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Published in:
International Journal of Cancer

Document version:
Publisher's PDF, also known as Version of record

Publication date:
2007

Citation for published version (APA):

Download date: 11. Aug. 2020
Increased health care utilization among long-term cancer survivors compared to the average Dutch population: A population-based study

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In the present study, self-reported health care utilization of cancer survivors is compared with those of an age- and gender-matched normative population and predictors of health care utilization are identified. A population-based, cross-sectional survey among 1893 long-term survivors of endometrial and prostate cancer and malignant lymphomas (Hodgkin’s and non-Hodgkin’s) diagnosed between 1989 and 1998 was conducted using the cancer registry of the Comprehensive Cancer Centre South. Cancer survivors visited their general practitioner somewhat more often compared to the age and gender-matched general Dutch population but this effect was not always statistically significant. In addition, they visited their medical specialist significantly more often. Survivors only sporadically (0–3%) visited or required a dietician, sexologist, oncology nurse, pastor, creative therapy or recovery program. Contact with a psychologist, physiotherapist and other cancer survivors took place somewhat more often. Patients visited a medical specialist less often if they were diagnosed with endometrial cancer (OR = 0.2; 95% CI = 0.1–0.5), if they were diagnosed between 10–15 years ago (OR = 0.6; 95% CI = 0.1–0.5) and if they were not married or divorced (OR = 0.5; 95% CI = 0.3–0.9). Contact with a psychologist was related to having a university or college degree (OR = 3.6; 95% CI = 1.3–9.4). Cancer survivors visited their specialist more often compared to the normative population.

Changes in health care, such as less administrative work for the specialist and more efficiency, are probably necessary in order to cope adequately with the increasing demand on the system.

Key words: health care utilization; endometrial cancer; prostate cancer; Hodgkin’s lymphoma; non-Hodgkin’s lymphoma; long-term survivors

The prevalence of cancer is rising. The increasing incidence of cancer in general, the aging of the population, and more effective treatment all contribute to this rapid increase.1 In addition, cancer is changing from a life-threatening disease into a chronic condition.2 A large number of cancer patients will therefore become long-term survivors: i.e., those alive 5 years after initial diagnosis.3 Cancer and its treatment can have a significant effect on a patient’s life during diagnosis and treatment but also years after treatment has been completed. Prostate cancer patients can experience permanent erectile dysfunction after prostatectomy (88%) or radiotherapy (64%).4 In addition, long-term Hodgkin lymphoma survivors experience a lower general and mental health and feel less vital compared to an age-matched normative sample.5 Finally, endometrial cancer survivors treated with surgery and adjuvant radiotherapy feel less vital compared to patients treated with surgery alone.6 The consequences of these effects on health care utilization of long-term cancer survivors have rarely been studied. It is known that long-term breast cancer survivors used more health care services compared to an age-matched female norm population.7 Furthermore, a large majority of breast cancer patients (23–26 months after diagnosis) required supportive care (e.g., psychologist, physiotherapist) but about one-third of patients were unable to access at least one of these services.8 Moreover, cancer survivors reported a greater need for mental health services than individuals without a history of cancer, especially those who were under the age of 65 and diagnosed at a younger age, were formerly married, or had other comorbid chronic conditions.9 The difference in health care utilization between long-term cancer survivors and the general population could not be attributed to the higher prevalence of common complaints. Cancer-related health issues might explain the increase in use of health care.10 Furthermore, 2 years after diagnosis, one-third of prostate cancer patients used complementary and alternative medicine; this could be predicted by the presence of comorbid diseases.11

We hypothesize health care utilization among long-term cancer survivors to be higher than among age and gender matched controls because of the late effects of cancer and its treatment. In addition, we expect that tumor type, stage, comorbidity, time since diagnosis and quality of life (QOL) indices predict health care utilization. Insight into the health care utilization of cancer patients is therefore essential for health care planning and may also reveal the need for specific care programs for cancer survivors. However, only a few studies on health care utilization of long-term cancer survivors exist. In the present study therefore self-reported health care utilization of cancer survivors are compared with those of the general population and predictors of health care utilization are identified.

