



## Distress in primary caregivers and patients listed for liver transplantation



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### ABSTRACT

Orthotopic liver transplantation (LTx) has become a routine procedure in the treatment of end-stage liver disease. During the waiting period for transplantation, the patient's family members are also highly affected. We examined the course of distress and quality of life (QOL) in 47 patients awaiting LTx and distress in 24 caregivers at baseline and in intervals of 4–6 weeks, using The Hospital Anxiety and Depression Scale (HADS) and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30). All subscales of the EORTC QLQ-C30, except emotional functioning, were lower than normal at baseline. Little change in patients' QOL was observed during the waiting period. In the HADS, there were significantly higher anxiety scores in caregivers than in patients both at baseline and after 1–2 months and the third assessment, with the difference after 3–5 months reaching almost significance. Caregivers' anxiety levels increased significantly. Relatives showed more depression than patients only at month 1–2 and a significant increase in depression from baseline to month 1–2. In patients, depression scores remained relatively stable throughout all visits. Our results emphasize the importance of evaluation of psychic stress especially in relatives during the waiting period for LTx.

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### 1. Introduction

During recent years, orthotopic liver transplantation (LTx) has become a routine procedure in the treatment of end-stage liver disease.

The indications for LTx are diverse: alcoholic liver disease, hepatitis C and B virus infection, cryptogenic cirrhosis, primary sclerosing cholangitis, primary biliary cirrhosis, autoimmune hepatitis and to a constantly wider extent non-alcoholic steatohepatitis are amongst the diagnoses of transplanted patients in the USA (Charlton et al., 2011).

Steady improvements in graft and patient survival have been achieved over the past two decades. One-year adjusted patient and graft survival rates were 87.9% and 82.3%, respectively, for deceased donor liver transplants in 2005 (Health Resources and Services Administration, 2007). With significant improvements in survival and a more recent plateau of these gains, focus on outcome measures has shifted towards inclusion of patient-reported quality of life (QOL). Hence, patient-reported outcomes are being increasingly emphasized in recent years and have become an integral component of several clinical trials (Atherton

and Sloan, 2006). Numerous studies in the field show a long-term improvement in QOL of patients after LTx (Duffy et al., 2010), while others have failed to do so (Aadahl et al., 2002). However, as the demand for donor organs exceeds their availability, patients have to face increasing waiting times. According to the annual report of EUROTRANSPLANT, as per Dec. 31st, 2010, 137 Austrian patients are on the active liver transplant waiting list (Superior Health Council, 2011). According to this data, 65.6% of patients of all included countries were transplanted in the first 5 months of being placed on the waiting list, with the rest waiting considerably longer. The waiting period for the transplant is a process of experiencing confinement, disciplining the self and surrendering one's self to accept resources for health (Baker and McWilliam, 2003). Patients exhibit a significant limitation in their psychological well-being and show higher levels of anxiety (Goetzmann et al., 2006). Physical impairment often requires help in daily living. Primary caregivers can help in day-to-day activities, assist in taking medication, communicate with the medical team and provide emotional support (Benning and Smith, 1994). Some studies have shown that medical outcome and compliance are highly influenced by the psychosocial environment of the patient (Bunzel and Laederach-Hofmann, 2000).

Most of the studies in the field have focused on QOL of the patients both before and after transplantation, although during that period, the transplant recipient's family members are also

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highly affected by performing emotional and instrumental caregiving tasks (Cohen et al., 2007; Rodrigues et al., 2010), and the prevalence of depression in primary caregivers is high (Miyazaki et al., 2010; Goetzinger et al., 2012). QOL of the caregivers may suffer during that process, though there seems to be evidence that some caregivers also experience benefits, such as gaining a new life perspective, and feeling wanted or needed (Meltzer and Rodrigue, 2001). On the contrary, a recent paper (Rodrigue et al., 2011) reported that in caregivers caregiving strain and mood disturbances are just as prominent in the months and years following LTx as they were during the pre-LTx waiting-period. As shown in an extensive review (Jay et al., 2009), the Hospital Anxiety and Depression Scale (HADS) is one of the most commonly used instruments in measuring anxiety and depression in transplantation patients.

The aim of our study was to focus on the pre-LTx waiting period, to measure the course of distress and quality of life in patients, and to relate it to the level of distress in primary caregivers during the waiting period for orthotopic LTx.

## 2. Methods

### 2.1. Subjects

Adult patients (age > 18 years) listed for LTx at Innsbruck Medical University Clinic were asked to participate in this survey. Patients showing hepatic encephalopathy > 2 (using West Haven criteria, (Atterbury et al., 1978)) or not enough knowledge of the German language were excluded from the study. Also, patients with a high urgent transplantation were not included. Primary caregivers of participants (e.g. spouses, relatives) were invited to attend the study. Patients and caregivers were informed about the trial and were included into the study after signing written informed consent. The study was approved by the Ethics Committee, Medical University Innsbruck.

