CHAPTER

5

SHARED DECISION MAKING IN TRANSPLANTATION: HOW PATIENTS SEE THEIR ROLE IN THE DECISION PROCESS OF ACCEPTING A DONOR LIVER

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ABSTRACT

At the time of organ offer for transplantation, donor-related risks such as disease transmission and graft failure are weighed against the patient's risk of remaining on the waiting list. The patient's commonly inactive role in decision making and the timing and extent of donor-specific risk information have been discussed in the medical literature. This is the first study revealing the opinion of liver patients on these issues. Forty patients listed for liver transplantation and 179 transplanted liver patients participated in an anonymous questionnaire-based survey. The majority of patients wanted to be informed about donor-related risks (59.8%-74.8%). The preferred timing for being informed about donor-related risks was the time of the organ offer for 53.3% of the patients. Among these patients, 79.8% wished to be involved in making the decision to accept or not to accept a liver for transplantation, 10.6% wished to make the final decision alone, and only 9.6% did not want to be involved in the decision-making process. Implementing this knowledge through the standardization of the content, the manner of transfer, and the amount of information that we provide to our patients will improve opportunities for shared decision making at different time points during the transplant allocation process. This will enable us to provide the same opportunities and care to every patient on the waiting list.

INTRODUCTION

Liver transplant waiting lists increase more rapidly than the supply of donor organs, and this leaves many patients stranded and without access to what is often a lifesaving therapy. Efforts to increase the donor pool include the acceptance of more donors at the expense of diminished organ quality [ie, extended criteria donors (ECD)]. An ECD implies a higher donor-related risk in comparison with a standard criteria donor (SCD). This risk may manifest as an increased incidence of poor allograft function, allograft failure, or transmission of a donor-derived disease.[1]

To what extent such donor-related risks are discussed with the liver transplant candidate (informed consent) varies between countries and hospitals; whether or not the transplant candidate is involved in the decision-making process (shared decision making) at the time of donor offer also varies.[2-4]

In the United States, since the 2007 implementation of the guidelines from the Centers for Medicare and Medicaid Services (US Department of Health and Human Services), consent forms have been required for various stages of the transplant process, which starts with the initial evaluation and ends with the surgery. However, consent for ECD liver transplantation is not a requirement of the Centers for Medicare and Medicaid Services; it is offered at the discretion of the provider.[3] A recent study by Bruzzone et al.[2] has provided insight in the European implementation of informed consent for ECD liver donation: the majority of transplant centers inform transplant candidates about the ECD status of the donor, but great variations were observed in the timing of informing (before listing and/or at the time of organ offer), in the topics discussed, and in whether a special consent form was signed.

Standardization for the timing and content of the informed consent and for the transplant patient's role in the decision-making process is currently lacking, although both topics are receiving increasing attention in medical literature.[5-9] *Informed consent* is the term used for a patient's voluntary authorization, with full comprehension of the risks involved, for medical and surgical treatment.[10] *Shared decision making* is the process by which a health care provider communicates personalized information about options, outcomes, probabilities, and the uncertainties of the available options and a patient communicates values and the relative importance of benefits and harms.[11] For both informed consent and shared decision making, informing patients of all risks involved with a certain treatment is essential. Health researchers and policy-makers increasingly urge both patient and clinician engagement in shared decision making to facilitate the greater involvement of patients in their personal healthcare management.[12] Paternalistic health care has fallen out of favour and has been replaced by the patient-centered model, which emphasizes patient autonomy, informed consent and empowerment.[13]

