


# Management of lymphoma survivor patients in Italy: an evaluation by Fondazione Italiana Linfomi

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## Abstract

Several outpatient models for the follow-up of cancer survivors have been developed worldwide. A multidisciplinary approach is often necessary to guarantee the best monitoring of long-term toxicities. Guidelines also indicate a close education on healthy lifestyles. In this context, we have analyzed the Italian follow-up modalities of lymphoma survivors, with the aim to have a starting line to hypothesize and plan the best model for Italian hematology centers.

## Keywords

Lymphoma, cancer survivor, epidemiology and prevention

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## Introduction

A multidisciplinary approach is desirable for lymphoma survivors' follow-up, to manage the treatment-related toxicities and late side effects, from the best known to emerging ones, and to train patients in healthy lifestyle behaviors.<sup>1,2</sup>

In this context, several outpatient models have been developed. The most organized models exist in the United States, where survivors can be evaluated in cancer survivorship clinics. Different models are present, such as multidisciplinary survivorship clinics, which provide a specialized team and are mainly dedicated to pediatric cancer and adolescent/young adult survivors; disease/treatment-specific survivor clinics, which are managed by experts in one particular area, e.g. breast cancer or colorectal cancer; and general survivorship clinics, providing survivorship services for a broad spectrum of diseases.<sup>3</sup> The National Comprehensive Cancer Network and American Cancer Society guidelines recommend the development of a survivorship care plan (SCP) individualized for each patient and including indications for monitoring and maintaining patient health.<sup>4</sup> The most relevant experience on survivorship was mainly developed in patients with breast cancer and childhood acute lymphoblastic leukemia, while in recent years, interest in these aspects on lymphomas is rising. The application of SCPs to lymphoma patients has

been reviewed at the Cancer Clinic of Mayo Clinic–Rochester Hospital. From November 2013 to May 2015, a SCP focusing on improving lifestyle habits (healthy diet and physical exercise) was tested in 96 patients in comparison to controls, revealing that those who attended the program had better self-reported overall health, mostly among younger patients.<sup>5</sup> Few experiences of nurse-led lymphoma survivorship clinics, with tailored SCPs, have been reported for lymphoma survivors.<sup>6,7</sup> Some other

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models of cancer-free programs have been developed in the main oncologic and research centers worldwide. Emerging experiences suggest that educational interventions to promote healthy lifestyles could also be conducted by participating in e-health models.<sup>8,9</sup> In addition, international guidelines recommend a close coordination of care between primary care providers (PCPs) and specialists, with the aim of ensuring that all survivors' health needs are met.

In Italy, there is a growing number of outpatient cancer-free programs addressed to lymphoma survivors, starting in the 1990s at the Centro di Riferimento Oncologico in Aviano and the Humanitas Research Hospital in Milan. It is not known how the follow-up of lymphoma survivors is organized in the Italian hematology centers and which disciplines are involved. Only by the knowledge of the real-time situation, it will be possible to homogenize and improve health care for the growing number of Italian lymphoma survivors.

Within the Fondazione Italiana Linfomi (FIL), we have conducted an analysis focused on the current follow-up modalities of lymphoma survivors, with the aim to hypothesize the best applicable model for care and research in Italy.

## Methods

From November 2018 to January 2019, the FIL launched an online email survey among its affiliated centers ( $n = 154$ ). The survey included 4 short questions about the clinical practice on lymphoma survivors' management. Questionnaires referred to classical Hodgkin lymphoma and diffuse large B-cell lymphoma in continuous complete remission. Physicians were asked about the following: 1) the length of follow-up: up to 5 years from the end of the antineoplastic treatments (chemotherapy and/or radiotherapy), up to 10 years, or to more than 10 years; 2) the existence of an outpatient program dedicated to lymphoma survivors; 3) the possibility to perform a multidisciplinary approach; and 4) the existence of a research program tailored on survivorship. The questions were established by a panel of experts belonging to the scientific committee "Lymphoma survivors, comorbidity and quality of life" of FIL and reviewed by 2 methodologists of Istituto di Ricerche Farmacologiche Mario Negri IRCCS in Milan. The survey had been presented previously during the national FIL meeting in early November 2018. The obtained responses have been collected in a dedicated database. Statistical analyses were performed using MedCalc software for Macintosh (MedCalc Software, Ostend, Belgium). A descriptive analysis was used for sample description and frequencies.

