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Arts, Lindy; Oerlemans, Simone; Tick, Lidwine; Koster, Ad; Roerdink, Henk T. J.; van de Poll-Franse, L.V.

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More Frequent Use of Health Care Services Among Distressed Compared With Nondistressed Survivors of Lymphoma and Chronic Lymphocytic Leukemia: Results From the Population-Based PROFILES Registry

Lindy P. J. Arts, MSc; Simone Oerlemans, PhD; Lidwine Tick, MD, PhD; Ad Koster, MD; Henk T. J. Roerdink, MD; and Lonneke V. van de Poll-Franse, PhD

BACKGROUND: Follow-up care for a growing population of survivors of lymphoma and chronic lymphocytic leukemia (CLL) together with the adverse effects these survivors may experience as a result of their cancer and treatment have led to more pressure being placed on health care services. The objectives of the current study were to: 1) compare the use of medical care services by survivors with that of a normative population; 2) evaluate the use of medical and psychosocial care services among distressed and nondistressed survivors; and 3) identify associated sociodemographic and clinical factors. METHODS: Survivors of lymphoma and CLL diagnosed between 1999 and 2012 were selected via the population-based Netherlands Cancer Registry and completed the Hospital Anxiety and Depression Scale questionnaire and questions regarding health care. Outcomes were compared with an age-matched and sex-matched normative population. RESULTS: A total of 1444 survivors responded (69%). Survivors of lymphoma and CLL contacted their general practitioner (3.8 vs 2.3; \( P < 0.001 \)) and medical specialist (5.7 vs 1.6; \( P < 0.001 \)) more often within the last year compared with a normative population. In addition, psychologically distressed survivors had even more medical contacts and received psychosocial care more often compared with nondistressed survivors. In addition to psychological distress, comorbidity, female sex, and older age were found to be associated with a greater use of medical services, whereas younger age was associated with receiving psychosocial care. CONCLUSIONS: Survivors of lymphoma and CLL, especially those who are psychologically distressed, report an increased use of health care services compared with a normative population. Further studies are needed to explore whether the use of widely applicable psychosocial interventions could reduce the frequency of medical contacts. Cancer 2018;124:3016-24. © 2018 Netherlands Comprehensive Cancer Organisation. Cancer published by Wiley Periodicals, Inc. on behalf of American Cancer Society. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

KEYWORDS: chronic lymphocytic leukemia (CLL), health care use, lymphoma, medical contacts, psychological distress, psychosocial care, survivors.

INTRODUCTION

Due to advances in the treatment of lymphoma and chronic lymphocytic leukemia (CLL), a rising incidence, and aging of the population, the number of patients who are living with a history of lymphoma or CLL continues to grow. It is expected that in 2020 there will be approximately 40,000 patients in the Netherlands who either are cured of their lymphoma or are living with it as a chronic disease, an increase of approximately 65% compared with 2010. As a result of the disease and its treatment, survivors of lymphoma and CLL are at risk of experiencing adverse physical and psychosocial effects such as second malignancies, neuropathy, persistent fatigue, cognitive impairment, and psychological distress. Therefore, regular follow-up care with monitoring of long-term and late adverse effects is extremely important. Follow-up care for a growing population of survivors of lymphoma and CLL together with the various adverse effects that these survivors may experience has resulted in more pressure being placed on health care services.

