtain a different or more coverage of their health care insurance experienced problems and in most cases, these were eventually resolved. Problems with life insurance were more common with 20.3% of those who tried to obtain a life insurance experiencing problems. The majority of these patients got rejected by the insurance company (61%) or were accepted but had to pay a higher premium (22%). The number of patients experiencing problems obtaining health insurance or life insurance was mostly in line with the literature5,7,17,18 although two studies among Hodgkin and non-Hodgkin lymphoma survivors reported higher rates of patients experiencing problems with health insurance (25 and 12%, respectively) and life

---

*This overview only shows the patients that actually tried (n=1748).

---

*This overview only shows the patients that actually tried (n=586).

---

*This overview only shows the patients that actually tried (n=557).

---

**Fig. 1 – Overview of socio-economic implications of cancer survivorship problems.**
These differences with previous studies were still present after doing separate analyses for Hodgkin and non-Hodgkin lymphoma survivors within our cohort (data not shown). This difference might be explained by a change in the rules and regulations of insurance companies in the past years since the lymphoma survivors in the current cohort were diagnosed between 1999 and 2008 while the lymphoma survivors in the two described studies were diagnosed between 1989 and 1998.

Survivors also experienced problems with home loans. Of the 21.2% who tried to obtain a home loan, 9.5% experienced problems. This percentage is quite comparable to two small studies where problems were reported by 2% of hereditary non-polyposis colorectal cancer mutation carriers,5 and 6% of melanoma survivors.7 However, two other studies among Hodgkin and non-Hodgkin lymphoma survivors in the Netherlands showed much higher rates of problems with obtaining a home loan among those who actually tried (63% and 73%, respectively).17,18 Differences might be explained by a shift in bank rules and regulations over the past decades.

The present study has some limitations that should be mentioned. Although information was present concerning the initial cancer and treatment characteristics of the non-respondents and patients of whom the addresses could not be verified, whether non-respondents declined to participate in the study because of poor health remains unknown. Also, the cross-sectional design of our study limits the determination of causal association between cancer survivorship and occupational and financial problems. Despite these limitations, the present study provides an important contribution to the limited data available on work problems, and problems with obtaining insurance and home loans in cancer survivors. Since this is a population-based study among a large group of patients with a high response rate, extrapolating these results to the larger population of cancer survivors seems justified. These results call for further research on the socio-economic implications of cancer survivorship among patients followed over a longer period of time since occupational problems and financial problems can have a major impact on the lives of those who experienced these problems and because these problems are most often not justified according to patients current health status.

In conclusion, almost a third of cancer survivors experienced changes in their work situation after cancer. Most of them switched to part-time work or stopped working entirely. In addition, problems with obtaining health insurance, life insurance and home loans were less common, but still one in five experienced problems obtaining a life insurance. More attention should be paid and more information should be given to patients on the socio-economic implications of cancer survivorship.

Research Award from the Dutch Cancer Society (#UVT-2009-349) to Lonneke van de Poll-Franse. The data collection of this study was funded by an Investment Subsidy (#480-8-009) of the Netherlands Organisation for Scientific Research for setting up the PROFILES registry. These funding agencies had no further role in study design; in the collection, analysis and interpretation of data; in the writing of the report and in the decision to submit the paper for publication.

Conflict of interest statement

None declared.

Acknowledgements

We would like to thank all patients and their doctors for their participation in the study. Special thanks go to Dr. M. van Bommel, who was willing to function as an independent advisor and to answer questions of patients. In addition, we want to thank the following hospitals for their cooperation: Amphia hospital, Breda; Catharina hospital, Eindhoven; Elkerliek Hospital, Helmond and Deurne; Jeroen Bosch hospital’s Hertogenbosch; Maxima Medical Centre, Eindhoven and Veldhoven; Sint Anna hospital, Geldrop; St. Elisabeth hospital, Tilburg; Twee Steden hospital, Tilburg and Waalwijk; VieCury hospital, Venlo and Venray; Hospital Bernhoven, Oss and Veghel.

REFERENCES

9. van de Poll-Franse LV, Horevoorts N, Eenbergen MV, et al. The patient reported outcomes following initial treatment and long term evaluation of survivorship registry: scope, rationale and design of an infrastructure for the study of physical and...