Although shared decision making has been examined and implemented in numerous clinical settings,[14,15] it has received little attention in solid organ transplantation, especially in the field of (deceased donor) liver transplantation.[8,12] In a transplant setting, decisions often have to be made quickly, and the risks and benefits are difficult to explain fully at the time of an organ offer; this complicates informed consent and particularly patient involvement in shared decision making. Moreover, medical decision

making for liver transplantation raises additional challenges for shared decision making because liver transplant patients have no effective medical alternatives to transplantation such as dialysis in renal patients.[12]
Various ideas about the patient's role in decision-making and the timing and extend of informed consent have been proposed in medical literature.[6,8,16] However, there is a more fundamental question to be answered first: what do patients really want? There is very limited information on (1) the donor-related risk information that patients want to receive, (2) the preferred timing of ECD informed consent, (3) whether potential transplant candidates want to be involved in decision-making at the time of organ allocation, and (4) how much risk they are willing to accept. We, therefore, performed an anonymous questionnaire-based survey among patients listed for transplantation and liver transplant patients that addressed these questions.

PATIENTS AND METHODS

Participants and study design

All liver transplant recipients who underwent transplantation at an adult age at the University Medical Center in Groningen between 2000 and 2010, and who were still receiving posttransplant care at our center were invited to participate. In addition, adult patients that were actively listed for transplantation on February 1, 2013, were invited to participate. All eligible posttransplant and pretransplant patients received an information letter and a self-administered questionnaire by mail. Questionnaires were coded, and confidentiality was guaranteed. After 4 weeks, a reminder was sent to non-responders, and they were allowed another 4 weeks for completion. The study met the criteria for an exemption from approval (approval letter METc2012.306). The questionnaire was composed for the purpose of the study under guidance of an experienced health psychology researcher (A.V.R.) because no standard questionnaire was available for this topic. Internal validation questions were added to assess patients' understanding of the questionnaire, and the demonstrated conformity of 90% to 96%. The questionnaire was divided into two parts: (1) donor organ information, which contained 18 questions, and (2) general information, which contained 6 questions. All of the questions are addressed in the assessment section.

Assessment

All liver patients were approached by mail and asked to complete a 20 to 30 minute questionnaire. Patients were first reminded of the distinction between SCD livers and donor livers with an increased risk of complications after transplantation (so-called ECD livers). The difference between the general risk of a transplant procedure and (specific) donor-related risks was explained. An age >60 years, steatosis, and donation after cardiac death (DCD) were described as risk factors for liver failure and bile duct complications. Also, the potential risk of a transfer of a malignancy or an infectious disease from

the donor to the recipient was explained. After this introduction, patients were asked 4 personal questions concerning their time on the waiting list, previous experience with liver transplantation, and experience with complications after liver transplantation (questions 1-4).

Patients' acceptable risk of disease transmission (questions 5-8).
Next, patients were informed that the risk of a malignancy or infectious disease being transferred from a SCD livers is generally kept at less than 1%, and this leads to the discarding of livers that are otherwise suitable for transplantation. Patients then were asked to indicate on a visual proportion scale (1-50%) the risk of disease transmission that they considered high, and they were then asked to indicate the risk of disease transmission that they were willing to accept. The latter 2 questions were repeated (on the following page) after the patients were informed about the 15% mortality rate on the waiting list.

Informing patients about donor-related risks (questions 9-12)
In the subsequent questions, patients were asked whether they wished to be informed when a donor liver was offered with (1) an increased risk of transferring an infectious disease such as hepatitis or human immunodeficiency virus (HIV), (2) an increased risk of transferring a malignant disease (tumor), (3) an increased risk of bile duct strictures, or (4) an increased risk of early graft failure. Early graft failure was explained as requiring re-transplantation within 2 weeks after transplantation.

Timing of donor-specific informed consent (questions 13 and 14).
Next, it was explained that patients are informed (in general terms) about donor-related risks before waiting-list registration. It is currently not common practice to inform patients about specific donor-related risks at the time of donor offer. First, patients were asked to agree or disagree on a 5-point Likert scale (strongly disagree to strongly agree) with 4 statements through motives for wanting or not wanting information about donor-related risks were explored:

13a. It would cause distress (I would worry) if I received information about donor-related risks at the time of donor offer.
13b. I would like to receive information about donor-related risks at the time of donor offer, because it will allow me to be mentally prepared.
13c. I prefer not to receive information about donor-related risks at the time of donor offer, because I will already be overwhelmed.
13d. I would like to receive information about donor-related risks at the time of donor offer, since it will allow me to decide whether I do or do not want to receive that donor liver.

