

Research Article

Follow-up of lymphoma Survivors: A Role for the Nurse Navigator in Improving Quality of Life

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Editorial

The prognosis of non-Hodgkin and Hodgkin lymphoma (NHL and HL, respectively) has dramatically improved in the last two decades due to the remarkable efficacy of chemotherapy, namely the ABVD / BEACOPP and RCHOP21 / RCHOP14 regimens for HL and NHL, respectively [1,2]. With the notable exception of aggressive forms or particular subtypes such as T-cell-derived NHL (10% of cases), the response rate is between 70% and 90%, with a relapse rate between 10% and 20% [1,2]. Thus, following chemotherapy, most lymphoma patients enter the phase of “cancer survivorship” for a prolonged period of time, with follow-up being generally discontinued after 5 years. During this phase, although the disease is under control and potentially cured, some patients experience a wide variety of physical and mental disorders and/or are confronted with socio-professional difficulties, especially in the first two years. For example, we and others have described a high incidence of neuropathy symptoms, benign but frequent pulmonary and urinary infections, sexual disorders, arthralgias, gastritis, cardiovascular complications and carcinomas [3,4]. Moreover, fatigue also occurs, notably in HL [5], along with mental disorders such as anxiety, depression, Post-Traumatic Stress Disorder (PTSD) [3,4,6] and Fear of Cancer Recurrence (FCR) [7]. All these components impact the Health-Related Quality of Life (HRQoL) and slow the return to normal for both HL [8] and NHL [9] patients. This may explain why the HRQoL of lymphoma patients is relatively poor overall, particularly when compared with other cancers that have worse prognoses such as lung cancers or renal cancers [10]. This may also explain why informal caregivers play such an important supportive role [11]. The contrast between HRQoL limitations and excellent control of the disease raises at least two important questions. The first relates to the identification of patients at risk; the second seeks an appropriate model of follow-up for these patients. In a prospective study on 200 lymphoma survivors, we found that approximately 20% of patients displayed severe alterations in the HRQoL (global SF-36 scores < 50) extending over the 2-year period [4]. Several parameters associated with this unfavorable outcome in this group of patients included low educational level, occurrence of mental disorders such

as PTSD or depression, cardiovascular complications, and recurrent infections [4]. Return to work was significantly delayed in these patients compared with the standard group [4]. The question of the care model has given rise to controversies about the respective role of General Practitioners (GP), oncologists and potentially other care providers including, for example, other specialists, psychologists, and social workers. Broadly speaking, two models have been implemented. The “oncologist model” (which even today remains the reference) is based on planned regular visits to the hospital. This model has been called into question because it lacks productivity and is ineffective for detecting relapses [12]. More importantly, this model has been also criticized by the patients themselves due to perceptions that the doctor does not have time to discuss their problems, notably in the areas of emotional and social functioning [13]. In the “GP model”, GPs assume exclusive responsibility for routine follow-up care, potentially after a certain period of time following the end of treatment (3 years for lymphoma in the Canadian study referenced below) [14]. However, this model has also been criticized by patients (lack of confidence) and by oncologists (lack of individual skill) [15]. In a previous report, we described the Ambulatory Medical Assistance–After Cancer (AMA-AC) program, a shared care model derived from the patient navigator, which involves the GP, Nurse Navigator (NN) and oncologist [3]. The follow-up consists of controls every 3 months for the first year, and then every 6 months for a total of 5 years. After a pre-AMA-AC consultation and obtaining consent from the patient and GP for the procedure, the patient visits his/her GP to make an inventory of physical symptoms using a 41-item Clinical Reporting Form (CRF), which has been prepared by the oncologist, along with laboratory tests. The CRF and lab tests are sent to an NN who calls the patient at home to identify possible social problems and mental disorders using specific psychometric scales (HAD and PTSD check-list at the minimum). The physical, psychological and social tryptic is ultimately addressed to the oncologist who creates a synthesis from all the analyses and consultations. If necessary, the oncologist intervenes through the NN to refer the patient to the appropriate care provider. The patient is encouraged to contact the NN in case of problems and is allowed to visit the oncologist on request (or per GP request). There are no systematic hospital visits. In our institution, the AMA-AC was started in December 2011. Today, 541 lymphoma patients have been managed through this program. An NN (70% full-time position) is specifically dedicated to the AMA-AC program (pre-AMA-AC visit, phone calls, preparation of medical files and events management). The AMA-AC was found to be feasible as well as remarkably efficient for detecting physical and mental complications during lymphoma survivorship [4]. The AMA-AC is also useful for detecting variations throughout the course of lymphoma survival, notably in terms of mental disorders. Due to the

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immediate positive perceptions of patients, GP and medical staff, the AMA-AC was not subjected to a randomized study. The AMA-AC became rather our standard management protocol, not only for lymphomas but also for leukemias, and will soon be extended to other patients with malignancies such as breast cancer. Three years ago, we conducted an investigation seeking the opinion of patients about the procedure. Based on 117 questionnaires (out of 152 sent), it appears that the AMA-AC was greatly appreciated by the patients, with more than 90% satisfaction concerning availability, quality of information, ability to listen, and reactivity. Importantly, 67% of patients do not miss the oncologist (unpublished data). To conclude, about one-fifth of lymphoma survivors are exposed to severe and durable HRQoL degradation with significantly harmful personal, familial and social consequences. Patients at risk of developing such unfavorable outcomes deserve specific attention and should benefit from optimal follow-up. We believe that models based on nurse navigators like the AMA-AC or similar care management procedures meet this demand.

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