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### What's on your mind?

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CHAPTER

**1**

GENERAL INTRODUCTION

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For patients with end-stage liver disease, liver transplantation is the only treatment option. Orthotopic liver transplantation is a surgical procedure, in which the diseased liver is replaced by a donor liver. The first liver transplant was performed in the USA by Thomas E. Starzl in March 1963.<sup>1</sup> Since the start of the liver-transplant program in the Netherlands in 1979, over 3000 liver transplantations have been performed on more than 2500 patients (Eurotransplant, 2016). The main primary liver diseases before transplantation were viral hepatitis, cholestatic diseases, and hepatocellular carcinoma. At this point in time, liver transplantations are performed in three liver transplant centers in the Netherlands: the University Medical Center Groningen in Groningen (since 1979), the Erasmus Medical Center in Rotterdam (since 1986), and the Leiden University Medical Center in Leiden (since 1992). In the Netherlands, each year about 200 patients with end-stage liver disease are placed on the waiting list for a liver transplant, while about 145 patients receive a transplant.<sup>2</sup>

Due to improvements in medical and surgical procedures and immunosuppressive drugs, the clinical outcomes and survival of liver transplant patients have improved over the past decades. The European Liver Transplant Registry ([www.ELTR.org](http://www.ELTR.org)) reports survival rates at 1, 5, and 10 years after liver transplantation of 84%, 73%, and 63% respectively, and graft survival rates at 1, 5, and 10 years of 79%, 66%, and 56% respectively.

### **Psychological consequences of liver transplantation**

As a consequence of the improved survival after liver transplantation, other outcomes such as health-related quality of life and psychosocial consequences of transplantation have become increasingly important targets of evaluation.<sup>3</sup> Although health-related quality of life improves after liver transplantation, it does not restore to the level of the general population.<sup>4-6</sup> More specifically, meta-analyses have shown that quality of life after liver transplantation significantly improves in the domains of physical and social functioning, but not in the domain of psychological functioning.<sup>7,8</sup>

This might be due to the stressful nature of the transplant experience both before and after the transplantation. Having to undergo a liver transplantation is a major event in a person's life. After being diagnosed with a life-threatening disease and learning about the need for a transplant, patients have to wait for a suitable donor. For transplant candidates the waiting-list period is a period of unpredictability and uncertainty. They do not know when a donor organ will become available or if this donor organ will arrive in time. Each year, approximately 10%-15% of transplant candidates die while they are on the organ transplant waiting list.<sup>2</sup> If a donor organ becomes available, patients have to undergo major surgery that may be accompanied by medical complications. In general, the transplantation itself is beneficial for the health of the transplant recipients, but they also have to adjust to a life with a life-long regimen of immunosuppressive drugs and adherence to strict guidelines, and may have to deal with serious, potentially life-ending, complications. In fact, transplant recipients trade a chronic disease for a chronic situation. Given these stressors, it is not unlikely that the transplant process will cause psychological distress in a subset of transplant candidates and recipients, such as clinically relevant symptoms of anxiety, depression, and/or posttraumatic stress.

### **Anxiety**

Symptoms of anxiety, such as feeling tense, upset, or worried, can be a burden all by themselves but may also interfere with the daily functioning of transplant candidates and recipients. Prevalence rates of clinically relevant symptom levels of anxiety are described in 11%-52% of the adult liver transplant candidates,<sup>9,10</sup> and in 6%-33% of the adult liver transplant recipients.<sup>11,12</sup> Although several demographic variables, such as female gender, marital status, and employment status,<sup>13-15</sup> clinical variables, such as primary liver disease, time since transplantation, time on waiting list, and use of steroids,<sup>13-17</sup> and individual variables, such as self-perceived health status, coping style, and personality<sup>18-20</sup> have been associated with clinically relevant symptom levels of anxiety, these results are still inconclusive. The impact of anxiety on outcomes after transplantation is even less well studied. So far, a few studies have found that clinically relevant symptom levels of anxiety have a negative impact on outcomes after transplantation: impaired quality of life,<sup>11,14,21,22</sup> lower medication adherence,<sup>23</sup> and lower survival.<sup>24</sup>