Subsequently, patients were asked whether they wished to be informed about donor-related risks of the liver offered to them for transplantation, with the following options for answers:

- No, I do not want to be informed about the donor-related risks.
- I want to be informed at the time of donor offer, even when this is at 3 AM.
- I want to be informed afterwards, when I have recovered from the transplant surgery.

The patient's role in the decision process (questions 15 and 16)

The patients who wished to be informed at the time of the donor offer, were asked what they planned to do with the acquired information:

- I just want to know, the decision on whether or not to accept the liver should be made by my physicians.
- I would like to make the decision together with my physician; we should decide together on whether or not to accept the liver.
- I would like to make the final decision alone (by myself).

Next, it was explained that in some countries, listed patients are allowed to exclude certain groups of livers (ECD livers) from being offered to them for transplantation, such as donation after cardiac death livers, livers from older donors, and livers from donors with an increased risk of infectious disease transmission. They were told that this would decrease the risk of complications after transplantation, but it would also increase the waiting time for a donor liver and thereby increase the mortality risk while on the waiting list. Patients were asked if they wanted to be able to exclude certain groups of donor livers before they were listed for transplantation.

Presented cases (questions 17 and 18)

Finally, two cases were presented to the patients: one concerning an 18-year old donor acquainted with intravenous drug use and the other concerning a healthy 81-year old donor (Table 1). First, patients were asked to assess the expected risk of infectious disease transmission and early graft failure, respectively, in those 2 cases. Next, the patients were asked whether they would accept these livers for transplantation if (1) their personal medical situation were stable and (2) their liver disease was progressively severe and the situation were, therefore, unstable.

Through 6 additional questions, information was obtained about patient age, sex, country of origin, civil status, education, and employment status. Data regarding the primary liver disease etiology and the time on the waiting list were extracted from medical databases.

Statistical analysis

Data were expressed as means and standard deviations, medians, or percentage of participants with specific responses. Categorical variables were compared with the Pearson Chi-square test or Fisher's Exact test as appropriate. Continuous variables were compared with the Student *t* test. Repeated measurements of ordinal variables within one group were compared using the Wilcoxon signed-rank test. The level of significance was set at a *P* value of 0.05. Statistical analyses were performed using SPSS 16.0 for Windows (SPSS, Inc., Chicago, IL).

Table 1. Two cases and situations: Would you accept this liver?

	Acceptable?		
	Yes	**No**	**Uncertain**
Case A. A young man (18 years old) died of an acute stroke (brain death). He was in good health, and his blood liver tests were normal. There is no evidence of a (endured) virus infection like Hepatitis B or C virus or HIV. However, the donor was acquainted with intravenous heroin use. Situation 1: You have been listed for transplantation for 8 months, and your condition is deteriorating: you are admitted to the hospital with significant jaundice, ascites and fatigue. There are concerns about whether there will be a liver available for transplantation in time**.**	74.3%	2.8%	22.9%
Case B. The donor profile is the same as that for case A. Situation 2. You have been listed for transplantation for 8 months, and your condition is fairly stable. You work part-time (half days) because of your liver disease, and you suffer mild jaundice. Arguably, you have some time to wait for a suitable organ offer.	40.7%	16.8%	42.5%
Case C. An 81-year-old woman died of an acute stroke. She lived more or less independently and relied on her neighbours only for help with groceries. She was healthy for her whole life. Her blood liver tests were normal. Situation 1. You have been listed for transplantation for 8 months, and your condition is deteriorating: you are admitted to the hospital with significant jaundice, ascites and fatigue. There are concerns about whether there will be a liver available for transplantation in time.	73.1%	3.3%	23.6%
Case D. The donor profile is the same as that for case C. Situation 2: You have been listed for transplantation for 8 months, and your condition is fairly stable. You work part-time (half days) because of your liver disease and you suffer mild jaundice. Arguably, you have some time to wait for a suitable organ offer.	39.2%	14.6%	46.2%

