



## Analysis of Patients' Needs After Liver Transplantation in Tuscany: A Prevalence Study

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### ABSTRACT

**Background.** The reorganization of the healthcare system in Tuscany aims at characterizing the hospitals as a place for the treatment of acute patients. This event, together with the improvement of long-term survival after orthotopic liver transplantation (OLT), calls for a management network able to ensure effective continuity of care for patient needs in the posttransplantation period.

**Materials and Methods.** An observational study of prevalence has been carried out with the primary objective to evaluate patients' needs and criticalities both in routine daily life and in urgency in the posttransplantation period and the capacity of the regional health system to support them. A survey, using a semi-structured questionnaire consisting of 27 questions, was administered to all patients resident in Tuscany who underwent transplantation from 2000 to 2010. The survey tool assessed the following: socio-demographic data, personal, family and social difficulties, problems emerged in the clinical routine and urgency, resolution modality, relationships with the general practitioner and the referral specialist, and services the patients would appreciate receiving in their province of residence.

**Results.** In the study, 346 patients matched the inclusion criteria of the study, 324 gave telephone consent to participate in the survey, and 225 responded (69.4%). The most frequent difficulties were as follows: depression (39.5%), difficulty in returning to work (29.3%), low income (22.6%), lack of self-sufficiency (22.6%), addictions (19.1%) (cigarette smoking 16.4%), 12.4% eating disorders, and 18.9% other difficulties (social isolation, absence of a family network, and so on). The main reasons for dissatisfaction were as follows: difficulty to obtain the required laboratory tests and lack of a reference structure at the local health facility. Few patients have a referral specialists in their area and most of them primarily refer to the Transplant Center even late after the procedure.

**Discussion.** Early diagnosis of specific conditions (depression, addiction, and eating disorders) should be implemented in the follow-up period and services such as counselling, dietary support, rehabilitation, and social services should be provided locally. An integrated management system between the transplantation center and the local facilities (hospitals, general practitioners, primary care, and laboratories) should be implemented and referral specialized centers should be identified locally.

**T**RANSPLANT recipients require life-long immunosuppression and periodic health checks to preserve the health-care status obtained with the transplant and to be able to intervene promptly in case of complications.<sup>1,2</sup> The reorganization of the healthcare system in Tuscany aims to characterize the hospital as a place of treatment of acute patients<sup>3</sup> but it is necessary to enhance the local assistance to guarantee an effective continuity of care.<sup>4,5</sup> The aim of this study was to evaluate patient care needs after ortho-

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topic liver transplantation (OLT). This may be the basis for future improvement of outpatient health care.

## MATERIALS AND METHODS

A spontaneous, monocentric, observational study of prevalence was conducted at our institution. The study was performed after having obtained the approval of the Local Ethics Committee for Human Experimentation and in accordance with the Helsinki Declaration of 1975. The main goal was to evaluate patients' needs post-OLT both for routine care and urgent care. Selection criteria were the following: patients resident in Tuscany, undergone OLT in the period between January 1, 2000 and December 31, 2010 (11 years), and 18 years of age or older. Retransplantation patients were excluded. Selected patients received a semi-structured questionnaire composed of 27 close-ended questions and 3 open-ended questions to evaluate the following: socio-demographic data, personal, social, and familiar factors met after transplantation, clinical difficulties that happened in routine and urgency, timing of the adverse event and resolution modality, relationship with the general practitioner, episodes of particular anxiety, concern or loss of referral points, and services that the patient would like to have in his or her own area. The questionnaire, together with the informed consent form, were shipped by regular mail. Patients had the possibility to give multiple answers for some questions, so the answers are not mutually exclusive. Data were gathered anonymously on specifically created Excel mask. For the purpose of the multivariate analysis, variables of exposition (and/or confounding) and variables of effect (reported by patients) were translated in dichotomous (value, 0–1). Data were investigated in 3 different time sets: first 6 months post-OLT, after sixth month post-OLT, and on urgency.

### Data Analysis

The study of prevalence was performed according to logistic multivariate analysis calculating Prevalence Odds Ratio (POR) with Stata Software version 11, adjusted for gender and age.