Setting and participants

A population-based, cross-sectional survey was conducted at the Eindhoven Cancer Registry (ECR). The ECR records data on all patients newly diagnosed with cancer in the southern part of the Netherlands, an area with 2.3 million inhabitants, 10 hospitals, with 18 hospital locations and 2 large radiotherapy institutes.12 The ECR was used to select all patients diagnosed with prostate cancer or endometrial cancer between 1994 and 1998 and all patients diagnosed with Hodgkin’s lymphoma or non-Hodgkin’s lymphoma between 1989 and 1998. Participants older than 75 years at diagnosis were excluded as it was expected that they would have difficulty in completing a self-report questionnaire without assistance. To exclude all persons who had died before November 1, 2004, our database was linked to the database of the Central Bureau for Genealogy, which collects data on all deceased Dutch citizens via the civil municipal registries. After having excluded all persons who had died, data collection was started in November 2004. Approval for this study was obtained from a local certified Medical Ethics Committee.

Grant sponsors: Rotary Tilburg Triborch; the Regional Interzol Clinical Study Group for Heamato-Oncology; the Comprehensive Cancer Centre South.

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Received 22 November 2006: Accepted after revision 16 February 2007 DOI 10.1002/ijc.22739
Published online 6 April 2007 in Wiley InterScience (www.interscience.wiley.com).
Data collection

Medical specialists sent their (former) patients a letter to inform them about the study, together with the questionnaire. The letter explained that, by returning the completed questionnaire, the patient agreed to participate and consented to linkage of the questionnaire data with their disease history as registered in the ECR. Patients were reassured that nonparticipation would not have any consequences for their follow-up care or treatment. If the questionnaire was not returned within 2 months, a reminder-letter with an additional copy of the questionnaire was sent.

Measures

The ECR routinely collects data on tumor characteristics, including date of diagnosis, grade (Tumor-Node-Metastasis clinical classification13), clinical stage,11 treatment and patient background characteristics including date of birth and comorbidity at the time of diagnosis (a slightly adapted version of the Charlson comorbidity index13). The questionnaire also included questions on sociodemographic data, including marital status, current occupation, educational level as well as disease progression and current comorbidity.

The Dutch version of the SF-36 questionnaire was used to assess generic health related quality of life (HRQL).13 According to standard scoring procedures, all scales were linearly converted to a 0–100 scale, with higher scores indicating better functioning. The internal consistency and reliability of all scales was above the 0.70 criteria recommended for group comparisons. Only the 2 higher-order component scores for physical and mental health were used.

Generic HRQL survival issues were assessed with the validated Dutch version of the Quality of Life Cancer Survivors (QOL-CS) questionnaire,16,17 which included 45 visual analogue scales, each of which ranged from 0 (worst outcome) to 10 (best outcome). These 45 visual analogue scales were grouped into 4 multi-item subscales on well-being: physical, psychological, social and spiritual. They assess issues of particular concern to long-term cancer survivors such as distress, sexuality, employment, uncertainty about the future and the role of spirituality and religion.18 The QOL-CS has been demonstrated to be a valid and reliable instrument when administered to cancer survivors.16,17,19,20

This study was done in the Netherlands, a country in which every person has equal access to care. After treatment, patients go to their specialist for control visits for a number of years and this varies by site. Endometrial cancer survivors are followed up until 5 years after diagnosis. Prostate cancer patients are followed up until 10 years after diagnosis. Patients with Hodgkin’s and non-Hodgkin’s lymphoma are in follow up for at least 5 years. However, it is well accepted to keep non-Hodgkin and Hodgkin lymphoma survivors under specialist surveillance for a longer period of time (Dutch guidelines; http://www.oncoline.nl).

The items concerning health care utilization included questions on the number of visits to a general practitioner (e.g. primary care physicians), medical specialist (including those specialists involved in cancer care) and other health care professionals. These questions were asked in a similar way as is done via the annual monitoring of the health care situation of a random sample (N = ±10,000) of the Dutch population by Statistics Netherlands (http://statline.cbs.nl).

Statistical analyses

All statistical analyses were performed using SAS (version 9.1 for Windows, SAS Institute, Cary NC). Routinely collected data from the ECR on patient and tumor characteristics enabled us to compare the group of respondents, nonrespondents and patients with unverifiable addresses, using the $\chi^2$ test for categorical variables. Sociodemographic characteristics, clinical characteristics and HRQL scores of patients with different types of cancer are given in percentages. A number of these respondents were excluded from the primary analyses because they exhibited disease progression (95 new primary tumor, 114 metastasis and 164 recurrence), resulting in 1,231 patients to be analyzed.

The percentages of patients visiting a general practitioner or medical specialist in the past 12 months were compared to the percentage of people from the general population visiting these health care professionals. This comparison was made according to tumor type; for each tumor type, an age-matched reference group from the general population was formed. Percentages were compared using binominal distributions.