## Results

A total of 58 hematology centers took part in the survey. These centers were distributed over the Italian region and

included 38 hematology centers with or without a bone marrow transplant unit, 13 hematologic academic centers, and 7 national research centers in oncology (IRCCS).

The majority of centers (79.3%) continue to follow patients beyond the 5th year of remission (34.5% until the 10th year and 44.8% beyond the 10th year); 20.7% address the patient to the primary care physician (Figure 1).

A total of 23 centers (39.7%) have an outpatient program specifically addressed to lymphoma survivors. It consists exclusively of onco-hematologic evaluation for 39.1% of centers and of a multidisciplinary approach for the remainder (60.9%). A dedicated program was present in 31.5% of hematology centers, 46.1% of academic centers, and 75% of IRCCS. The provided assessment includes the following disciplines: cardiology (56.5%), endocrinology (30.4%), gynecology (21.7%), psychology (21.7%), nutrition (17.3%), neurology (17.3%), radiotherapy (17.3%), pneumology (13%), radiology (8.6%), and internal medicine, ophthalmology, orthopedics, and physiatry (4.3% each). Five centers (21.7%) offer 1 or 2 specialist evaluations other than onco-hematologic and 9 centers (39.1%) offer more than 3.

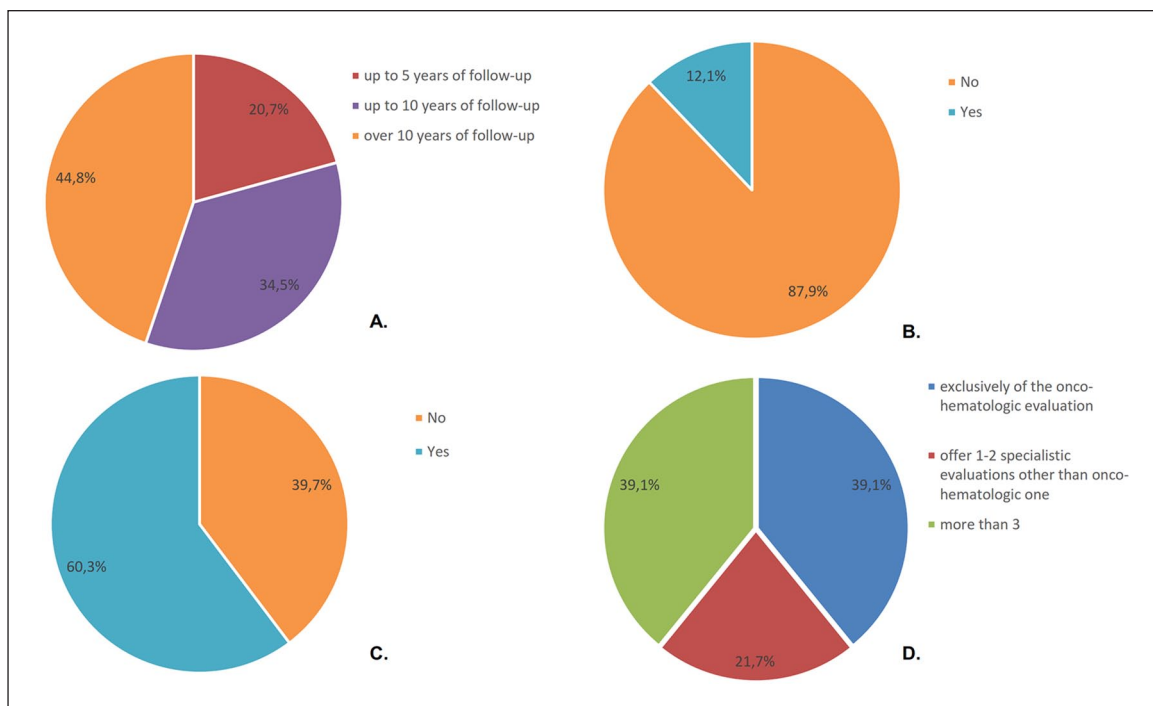
A total of 7 centers out of 58 (12%) are involved in research activities on survivorship. Clinical research has been conducted by 5.2% of hematology centers, 23% of academic centers, and 37.5% of IRCCS.

