ORIGINAL ARTICLE

Patients' preferences in transplantation from marginal donors: results of a discrete choice experiment

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SUMMARY

To increase the donor pool, the strategy of transplantation from "marginal" donors was developed though patients' preferences about these donors were insufficiently known. The preferences of patients registered on the waiting list or already transplanted in eight transplant teams covering four main organs (i.e., kidney, liver, heart, and lung) were evaluated using the discrete choice experiment method. In each center during 2 days, patients were interviewed on four scenarios. Of 178 eligible patients, 167 were interviewed; 40% accepted marginal graft in their own situation and 89% at least in one of the scenarios. Imagining urgent situations or rare profiles with difficult access to transplantation, respectively, 86% and 71% accepted these grafts. Most (76%) preferred to be informed about these grafts and 43% preferred to be involved in decision. The emergency [OR = 1.24; 95% CI: (1.06–1.45)] and the hazardousness [OR = 0.88; 95% CI: (0.78–0.99)] of the transplantation were factors independently associated with marginal graft acceptance. Most patients preferred to be informed and to be involved in the decision. Marginal grafts could be more accepted by patients in critical medical situations or perceiving their situation as critical. Physicians' practices in transplantation should be reconsidered taking into account individual preferences. This study was performed in a single country and thus reflects the cultural bias and practice thereof.

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Key words
information to provide to patient, marginal donor, marginal graft, patients' preferences, shared decision

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Introduction

The current organ shortage is well established especially for kidney and liver transplantations [1,2]. To increase the donor pool, the strategy of accepting so-called marginal donors whose organs would have been considered unsuitable before was developed in most countries

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[3–5]. These donors are also referred as "expanded" or "extended" criteria donors.

The Declaration of Alma Ata [6] stated that "The people have the right and duty to individually and collectively participate in the planning and implementation of their health care". Patient involvement is widely advocated to improve patient satisfaction and relationships with healthcare professionals [7,8] because patient may give different and complementary perspectives to those of professionals [7].

During the transplantation process, physicians must often choose between transplanting a patient with a marginal graft as soon as possible and waiting for a standard graft that might arrive too late.

For involving patients in the decision, we should firstly inform them about "marginal" grafts. Informing patients about this type of grafts is a delicate subject and is not currently practiced in every transplant centre. Patients on transplant waiting list are subject to significant stress. We thus decided to create an indirect questionnaire, avoiding additional stress but allowing evaluating patients' reactions and the possibility of their participation in the real situation of transplantation from marginal donor in the future.

We hypothesized that some patients preferred to be transplanted, as soon as possible, even with a marginal graft than waiting for a standard graft that might arrive too late and that most patients wanted to be informed about these grafts and involved in a shared decision with their physicians.

Our objectives were (i) to know whether or not patients wanted to be transplanted with organs from marginal donors; (ii) to identify the situations in which patients would accept these grafts; and (iii) to assess patients' preferences on the type of information about the benefits and risks of marginal grafts and on their involvement into the decision-making process.

Materials and methods

Pilot study

Through a systematic review [9–19], we identified four scenarios explored by the discrete choice experiment method. The questionnaire was validated by a pilot study. This pilot study was a single-center survey to evaluate if patients easily answered to the question of whether or not they would accept a marginal graft. Ten patients attending the outpatient consultation of one liver transplant team in Paris were questioned on February 27, 2014.

Design

A cross-sectional survey was conducted from April 2 to December 3, 2015, among the patients of eight transplant teams (Fig. 1) covering four main organs (i.e., kidney, liver, heart, and lung). For 2 days, all eligible patients from each center were interviewed using a structured questionnaire (Appendix 1).

Setting

For each organ, a transplant team located in Paris and another in another French region were chosen. Actually, the number of transplants performed in the Paris region is more important than in the other regions but it was decided to have a representative sample of other regions as well. The selected transplant teams were among those performing the greatest number of transplants [1]. The agreement of their medical or surgical physicians, heads of transplant activity to participate in the survey was collected during a previous study.

Population

The eligible patients were every patient older than 18 years registered on the National Waiting List (NWL) or patients already transplanted since the age of 18 and who were attending outpatient consultations. Both the physician in charge of the patient's care and the investigator explained to patients the objectives of the study guaranteed that the survey would not lead to a change in care and explained the possibility for patients to refuse to participate. Questionnaires were anonymous. We obtained no-opposition statements from patients. This procedure was approved by an ethics committee (CPP Ile de France III).

Patients with understanding difficulties, and the foreign patients not speaking French, were excluded (Fig. 2).

Data collection

The interviews were conducted by a single investigator in an enclosed area to ensure confidentiality. The number of eligible patients who were not interviewed was recorded by the investigator.