Corresponding author: Lindy P.J. Arts, MSc, Department of Research, Netherlands Comprehensive Cancer Organisation, PO Box 19079, 3501 DB Utrecht, the Netherlands; larts@ioknl.nl

1Department of Research, Netherlands Comprehensive Cancer Organisation, Utrecht, the Netherlands; 2Department of Medical and Clinical Psychology, Center of Research on Psychology in Somatic Diseases (CoRPS), Tilburg University, Tilburg, the Netherlands; 3Department of Internal Medicine, Maxima Medical Centre, Eindhoven and Veldhoven, the Netherlands; 4Department of Internal Medicine, VieCuri Medical Centre, Venlo and Venray, the Netherlands; 5Department of Internal Medicine, Elisabeth-TweeSteden Hospital, Tilburg, the Netherlands; 6Division of Psychosocial Research and Epidemiology, Netherlands Cancer Institute, Amsterdam, the Netherlands

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Psychological distress is a significant psychosocial issue for at least 25% of patients with lymphoma and CLL. Psychological distress includes persistent levels of anxiety, depressive feelings, and fears, and has a great impact on a patient’s daily life. Some patients experience psychological distress as somatic symptoms such as headaches, sleeping problems, and gastrointestinal symptoms and seek medical help for these issues. Research has suggested that patients with a background of psychological problems contact their general practitioner (GP) nearly twice as often for both psychological and somatic symptoms compared with patients without a background of psychological problems.

Evidence has demonstrated that integrated psychosocial care, which combines psychological screening and psychological interventions, is an effective means of treating psychological distress. However, psychosocial care appears to be suboptimal. Although patients with high levels of distress are more likely to receive psychosocial care, nearly one-half of distressed cancer survivors did not.

To our knowledge, the association between psychological distress and the use of medical and psychosocial care services rarely has been studied among survivors of lymphoma and CLL. Insights regarding this association will provide information concerning the potential value of screening for psychological distress and the use of psychosocial interventions in the care of patients with lymphoma. Therefore, the objectives of the current study were to: 1) compare the use of medical care services by survivors with that of a normative population without cancer; 2) evaluate the use of medical and psychosocial care services among distressed and nondistressed survivors of lymphoma and CLL; and 3) identify factors that are associated with the use of medical and psychosocial care services among survivors of lymphoma and CLL. We hypothesized that survivors of lymphoma and CLL overall have more medical contacts compared with a normative population without cancer, and that distressed survivors have more medical contacts and receive more psychosocial care than nondistressed survivors. Furthermore, based on the model of health services use of Andersen and Newman, we hypothesized that not only psychological distress, but also individual sociodemographic and clinical factors such as age, sex, educational level, cancer type, treatment, and comorbidity, are associated with the use of health care.

**MATERIALS AND METHODS**

**Setting and Population**

Data from the Eindhoven area of the population-based Netherlands Cancer Registry were used to select patients with a diagnosis of Hodgkin lymphoma, non-Hodgkin lymphoma, and CLL between January 1999 and May 2012. Only patients aged ≥18 years at the time of diagnosis were included. Patients who had died, were in transition to terminal care, or who had serious cognitive impairment (ie, dementia) were excluded. We used the term “survivor” to include all living individuals who ever received a diagnosis of lymphoma or CLL. Ethical approval for the study was obtained from a certified Medical Ethics Committee of the Maxima Medical Centre (Veldhoven, the Netherlands; 0734).

**Study Measures**

Two open questions were asked to assess the use of medical care services: 1) “How often did you contact a GP in the past 12 months?” and 2) “How often did you visit a medical specialist in the past 12 months?”. Patients also were asked whether they received care after their cancer treatment (no/yes). If they answered yes, patients could choose multiple additional care services from a list. Psychosocial care was defined as receiving care from a psychologist, social worker, oncological rehabilitation, or oncology nurse.

The 14-item Hospital Anxiety and Depression Scale (HADS) was used to assess psychological distress. The scale consists of two 7-item joined subscales: the HADS-Anxiety and HADS-Depression. Items were scored on a 4-point scale. A sum score was obtained by adding all items, with a higher score indicating more distress. Survivors with a HADS score ≥13 were categorized as being “distressed.”

Comorbidity at the time of the survey was categorized according to the adapted Self-Administered Comorbidity Questionnaire. Patients were asked to identify comorbid conditions present within the past 12 months. Positive responses were summed to obtain a total score (range, 0-13).

