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### What's on your mind?

Annema-de Jong, Coby

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## CHAPTER

# 4

## OPINIONS OF DUTCH LIVER TRANSPLANT RECIPIENTS ON ANONYMITY OF ORGAN DONATION AND DIRECT CONTACT WITH THE DONOR'S FAMILY

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*Coby Annema, Sanna op den Dries, Aad P. van den Berg,  
Adelita V. Ranchor, Robert J. Porte*

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# ABSTRACT

## **Background**

In the Netherlands, anonymity of organ donation, which is currently protected by legislation, has come under discussion. In the Dutch society, a tendency to allow direct contact between transplant recipients and their donor's family is noticeable. As little is known about the opinion of Dutch liver transplant recipients on anonymity of organ donation and direct contact with the donor's family, this study examines their opinion.

## **Methods**

A cross-sectional study was conducted in 244 liver transplant recipients. Their opinions were examined in relation to demographic, transplant-related and emotional variables. Data were collected by questionnaire. Transplant-related variables were retrieved from the hospital's liver transplant database.

## **Results**

Fifty-three percent of the respondents (n = 177) agreed with anonymity of organ donation, mainly out of respect for the donor. Living situation, age, and level of positive affect influenced this opinion. The majority of the respondents (65%) indicated that they would like to receive some information about their donor, like age, sex, and health status. Only 19% of the respondents favored direct contact with the donor's family, mainly to express their gratitude personally. Respondents transplanted for alcoholic cirrhosis were less in favor of direct contact. Respondents with feelings of guilt doubted more about direct contact.

## **Conclusions**

There is no need to change the current legislation on anonymity of organ donation. However, most liver transplant recipients would like to receive some general information about their donor. Therefore, clear guidelines on the sharing of donor data with recipients need to be established.

## INTRODUCTION

In the Netherlands, the anonymity of organ donors and recipients is protected by legislation. The “Act on Safety and Quality of body materials” states that the identity of the donor or recipient of a donor organ may never be disclosed ([www.st-ab.nl/wetten-nr06/0681-04\\_Eisenbesluit\\_lichaamsmateriaal\\_2006.htm](http://www.st-ab.nl/wetten-nr06/0681-04_Eisenbesluit_lichaamsmateriaal_2006.htm); Article 9.1, lid1; Accessed February 2014). Anonymity is protected to avoid possible undesirable and adverse consequences for both the donor family and the transplant recipient, such as feelings of obligation to do something in return, emotional issues or disappointment when expectations are not met.<sup>1-3</sup> Based on the legislation, transplant programs forbid direct contact after deceased organ donation. Contact between transplant recipients and the donor’s family is only possible indirectly, by means of sending an anonymous letter of appreciation. Sometimes information about sex and approximate age of the donor is given upon request of the recipient. However, because there are no uniform guidelines regarding the sharing of donor data, differences in practices can occur among and within transplant programs.

The current practice seemed sufficiently satisfying for both the transplant recipients and the donor families. However, the legislation on anonymity of organ donation has recently come under discussion. This discussion is influenced by documentaries on national television in which transplant recipients meet the family of their donor in person, and Internet networking websites that enable transplant recipients to search for their donor’s family. As a result of this discussion, the public opinion in the Dutch society shows a tendency to allow direct contact. Also, health care workers increasingly receive requests from transplant recipients to provide more information about their donor.

These developments have also been described in other countries, like the United States and Israel, resulting in organ procurement organizations acting as an intermediary for contact between transplant recipients and donor families.<sup>4-7</sup> Recently, the anonymity of living donation to an unspecified recipient has also been brought to discussion.<sup>3</sup>

This made us wonder if health care workers in the field of transplantation should advocate for allowing direct contact between transplant recipients and donor families in the Netherlands. However, little is known about the opinions of Dutch transplant recipients on anonymity of organ donation and direct contact with their donor’s family. To date, a few studies among (South-)American transplant recipients<sup>5,6,8,9</sup> have been performed, showing that the majority (~70%) of the recipients wished to have contact with the donor’s family. In contrast to these studies, a survey among Belgian liver transplant recipients<sup>2</sup> found that 60.5% agreed with the principle of anonymity. Only 36% was interested in direct contact with the donor family, mainly to express their gratitude personally. A recent study from Israel showed that 29% of the transplant recipients had contact with the donor’s family, of which 89% reported benefits of the contact, 49% reported disadvantages.<sup>4</sup>