### **Depression**

Symptoms of depression, such as persistent feelings of sadness and worthlessness, and loss of interest in previously enjoyed activities, affect how people feel, think, and behave. Among adult liver transplant candidates prevalence rates of 17%-60% of clinically relevant symptom levels of depression have been described.<sup>10,12</sup> In adult liver transplant recipients, prevalence rates of 4%-58% have been described.<sup>4,13</sup> Variables associated with clinically relevant symptom levels of depression are basically the same as for symptoms of anxiety. Only with respect to clinical variables, medical complications after the transplant, such as graft failure, diseases recurrence, and rejection, have been mentioned more often as associated variables.<sup>14-16,25</sup> Regarding individual variables, depression before the transplant and low self-efficacy have been identified as influencing factors.<sup>21,26</sup> However, results regarding variables associated with depression in liver transplant candidates and recipients also remain inconclusive. With respect to outcomes, depressive symptoms have been related to impaired quality of life in transplant candidates and recipients,<sup>11,14,15,25</sup> and seem to have a negative impact on survival after transplantation.<sup>24,27,28</sup>

### **Posttraumatic stress**

Showing high symptom levels of posttraumatic stress, such as intrusive memories, avoidance of reminders of the event, hopelessness, and hyper-arousal, can be seen as a failure to adapt to extreme stress and may lead to posttraumatic stress disorder (PTSD). PTSD is described as a trauma and stress-related disorder, triggered by exposure to actual or threatened death, serious injury or sexual violation, either experiencing it or witnessing it,<sup>29</sup> and is often accompanied by impairments in areas of functioning. Posttraumatic stress has been less well studied in adult liver transplant recipients. One study among liver transplant candidates revealed a prevalence rate of PTSD of 2%,<sup>9</sup> while PTSD after transplantation has been found in 2%-9% of the liver transplant recipients based on DSM-IV criteria,<sup>30,31</sup> and 23%-47%<sup>4,12</sup> based on clinically relevant symptom levels. Regarding associated variables, only demographic and clinical vari-

ables have been investigated, showing that a lower educational level, a higher Model for End-stage Liver Disease-score (MELD), medical complications, a shorter waiting period, a longer stay in the Intensive Care Unit, and an episode of acute rejection of the transplanted organ are associated with higher symptom levels of PTSD.<sup>4,30</sup> The impact of PTSD on outcomes after liver transplantation has not been studied so far.

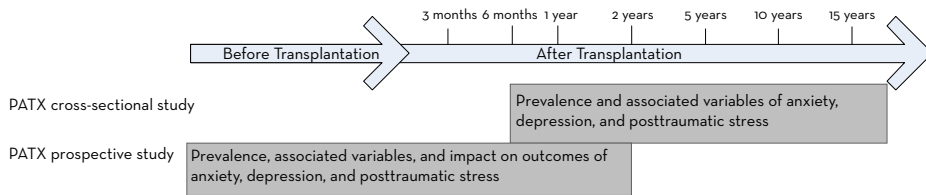
The above mentioned studies show that psychological problems are common in liver transplant candidates and recipients. However, relatively little attention has been paid to the subjective experience and psychological processing of the transplant process.<sup>32</sup> The care for liver transplant candidates and recipients is usually provided by a multidisciplinary team of medical doctors, surgeons, nurse practitioners, staff nurses, social workers, and physiotherapists. Nursing care for transplant recipients mainly focuses on the ability to perform everyday tasks and a return to daily living. Counseling by a psychologist or psychiatrist is provided on an as-needed basis, for example in cases of alcohol-dependency or if psychiatric problems are suspected.

Despite the multidisciplinary approach, the focus of care for transplant patients is mainly on the somatic medical management of the patient both before and after transplantation.<sup>33</sup> In addition to this, studies on the psychosocial aspects of transplantation in Dutch liver transplant candidates and recipients have focused mainly on quality of life and non-adherence.<sup>34-37</sup> Therefore, little is known about psychological problems in Dutch liver transplant candidates and recipients. To be able to optimize the psychosocial care for liver transplant candidates and recipients, more insight into the psychological functioning of those patients is needed.