## Discussion

This work was born within the FIL from the need to have a better knowledge of the Italian situation on the care and research approach to lymphoma survivors. The model of the survey applied in this study presents limitations as well as advantages. Through specific questions formulated by a panel of experts and reviewed by 2 methodologists, it allowed reaching the national territory in 3 months' time and answering the initial proposal of the study. Even with the limitation that not all the questioned centers joined the survey, the obtained results are representative of the Italian situation.

The number of hematology centers that offer a dedicated outpatient program for lymphoma survivors is not high, but the interest of hematologists in this topic is increasing. In centers where the outpatient program is well-structured, the patient receives a multidisciplinary approach, including mostly cardiologic, nutritional, and gynecologic (for fertility) evaluations.

This information represents a starting point to hypothesize a clinical model that allows offering the best follow-up in the long-term period and could reflect the organization capabilities of both territorial and hub hospitals in Italy. A model including the mentioned disciplines (cardiology, nutrition, and gynecology in close contact with the hematologist) could be applicable within the hematologic centers of the FIL. This model could be expanded including other complementary figures, e.g. PCPs and dedicated nurses.



**Figure 1.** Follow-up modalities of lymphoma survivors in 58 Italian hematology centers of the Fondazione Italiana Linfomi: (A) length of follow-up; (B) involvement in research projects on survivorship; (C) availability of a multidisciplinary approach; (D) multidisciplinary assessments provided.

PCPs could play a role of great importance in the field of cancer survivors in Italy, but the definition of specific competences needs to be better determined. Some American models suggest that the follow-up of cancer survivors, not specifically referred to lymphoma survivors, could be guided by an adapted risk model, in which patients considered at low risk for the characteristics of the disease, complexity of antineoplastic treatments, and comorbidities could benefit from primary care-based follow-up; intermediate-risk patients by both oncologists and PCPs; and high-risk patients by oncologists with expertise in survivorship.<sup>3,10</sup> A nurse-led approach could also be considered.

The creation of cancer survivorship clinics is far from the Italian health organization, but perhaps it will be structured in the future, considering the growing numbers of cancer survivors in Italy, which in 2010 reached 2,587,347 people.<sup>2,9,11</sup> It is realistic to potentiate the existing multidisciplinary models and expand them to the remaining main Italian hospitals. This process needs the presence of a dedicated onco-hematologist with expertise in survivorship, who will become the reference figure for the outpatient program and will involve all the other complementary physicians. This will require reorganization, which will not need increased resources but mainly education and integration among existing figures.

Both care of and research on lymphoma survivors in Italy emerges from an educational path, which was started several years ago by FIL researchers, members of the

dedicated committee mentioned above. In this context, national congresses among researchers, multidisciplinary meetings, and meetings involving PCPs and patients are organized annually. Furthermore, clinical research projects are ongoing, with the aim to homogenize the follow-up of classical Hodgkin lymphoma and diffuse large B-cell lymphoma and the management of long-term toxicities, and to increase the knowledge of and education on healthy lifestyles. An additional goal for FIL will be to create SCPs meeting Italian patients' needs and including follow-up and healthy behaviors training.

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