The opinion of transplant recipients on anonymity of organ donation and direct contact may be influenced by variables like age, sex, and primary disease, as well as emotions.<sup>2</sup> To date, no studies have examined the influence of demographic, transplant-related or emotional variables on the opinion of transplant recipients regarding these issues.

Therefore, it is not known whether female recipients have different opinions on these topics than male recipients, whether younger or older recipients are more in favor of direct contact, or whether recipients transplanted for alcoholic liver disease feel less need to meet the donor's family because of feelings of guilt or embarrassment.

To be able to make an informed decision whether to advocate for a change in legislation regarding anonymity of organ donation, the aim of this study was to gain insight into the opinion of Dutch liver transplant recipients on anonymity of organ donation and direct contact with the donor's family. Additionally, reasons for being in favor or against anonymity, and the willingness for direct contact were examined. To place their opinions into context, it was examined in relation to demographic, transplant-related and emotional variables.

## RESULTS

### Study population

Of the 244 eligible liver transplant recipients, 179 (73%) returned the questionnaire. Data of two respondents were insufficient and therefore excluded from the analysis. Demographic and transplant-related variables of the study population are presented in Table 1.

### Anonymity of organ donation

Fifty-three percent of the respondents agreed or strongly agreed with the principle of anonymity of organ donation, 17% disagreed or strongly disagreed, and 30% were neutral (Figure 1).

Reasons to be in favor or against anonymity are presented in Table 2. Overall, most respondents disagreed with the statements that they had feelings of guilt towards the donor (84%), or that they felt obliged to do something in return (66%). Significant differences in agreement between respondents with different opinions on anonymity of organ donation were found regarding three statements. Respondents in favor of anonymity of organ donation indicated more often that they found that anonymity of organ donation was an expression of mutual respect ( $P < 0.001$ ). Respondents who were against anonymity of organ donation agreed more often with the statements "Anonymity of organ donation should not be imposed by law, but should be decided upon by the transplant recipient and the donor's family" ( $P < 0.001$ ), and "I would like to support the donor's family" ( $P < 0.001$ ). None of the respondents added other reasons to be in favor or against anonymity of organ donation.

Respondents with a higher level of positive affect disagreed more frequently with the principle of anonymity of organ donation ( $P = 0.025$ ), mainly because they found that this should not be imposed by law ( $P = 0.009$ ). They also disagreed more often with the statement "I have feelings of guilt towards the donor" ( $P = 0.015$ ). Respondents who lived alone ( $P = 0.043$ ), and respondents who were younger than 40 years or older than 60 years ( $P = 0.019$ ) were more in favor of anonymity of organ donation. For these variables no distinct underlying reasons were found.