RESULTS

Respondent characteristics

Patients on the waiting list with an inactive status (n = 18) and patients who were <18 years old (n = 15) were excluded. In all, 243 transplanted patients and 66 patients on the waiting list were invited to participate. The overall response was 70.9% (n = 219); this included 60.6% (n = 40) of the approached waiting list patients and 73.7% (n = 179) of the transplant patients.

The study population was predominantly middle-aged, male, Dutch, married, and educated at an intermediate level (Table 2). The most common indications for transplantation were non-cholestatic cirrhosis (34.7%), cholestatic cirrhosis (33.3%), and metabolic disease (10.5%). The time since (last) liver transplantation was 6.4 ± 3.1 years (mean and standard deviation) for transplant patients and 9.4 ± 4.2 years for patients on the waiting list who had been transplanted before (n = 8; 20% of all participating listed patients). Ninety-nine of all transplant patients, 55.3% had developed 1 or more complications after transplantation, with biliary complications being the most common (n = 55 or 30.2%). The average time on the waiting list was 34.9 months (median = 26 months, interquartile range = 6-49 months) for the waiting-list patients. Nonresponders did not differ significantly from responders with respect to sex, liver disease before transplantation, or time since last transplantation. However, nonresponders were significantly younger (46.7 ± 16.6 versus 54.5 ± 13.1, *P* <0.001). During the study period, 2 nonresponders died, and 1 was admitted to the hospital.

Patient's view on acceptable risk of disease transmission

In general practice, the risk of disease transmission during organ transplantation is kept at less than 1% (no additional risk). Patients reported a significantly higher willingness to accept an increased risk of disease transmission after they had received information about the current 15% waiting-list mortality rate (Figure 1). The risk of disease transmission that patients were willing to accept was 7% ± 1% (mean and standard error), which increased to 12% ± 1% after they had received information about the current waiting-list mortality (*P* <0.001). No significant differences were found between subgroups based on patient status (transplant/waiting list), age, sex, level of education (low/intermediate/high), country of origin (Netherlands/other), or civil status (living alone/living with partner).

Informing about different types of donor-related risks

The vast majority wished to be informed when donor-related risks increased. When there was an increased risk of the transmission of an infectious disease or a malignant tumor, 73.5% and 74.8% of respondents, respectively, wished to be informed. In the case of an increased risk of bile duct strictures, 59.8% of respondents wished to be informed. When an increased risk of early graft failure was present, 70.1% of the patients wished to be informed (Table 3). Experience with bile duct complications or early graft failure after liver transplantation (the patient or an acquaintance) was not associated with an increased wish to be informed about an increased risk of bile duct strictures