### **The Psychological Aspects of Transplantation-study**

The aim of the Psychological Aspects of Transplantation-study (PATx) was to examine psychological problems among adult Dutch liver transplant candidates and recipients, both in the short term and long term after transplantation, by gaining insight into prevalence rates of symptoms of anxiety, depression, and posttraumatic stress, by examining demographic, clinical, and individual characteristics associated with these psychological problems, and by examining their association with outcomes after transplantation. For this purpose, the overall study comprised both a cross-sectional study and a prospective cohort study.

In the cross-sectional study, we examined the prevalence rates of anxiety, depression, and posttraumatic stress and their associated variables, from the short term (>6 months) after the transplantation to the long term (>15 years) after transplantation. All liver transplant recipients who received post-transplant care at the University Medical Center Groningen (UMCG) in April 2010 were invited to participate. Liver transplant recipients who were transplanted between 1979 and October 2009 at the UMCG, received their transplant at an adult age, and were still receiving post-transplant care at the UMCG were included. Transplant recipients who were unable to fill out a questionnaire (due to impairments in physical, mental or cognitive functioning, or due to a language barrier), who were enlisted for re-transplantation, or who were lost to follow-up care were excluded. Eligible recipients received an explanatory letter together with a



**Figure 1.** Overview PATx-study.

questionnaire and an informed consent form regarding permission to obtain data from the recipient's medical record.

The prospective cohort study was performed among transplant patients from all three liver transplant centers in the Netherlands: the University Medical Center Groningen (UMCG), the Erasmus Medical Center of Rotterdam (EMC), and the Leiden University Medical Center (LUMC). The study started in October 2009 in the UMCG, followed by the EMC in June 2011, and the LUMC in September 2011.

Transplant candidates who were on the waiting list at the start of the study, or were placed on the waiting list after the start of the study until April 2013, were asked to participate. Inclusion criteria for this study were:  $\geq 18$  years of age, and receiving medical treatment in one of the three transplant centers. Exclusion criteria were: unable to fill out a questionnaire due to physical, mental, or cognitive functioning, or due to a language barrier.

After written informed consent, respondents received a baseline questionnaire (T0). Measurements of psychological functioning were repeated every six months after inclusion in the study until transplantation or removal from the waiting list. After transplantation, respondents filled out a questionnaire at three (T1), six (T2), twelve (T3), and twenty-four (T4) months after transplantation. Transplant recipients who could not be included in the study before transplantation (eg, in case of acute liver failure or transplantation soon after placement on the waiting list) were invited to participate in the study, starting at 3 months after transplantation. Clinical data were retrieved by medical record review.

Power analysis, based on a difference in symptom levels of posttraumatic stress of at least 10%, and on inclusion of five associated variables, revealed that a sample size of  $n = 87$  liver transplant recipients, who filled in a questionnaire at all five measurement-points, was needed to answer our various research questions.

### **Opinions of transplant candidates and recipients concerning topics related to the transplant process**

Knowledge about the functioning of transplant candidates and recipients is important in order to provide appropriate care for this patient group. Moreover, it is important to know how patients think about topics related to the transplant process which might influence care or policies. In recent years, two topics of interest for transplant patients received increased attention: the principle of anonymity of organ donation and shared decision making regarding the acceptance of an organ offer.

The principle of anonymity of organ donation was questioned by the general public and by a subset of transplant recipients in reaction to a television documentary, in which transplant recipients were given the possibility of meeting the family of their donor. In the Netherlands, the anonymity of organ donors and recipients is protected by legislation to avoid possible undesirable and adverse consequences for both the donor family and the transplant recipient.<sup>38-40</sup> However, should the majority of transplant recipients favor a change in this policy, transplant healthcare professionals may play a role in advocating this change. To be able to make an informed decision as to advocate a change in the legislation regarding anonymity of organ donation, the opinion of Dutch liver transplant recipients about the principle of anonymity of organ donation and direct contact with the donor's family was investigated.

