Impact of an educational program on the quality of life of patients with lymphedema: A preliminary evaluation

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ABSTRACT

Objective: We report on the preliminary evaluation of a well-designed program, Living with Lymphedema. This longitudinal cohort study assessed patients' quality of life using questionnaires. Our main objective was to evaluate the satisfaction of the patients and their adherence to the program. This was done using a specific questionnaire of satisfaction as well as by noting patients' adherence to the program (number of patients attending all three consultations). The secondary objective was to assess the effect of the program on the patient's quality of life. The assessment criteria were the evolution of the Medical Outcomes Study 36-Item Short Form Health Survey and EuroQol questionnaire scores between the first (C1) and third (C3) consultations.

Methods: The Living with Lymphedema program targeted all patients with lymphedema in the Grenoble (France) conurbation and within the GRANTED health care network that includes vascular medicine specialists, primary care physicians, physical therapists, and dietitians in the Alpine region of France. All studied patients were ambulatory patients. The GRANTED network took care only of the educational aspect of the disease. All patients with primary or secondary lymphedema were offered the Living with Lymphedema program, whatever their age and the location of the lymphedema (upper or lower limbs). The collection of patient data conformed to the ethical and administrative regulations of the regional health authority. Grenoble Institutional Review Board (CPP Sud-Est V; No. 5891) approval for the study was specifically obtained for this evaluation on December 24, 2012. The program was built around one-to-one consultations, group workshops, and more specialized appointments. It was complementary to the routine medical care received by the patient (not evaluated in this study). It proposed three individual "educational" consultations, seven group workshops, and two specialized consultations with a dietitian. All the consultations or workshops were led by certified professionals trained in therapeutic education.

Results: The cohort was the 34 patients included in the program. We found a significant improvement in the physical dimension of the Medical Outcomes Study 36-Item Short Form Health Survey score ($P = .01$) between C1 and C3 but not for the psychic dimension. Visual analog scale scores of the ability to cope with the lymphedema showed a statistically significant improvement between C1 and C3 ($P = .05$). No difference was observed in adherence to compression therapy.

Conclusions: This therapeutic educational program showed a significant improvement in several criteria of quality of life and in the autonomy of patients with lymphedema. (J Vasc Surg: Venous and Lym Dis 2017;5:715-22.)

Lymphedema is a chronic disease that is difficult to manage both for patients and for their physicians.[1] Secondary lymphedema is most frequent and can induce physical and psychological morbidity that becomes a handicap, with deterioration in quality of life. It is particularly frequent in women with a history of breast cancer, although the reported rate of incidence of lymphedema after breast cancer treatment varies widely from one publication to another.[2] In 2008, the authors of a systematic review for the National Breast and Ovarian Cancer Centre concluded that about one in five woman treated for breast cancer would develop upper limb lymphedema within 6 months of surgery (mean incidence, 22%) and that this rate would continue to increase in longer term follow-up.[3] However, the incidence is difficult to determine as there is no consensus agreement on definitions and methods of diagnosis.[4] Nevertheless, based on existing data, the prevalence is estimated as being close to 100,000 patients throughout France.

Treatment is essentially based on physiotherapy and bandage compression. Recommendations for medical compression in the treatment of lymphedema were issued by the French National Authority for Health (Haute Autorité de Santé) in December 2010[5,6] and more recently by the International Union of Phlebology.[7] Lee et al pointed out that "the lifestyle measures and the compression require an education of the patient" as well

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as of all concerned health care professionals. To meet this need, we designed an educational program for lymphedema patients called Living with Lymphedema. This received authorization from the Rhône-Alpes Regional Agency for Health in March 2011.[8] The program was slightly modified after comments by a group of patients (Appendix, online only).

The Living with Lymphedema program targeted all patients with lymphedema in the Grenoble conurbation and within the GRANTED health care network that includes vascular medicine specialists, primary care physicians, physical therapists, and dietitians in the Alpine region of France. It was adapted to the specific problems of patients with lymphedema and aimed to improve understanding, motivation, and active participation of patients in the various dimensions of medical care, physiotherapy, rehabilitation, skin care, and nutrition. As for all patient education programs for chronic diseases, called patient therapeutic education programs in France, evaluation is difficult. Indeed, the possible impacts of education programs on particular changes in behavior are generally slow to occur and require long-term follow-up. Medical effects are more difficult to demonstrate than behavioral changes. The aim of this study was to evaluate the educational component of the program in terms of patients' quality of life.

METHODS

Studied population

All patients with primary or secondary lymphedema were offered the Living with Lymphedema program, whatever their age and the location of the lymphedema (upper or lower limbs). The estimation of the number of patients potentially concerned by the project was based on the incidence of secondary lymphedema after breast cancer. This was about 1000 patients for the Grenoble area. All studied patients had given written consent to be included in the GRANTED network. The collection of patient data conformed to the ethical and administrative regulations of the regional health authority. Grenoble Institutional Review Board (CPP Sud-Est V; No. 5891) approval for the study was specifically obtained for this evaluation on December 24, 2012.

Educational program

Educational programs for patients need to have precise aims and to be well structured. The approach, target population, contents, design, and how they will be evaluated all need to be clearly defined. The Living with Lymphedema program was inspired by the recommendations of the Haute Autorité de Santé and the National Institute for Prevention and Health Education on the structure and contents of therapeutic educational programs for patients with chronic diseases produced in 2007.[9] This program was designed on the initiative of a group of French vascular physicians who had been trained to a program on chronic limb arteriopathy. The design has already been described in a previous puplication.[8] It was adapted to the specific problems of patients with lymphedema and included sessions on medical treatments and physical re-education as well as the dermatologic and nutritional aspects. It provided information on vascular pathologic processes and discussed the problem of chronicity. The main objective of the patient's therapeutic education was to involve patients with lymphedema in the care of their chronic disease and to encourage them to become more autonomous. The secondary objectives were to improve the patient's knowledge about the disease to reduce aggravating factors and the occurrence of complications; to improve quality of life; and to establish a structure for the exchange of information between the patients, their families, and health care professionals. A group of patients were consulted at all stages in the design of the program.

The program was built around one-to-one consultations, group workshops, and more specialized appointments (Fig 1). It was complementary to the routine medical care received by the patient, which usually included various types of physiotherapy and physical re-education training carried out by freelance physiotherapists or in re-education centers. The program could be proposed at the time of routine medical care. The patients continued to see their usual lymphedema therapist in parallel. A secretary is specifically dedicated to the organization and to the convocation of the patients, in particular for the logistics of the group workshops. The program proposed three individual "educational" consultations, seven group workshops, and two specialized consultations with a dietitian (Fig 1). All the consultations or workshops were led by certified professionals trained in therapeutic education in addition to their nursing or medical qualification. The program was tailored to the needs and expectations of each patient. A report was made at the end of every individual session with copies sent to the patient and his or her primary care physician.

In the first consultation (C1), a "shared educational assessment" or "educational diagnosis" was made. Together, the health care professional and the patient drew up a personalized plan with workshops or specialized consultations according to the patient's choices and needs. During this consultation, the patient's real-life experience of the disease, knowledge of the disease, adherence to treatment (in particular compression), and extent of the social or professional handicap were assessed. The second consultation (C2) reviewed the activities in which the patient had participated (workshops or specialized consultations), and the objectives concerning managing the lymphedema were fixed with the patient along with the ways to reach these. In addition, a personalized skin care plan was set up.