Overall, 78 patients, of which 31 met exclusion criteria, were screened. Of the 47 included patients, only 24 primary caregivers participated in the study, 23 refused to participate. Twelve of the patients could not name a caregiver. To allow comparison of patients' QOL with normative QOL data, we drew an age and gender-matched sub-sample of healthy controls from a representative sample of the Austrian general population (Holzner et al., 2001). Except for the criteria used for matching (age and gender) the healthy subjects were randomly drawn.

The first assessment was performed on patients during a routine pre-organ-transplant evaluation examination conducted by the Department of Psychiatry and consisted of a clinical interview, the German versions of the Alcohol Use Disorders Identification Test (AUDIT) and the Transplant Evaluation Rating Scale (TERS). The Hospital Anxiety and Depression Scale (HADS) via examiner-rating and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) via self-rating were used to evaluate patients at baseline, the former also to evaluate caregivers. Consecutive assessments of patients and caregivers were conducted after the definite listing for transplantation in intervals of 4–6 weeks up to the time of surgery. Our hypothesis is that QOL decreases in patients while psychic distress, both in patients and caregivers, increases with the length of the waiting period.

#### 2.1.1. Statistical methods

For a comparison of patients and caregivers with respect to socio-demographic variables, the Mann–Whitney *U* test, the  $\chi^2$  test and Fisher's exact test were used, depending on the variable type. To compare the patients' QOL with that of a normative sample, the Mann–Whitney *U* test was applied, as the QOL data showed notable departure from a normal distribution.

To analyze the time course of QOL and psychological distress during the waiting period, we had to take into account the fact that, due to transplantations and dropouts, the number of patients still waiting for transplantation decreased steadily over time. In order to retain as many subjects as possible in the analysis, we did not apply repeated-measures analysis of variance but split the entire waiting period into three phases (short term: 1–2 months, medium term: 3–5 months, long term: 6 or more months) and separately analyzed changes from baseline to phases 1, 2 and 3, respectively. The Wilcoxon matched-pairs test was used for this purpose. Findings are presented both with Bonferroni correction and without.

The Wilcoxon matched-pairs test was also employed to compare patients and their caregivers with regard to emotional distress (HADS). As the patient and caregiver samples differed significantly in their gender distribution, a second analysis of the two groups was performed by analysis of covariance using gender as a covariate.

**Table 1**

Subject characteristics (patients and primary caregivers).

Variable	Patients	Primary caregivers
	N=47	N=24
Age		
Mean $\pm$ S.D.	56.9 $\pm$ 7.4	50.0 $\pm$ 14.2
Gender <sup>*a</sup>		
Male	37 (79%)	5 (21%)
Female	10 (21%)	19 (79%)
Marital status		
Married/fixd partner	36 (77%)	22 (92%)
No fixed partner	11 (23%)	2 ( 8%)
Employment situation <sup>*b</sup>		
Regular work	7 (15%)	11 (46%)
Early retirement	24 (51%)	1 ( 4%)
Regular retirement	8 (17%)	9 (38%)
Others	8 (17%)	3 (12%)
Relation with primary caregiver		
Partner	20 (84%)	
Child	1 ( 4%)	
Parent	2 ( 8%)	
Other	1 ( 4%)	
Child-Pugh class		
A	11 (23%)	
B	29 (62%)	
C	7 (15%)	
Primary diagnosis		
Alcohol-induced	19 (40%)	
Hepatitis-induced	14 (30%)	
Cholestatic liver disease	5 (11%)	
Others	9 (19%)	
Hepatocellular carcinoma (HCC)	21 (45%)	

<sup>a</sup>  $\chi^2=22.4$ , d.f.=1,  $p < 0.001$ .

<sup>b</sup>  $\chi^2=18.9$ , d.f.=3,  $p < 0.001$ .

## 3. Results

### 3.1. Description of patient sample and primary caregiver sample

Sociodemographic data of the patients are displayed in Table 1. Mean age of the patients was 56.9  $\pm$  7.4 years, with the primary caregivers being slightly younger at 50.0  $\pm$  14.2. Main reasons for LTx listing were alcohol- and hepatitis-induced cirrhosis, 45% of the patients had hepatocellular carcinoma, based on one of the primary diagnoses. There were statistically significant differences in gender distribution, with caregivers being mainly female and patients being mainly male. Eighty four percent of the primary caregivers were spouses of the patients. Most of the patients were in class B according to Child Pugh criteria. Four patients had a history of clinical depression, but no antidepressant medication at the time of the evaluation.

### 3.2. Patients' quality of life during the waiting period

Patients' EORTC QLQ-C30 scores are shown in Table 2. All subscales, except emotional functioning, were significantly lower than in an age- and gender matched normative sample at baseline. Overall, fairly little change in patients' QOL was observed during the waiting period. A slight, but statistically significant reduction in QOL was found for the physical functioning subscale after 1–2 months ( $p=0.036$ ) and for the emotional functioning subscale after 3–5 months ( $p=0.022$ ), with values at 6+ months reaching almost significance ( $p=0.057$ ). However, after Bonferroni correction for multiple testing none of these significances is retained.

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