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ORIGINAL ARTICLE

Donor organ distribution according to urgency of need or outcome maximization in liver transplantation. A questionnaire survey among patients and medical staff

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Summary

Low donor rates in Germany cause a trade-off between equity in the distribution of chances for survival and efficiency in dead-donor liver transplantation. Public attitudes concerning the principles that should govern organ allocation are of interest. We performed a questionnaire-based study among patients and medical staff. 1826 of 2200 questionnaires were returned. 79.2%, 67.1%, and 24.4% patients wanted to accept liver transplantation for themselves if expected 1-year survival was 80%, 50%, and 20%, respectively. 57.7% affirmed 'averting immediate risk of death (urgency) is a more important criterion for organ allocation than expected long-term success' ($P = 0.002$ against indifference). The majority of medical staff took the opposite decision. 20.7%, 8.8%, and 21.2% of patients chose 50%, 33%, and 10% as lowest acceptable 5-year survival, respectively. 49.3% accepted a survival of <10%. Variables associated with preferring urgency over efficiency as criterion for allocation were age (OR 1.009; 95% CI: 1.000–1.017; female gender (OR 1.331; 95%CI 0.992–1.784); higher education (OR 0.881; 95%CI 0.801–0.969); and refusal of transplantation for oneself (OR 1.719; 95%CI 1.272–2.324). Most patients supported urgency-based liver allocation. Patients and medical staff would accept lower survival rates than the transplant community.

Introduction

With the development of organ transplantation from an experimental procedure into a liver-saving routine intervention, the scarcity of donor organs has become a defining issue at the heart of transplant medicine [1] necessitating tragic choices on a daily basis [2]. When donor organ allocation became institutionalized, criteria were developed that were thought to be acceptable to guide allocation decisions: probability of benefit for the patient, increase in quality of life, duration of the benefit, expected consumption of resources, urgency of the procedure [3]. Under the present condition of extreme scarcity of the life-sustaining donor organs, decisions on the principles that should guide organ allocation become critical as a conflict of aims between urgency of need on the one hand and the prospects of success per procedure on the other hand arises. This conflict is illustrated by data showing that patients who are in grave conditions at the time of liver transplantation have inferior survival rates than patients who are transplanted in a better physiological state [4,5]. As by current guidelines in Germany the sickest-first principle is implemented in donor liver allocation, average long-term survival may be negatively affected and calls have been made to exclude severely ill patients from liver transplantation and introduce outcome-oriented parameters in liver-allocation algorithms [6]. However, it may be questioned whether the benefit of a transplant system should be measured in

aggregate outcome figures. As transplant services depend on public support not only due to high costs but also because the essential prerequisite for solid organ transplantation is a sufficient number of organ donors, the public conceptions of what a transplant service should aim for are of substantial interest. This notion is also based on the founding premise of societal regulation of organ allocation: that donor organs are a public resource and not private property [7]. There is a scarcity of empirical data on public preferences concerning donor liver allocation in spite of their perceived importance. We conducted a survey focused on the trade-off between urgency of need and prospects of success in dead-donor liver transplant allocation.

Methods

Based on the results of a pilot study among 204 patients of an internal medicine outpatients department, a multiple choice questionnaire was developed. Sample size calculations were based on this pilot study to supply a sufficient number of valid answers to perform a multivariable analysis of factors associated with support or antagonism of urgency-based liver allocation and to detect contrasting views between patients and medical staff. Between January and March 2014, 2000 questionnaires were issued to patients during their anesthesiological premedication visits with their consent forms for the respective elective surgical interventions. After the premedication consultations, the completed forms were recollected.

Questionnaire

In a general introduction, the interviewees were informed of the discrepancy between the numbers of potential transplant recipients and donor organs offered.

The actual questionnaires consisted of four parts:

1. Questions regarding the life situation of respondents and their attitude toward expected risk and outcome if they ever needed a liver transplant for themselves. For the latter part of the questions, participants were given a detailed account of the live quality and situation of a person with decompensated liver disease and asked to imagine they were in that position.

2. The interviewees were then asked to imagine they had to decide which patient out of two case examples should receive one available donor liver. The case examples contained information concerning age, urgency (as mortality without transplant), and expected outcome (as mortality with transplant) (Table 1). There were two randomly mixed versions of questionnaires with different ages for patient A to detect the influence of age disparities on organ allocation. The participants were then asked to approve or disapprove of statements concerning the possible motivation of the above decision, and, at last, they were asked to approve or disapprove of the following statement: 'Averting impending death (urgency) is a more important criterion for allotting a donor liver than optimizing long-term success (efficiency).'

Table 1. Patients' characteristics for the two case examples.