Sociodemographic characteristics and clinical information were available from the Netherlands Cancer Registry, which routinely collects data regarding patient age and sex, date of cancer diagnosis, cancer type, and treatment. Information concerning marital status, educational level, and employment status was assessed in the questionnaire.

**Data Collection**

Data were collected within Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship (PROFILES). Details regarding the data collection method have been described previously. In May 2009, patients diagnosed between January 1999 and
January 2009 were included in the study and received the first questionnaire. In November 2009, May 2011, May 2012, and May 2013, patients newly diagnosed up to June 1, 2012, subsequently were invited to participate and all completed a baseline questionnaire.

**Normative Population**

Data regarding a normative population were obtained from CentERpanel, an online household panel that is representative of the Dutch population. The process of the annual collection of data, which was initiated in 2009 by our study group, has been described elsewhere.\(^3^5\) Data collected in 2011 included the assessment of health care use. From this normative population, an age-matched and sex-matched selection was made to compare health care use with that of survivors of lymphoma and CLL. For matching, 14 strata were formed using sex and age (7 categories). Within each stratum, a maximum number of individuals from the reference cohort randomly were matched according to the strata frequency distribution of the patients. This resulted in 563 matched cancer-free individuals for the 1444 survivors of lymphoma and CLL who completed the baseline questionnaire.

**Statistical Analyses**

All comparisons of the number of medical contacts were adjusted for age, sex, and comorbidity. Continuous variables were compared using analysis of variance and categorical data were compared using chi-square tests. Multivariable logistic regression analyses were performed to investigate the independent association between sociodemographic, clinical, and psychological variables and health care use. Statistical significance was set at \(P < .05\) and analyses were performed using SAS statistical software (version 9.4; SAS Institute Inc, Cary, North Carolina).

| TABLE 1. Sociodemographic and Clinical Characteristics of 1444 Questionnaire Respondents, Nonrespondents, and Patients With Unverifiable Addresses and of an Age-Matched and Sex-Matched Normative Population (\(N = 563\)) |
|---|---|---|---|---|
| Characteristics | Respondents \(N = 1444\) | Nonrespondents \(N = 381\) | Patients With Unverifiable Addresses \(N = 276\) | Normative Population \(N = 563\) |
| No. (%) | No. (%) | No. (%) | No. (%) |
| Sex | | | | |
| Male | 870 (60) | 223 (59) | 159 (58) | 341 (61) |
| Female | 574 (40) | 158 (41) | 117 (42) | 222 (39) |
| Mean age at time of survey (SD), y | 62.0 (14.5) | 61.9 (16.6) | 55.9 (16.8)* | 62.0 (14.6) |
| Mean y since diagnosis (SD) | 3.3 (2.5) | 2.6 (2.8)* | 3.4 (2.9) | |
| Tumor type | | | | |
| HL | 210 (15) | 61 (16) | 64 (23)* | |
| NHL-HG | 554 (38) | 116 (30)* | 92 (33) | |
| NHL-LG | 454 (31) | 126 (33) | 78 (28) | |
| CLL | 226 (16) | 78 (21) | 42 (15) | |
| Primary treatment | | | | |
| Active surveillance | 340 (24) | 125 (33)* | 78 (28) | |
| Systemic therapy | 644 (45) | 148 (39)* | 124 (45) | |
| RT | 97 (7) | 25 (6) | 16 (6) | |
| Chemotherapy and RT | 248 (17) | 64 (17) | 52 (19) | |
| Missing data | 115 (8) | 19 (5) | 6 (2) | |
| Self-reported comorbidity | | | | |
| No comorbid condition | 652 (45) | | 228 (41) | |
| 1 comorbid condition | 371 (26) | | 177 (31)* | |
| ≥ 2 comorbid conditions | 346 (24) | | 158 (28) | |
| Missing data | 75 (5) | | 0 (0)* | |
| Most frequent comorbid conditions | | | | |
| Hypertension | 223 (16) | | 173 (31)* | |
| Arthritis | 252 (18) | | 118 (21) | |
| Educational levelc | | | | |
| Low | 286 (21) | | 22 (4)* | |
| Medium | 804 (59) | | 313 (56) | |
| High | 273 (20) | | 228 (41)* | |
| Partner (yes) | 1096 (77) | | 395 (70)* | |