Table 2. Patient characteristics

	Overall (n=219)	After transplantation (n=179)	Waiting list (n=40)
Age (years)*	54.5 ± 13.1	55.8 ± 12.8	48.6 ± 13.1
Sex: female {n/N(%)}	94/219 (42.9)	76/179 (42.5)	18 (45.0)
Country of origin			
Netherlands	203/219 (93.1)	164/179 (92.1)	39/40 (97.5)
Other	15/218 (6.9)	14/179 (7.9)	1/40 (2.5)
Civil status			
Married	145/217 (66.8)	120/177 (67.8)	25/40 (62.5)
De facto union	17/217 (7.8)	12/177 (6.8)	5/40 (12.5)
Partner, not living together	8/217 (3.7)	6/177 (3.4)	2/40 (5.0)
No partner	33/217 (15.2)	26/177 (14.7)	7/40 (17.5)
Divorced	7/217 (3.2)	6/177 (3.4)	1/40 (2.5)
Widow	7/217 (3.2)	7/177 (4.0)	0/40 (0.0)
Highest education achieved			
Lower vocational education or primary school	53/216 (24.5)	47/177 (26.6)	6/39 (15.4)
Intermediate vocational education	99/216 (45.8)	80/177 (45.2)	19/39 (48.7)
Higher vocational education or university	64/216 (29.6)	50/177 (28.2)	14/39 (35.9)
Occupation			
Full-time/part-time job	56/208 (26.9)	42/169 (24.9)	14/39 (35.9)
Retired	55/208 (26.4)	49/169 (29.0)	6/39 (15.4)
Partial or complete incapacity to work	58/208 (27.9)	44/169 (26.0)	14/39 (35.9)
Other†	39/208 (18.8)	34/169 (20.1)	5/39 (12.8)
Liver disease (before transplantation)			
Acute hepatic failure	13/219 (5.9)	13/179 (7.3)	0/40 (0.0)
Non-cholestatic cirrhosis	76/219 (34.7)	59/179 (33.0)	17/40 (42.5)
Cholestatic cirrhosis	73/219 (33.3)	55/179 (30.7)	18/40 (45.0)
Metabolic disease	23/219 (10.5)	22/179 (12.3)	1/40 (2.5)
Hepatocellular carcinoma	18/219 (8.2)	17/179 (9.5)	1/40 (2.5)
Congenital pediatric liver disease	4/219 (1.8)	3/179 (1.7)	1/40 (2.5)
Miscellaneous	12/219 (5.5)	10/179 (5.6)	2/40 (5.0)
Liver transplantation in the past	187/219 (85.4)	179/179 (100)	8/40 (20.0)
Time since (last) liver transplantation, years	6.5 ± 3.1	6.4 ± 3.1	9.4 ± 4.2 (n=8)
Time on waiting list, months	NA	NA	34.9 ± 43.2

The data are presented as n/total n (%).
*The data are presented as means and standard deviations.
†Student, volunteer, job seeker, etc.

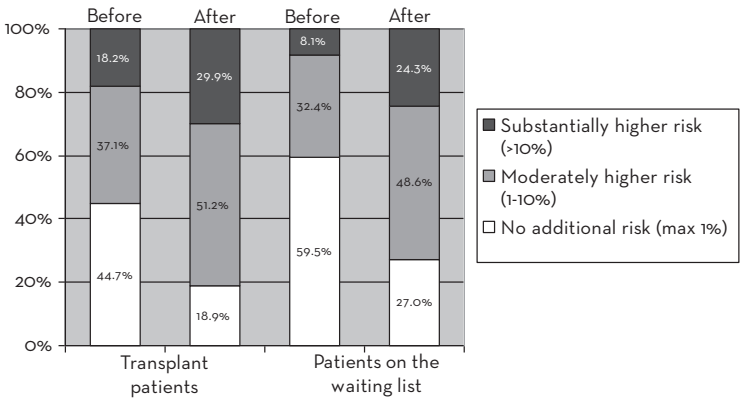

Figure 1. Risk of disease transmission that is viewed as acceptable: acceptable risk of disease transmission before and after the receipt of information about the 15% waiting-list mortality rate. No differences were observed between transplant patients and patients on the waiting list for liver transplantation

Table 3. Number of patients wishing to be informed about donor-related risks

Information about:	Overall	After transplantation	Waiting list	*P* value
Increased risk of infectious disease transmission	150/204 (73.5)	115/166 (69.3)	35/38 (92.1)	0.02
Increased risk of malignant tumor transmission	154/206 (74.8)	120/168 (71.4)	34/38 (89.5)	0.06
Increased risk of developing bile duct strictures	122/204 (59.8)	95/166 (57.2)	27/38 (71.1)	0.27
Increased risk of early graft failure*	143/204 (70.1)	109/166 (65.7)	34/38 (89.5)	0.02

NOTE: the data are presented as numbers and percentages.
* Re-transplantation was required within 2 weeks after transplantation

or early graft failure, respectively. No significant differences were found between subgroups based on age, sex, level of education (low/intermediate/high), country of origin (Netherlands/other) or civil status (living alone/living with partner). However, in comparison with transplant patients, significantly more waiting-list patients wished to be informed about donor-related risks (Table 3).