Questionnaire

We defined the risk factors for recipients of a marginal graft as either an increased risk of graft dysfunction

Transplant International 2017; 30: 589–602

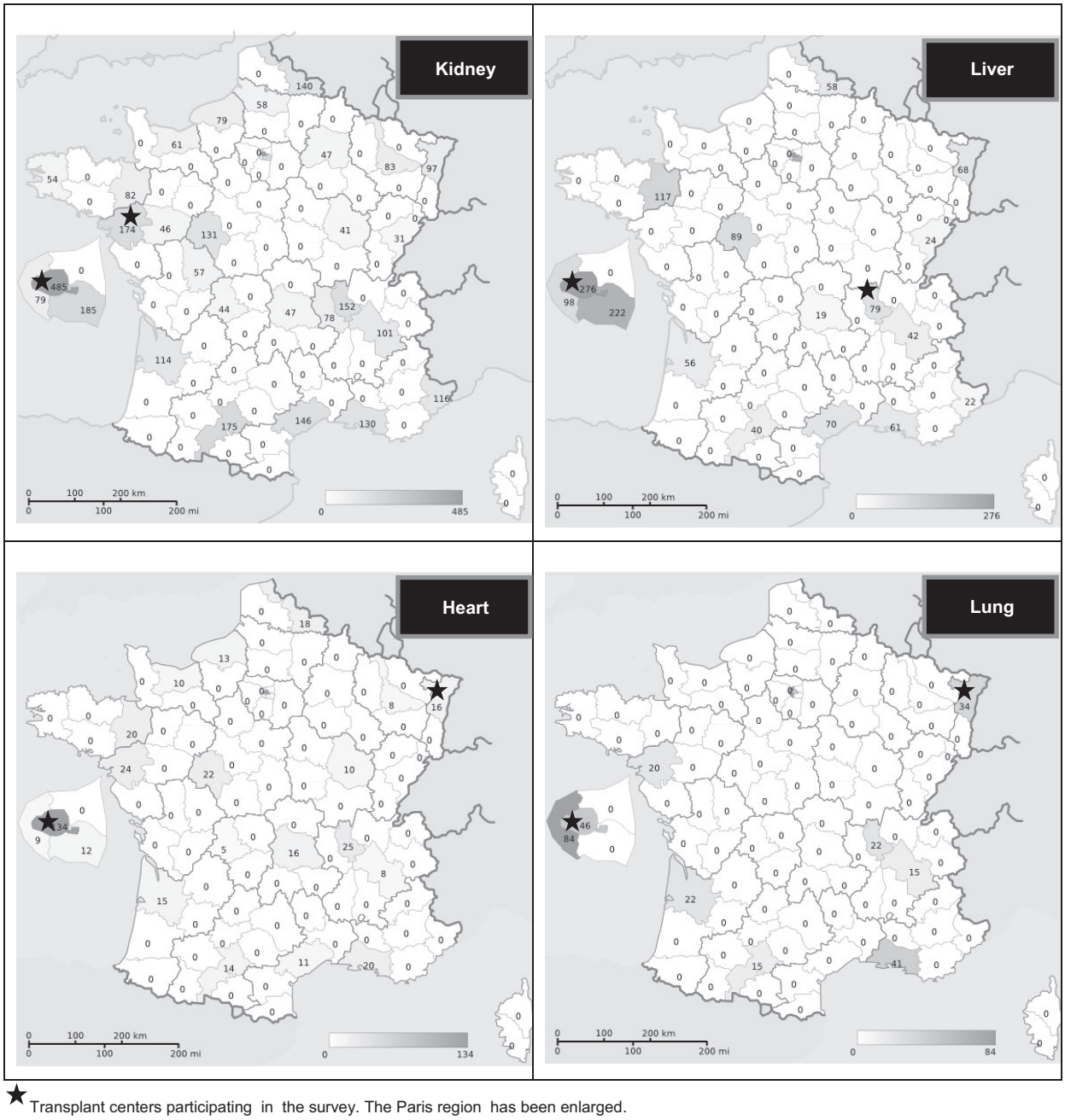

Figure 1 Distribution of transplants performed in France in 2013 with regard to administrative area and to the transplant centers participating in the survey.

(i.e., expanded criteria donor defined by the United Network for Organ Sharing (UNOS) [5], non-heart-beating donation [20], extended cold or warm ischemia time, split liver transplantation [21]), or an increased risk of infectious [22] or cancerous diseases transmission.

The first part of the questionnaire explored patients' preferences for being or not being transplanted with a marginal graft using discrete choice experiment method [23–26] in four scenarios: (i) current medical situation of the patient (real situation of the patient that remain unknown of the investigator [i.e., not asked]), (ii) urgent situation in which the lack of transplantation could have serious consequences for the patient, (iii) urgent situation in which the patient belongs to the top ten of the NWL, (iv) nonemergency situation in which the patient has a rare profile resulting in difficulties to find a compatible graft.

