EUROPEAN JOURNAL OF CANCER 48 (2012) 2037–2042

Available at www.sciencedirect.com

SciVerse ScienceDirect

journal homepage: www.ejconline.com

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.

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

---

[*] *Corresponding author:* Address: CoRPS, Department of Medical Psychology and Neuropsychology, Tilburg University, PO Box 90153, 5000 LE Tilburg, The Netherlands.

E-mail address: F.Mols@uvt.nl (F. Mols).

URL: http://www.tilburguniversity.nl/corps (F. Mols).

0959-8049/$ - see front matter © 2011 Elsevier Ltd. All rights reserved.
doi:10.1016/j.ejca.2011.11.030

survivors experience problems with respect to employment.[3,4] In addition, to additional health care costs, cancer survivors may also experience financial problems like obtaining health care insurance, life insurance and home loans.[5–7]

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[8] and is most often done among small specific subgroups of survivors.[5–7] 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.[9] These surveys were conducted to evaluate different patient reported outcomes among cancer 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.[10] 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.[11] Due to the large number of melanoma survivors, we only selected patients diagnosed in 3 out of 10 regional hospitals.[12,13]

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,[14] clinical stage,[14] 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.[15] 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.[16] 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