Preferred time for providing donor-related risk information

Approximately half of the patients (53.3%) wished to be informed at the time of the organ offer, 18.8% of the patients preferred to be informed after the transplant procedure, and 27.7% did not wish to be informed at all. Significantly more waiting-list patients wished to be informed at the time of organ offer (71.1%) in comparison with transplant patients (49.4%, $P = 0.02$; Figure 2). Younger patients (<40 years) wished to be informed at the time of the organ offer more often (70.3%), than older patients (55.6% for patients 41-60 years old and 44.0% for patients >60 years old). More pa-

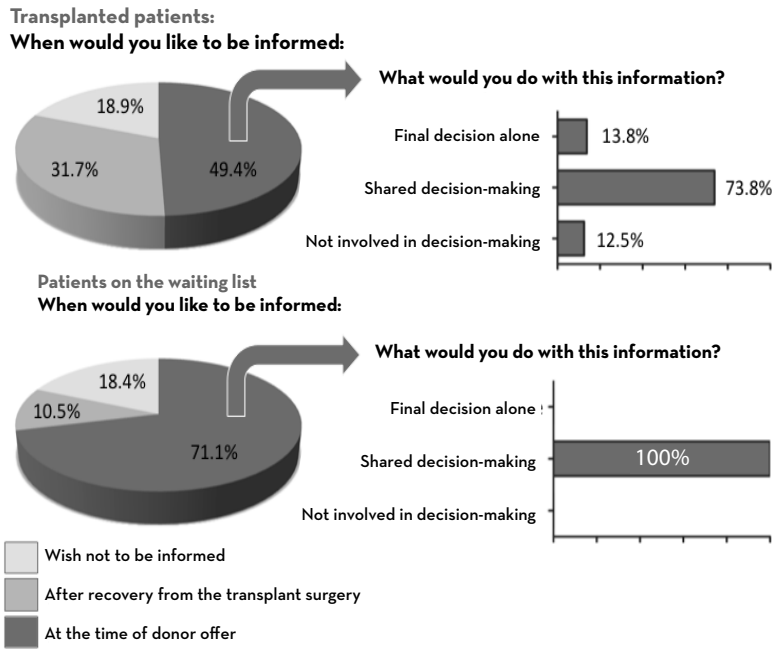

Figure 2. Timing and results of providing donor-related risk information. The majority of the patients wanted to be informed about donor-related risks at the time of organ offer (pie charts on left) and wished to be involved in the decision-making process (bars graphs on right).

tients with a lower level of education preferred not to be informed at all (43.8%) in comparison with intermediately educated patients (25.5%) or more highly educated patients (16.9%, $P = 0.03$). No significant differences were found between subgroups based on sex, country of origin (Netherlands/other), or civil status (living alone/living with partner). In comparison with waiting-list patients, significantly more transplant patients indicated that they would feel worried if donor-related risk information were provided at the time of organ offer (59.5% versus 39.5%, $P = 0.048$) and that they would feel overwhelmed (39.2% versus 18.4%, $P = 0.047$).