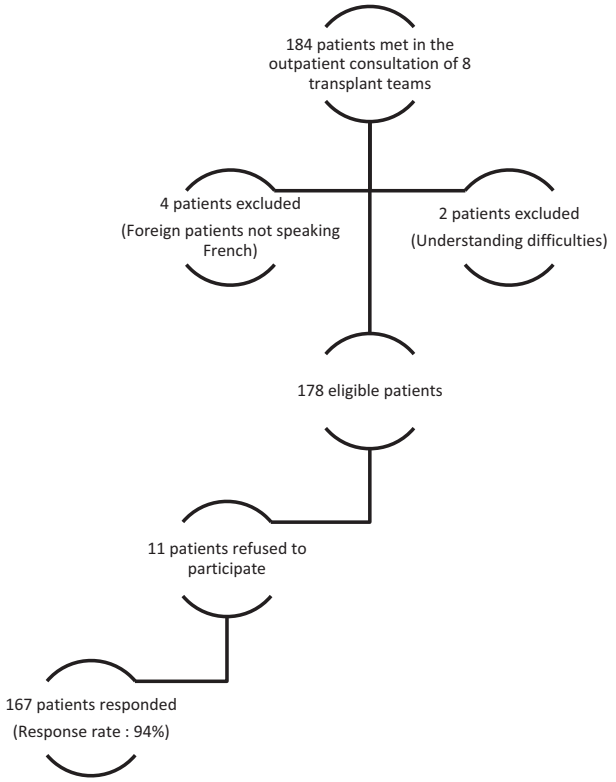

Figure 2 Description of the population.

The second part of the questionnaire explored patients' preferences on being informed about the existence of marginal grafts, on how this information should be provided and on their involvement in the decision-making process.

The third part asked about demographic data and evaluated patients' perception about the degree of emergency for and the hazardousness of their transplantation using numerical scales going from 0 to 10.

Definition of variables

Patients were categorized according to:

1. Their organ type into four groups. Patients with multi-organ transplants were classified according to the organ transplant center in which they were interviewed.
2. Their age into two groups: higher or lower than the mean age.
3. Their transplant situation into two groups: transplanted patients or patients on the NWL.

Waiting time was measured in months from registration on the NWL to the time of the interview for patients not already transplanted, from registration on the NWL until transplantation for transplanted patients, and average waiting time was used for patients transplanted several times of the same organ.

Statistical analysis

All questionnaires were analyzed (even if incomplete). Descriptive statistics were mean (SD: standard deviation) or median (range) for quantitative data and percentages for categorical data. Percentages were calculated on the basis of the number of answers by question.

Three different outcomes defining patients' preferences were used:

Patients not ready to accept a marginal graft in any scenario (versus patients ready to accept a marginal graft at least in one of the scenarios);

Patients ready to accept a marginal graft in their current medical situation (scenario 1 versus patients not ready);

Patients preferring to be informed about marginal grafts (versus patients not preferring);

Student's *t*-test and chi-square test were used to assess univariate relationship between outcomes and the following factors: gender, age (>55 years), degree of emergency for and hazardousness of their transplantation, waiting time, transplant situation, organ type, time since last transplantation (for transplanted patient, this variable was not included in multivariate analysis).

Missing data were treated by multiple imputations by chained equation assuming the missing data to be missing at random. Predictive mean matching was used for imputing quantitative variable with $m = 20$ imputations. The covariates used to generate the multiple imputed data sets were gender, age, degree of emergency for and hazardousness of transplantation, waiting time, transplant situation, organ type, and the three outcomes.

After completion, all studied factors were entered is an explanatory logistic models to identify independent factors associated with each outcome defining patients' preferences (full model). A backward selection algorithm was applied to each imputed dataset to select variables for reduced model. Variables that appeared in at least 12 of 20 models (60%) were retained. All analyses were adjusted on organ type and transplant situation (these variables were forced for each model). Results of full (before backward selection) and reduced (after backward selection) models were expressed as odds ratios (ORs) with their 95% confidence intervals (95% CI). *P* values <0.05 were considered statistically significant. All statistical analyses were performed using SAS software version 9.4 (SAS Institute Inc., Cary, NC, USA).

Results

During the pilot study, patients completed the questionnaire in 5.75 min on average. Following this study, it was decided to replace the self-administered questionnaire by an interview with structured questionnaire. Patients easily answered to the questionnaire. The questionnaire was improved thanks to this study and thanks to several contacts with experts in discrete choice experiment method. The term "marginal graft" was replaced by another term (i.d. nonoptimal graft). Two parts were added to the questionnaire to evaluate patients' preferences to be informed and involved in the decision process of transplantation.

Among the 178 eligible patients, 167 (response rate: 94%) participated over 16 days. Eleven patients refused to participate (Fig. 2).

The sociodemographic and clinical characteristics of the respondents are detailed as well as their feelings with regard to transplantation (Table 1). Respondents lived in 20 regions of France and were followed by eight transplant teams. Six patients had multi-organ transplants and 11 were transplanted several times for the same organ. Among the 27 patients registered on the NWL, three had already been transplanted once.