Based on the following question: “After cancer treatment, did you receive any additional care for cancer-related problems? If yes, please indicate the kind of additional care from the list below”, the health care utilization of groups of patients with different types of cancer were expressed in percentages.

Multivariate Logistic Regression analyses were carried out to analyze the association between patient (age, gender, comorbidity, marital status, educational level and HRQL) and tumor characteristics (type of tumor, stage at diagnosis, time since diagnosis and primary treatment) with health care utilization (the percentage of patients visiting a general practitioner or medical specialist in the past year and the percentage of patients visiting a psychologist or physiotherapist after cancer treatment). If the patient or tumor characteristics appeared to be statistically significant ($p < 0.1$) in univariate analysis, they were included in the multivariate analysis. The percentages of patients visiting, for example, a dietician, sexologist or oncology nurse were excluded from our analyses because of the small numbers of patients involved.

Results

One thousand five hundred and eleven (80%) of 1,893 patients returned a completed questionnaire (Fig. 1). A comparison of respondents, nonrespondents and patients with unverifiable addresses indicated that the nonrespondents were significantly older, more often diagnosed with stage I disease, more likely to have been treated with surgery and were less likely to have received chemotherapy than respondents (Table I).

Sociodemographic characteristics, clinical characteristics and HRQL of cancer survivors, according to type of tumor, are presented in Table II. Hodgkin’s and non-Hodgkin’s lymphoma survivors were more often diagnosed at a later stage compared to endometrial and prostate cancer survivors. Endometrial and prostate cancer survivors usually underwent surgery, while lymphoma survivors predominantly received radiotherapy and chemotherapy. Endometrial and prostate cancer survivors reported comorbidity more often, in particular hypertension and arthritis. The majority of patients were married, but endometrial cancer survivors were more often widows, they also had a lower educational level and were more often unemployed. Hodgkin’s lymphoma survivors were most often employed; prostate cancer survivors were most often retired. The latter also reported the highest HRQL (QOL-CS) and mental well-being (SF-36), whereas the Hodgkin’s lymphoma survivors had the lowest scores on both scales. They did however report the highest physical HRQL (SF-36).

Compared to the age-matched sample from the female norm population, endometrial cancer survivors visited their general practitioner somewhat more often (91 vs. 86%) and their medical specialist significantly more often (72 vs. 55%; $p < 0.05$) (Fig. 2). The percentage of prostate cancer patients who visited their general practitioner was higher (92 vs. 84%) but not significantly different from that of the general age-matched male population, whereas the percentage of prostate cancer patients who visited their medical specialist was significantly higher (94 vs. 62%; $p < 0.001$). The percentages of Hodgkin’s lymphoma survivors who visited their general practitioner (87 vs. 75%; $p < 0.05$) and medical specialist (90 vs. 40%; $p < 0.001$) in the past year were significantly higher compared to the age-matched sample from the norm population. Finally, the percentage of non-Hodgkin’s lymphoma survivors visiting the general practitioner was higher (86 vs. 79%)
but not significantly different compared to the age-matched norm population. Non-Hodgkin’s lymphoma survivors however visited their medical specialist more often in the past 12 months (88 vs. 51; \( p < 0.001 \)).

Cancer survivors, with little variation per tumor, only sporadically (0–3%) used the following additional care services after cancer treatment: dietician, sexologist, pastor, creative therapy, recovery program and oncology nurse (Table III). Additional support of a psychologist, physiotherapist and contact with other cancer survivors occurred somewhat more often. Lymphoma survivors consulted a psychologist most often (6–10% vs. 1–3%) and they also had more contact with other survivors (5–6% vs. 0–1%). Hodgkin’s lymphoma survivors visited a physical therapist the most (13% vs. 3–4%).

Factors predicting health care utilization are summarized in Table IV. If patients had 1 or more comorbid diseases, contact with a general practitioner (OR = 2.1; 95% CI = 1.3–3.2) and contact with a medical specialist (OR = 1.9; 95% CI = 1.2–3.0) was also almost doubled. Patients had contact with a medical specialist less often if they were diagnosed with endometrial cancer (OR = 0.2; 95% CI = 0.1–0.5), if they were diagnosed between 10–15 years ago (OR = 0.6; 95% CI = 0.1–0.5) and if they were not married or divorced (OR = 0.5; 95% CI = 0.3–0.9). Contact with a psychologist was clearly related to a high educational level.
None of the factors in our model predicted the frequency of visiting a physiotherapist.