The patient's role in the decision process

All respondents who wished to be informed about donor-related risk at the time of organ offer were asked whether they wished to be actively involved in the decision-making process for accepting or declining the liver for transplantation. Overall, 79.8% of the respondents preferred shared decision-making, 10.6% wished to make the final decision alone, and only 9.6% did not want to be involved in the decision-making process. No significant differences were found between subgroups based on age, sex, level of education (low/intermediate/high), country of origin (Netherlands/other), or civil status (living alone/living with partner). As presented in Figure 2, significantly more

waiting-list patients wished to be involved in shared decision making (100%), when compared to transplant patients (73.8%, *P* = 0.02).
Patients were asked whether they want to be able to exclude certain groups of donor livers before they were listed for transplantation. Only 21.6% of the transplant patients and 31.6% of the waiting-list patients wished to be able to exclude certain groups of donor livers, before they were listed for transplantation. No differences were found between the aforementioned subgroups.

Presented cases

Finally, 2 potential donor cases were presented: a healthy 18-year-old previous heroin user who had tested negative for HIV and a healthy 81-year-old donor. Only 19.4% of all patients judged the risk of disease transmission associated with accepting the liver from the 18-year-old donor to be high. Similarly, only 16.5% of the patients judged the risk of potential nonfunction for the 81-year-old liver to be high. If the respondent's own condition were deteriorating, no less than 74.3% would accept the liver from the 18-year-old previous heroin user, and 73.1% would accept the liver from the healthy 81-year-old donor. If the respondent's own condition were moderately stable, still 40.7% would accept the 18-year-old liver, and 39.2% would accept the 81-year-old liver (Table 1).
In the case of the healthy 18-year-old previous heroin user, no significant differences were found between subgroups based on patient status (waiting list/transplant), age, level of education (low/intermediate/high), country of origin (Netherlands/other) or civil status (living alone/living with partner). However, significantly more male respondents were willing to accept this 18-year-old liver in comparison with female respondents: 50.4% versus 27.5% (*P* <0.001) if the respondent's condition were moderately stable and 80.5% versus 65.9% (*P* = 0.05) if the respondent's condition were deteriorating. In the case of the healthy 81-year-old donor, no significant differences were found between the aforementioned subgroups.

DISCUSSION

Various ideas about the patient's role in decision-making and the timing and extent of informed consent in transplantation have been proposed and discussed in literature by medical professionals.[5-9,16] This is the first study revealing the opinions of liver patients on these issues. The 4 main findings are as follows: (1) most liver patients want to be informed about donor-related risks, (2) half of the liver patients want to be informed at the time of organ offer, (3) the majority of these patients wish to participate in making decision to accept or decline a potential donor liver, and (4) liver patients are willing to accept a relatively high risk of disease transmission and graft failure in comparison with the risk commonly accepted by physicians.
The vast majority of patients (59.8%-74.8%) want to be informed when the donor-related risk of infectious disease, a malignant tumor, bile duct strictures, or early graft

failure is increased. The need for a full, clear, and frank explanation about general and donor-specific risks of transplantation is supported in the literature.[7,9] Moreover, better-informed patients may establish more realistic expectations, which in turn have been shown to improve postsurgical health outcomes and decrease legal claims.[10,17] This finding also supports the call for the standardization of informed consent before placement on the waiting list, which would promote the autonomy of recipients by helping to ensure that they are informed of all relevant donor risk factors.[6]

Interestingly, for more than 50% of the patients, the preferred timing of donor-related risk information is at the time of organ offer. Additionally, more than 90% of those patients want to be involved in making the decision to accept or decline a potential donor liver (shared decision making). This confronts medical teams with a dilemma: on one hand, the principles of patient autonomy and dignity require nothing less than complete disclosure, especially when potentially risky therapies are being offered,[16] but on the other hand, the disclosure of donor-specific risks requires extra time precisely when time is at a premium (during organ offer), and this could, therefore, prevent the optimal use of the organ supply.[6]

A suggested alternative to informed consent and shared decision making at the time of organ offer is to give patients the opportunity to accept or decline ECD organs as a group before transplantation.[6] However, a classification of organs into 2 groups might be inaccurate, because some of the standard organs would not be acceptable for certain recipients and not all ECD organs are of equal quality and risk.[8] It has, therefore, been suggested that ECD organs be classified in several groups, but it is still questionable whether the patient can understand the impact of these risks and make a good decision, especially because the patients' own medical condition is a dynamic process that will change his or her willingness to accept ECD livers, as shown in this study. Only a quarter of the patients in this study wished to be able to exclude certain groups of donor livers before they were listed for transplantation.