Table 1. Distribution of sociodemographic and clinical characteristics of the patients, and patients' feelings with regard to transplantation.

Age	*N* = 167
Mean (SD)	55 (13.73)
Median (extreme values)	58 [19–90]
Gender	*N* = 167
Male	109 (65%)
Female	58 (35%)
Transplant situation	*N* = 167
Transplanted patient, *n* (%)	140 (84%)
Registered on the NWL	27 (16%)
Organ type, *n* (%)	*N* = 167
Kidney	60 (36%)
Liver	50 (30%)
Heart	28 (17%)
Lung	29 (17%)
Waiting time (month)*	*N* = 165
Mean (SD)	14.1 (21.2)
Median (extreme values)	8.0 [2.0–18.0]
Time since last transplantation (years)	*N* = 143
Mean (SD)	5.9 (7.1)
Median (extreme values)	4.0 [0.0–9.0]
Transplantation emergency (0–10)	*N* = 166
Mean (SD)	7.3 (2.4)
Median (extreme values)	8.0 [5.0–10.0]
Transplantation hazardousness (0–10)	*N* = 162
Mean (SD)	3.3 (3.0)
Median (extreme values)	3.0 [0.0–5.0]

*For patients transplanted several times for the same organ type, the average waiting time was used.

Patients' preferences

Forty percent accepted a marginal graft in their own situation but imagining urgent situation or a rare profile with difficult access to transplantation, most accepted a marginal graft. Among the respondents, 28% accepted these grafts in all of the scenarios proposed (Fig. 3).

Of 167 respondents, 149 (89%) were ready to accept a marginal graft at least in one of the scenario, 127 (76%) preferred to be informed about it, and 72 (43%) preferred to be involved in the decision-making process of whether or not to accept a marginal graft (Table 2).

Among 127 patients preferring to be informed, 85 (67%) preferred to receive detailed information on each potential risk: 56 of 127 (44%) preferred this detailed piece of information to be provided during the first pretransplant consultation while 29 of 127 (23%) preferred it to be provided during a subsequent consultation. In contrast, 42 of 127 (33%) preferred to receive general information: 25 of 127 (20%) preferred it to be received during the first pretransplant consultation and 17 of 127 (13%) preferred general information to be provided during a subsequent consultation. Of 127 patients, 47 (37%) preferred to be informed orally, eight (6%) by written documents, and 72 (57%) both ways.

Among 72 patients preferring to be informed and involved in the decision-making, 67 (93%) preferred a shared decision-making process with their physicians and 39 (54%) preferred their transplant nurse coordinator to participate as well in this shared decision-making process. Four patients (6%) preferred to decide alone after being informed. One patient (1%) could not decide between a shared decision-making process with health professionals and deciding alone.

Factors associated with patients' preferences

In univariate analysis, some factors were associated with marginal graft acceptance in patients' current medical situation (Table 3). The transplanted patients were more ready than the others to accept a marginal graft. The type of graft was not statistically associated ($P = 0.069$) but the patients of liver and heart transplant teams tend to accept marginal graft in their current medical situation more than kidney and lung patients. After adjustment on organ type and transplant situation, two factors remained

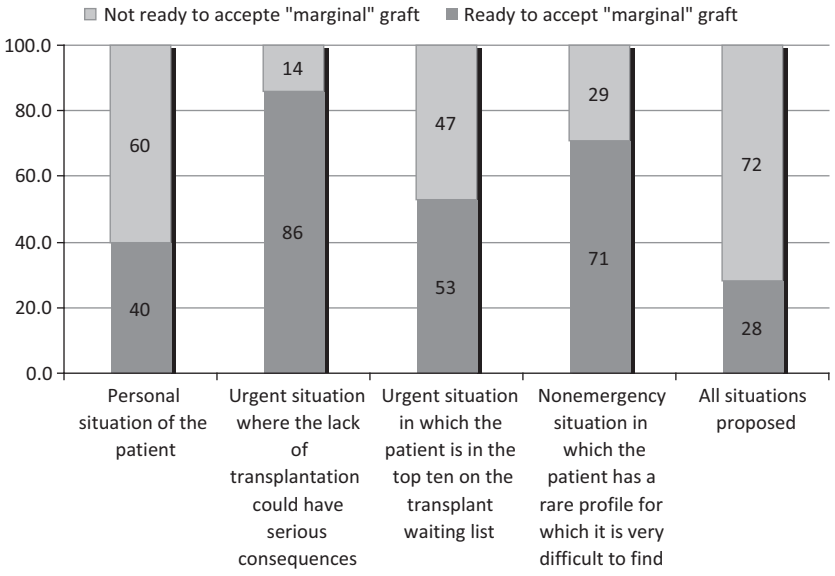

Figure 3 Distribution of patients' preferences to accept or not a marginal graft according to various situations.