Abbreviations: CLL, chronic lymphocytic leukemia; HL, Hodgkin lymphoma; NHL-HG, high-grade non-Hodgkin lymphoma; NHL-LG, low-grade non-Hodgkin lymphoma; RT, radiotherapy; SD, standard deviation.

*Significantly different from respondents \((P < .01)\).

b Significantly different from respondents \((P < .05)\).

* For educational levels, low indicates none/primary school; medium, lower general secondary education/vocational training; and high, pre-university education/high-level vocational training/university.
RESULTS

Study Sample

Of the 2101 survivors of lymphoma and CLL who were invited to participate, 1444 completed the questionnaire (69%). Respondents on average were older compared with nonresponding survivors with unverifiable addresses ($P<.01$). Furthermore, respondents were further from diagnosis compared with nonrespondents ($P<.01$) (Table 1).

The mean age at the time of completion of the questionnaire was 62.0 years, with a mean time since diagnosis of 3.3 years. Approximately 60% of respondents were male. Systemic therapy was the most frequent primary treatment (45%) (Table 1). Approximately 50% of survivors of lymphoma and CLL reported $\geq$1 comorbid conditions, with the most common being arthritis and hypertension. Approximately 26% of the survivors reported being psychologically distressed.

The mean age of the age-matched and sex-matched normative population at the time of completion of the questionnaire was 62.0 years. Approximately 61% were male. Nearly 6 of every 10 respondents (59%) reported $\geq$1 comorbid conditions, with the most common being...
hypertension and arthritis (Table 1). Compared with the survivors, the normative population more often had a higher educational level (20% vs 41%; \( P \leq .001 \)) and less often had a partner (77% vs 70%; \( P = .001 \)).

**Use of Medical and Psychosocial Care Services**

Approximately 89% of all survivors of lymphoma and CLL reported having contacted a GP at least once within the last 12 months, with 4 contacts on average. Compared with an age-matched and sex-matched normative population, survivors of lymphoma and CLL contacted their GP more often (3.8 times vs 2.3 times within the last 12 months, respectively; \( P < .001 \)). No differences in the number of GP contacts between male and female survivors were observed. The average number of GP contacts was highest within the first year after diagnosis compared with the other time periods (\( P = .002 \)) (Fig. 1 Top). Distressed survivors contacted their GP more often than nondistressed survivors (5.2 contacts vs 3.3 contacts, respectively; \( P \leq .001 \)).

Approximately 98% of all survivors of lymphoma and CLL reported having contacted a medical specialist at least once within the last 12 months. Survivors contacted their medical specialist more often compared with an age-matched and sex-matched normative population (5.7 contacts vs 1.6 contacts; \( P < .001 \)). Male survivors contacted their medical specialist more often compared with female survivors (6.0 contacts vs 5.1 contacts; \( P = .004 \)). Survivors of lymphoma and CLL were found to have contacted their medical specialist most often within the first year after diagnosis, with on average 7 contacts. Between 2 to 4 years, 5 to 7 years, and 8 to 10 years after diagnosis, the average number of contacts with the medical specialist decreased to 5.7 contacts, 4.2 contacts, and 4.1 contacts, respectively. At all time points, distressed survivors contacted their medical specialist more often than survivors who were not distressed (Fig. 1 Bottom).