It is recognized that shared decision making may not suit all types of patients. Studies of shared decision making have found that patients with more serious or life-threatening illnesses and those for whom there are no alternative treatments do not wish to participate in the decision-making process.[18] In contrast to renal patients, patients with end-stage liver disease have no effective medical alternatives to transplantation such as dialysis. Interestingly, this study showed that the majority of the liver transplant patients actually did want to be involved in shared decision making at the time of organ offer.

This study also showed that patients are willing to accept a relatively high risk of disease transmission and potential graft failure, especially when their clinical situation is deteriorating. Previous studies have shown a similar high willingness of patients to accept donor-related risks such as ECD donor livers or donor kidneys at risk for viral infections.[19,20] Interestingly, we noticed that informing the patients of the 15% waiting-list mortality rate significantly increased their willingness to accept more donor-related risk. This suggests that providing information affects the decision-making process. Providing standardized information on the risks and benefits of the different types of ECD donor transplantation at the time of waiting-list registration, potentially in combination with comprehension assessment tools and e-health educational tools, might enable

liver patients to participate in shared decision making at the time of organ offer. Decision aids have been demonstrated to affect long-term behavior and appear to promote informed decision-making.[21]

A potential bias could reside in the fact that we do not know whether the nonresponders to this questionnaire would have given the same answers to the questions in comparison with the responders. We did, however, compare responder and nonresponder characteristics, and we found no significant differences with respect to sex, liver disease, or time since transplantation. On the other hand, non-responders were approximately 8 years younger. During the study period, 2 non-responders died, and 1 was admitted to the hospital.

This study is clinically relevant to anyone who is involved in transplantation. Decisions concerning the patient's role in decision making and the timing and extent of informed consent in transplantation need to be made by every transplant center. Both the physician's opinion and the patient's opinion on these issues should be taken into consideration. Standardization of both the information about the different donor types provided before patient listing and shared decision-making at the time of organ offer is important for providing the same opportunities and care to every patient. We are aware that the results of the current study only represent the opinion of liver patients in the Netherlands. This study was undertaken at a transplant center in the north of the Netherlands, an area that is known to be more culturally homogeneous than transplant centers in the south of the Netherlands. The opinion of patients elsewhere in the world could be different. We hope that this study stimulates other transplant centers to perform a similar survey to reveal the local need for information and involvement of patients in the decision-making process surrounding liver transplantation.

In the case of deceased donor liver transplantation, decisions often have to be made quickly, and the risks and benefits are difficult to explain fully at the time of an organ offer. The involvement in shared decision making should be consistent with patient preferences; the process of involvement may be as important as who eventually makes the decision.[11,22] On the basis of the results of this study, we suggest that information on risks related to SCD and ECD transplantation be provided in detail to all patients listed for transplantation. Moreover, patients who want to be informed and involved in shared decision making at the time of the organ offer should be identified at the time of listing for transplantation. Accordingly, these patients should receive additional information and potentially decision aids to allow shared decision making at the time of the organ offer.

In conclusion, the questionnaire presented in this paper provides unique information on the opinion of liver patients on donor-related risks. The majority of respondents wished to be informed about donor-related risks and wanted to be involved with shared decision making at the time of organ offer. Implementing this knowledge and standardizing the content, the manner of transfer, and the amount of information that we provide to our patients at different time points during the transplant allocation process will be important for providing the same opportunities and care to every patient on the waiting list.

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