	Patient A	Patient B
Age	Version 1 (n = 1800): 60 years Version 2 (n = 200): 40 years	40 years
Gender	Male	Male
Expected mortality without transplant	100% at 3 months	50% at two years
Expected survival after transplant	50% at 5 years	80% at 5 years

3. Whereas the case examples implicitly contained the trade-off between urgency-based allocation and maximization of long-term survival, participants were now again informed explicitly that if only the sickest patients were receiving scarce donor organs, long-term success rates would deteriorate. Following this information, they were asked to approve or disapprove of two statements: 3.1.: The sickest patients should not be transplanted at all. Scarce donor organs should not be used for patients with uncertain outcome; 3.2.: Patients with no other chance of survival should be prioritized for transplantation even if long-term results are worse.

4. Interviewees were again informed that patients on the waiting list who had no chance to survive three months without transplantation would have inferior outcomes after transplantation. They were then asked to select the minimal expected survival after transplantation.

For comparison, 200 more questionnaires were issued to medical staff during morning rounds and on the wards of the surgical, anesthesiological, and internal medicine departments and during professional educational events.

The survey was approved by the institutional ethics committee of the Medical Faculty of the Technical University of Munich.

Analysis

Primary end point was the affirmation of the question: 'averting immediate death (urgency) is a more important criterion for organ allocation than expected long-term success of transplantation'. Secondary end point was the allocation to patient A vs. B in the case examples. The proportional preferences expressed for the questions addressing the primary and secondary end points, respectively, were compared to indifference using the sign test.

Factors associated with the primary end point were first analyzed by contingency tables using the chi-squared test for binary (yes/no) categorical variables and the *t*-test for comparison of numerical data of unrelated groups. Parameters unevenly distributed between groups were further analyzed by including them as factors in a binary logistic regression analysis with backward exclusion (Wald). Factors were excluded for any $P > 0.100$. All comparisons were two-tailed, and significance was assumed for $P < 0.05$. Statistical analysis was performed using EXCEL for Mac, version 14.4.2 (Microsoft Corporation, Redmont, WA, USA), and SPSS 22 for Mac (IBM Corporation, Armonk, NY, USA).

Results

1720 (86%) patients returned the completed forms [979 (57%) male; age 50 ± 20 years]. Personal data of the interviewees are presented in Table 2.

Acceptance of liver transplantation

Interviewees were asked whether they would accept liver transplantation for themselves if they were suffering from decompensated liver cirrhosis and had a life expectancy of less than one year. For prospective chances of survival after transplantation of 80%, 50%, and 20%, answers were positive in 79.2%, 67.1%, and 24.4%, respectively.

Abstract questions concerning the trade-off between urgency of need and prospect of success

After a short introduction explaining decreasing success rates of transplantation in sicker patients and therefore the possible loss of donor organs, the general statements regarding criteria for organ allocation were judged as follows:

1. 'Averting impending death (urgency) is a more important criterion for allotting a donor liver than optimizing long-term success (efficiency).' Of 695 interviewees (57.7% of valid answers) were affirmative of this statement ($P = 0.002$ compared to indifference). On 515 questionnaires, this question remained unanswered.

2. 'The sickest patients should not be transplanted at all. Scarce donor organs should not be used for patients with uncertain outcome.' 617 interviewees refused this statement (54% of valid answers) ($P = 0.001$ compared to indifference).

3. 'Patients with no other chance of survival should be prioritized for transplantation even if long-term results are worse.' 753 interviewees (63.2% of valid answers) approved this statement ($P = 0.001$ against indifference).

Finally, interviewees were asked which minimal long-term survival after transplantation they deemed acceptable under the condition that unsuccessful transplantations meant a loss of donor organs that could have helped others. Answers are presented in Table 3.

Differences in personal data and the acceptance of transplantation for themselves between interviewees who favored organ allocation according to urgency and those advocating allocation according to prospects of success are presented in Table 4.

Table 2. Personal data of interviewees.

	Number	Percent of responses
Health-care-related work	296	17.5
Driver's license	1499	87.8
Insurance		
Public	1178	69.5
Private	178	10.5
Combined	339	20.0
Highest level of education		
Basic secondary ('Hauptschule')	530	31.9
Advanced secondary ('Realschule')	395	23.8
Final secondary	179	10.8
Technical college	226	13.6
University diploma	332	20.0
Salaried work at any time in life	1542	91.3
Employment status		
Worker	252	16.1
Employee	949	60.6
Public servant	236	15.1
Self-employed	128	8.2
Donor card	346	20.3
Of these: affirmative	304	88.6
Consumption of alcohol		
Two times per week or more	392	23.3
Less than two times per week	571	33.9
On special occasions	335	19.9
Never	386	22.9
Close persons on organ replacement therapy	110	6.5
Self-assessed health-related quality of life		
Very good	19	1.1
Good	83	4.8
Moderate	279	22.0
Bad	918	53.4
Very bad	298	17.3
'I consider myself a religious person'	823	50.1

Table 3. Lowest accepted survival.