**Discussion**

Cancer survivors visited their medical specialist significantly more often compared to the age- and gender-matched general Dutch population. Survivors only sporadically visited a dietician, sexologist, pastor, or required creative therapy, a recovery program or an oncology nurse. Additional support of a psychologist, physiotherapist and contact with other cancer survivors occurred somewhat more often.

Our results partly confirm the results of a Norwegian study among cancer survivors who were alive for 5 or more years after diagnosis. In that study, the use of specialist health care services was significantly higher among breast cancer survivors (49%) than among controls (27%). The difference in visiting a medical specialist remained, even 10 years after diagnosis, but the frequency of visiting a general practitioner normalized over time. In addition, previous findings of a Dutch study among 10-year breast cancer survivors partly confirmed our findings. The proportion of breast cancer survivors (79%) who visited a specialist in the past 12 months was significantly higher compared to controls (53%). However, no differences were found in the number of visits to a general practitioner.

In our study, the percentage of patients visiting a general practitioner was only significantly higher among Hodgkin’s lymphoma survivors, not patients with non-Hodgkin’s lymphoma, prostate cancer or endometrial cancer. In the general population, older persons visit their general practitioner more often compared to younger persons. This is mainly due to comorbidity. This could explain why we did not find a difference between the percentage of survivors and the normative population who visited their general practitioner in the past 12 months. The normative population did not have cancer but they probably had a number of other diseases for which they visited their general practitioner. We compared Hodgkin’s lymphoma survivors with a normative population of the same age. The individuals in the normative population were young and did not have comorbid diseases very often; they therefore did not visit their general practitioner often.

The high proportion of survivors who visited a medical specialist in the past 12 months compared to the norm population can partly be explained by routine annual follow-up examinations. For example, patients with Hodgkin’s and non-Hodgkin’s lymphoma are in follow up for at least 5 years (Dutch guidelines; www.oncoline.nl). However, most of them stay longer in follow-up.
especially patients with non-Hodgkin’s lymphoma. Additionally, prostate cancer patients visit their urologists until 10 years after diagnosis for annual follow-up. These follow-up examinations explain, at least in part, the higher proportion of survivors visiting a medical specialist compared to the general population.

Endometrial cancer survivors are only in follow-up until 5 years after diagnosis. This can explain why they visited a medical specialist less often compared to survivors with other tumors who are in follow-up trajectories for a longer period of time. However, between 5–10 years after diagnosis, endometrial cancer survivors visited their specialist more often compared to population controls; this cannot be explained by routine annual follow-up examinations as described in the guidelines (Dutch guidelines; www.oncoline.nl). This is partly confirmed by an American study among long-term cancer survivors. The medical costs for survivors proved to be much higher compared to the general population and these costs exceeded the expected costs for surveillance 6–10 years after initial diagnosis.21

Comorbidity was associated with more visits to a general practitioner or medical specialist. A previous study of our breast cancer research group also showed that comorbidity predicted visits to a general practitioner.7 However, in that particular study, visits to a medical specialist were not significantly related to the presence of comorbid diseases. Another Dutch study of individuals with at least one chronic disease also showed that comorbidity was closely associated with the volume and variety of health care services used.22 An American study among prostate cancer patients concluded that comorbidity predicted the use of complementary and alternative medicine.11

In our questionnaire, we asked patients whether they received any additional care for cancer-related problems after cancer treatment. Survivors only sporadically received additional support.

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**TABLE III – LONG-TERM CANCER SURVIVORS AND THEIR PERCENTAGE OF HEALTH CARE USE RELATED TO CANCER TYPE**