Table 2. Distribution of patients' preferences to accept or not a marginal graft, to be informed about this type of graft and to be involved in the decision-making process.

	Patients' preferences to be informed and involved in the decision-making process (%)	Patients' preferences to be informed but not to be involved in the decision-making process (%)	Patients' preferences not to be informed (%)	Total (%)
Patient ready to accept a marginal graft at least in one of the scenarios	66 (39)	49 (29)	34 (20)	149 (89)
Patient ready to accept a marginal graft in any scenario	6 (4)	6 (4)	6 (4)	18 (11)
Total	72 (43)	55 (33)	40 (24)	167 (100)

independently associated with marginal graft acceptance in the patient own situation (OR obtained from full and reduced model were concordant): positively the emergency of the transplantation [OR = 1.24; 95% CI: (1.06–1.45)] and negatively the hazardousness of transplantation [OR = 0.88; 95% CI: (0.78–0.99)]. The most urgent and the less hazardous the transplantation was felt by a patient; the most likely he or she would be to accept a marginal graft.

In univariate analysis and multivariate analysis, no factors were statistically associated with patients ready to accept a marginal graft in any situation (Appendix 2) or with patients preferring to be informed about marginal grafts (Appendix 3).

Discussion

We evaluated patients' preferences for accepting or not a marginal graft, for being informed about this type of graft, and for being involved in the decision-making process. Other studies [27–29] were performed about information to propose to patients with regard to marginal donors. For the first time, our study used scenarios to evaluate patients' preferences with regard to transplantation of four types of organ in a multicenter survey. We paid a special attention to the survey method because informing patients about this type of grafts was not currently practiced in most European transplant centers. Patients are especially vulnerable because already exposed to the important stress of the transplant process. The discrete choice experiment method, never used before in this field, allowed us to indirectly question patients without increasing their anxiety thanks to the use of scenarios. Patients easily answered to the questionnaire. This result was also found in a Swedish study [29]. Most patients thought it was easy to make a decision about accepting a kidney from a marginal donor and that it was correct to be asked about it.

Transplant International 2017; 30: 589–602

Table 3. Comparison of patients ready to accept a marginal graft in their current medical situation with patients not ready to accept this type of graft in their current medical situation.

	Ready to accept a marginal graft in their current medical situation (*N* = 66)	Not ready to accept a marginal graft in their current medical situation (*N* = 101)	*P**	OR (95% CI) Full model	OR (95% CI) Reduced model	*P*†
Age (≥55 years), *n* (%)	42 (63.6%)	59 (58.4%)	0.50	0.96 (0.47;1.96)	–	–
Male, *n* (%)	47 (71.2%)	62 (61.4%)	0.19	1.67 (0.80;.3.49)	–	–
Transplanted patient, *n* (%)	60 (90.9%)	80 (79.2%)	0.047	1.85 (0.65;5.31)	1.81 (0.65;5.06)	0.17
Organ type, *n* (%)						
Kidney	19 (28.8%)	41 (40.6%)		1	1	
Liver	26 (39.4%)	24 (23.8%)		1.53 (0.62;3.80)	1.83 (0.77;4.33)	0.26
Heart	13 (19.7%)	15 (14.9%)	0.069	0.98 (0.33;2.91)	1.38 (0.50;3.80)	0.17
Lung	8 (12.1%)	21 (20.8%)		0.50 (0.17;1.49)	0.61 (0.21;1.73)	0.35
Waiting time (month)‡, mean (SD)	10.5 (13.1)	16.4 (24.9)	0.079	0.99 (0.96;1.01)	–	–
Time since last transplantation (years)§, mean (SD)	6.1 (6.9)	5.8 (7.4)	0.792	–	–	–
Transplantation emergency (0–10), mean (SD)	8.1 (2.1)	6.9 (2.5)	0.001	1.22 (1.05;1.44)	1.24 (1.06;1.45)	0.008
Transplantation hazardousness (0–10), mean (SD)	2.7 (2.7)	3.7 (3.1)	0.028	0.87 (0.77;0.98)	0.88 (0.78;0.99)	0.033

OR, Odds ratio; 95% CI, 95% confidence interval.

**P*-value from chi-square tor *t*-test.

†*P*-value from Wald test after multiple imputation.

‡For patients transplanted several times for the same organ type, the average waiting time was used.

§Time since last transplantation was not included in multivariate analysis.

Our main findings were that 89% of patients were ready to accept a marginal graft at least in one of the scenarios proposed, 76% preferred to be informed about these grafts but only 43% preferred to be involved in the decision-making process.

Op den Dries and *al.* [28] performed a survey, among liver transplant recipients and patients on waiting list at one transplant center in the Netherlands. Similar to our study, the majority of the patients wanted to be informed about donor-related risks. However, preferred timing for being informed about donor-related risks was the time of the organ offer for 53.3% of the patients. Taking into account transplant context in which decisions often have to be made quickly, it seems very difficult to explain the risks and benefits to a patient with high level of stress before transplant. According to our study, most of patients wanted to be informed during the first consultation in transplant center and some during a subsequent consultation.