Survival rate	Number	Percent of valid answers
50%	250	20.7
33%	106	8.8
10%	257	21.2
Lower than 10% as long as there is any chance of survival	597	49.3

There were no significant differences between both groups regarding the possession of a driver's license or a donor card, for the employment status, the presence of a close person dependent on organ replacement therapy, consumption of alcohol, or self-assessed quality of life.

Results of binary logistic regression analysis of factors associated with preferring urgency to success rate as criterion for organ allocation are displayed in Table 5.

Allocation decision regarding the case examples

With both patients having the same age 55% of respondents wanted to give the available donor organ to patient A, the patient with higher urgency but lower expected chance for survival after transplantation. With patient A being 20 years older than patient B, 63% decided in favor of patient B. The difference was significant ($P < 0.0001$).

Table 4. Comparisons between groups.

Parameter	Favoring urgency	Favoring success	*P*
Age	50 ± 18	46 ± 18	0.0005*
Gender: female	62%	55%	0.008†
Health-related work	16%	21%	0.042†
Highest level of education			0.0003†
Basic secondary ('Hauptschule')	30%	22%	
Advanced secondary ('Realschule')	24%	25%	
Final secondary	11%	12%	
Technical college	16%	12%	
University diploma	19%	28%	
'I consider myself a religious person'	64%	41%	0.0002†
Would accept transplantation			
At 80% survival	84%	79%	0.017†
At 50% survival	65%	74%	0.004†
At 20% survival	48%	34%	0.00003†

*t-test.
†Chi-squared test.

Table 5. Binary logistic regression: allocation according to urgency as dependent variable.

Independent variable	OR	95% confidence interval	*P*
Age (per year)	1.009	1.000–1.017	0.040
Gender: female	1.331	0.992–1.784	0.056
Education (higher group)	0.881	0.801–0.969	0.009
Accept transplantation for oneself at 20% survival rate	1.719	1.272–2.324	0.0004

Survey among medical staff

106 questionnaires were returned. 58% of respondents were male, mean age was 37 ± 13 years. In comparison with the interviewed patients, respondents from the medical staff were significantly younger, more likely to be male and had undergone higher education. Only 30% of medical staff favored an urgency-based allocation compared to 59% of patients not occupied in health care ($P < 0.001$). As the lowest accepted five-year survival after life-saving transplantations, 16% of interviewees chose 50% survival, another 16% chose 33%, and 34% chose 10%. Another 34% of respondents among the medical staff answered that <10% of survival were acceptable as long as there was any reasonable chance of survival.

Between the lines: missing answers and handwritten remarks

Whereas questions regarding personal data were answered in over 90% each (missing answers median 1.68%, minimum 0.6%, maximum 9.0%), among questions concerning acceptable transplant outcome and organ allocation a third remained unanswered (median 38.8%, min 26.9%, max 40.8%).

In 89 patient-questionnaires, additional remarks had been written. 14 pronounced rejection of the questions ('Am I God?'; 'I do not decide about life and death'), 11 complained about not having enough information regarding the case examples ('this is not that simple'; 'too little information'). Nine remarks expressed a feeling of strain caused by answering the question ('I just cannot decide this'). Seven suggested other criteria for allocation ('children, productivity'; 'age is paramount'; 'only declared donors should receive transplants'. Three refused decision making based on judging the patients and proposed a lottery: ('dice should be thrown'; 'one should draw lots'). Nine respondents expressed their repudiation of transplantation medicine.

Discussion

In this study, a majority of those who did respond to the pertinent questions supported urgency-based liver allocation. This finding was more pronounced among respondents considering transplantation an acceptable option for themselves. However, there was an apparent averseness to answer the corresponding questions, as response rates for allocation-related questions were much lower than for questions concerning personal data.

However, the preference for urgency as a criterion for organ distribution was underlined by very low survival rates that most respondents were willing to accept. Respondents

among the interviewed patients, who were working in health care, expressed the opposite preference (data not shown). In multivariable analysis, however, this difference was accounted for by differences of age and educational status. The most important factor associated with outcome-oriented allocation was a negative attitude toward transplantation for oneself: interviewees who rejected life-saving transplantation with a prospect of good outcome for themselves, favored outcome-oriented allocation significantly more often—even after correcting for differences in age and education.

In the present study, we chose short-term mortality without transplantation as measure of urgency. Outcome of transplantation was presented as expected proportion (ratio and percentage) of groups of similar waitlisted patients expected to survive 5 years. Such simple proportions do not require the study subjects to operate with complex-interdependent probabilities [8,9].