Approximately 22% of all survivors of lymphoma and CLL reported that they received psychosocial care after treatment. The percentage of distressed survivors who received psychosocial care was significantly higher compared with survivors without psychological distress (32% vs 19%; \( P \leq .001 \)). Survivors aged \( \leq 35 \) years (adolescents and young adults) received psychosocial care more often compared with survivors aged \( > 35 \) years (42% vs 20%; \( P \leq .001 \)), although they reported being distressed somewhat less often compared with older survivors (Fig. 2).

**Factors Associated With the Use of Psychosocial and Medical Care Services**

Multivariable logistic regression analyses showed that survivors who received psychosocial care after treatment were more likely to be psychologically distressed. Receiving psychosocial care also was found to be associated with being female and of a younger age at the time of questionnaire completion. Furthermore, receiving psychosocial care was associated with having multiple comorbidities and treatment with systemic therapy (Table 2).

Survivors of lymphoma and CLL who visited a GP \( \geq 3 \) times within the last 12 months (median split) were more likely to have psychological distress. In addition, visiting a GP \( \geq 3 \) times was found to be associated with being female, of older age, and reporting \( \geq 1 \) comorbid
conditions. Furthermore, visiting a GP \(\geq 3\) times was associated with a more recent diagnosis. Survivors who visited their medical specialist \(\geq 4\) times within the last 12 months (median split) were found to be more likely to have psychological distress. Visiting a medical specialist \(\geq 4\) times also was associated with a more recent diagnosis and reporting more comorbid conditions. In addition, survivors who visited their medical specialist \(\geq 4\) times were less likely to be diagnosed with Hodgkin lymphoma.

**DISCUSSION**

Survivors of lymphoma and CLL contacted both a GP and medical specialist more frequently compared with an age-matched and sex-matched normative population without cancer, which is in keeping with our hypothesis. Survivors who reported being psychologically distressed contacted a GP and medical specialist even more often. In addition to psychological distress, comorbidity, female sex, and older age were found to be associated with more frequent medical contacts, whereas younger age was associated with receiving psychosocial care.

Previous findings of our group demonstrated that the frequency of contacts with both a GP and medical specialist was higher among long-term cancer survivors compared with a normative population.\(^{36}\) These results also correspond with findings from studies among specific cancer groups that reported the more frequent use of health care services for cancer survivors.\(^{37-40}\) The difference between cancer survivors and the normative population with regard to the number of contacts with a medical specialist persisted, even 10 years after diagnosis. However, the number of GP contacts normalized over time, which is in keeping with previous studies.\(^{36,39}\) The higher number of contacts with a medical specialist observed among survivors of lymphoma and CLL can be explained by follow-up appointments as advised in the Dutch guidelines for the treatment of patients with lymphoma (available at http://www.hovon.nl/).

The current study findings that survivors who were psychologically distressed had more frequent medical
contacts compared with nondistressed survivors correspond with previous results demonstrating that patients with cancer and psychological problems contacted a health care professional more frequently than patients without psychological problems.21,23,41 Psychological problems that arise from or are aggravated by cancer might cause additional suffering, resulting in more frequent medical contacts. Adequate recognition and treatment of psychological distress might help in reducing the frequency of medical contacts among distressed survivors.18 Psychosocial care should be considered to be an integral and standardized part of cancer care.42 However, some health care professionals believe that psychosocial care is too costly to be part of standard cancer care,43 although to the best of our knowledge one study found that minimal psychosocial interventions may increase a patient’s quality of life and reduce overall health care expenditures.44 Many survivors are faced with psychosocial issues, and they may not receive the support they need. It is important to learn what support might benefit survivors of lymphoma and CLL.45 The results of the current study demonstrated that patients who are psychologically distressed more often reported having received psychosocial care after treatment compared with nondistressed survivors, which is positive. Conversely, fewer than 1 in every 3 distressed survivors of lymphoma and CLL received psychosocial care. Therefore, although information is lacking regarding the percentage of patients who refused psychosocial care when offered, potentially many more survivors could have benefitted from it. It is possible that survivors are unwilling to ask their GP or medical specialist for help with psychosocial concerns because they believe it is not the physician’s role to help with such problems.46 Moreover, survivors may normalize or somatize their psychological distress, and consequently psychological distress may be underrecognized and undertreated.47 Screening tools for psychological distress can be useful for its better recognition. In addition, providing feedback to survivors on their patient-reported outcomes can help them to monitor their functioning and symptoms and may help to empower them to discuss their symptoms with a GP or medical specialist.48