## RESULTS

One thousand three hundred ten OLT were performed between 1996 and 2011 at our institution. Five hundred forty-five of these patients live in Tuscany and 346 of them were randomly selected for this study. Among these patients, 324 agreed to participate, 10 refused. Two hundred twenty-five questionnaires (69.4%) were returned. Responders socio-demographic characteristics are summarized in Table 1. Personal, family, and social factors reported by the patients were as follows: depression 39.5%, difficulty in resuming work 29.3%, low income 22.6%, lack of self-sufficiency 22.2% (due to asthenia 8%, difficulty to perform daily activities 6.2%, motor difficulties 3.1%, inability to drive 2.5%, medical complications 0.8%, diffuse pain 0.4%, and migraine 0.4%), addictions 19.1% (cigarette smoking 16.4%, illicit drugs 1.3%, morphine 0.8%, and alcohol 0.4%), eating disorders 12.4% (increase of appetite 4.8%, lack of appetite 3.1%, digestive difficulties 3.1%, anosmia 0.8%, and postprandial diarrhea 0.4%), social isolation 5.3%, insufficient family support 4.8%, and other 8.8% (weight gain 4.4%, erectile dysfunction 1.7%, insomnia

**Table 1. Socio-Demographical Characteristics of the Sample**

Variables of Exposition	Patient Data	n	%
Gender	Female	57	25.3
	Male	168	74.6
Age group	< 20 y	0	0
	21–30 y	4	1.78
	31–40 y	6	2.67
	51–60 y	86	38.22
	61–70 y	76	33.78
	>70 y	7	3.11
Educational level	Primary school	44	19.56
	Junior high school	83	36.89
	High school	73	32.44
	College/university	25	11.11
Geographical area distribution	Center	93	41.3
	North-West	91	40.4
	South-East	41	18.2

1.3%, pruritus 0.4%, lack of psychological support 0.4%, and ataxia 0.4%). Twenty-four percent of the patients report not to have any personal, social, or family difficulties.

Most of difficulties were reported in the first 6 months post-OLT, generally from female patients (POR 1.46; 95% confidence interval [CI], 0.75–2.8) living far from the transplantation center (POR 1.33, 95% CI, 0.77–2.29). The most reported problems were the following: laboratory tests execution in the area of residency (16%), T-tube management (15.5%), immunosuppressive drug intake (14.6%), blood pressure control (13.3%), blood sugar control (12.8%), surgical wound dressing (9.3%), and other (4.4%). Forty percent of the patients referred to have had no criticalities in the first 6 months posttransplantation.

Patients primarily require the support of the transplantation center (87%) in case of need. Six month post-OLT, most of the criticalities in the management of routine needs were reported by patients living far from the transplantation centre (POR, 1.44; 95% CI, 0.83–2.47). There was no difference in the criticalities reported by the study population. Fifty-five percent of the patients did not report any specific problem. Again, they primarily referred to the transplantation center (82.2%).

The questionnaire also investigated the relationship between patients and the general practitioner: 46% of transplant recipients go to the general practitioner only for medical prescriptions, 38% for every kind of malaise, and 16% to receive information about drugs. Sixty percent of the patients do not have a local referral specialist.

## DISCUSSION

All data in this study came from perception of patients and not from direct medical observation, however, the research gave some interesting results that may help in the implementation of local post-OLT services.

From the evaluation of the personal, social, and familiar difficulties has been detected the presence of depression, difficulty to resume work, low income, and social isolation.

In fact, post-OLT depression, an extensively known problem,<sup>6</sup> could affect the ability to resume working<sup>7</sup> and, consequently, can lead to low income and isolation that aggravate depression itself.<sup>8</sup> Moreover, depression is associated with an increased long-term mortality.<sup>9</sup> Other major problems that can affect the outcome are loss of self-sufficiency, addictions, especially cigarette smoking, and eating disorders; addictions reduce posttransplantation survival and increase the risk of graft loss.<sup>10,11</sup> Smokers after OLT have an increased risk for lung, esophagus, kidneys, urinary tract, and head-neck tumors,<sup>12</sup> as well as an increased mortality for cardiovascular accidents and sepsis.<sup>13</sup>

In this setting early diagnosis and treatment might be extremely important in improving long-term results. Local dietary and psychological support and rehabilitation services are fundamental and should be fully implemented. An effective support could be reached through a new organizational model leading to a better integration between the transplantation center and the periphery by creating an integrated network that grants a direct communication system between healthcare facilities.

The network should be composed by the liver transplantation center (coordinator of the network), the departments of infectious diseases, hepatology, gastroenterology, and internal medicine, and those facilities that provide care to transplant recipients: outpatient visits, laboratories, and general practitioners.

The network should work planning routine health interventions (blood sampling, visits, and outpatient evaluation—instrumental control), prompt and appropriate management of any concerning clinical conditions, ensuring continuity of care between local facilities and the transplantation center after surgery, continuous training of the involved health staff, and creating uniform healthcare procedures in the territory. The integrated network would meet

patients' needs with appropriate, safe, and effective responses in terms of innovation, continuous improvement, and cost reduction through appropriateness of care.

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