Various studies [30–35] confirmed that most patients wanted to be informed, but their preferences for being involved in decision-making processes could vary with regard to the context of the study. A study in the United States [31] categorized patients with regard to their preferences for deliberating with their doctor in "deliberative" or "nondeliberative" cells. This same study also clustered their preference in keeping or not the decisional control in the selection of their treatment between "autonomists" and "delegators". The deliberative autonomists were the most numerous group. We found similar results in our study.

The study Op den Dries and al. [28] 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. In our study, patients' preferences on acceptance of a marginal graft varied widely according to the scenario proposed. Patients' preferences depended not only on their

medical situation but also on their own perception of this situation. We found that the most urgent and the less hazardous the transplantation was felt by the patient; the most likely he or she would be to accept a marginal graft.

The question is whether information about marginal graft should be proposed systematically to all patients who prefer to be informed or only to a specific group of patients with some clearly defined characteristics. It seems to us ethical to systematically propose information about the existence of marginal grafts to future recipients who want to be informed [36]. However, 24% of patients did not want to be informed about marginal grafts. This legally defined [36] right must be respected.

At this step, two patient groups may be defined at the time of registration on the NWL: those being in a critical situation (i.e., urgent or rare profile) (group 1) and those not being in a critical situation (group 2). A patient of group 2 could belong to group 1, later on.

Proposing a marginal graft to patients of group 2 who accept any type of graft could not be ethical, while their medical situation allows waiting. Marginal grafts should be proposed only to patients of group 1 anticipating that a standard graft could not be quickly available. Patients should provide an informed consent. Patients of group 2 could be informed about the existence of marginal grafts and should be asked about their opinion on the choice for a marginal graft. Their opinions should be registered in their records, because their medical situation could worsen.

Limits

Our study has some limitations. First, our survey was conducted in outpatient consultations of eight transplant teams. Therefore, we could lack national representativeness. However, these are the teams performing the most transplants in France and their patients come from 20 regions of France.

Second, the answers of some patients were based on their understanding and their capability in imagining/projecting into different situations explained by scenarios. However, a large part of them had already experienced the transplantation process.

Third, as patients interviewed in kidney and liver outpatient consultations were more numerous than patients in heart and lung consultations, this could lead to a lack of reliability in the comparison between organs.

Fourth, information on psychological and socio-professional situations was intentionally not collected for not leading patients to feel some discrimination. However, these factors might influence patients' preferences with regard to being informed about marginal grafts and to being involved into the decision-making process.

Fifth, this study was performed in a single country (France), and thus reflects the cultural bias and practice thereof.

Conclusion

Our study found that a marginal graft could be more accepted by patients who are in a critical medical situation or who perceive it as such.

Therefore, we propose to give patients with a critical situation the choice between acceptance of a marginal graft with a short waiting time and a reduced mortality risk on the NWL and long waiting time for a standard graft that usually works best than a marginal graft but could be available too late or never. Detailed and both oral and written information about marginal grafts should be provided to every patient, except those who do not want it.

In addition, patients should be clearly informed that those accepting a marginal graft have the same opportunity than others to be transplanted with a standard graft. The only difference is that they will have a better chance to be transplanted more quickly.

In conclusion, the patients should be better informed and more involved in the decision process but all patients' preferences cannot always be guiding for medical policies. Health professionals and patients should make a choice through a shared decision-making. The professionals may also against patient's preferences, help and convince, and educate them to take part in the decision.

Authorship

SK: made substantial contributions to conception and design of the study, acquisition, statistical analysis and the interpretation of data and drafted the manuscript. FC: participated in the design and the interpretation of data and revising the work critically for important intellectual content and helped to draft the manuscript. M-PP: participated in the interpretation of data and in revising the work critically for important intellectual content. GB: performed the statistical analyses and participated in the interpretation of data. YC: made substantial contributions to the conception and design of the study and the interpretation of data and revised the work critically for important intellectual content. GV-T: made substantial contributions to the conception and

Transplant International 2017; 30: 589–602

design of the study and interpretation of data and helped to draft the manuscript and also revised the work critically for important intellectual content and gave final approval of the version to be published. All authors: read and approved the final manuscript.

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Conflicts of interest

The authors declare no conflict of interests.

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APPENDIX 1. TRANSINFO Project

agence de la biomédecine

Société Francophone de Transplantation

This survey is anonymous and does not influence the process of your care. It takes place in the context of a scientific study under the sponsorships of the French National Agency for Transplantation (Agence de la Biomédecine) and the French speaking Transplantation Society (Société Francophone de Transplantation). Its objective is the evaluation of patients' preferences between two different processes of transplantation.