Survival per transplantation as a measure of outcome has been criticized both from the utilitarian perspective as it does not account for the benefit derived in comparison with the natural course of disease [10], and from the perspective of distributional justice, as urgency of need is not taken into consideration [11]. Benefit-based organ distribution has been advanced recently in an attempt to measure transplant-derived survival and prioritize waitlisted recipients in order to maximize life years gained [10,12]. This synthetic concept involves the trade-off between beneficence and nonmaleficence as well as weighing prognostic information of diverse reliability. It also touches the ethical controversy regarding the admissibility of comparing the values of lifetimes between different individuals. Questions concerning benefit-oriented organ distribution thus were not incorporated in our questionnaire.

In the transplant community, various threshold values for acceptable long-term survival after liver transplantation are being discussed. Generally, they range between 50% survival at one year [13] and 50% survival at 5 years post-transplantation [14]. Interviewees in our study, both among patients and medical staff, were reluctant to limit access to transplantation even for groups with much worse outcome. This was also true for the patients favoring outcome-oriented allocation of whom 32% and 36% declared they would accept minimal survival rates of 10% or <10%, respectively. Integrating these results, we summarize that our interviewees did not pursue a primarily efficiency-oriented (if efficiency is regarded as long-term survival) distribution of donor livers.

There is more empirical evidence showing that in the public opinion, the distribution of scarce health-care resources should not be based only on efficiency but that other factors need to be taken into consideration to satisfy aspects of fairness and equity [15–17]. It has also been shown that there is a prioritization of attempts at life-saving interventions, even if they have a certain probability of failure and the costs of these efforts would translate in higher gains of aggregate life years if spent for the reduction of the risk of future deaths [2,18]. Earlier studies on distributive choices by the community have shown that allocation decisions in a transplant medicine context also did not comply with strategies to maximize efficiency in terms of life years gained per transplantation or survival after transplantation [19–24]. Aspects of fairness and equity modified allocation decisions, such as waiting time and prognosis without transplantation [21,25,26] or the amount of perceived responsibility of the patient for his condition [27,28]. Up to now, only two studies on community preferences investigating the aspect of urgency in the field of liver transplantation have been published: In the first study by Skitka, medical need was an important factor in donor organ allocation. However, in patients with self-inflicted disease and with more severe scarcity of donor organs, the importance of urgency was diminished in favor of aspects of efficiency. This study also found an influence of ideological and personality attributes of the interviewees [27]. The second study by Ubel and coworkers showed that the interviewees allocated only part of a number of donor organs toward the patients with a better prognosis. Differences in medical need were not explicitly mentioned in the questionnaire, a number of interviewees, however, spontaneously asked for such information [19]. The most detailed attempt to investigate the balancing of urgency against efficiency by the public in solid organ transplantation is the study by Stahl and coworkers. With the means of visual scales, various parameters were investigated concerning their relative importance for allocation decisions. Analysis of the returned questionnaires showed that urgency (as survival without transplant) was of such importance that age differences of 30 years or differences in expected survival of 25 life years gained by transplantation were offset by small variations (up to 2.5 months) of expected survival without transplantation [26]. In our study, we did not explicitly ask about the importance of recipient age for allocation decisions. In the case examples, however, there were two versions of the questionnaire with the patient with higher medical urgency being described as either 60 or 40 years old. There was a significant difference of allocation decisions with more interviewees choosing to give the one available organ to the patient with higher urgency if he was younger. Recipient age therefore seems to matter for allocation decisions by the public, even if in the medical literature the admissibility of age as a criterion for allocation is controversial [29,30]. In Germany, at present, age is not considered in deceased donor liver allocation.

The results of our study cannot be assumed to quantitatively reflect the attitudes concerning allocation decisions in the general public, as our study sample is not representative for the general population but is recruited from patients and health workers of a university hospital in a metropolitan area of a politically conservative region in Germany. In addition, the quantitative results must be interpreted cautiously as laypersons, but also medical staff, may have problems with the interpretation and processing of information on risk probabilities [8,9]. We also do not suggest that allocation algorithms should directly reflect data obtained by opinion research. However, we believe that the associations found between the trade-off between urgency and efficiency on the one hand and attitudes toward transplantations for oneself, and the expectations concerning acceptable long-term outcome after transplantation found in our study may be valuable for future research and discussions aimed at incorporating public views into donor organ allocation algorithms. This might also increase public support for transplant services.

In summary, we found predominant support for urgency-based donor liver allocation in our study sample as presently implemented in Germany by the sickest-first principle. Study subjects accepted worse transplant outcomes than accepted by the transplant community. Factors associated with a more efficiency-oriented allocation decision were younger age, a higher educational status, male gender and refusal of transplantation for oneself.

Authorship

KSU and AU: design of study, collection of data, data analysis, preparation of manuscript. MT and AA: data collection, preparation of manuscript. MB: design of study, statistical analysis. ST: collection of data.

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