Because survivors with psychological distress may be unwilling to visit a mental health care professional, it is important to offer help in a way that is acceptable to them, without increasing the overall use of resources. In addition, the treatment of psychological distress has to be widely applicable because the number of distressed survivors continues to grow.7 In the current study, approximately 22% of survivors of lymphoma and CLL reported that they received psychosocial care after treatment. This does not correspond with the results of an American study by Hewitt and Rowland that reported that survivors of various cancer types contacted a mental health provider in only approximately 7% of cases.49 However, this could be due to different definitions. Hewitt and Rowland defined mental health care as talking to a psychiatrist, psychologist, psychiatric nurse, or social worker.49 In the current study, we also included oncology nurses as providers of psychosocial care because they appeared to be the ones who detect psychosocial concerns in patients.50 Furthermore, previous studies have indicated that the use of psychosocial care services among cancer survivors was somewhat higher compared with in a population without cancer.49,51 We could not relate these findings to the current study data because data regarding psychosocial care in the normative population were missing.

According to the Andersen and Newman model of health services use,27 not only psychological distress is associated with the use of health care services, but also individual sociodemographic and clinical factors. In the current study, comorbidity and a more recent diagnosis were found to be associated with more medical contacts. This corresponds to the findings of a previous Dutch study that also demonstrated a strong association between comorbidity and the volume and variety of health care services used.52 It also was reported previously that the frequency of medical visits is highest within the first year after diagnosis.38,39

The use of psychosocial care services is greater among younger survivors, females, those with ≥2 comorbid conditions, and those who received systemic therapy. Raphael et al found that younger age was an indicator of increased distress,45 which might explain the greater use of psychosocial care services noted among younger survivors herein. Furthermore, the results of the current study correspond to those of a study that observed a greater use of psychosocial care services among younger survivors, those with more comorbid conditions, and those with psychological problems.49 Another study also reported that older age was associated with a lower likelihood of being referred for psychosocial care regardless of the level of psychological distress and provided some possible explanations.53 It could be that physicians tend to perceive older survivors as less likely to need or to derive benefit from psychosocial care, or that physicians may underestimate the needs of older cancer survivors. More attention should be paid to older survivors with psychological problems because psychosocial care use in this group appears to be suboptimal.
The current study has a few limitations. Although information was available regarding the sociodemographic and clinical variables of the nonrespondents and patients with unverifiable addresses, it remains unknown why nonrespondents declined to participate in the study. In addition, the cross-sectional design of the current study limited the determination of causal associations between the study variables. The strengths of the study are its population-based sampling frame, the high response rate, and the large range in time since diagnosis. This facilitates the extrapolation of the results to a broad range of survivors of lymphoma.

Survivors of lymphoma and CLL, especially those who report psychological distress, demonstrate an increased use of health care services compared with a normative population without cancer. Further studies are needed to explore whether the use of widely applicable psychosocial interventions could reduce the frequency of medical contacts among distressed survivors and improve their quality of life.

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CONFLICT OF INTEREST DISCLOSURES
The authors made no disclosures.

AUTHOR CONTRIBUTIONS
Lindy P.J. Arts was responsible for data analysis and drafting the article. Simone Oerlemans was responsible for patient recruitment and data collection and was a major contributor to drafting the article. Lidwine Tick, Ad Koster, and Henk T.J. Roerdink were responsible for data collection and contributed to writing the article. Lonneke Tick, van de Poll-Franse was project leader and was a major contributor to drafting the article. All authors read and approved the final article.

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