Shared decision making (SDM) between health care providers and patients concerning treatment options has received increased attention in the medical literature in recent years.<sup>41-43</sup> SDM refers to the process in which a healthcare provider communicates personalized information about the options, outcomes, probabilities, and the uncertainties of treatments available to the patient, and the patient communicates his or her values and the relative importance ascribed to the benefits and potential harms.<sup>44</sup> Although SDM has been examined and implemented in clinical settings,<sup>45,46</sup> little attention has been paid to SDM in the field of solid organ transplantation.<sup>41,47</sup> In the field of liver transplantation, SDM would involve a discussion of, the use of standard criteria donors (SCD) versus extended criteria donors (ECD), organ availability, and the timing of transplantation.<sup>41</sup> But also the acceptance of a specific donor offer could be discussed. SDM at time of donor offer would involve a discussion about the donor-related risks of the organ offered, and the willingness to accept a specific ECD organ, versus the risk of remaining on the waiting list, while hoping for a better donor. However, little is known about the willingness of transplant recipients to be involved in the decision making process regarding accepting a donor offer and about the information they would like to receive. Therefore, opinions regarding these topics were explored.

Because both of the abovementioned topics are related to the donor and to communication about the donation, a combined study regarding these topics was carried out.

### **The Communication about Donation-study**

The aim of the "Communication about donation"-study was to gain insight into: 1) the opinion of Dutch liver transplant recipients about the principle of anonymity of organ donation and direct contact with the donor's family was investigated; and 2) the willingness of Dutch liver transplant candidates and recipients to be involved in the decision making process regarding accepting a donor offer and the information they would like to receive about donor-related risks.

This cross-sectional study was performed among liver transplant candidates and recipients receiving treatment at the UMCG in the fall of 2012. All liver transplant recipients transplanted at the UMCG between 2000 and 2010, who received their transplant at an adult age, and who were still receiving post-transplant care at the UMCG, were invited to participate. In addition, adult liver transplant candidates, who were actively listed for transplantation, were invited to participate in the part of the study regarding SDM.

Eligible transplant candidates and recipients received a letter explaining the purpose of the study, a questionnaire and a pre-addressed and stamped return envelope.

### **Aims and outline**

In this thesis, several psychosocial aspects associated with the liver transplant process were investigated. On the one hand, psychological problems and associated variables of liver transplant candidates and recipients, both in the short- and long-term after transplantation, were examined. On the other hand, opinions of liver transplant candidates and recipients regarding two topics of interest to these patient groups were explored. In addition, a research instrument measuring the emotional response to the receipt of a transplanted organ was translated and validated for use with Dutch transplant recipients. The outline of this thesis is as follows:

**Chapters 2 and 3** describe the results of the cross-sectional part of the “Psychological Aspects of Transplantation”-study. **Chapter 2** reports the prevalence rates of psychological problems and associated transplant-related variables among 281 transplant recipients at different time periods after liver transplantation. In **Chapter 3** the validation of the Dutch version of the Transplant Effects Questionnaire, a research instrument measuring the emotional response to the receipt of a transplanted organ, is presented. **Chapters 4 and 5** discuss the results of the “Communication about Donation”-study. In **Chapter 4**, the opinions of Dutch liver transplant recipients concerning the principle of the anonymity of organ donation and their wish for direct contact with the donor’s family, are described. **Chapter 5** reports the views of liver transplant candidates and recipients with respect to their role in the decision making process of accepting an organ offer.

**Chapters 6 to 8** involve the results of the prospective cohort study part of the “Psychological Aspects of Transplantation”-study. In **Chapter 6**, the trajectories of anxiety and depression of liver transplant candidates during the waiting-list period are described. Furthermore, associated clinical and individual variables are explored. **Chapter 7** reports prevalence rates, symptom occurrence, and the nature of re-experiencing symptoms of posttraumatic stress disorder before and during the first year after liver transplantation. In **Chapter 8**, the course of symptoms of anxiety and depression before and during the first two years after liver transplantation are described. In addition, the association of demographic, clinical, and individual variables with the distinct trajectories of anxiety and depression, and the influence of these trajectories on outcomes regarding health-related quality of life and medication adherence are described.

**Chapter 9** provides a general discussion of the study results, their clinical implications, and addresses possible directions for future research.



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