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Dietician</td>
<td>6 (2)</td>
<td>4 (1)</td>
<td>2 (2)</td>
<td>7 (3)</td>
<td>19 (2)</td>
</tr>
<tr>
<td>Psychologist</td>
<td>8 (3)</td>
<td>7 (1)</td>
<td>12 (10)</td>
<td>13 (6)</td>
<td>40 (3)</td>
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<tr>
<td>Sexologist</td>
<td>2 (1)</td>
<td>5 (1)</td>
<td>1 (1)</td>
<td>2 (1)</td>
<td>9 (1)</td>
</tr>
<tr>
<td>Pastoral care</td>
<td>2 (1)</td>
<td>2 (0)</td>
<td>0 (0)</td>
<td>3 (2)</td>
<td>7 (1)</td>
</tr>
<tr>
<td>Creative therapy</td>
<td>0 (0)</td>
<td>2 (0)</td>
<td>0 (0)</td>
<td>4 (2)</td>
<td>6 (1)</td>
</tr>
<tr>
<td>Recovery program</td>
<td>5 (2)</td>
<td>5 (1)</td>
<td>1 (1)</td>
<td>2 (1)</td>
<td>13 (1)</td>
</tr>
<tr>
<td>Oncology nurse</td>
<td>3 (1)</td>
<td>3 (0)</td>
<td>2 (2)</td>
<td>5 (2)</td>
<td>13 (1)</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>8 (3)</td>
<td>25 (4)</td>
<td>15 (13)</td>
<td>8 (4)</td>
<td>56 (5)</td>
</tr>
<tr>
<td>Contact with cancer survivors</td>
<td>1 (0)</td>
<td>6 (1)</td>
<td>7 (6)</td>
<td>10 (5)</td>
<td>24 (2)</td>
</tr>
</tbody>
</table>

Because of rounding errors, the numbers will not always add up to 100.
However, the survivors in our study were diagnosed and treated between 1989 and 1998. Additional care after cancer treatment was not common in those days. It would be interesting to ask the same question of patients diagnosed and treated in 2006 in order to estimate the increase in the percentage of survivors receiving additional care after cancer.

Additional care of a psychologist occurred somewhat more often. Hodgkin’s lymphoma survivors consulted a psychologist in 10% of cases while endometrial cancer, prostate cancer and non-Hodgkin’s lymphoma survivors visited a psychologist in 1–6% of cases. This effect could partly be explained by education. In our study, Hodgkin’s lymphoma survivors had the highest educational level and survivors with a high educational level visited a psychologist 3.6 times more often compared to patients with a low educational level. A Canadian study on the use of supportive care services by women with breast cancer (N = 1659) reported that 5% of women visited a psychologist. In addition, an American study reported that cancer survivors contacted a mental health provider in 7% of cases. In our study, the percentage of patients who visited a psychologist was positively related to a higher educational level. To our knowledge, this effect has not been described before for cancer patients. However, a higher educational level predicted the use of complementary and alternative medicine among cancer patients, and it also predicted the use of cancer support services in an American study.

Several limitations of the current study should be noted. First, only 15% of patients could not be sent a questionnaire because of unverifiable addresses and 20% of patients who were sent a questionnaire did not respond, so we do not know what their current health status is. Nonrespondents were significantly older, more often diagnosed with stage I disease, and more likely to have undergone surgery and less likely to have received chemotherapy than respondents or patients with unverifiable addresses. It is therefore possible that our results cannot be generalized to very old patients, patients diagnosed with stage I disease and patients treated with surgery or chemotherapy. Second, it is more difficult to draw conclusions from a cross-sectional study than a longitudinal study. No conclusions can be drawn on the nature and direction of the relationships. Since we only included disease-free survivors in our analyses, we cannot generalize the results of our study to those who have disease progression.
Despite these limitations, the results of this study form an important contribution to the limited information available on health care utilization in the growing group of long-term cancer survivors. This study included an unselected group of cancer patients, treated in various general hospitals, and not in centers of excellence or tertiary referral centers in contrast to most randomized trials. Results of a population-based study can more easily be generalized to the general population compared to results of randomized controlled trials. In addition, the large number of participants in this study and the high response rate of this study allow us to extrapolate to the broad population of long-term cancer survivors without disease progression.

Our study provided insight into health care utilization of long-term cancer patients. Given the fact that long-term cancer survivors visit their medical specialist more often than the general Dutch population, our findings may have implications for health care planning in the near future. In the Netherlands, the 20-year prevalence of cancer was estimated to be 386,000 in 2000, of whom 188,000 cancer patients survived more than 5 years after diagnosis. The Dutch Cancer Society predicts that the 20-year prevalence will increase to 692,000 in 2015, of whom 337,000 patients have survived cancer more than 5 years. This almost doubling of long-term survivors will have a major impact on health care planning activities, specifically for follow-up care visits. Changes in health care, such as less administrative work for the specialist and more efficiency, are probably necessary to cope adequately with this increasing demand on the system. Furthermore, studies are being performed to change the standard aftercare programs, which are identical for all patients, into “tailor-made” care programs. This could also alter the demand on the medical specialist.

Acknowledgements

The authors want to thank all the patients for their participation in the study.