In this questionnaire, for each question, you must choose between two options, A or B, the one that seems the most interesting to you.

We thank you kindly to put yourself in the situation when you have been registered on the National Waiting List.

(1) Which situation would you choose

Situation A	Situation B
Waiting time on the list: Short	Waiting time on the list: Long
The priority of your transplant center: transplanting you with the first compatible graft available	The priority of your transplant center: transplanting you with the best quality possible graft
The proposed graft: either an optimal graft or a non-optimal graft	The proposed graft: an optimal graft
In case of a transplantation with a non-optimal graft, it may function with delay or non-optimally	In case of a transplantation, the graft will usually function well
In case of a transplantation with a non-optimal graft, it may lead to a fairly reduced lifetime	In case of a transplantation, the graft will usually have a normal lifetime

(2) You are in an urgent situation in which the lack of transplantation could have serious consequences for you. Which situation would you choose. Which situation would you prefer?

Situation A	Situation B
Waiting time on the list: Short	Waiting time on the list: Long
The priority of your transplant center: transplanting you with the first compatible graft available	The priority of your transplant center: transplanting you with the best quality possible graft

Appendix 1. Continued

Situation A	Situation B
The proposed graft: either an optimal graft or a non-optimal graft In case of a transplantation with a non-optimal graft, it may function with delay or non-optimally In case of a transplantation with a non-optimal graft, it may lead to a fairly reduced lifetime	The proposed graft: an optimal graft In case of a transplantation, the graft will usually function well In case of a transplantation, the graft will usually have a normal lifetime

Which situation would you prefer?	Situation A ○	Situation B ○

(3) You are in an urgent situation in which you belong to the top ten in the NWL. Which situation would you choose

Situation A	Situation B
Waiting time on the list: Short The priority of your transplant center: transplanting you with the first compatible graft available The proposed graft: either an optimal graft or a non-optimal graft In case of a transplantation with a non-optimal graft, it may function with delay or non-optimally In case of a transplantation with a non-optimal graft, it may lead to a fairly reduced lifetime	Waiting time on the list: Long The priority of your transplant center: transplanting you with the best quality possible graft The proposed graft: an optimal graft In case of a transplantation, the graft will usually function well In case of a transplantation, the graft will usually have a normal lifetime

Which situation would you prefer?	Situation A ○	Situation B ○

(4) You are in a non-emergency situation but you have a rare profile so it is very difficult to find a compatible graft for you. Which situation would you choose

Situation A	Situation B
Waiting time on the list: Short The priority of your transplant center: transplanting you with the first compatible graft available The proposed graft: either an optimal graft or a non-optimal graft In case of a transplantation with a non-optimal graft, it may function with delay or non-optimally In case of a transplantation with a non-optimal graft, it may lead to a fairly reduced lifetime	Waiting time on the list: Long The priority of your transplant center: transplanting you with the best quality possible graft The proposed graft: an optimal graft In case of a transplantation, the graft will usually function well In case of a transplantation, the graft will usually have a normal lifetime

Which situation would you prefer?	Situation A ○	Situation B ○

(1) Would you like to be informed about marginal grafts?
○ Yes
○ No

(1-2) If you want to be informed about the risks, how would you prefer to be informed about it?
○ General information, during the first pre transplant consultation
○ Detailed information for each risk factors related to non-optimal grafts, during the first pre transplant consultation

○ General information, during a subsequent consultation
○ Detailed information for each risk factors related to non-optimal grafts, during a subsequent consultation

(1-3) If you want to be informed about the risks, in what way do you prefer to be informed?
○ Orally, during consultation
○ By written documents
○ Both

(1-4) Would you like to participate in the decision-making process with regards to transplantation from marginal donors?
○ Yes, I would like to participate in all decisions about my situation
○ No, I totally trust my physician to decide in the best way for me
(1-3-1) If you want to participate in the decision-making process, how would you like to participate?
○ Shared decision with your physician
○ Shared decision with the transplant nurse coordinator of your transplant center
○ Your personal decision

(2) Do you think that the transplantation is urgent for you? Choose the number that seems more suited to your situation, from 0 (not urgent) to 10 (very urgent).

0	1	2	3	4	5	6	7	8	9	10

(3) Do you think that the transplantation is hazardous for you? Choose the number that seems more suited to your situation, from 0 (not hazardous) to 10 (very hazardous).

0	1	2	3	4	5	6	7	8	9	10

You are a:	Woman	Man

How old are you?	I_I_I

You are: registered on the national waiting list ○	Already transplanted ○

In which type of transplant center are you being followed?

Kidney ○	Liver ○	Heart ○	Lung ○

What is your transplant center? ----------
What is your city of residence? ----------

If you are registered on the National Waiting List,

Is this your first transplantation?	Yes ○	No ○

For how long have you registered on the National Waiting List?	I_I_I years	I_I_I month

If you have already been transplanted once,

Transplant International 2017; 30: 589–602

How long was your waiting time on the national list?	I_I_I years	I_I_I month

When have you been transplanted (for the last time?)?	I_I_I_I_I

Thank you for your participation and your precious time!

APPENDIX 2. Comparison of patients not ready to accept a marginal graft in any situation with patients ready to accept a marginal graft at least in one of the situations

	Ready to accept a marginal graft at least in one of the situation (N = 149)	Not ready to accept a marginal graft in any situation (N = 18)	P*	OR (95% CI) Full model	OR (95% CI) Reduced model	P†
Age (≥55 years), *n* (%)	92 (61.7%)	9 (50.0%)	0.34	1.43 (0.51;4.03)	–	–
Male, *n* (%)	98 (65.8%)	11 (61.1%)	0.69	1.22 (0.41;3.57)	–	–
Transplanted patient, *n* (%)	126 (84.6%)	14 (77.8%)	0.50	1.02 (0.27;3.78)	1.37 (0.40;4.64)	0.61
Organ type, *n* (%)						
Kidney	51 (34.2%)	9 (50.0%)		1	1	
Liver	47 (31.5%)	3 (16.7%)		2.68 (0.62;11.64)	2.65 (0.67;10.49)	0.17
Heart	25 (16.8%)	3 (16.7%)	0.51	1.33 (0.28;6.22)	1.41 (0.35;5.74)	0.63
Lung	26 (17.4%)	3 (16.7%)		1.44 (0.32;6.38)	1.50 (0.37;6.04)	0.57
Waiting time (month)‡, mean (SD)	13.2 (20.9)	21.5 (22.7)	0.13	0.99 (0.97;1.01)	–	–
Time since last transplantation (years)§, mean (SD)	6.1 (7.2)	4.2 (5.9)	0.35	–	–	–
Transplantation emergency (0–10), mean (SD)	7.3 (2.4)	7.2 (3.0)	0.84	0.94 (0.75;1.19)	–	–
Transplantation hazardousness (0–10), mean (SD)	3.2 (2.8)	4.2 (3.8)	0.36	0.86 (0.72;1.03)	–	–

OR, Odds ratio; 95% CI, 95% confidence interval.

**P*-value from chi-square tor *t*-test.

†*P*-value from Wald test after multiple imputation.

‡For patients transplanted several times for the same organ type, the average waiting time was used.

§Time since last transplantation was not included in multivariate analysis.

APPENDIX 3. Comparison of patients preferring to be informed about the possibility of a marginal graft with patients preferring not to be informed about this type of grafts

	Preferring to be informed about marginal grafts (N = 127)	Not preferring to be informed about marginal grafts (N = 40)	P*	OR (95% CI) Full model	OR (95% CI) Reduced model	P†
Age (≥55 years), *n* (%)	74 (58.3%)	27 (67.5%)	0.30	0.55 (0.24;1.24)	–	–
Male, *n* (%)	84 (66.1%)	25 (62.5%)	0.67	1.02 (0.46;2.25)	–	–
Transplanted patient, *n* (%)	105 (82.7%)	35 (87.5%)	0.47	0.55 (0.17;1.78)	0.62 (0.21;1.79)	0.37
Organ type, *n* (%)						
Kidney	42 (33.1%)	18 (45.0%)		1	1	
Liver	40 (31.5%)	10 (25.0%)	0.50	1.50 (0.56;4.01)	1.82 (0.74;4.48)	0.19
Heart	21 (16.5%)	7 (17.5%)		0.95 (0.30;3.03)	1.36 (0.49;3.81)	0.56
Lung	24 (18.9%)	5 (12.5%)		1.69 (0.51;5.57)	2.12 (0.70;6.48)	0.19

Appendix 3. Continued

	Preferring to be informed about marginal grafts (*N* = 127)	Not preferring to be informed about marginal grafts (*N* = 40)	*P**	OR (95% CI) Full model	OR (95% CI) Reduced model	*P*†
Waiting time (month)‡, mean (SD)	11.9 (14.6)	21.1 (34.3)	0.121	0.99 (0.97;1.01)	–	–
Time since last transplantation (years)§, mean (SD)	6.0 (7.4)	5.5 (6.5)	0.71	–	–	–
Transplantation emergency (0–10), mean (SD)	7.4 (2.2)	7.0 (3.0)	0.67	0.94 (0.75;1.19)	–	–
Transplantation hazardousness (0–10), mean (SD)	3.3 (3.0)	3.4 (3.0)	0.87	0.86 (0.72;1.03)	–	–

OR, Odds ratio; 95% CI, 95% confidence interval.

**P*-value from chi-square tor *t*-test.

†*P*-value from Wald test after multiple imputation.

‡For patients transplanted several times for the same organ type, the average waiting time was used.

§Time since last transplantation was not included in multivariate analysis.

Transplant International 2017; 30: 589–602