**Table 1.** Demographic and transplant-related characteristics of the study population

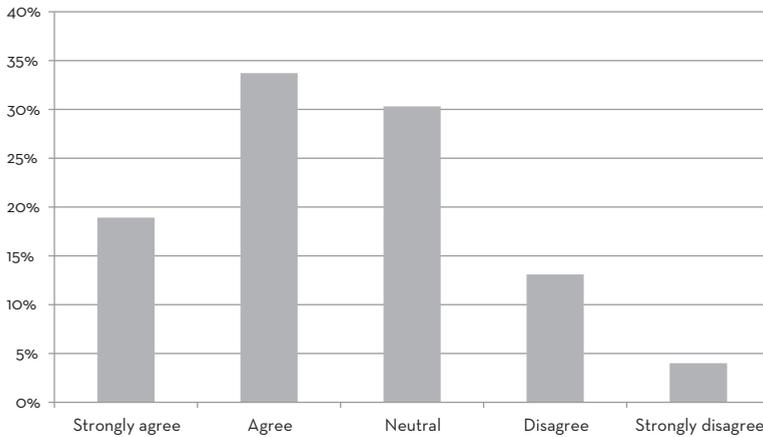
	Respondents (n = 179)	Nonrespondents (n = 65)	P
<i>Demographic characteristics</i>			
Sex, %			
Male	57.0%	52.3%	0.516 <sup>a</sup>
Female	43.0%	47.7%	
Age (mean±SD), yr	56.0 (± 12.6)	48.7 (± 17.6)	0.016 <sup>b</sup>
Living status, %			
With partner	75%	NA	-
Alone	25%		
Education, %			
Low	27%	NA	-
Moderate	45%		
High	28%		
Region, %			
North-East NL	55%	54%	.744 <sup>a</sup>
South-East NL	30%	28%	
West NL	15%	18%	
Country of origin, %			
The Netherlands	93%	NA	-
Other country	7%		
<i>Transplant-related characteristics</i>			
Time since transplantation (mean±SD),yr	6.4 (± 3.1)	6.9 (± 3.1)	0.312 <sup>b</sup>
Number of transplants, %			
1	83.8%	80.0%	0.094 <sup>a</sup>
2	13.4%	10.8%	
3 or 4	2.8%	9.2%	
Primary diagnosis, %			
Biliary cirrhosis	30.2%	27.7%	0.708 <sup>a</sup>
Cirrhosis eci	10.1%	15.4%	0.248 <sup>a</sup>
Viral hepatitis	8.9%	7.7%	0.759 <sup>a</sup>
Metabolic disorders	14.5%	13.8%	0.894 <sup>a</sup>
Alcoholic cirrhosis	15.1%	10.8%	0.390 <sup>a</sup>
Acute liver failure	7.3%	9.2%	0.512 <sup>a</sup>
Miscellaneous	14.0%	15.4%	0.780 <sup>a</sup>

<sup>a</sup> X<sup>2</sup> test<sup>b</sup> Mann-Whitney U-test

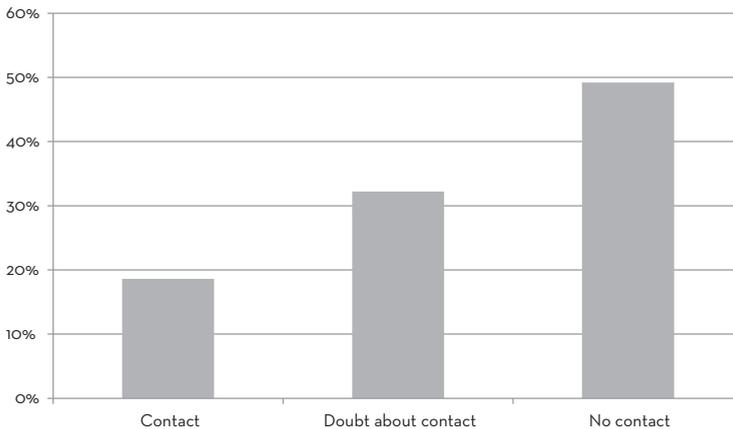
eci, of unknown etiology; NA, not available; NL, Netherlands; SD, standard deviation

### Direct contact with the donor's family

Most respondents (85%) reported that they sometimes thought about their donor (often, 12%; regularly, 8%; occasionally, 31%; seldom, 34%), whereas 15% reported that they never thought about their donor. Sixty-five percent of the respondents reported



**Figure 1.** Percentage of respondents who (strongly) agree, are neutral, or (strongly) disagree with the principle of anonymity of organ donation (n = 177)



**Figure 2:** Percentage of respondents in favor of, with doubts about, or no wish for direct contact with the donor's family (n = 177)

that they would like to know more about their donor (general information 39%, personal information 26%), and 35% indicated that they did not wish to receive information about their donor. In the additional comments, respondents indicated that besides information about age and sex, they would like to receive information about the health status of the donor.

Although almost 30% percent of the respondents felt that contact with the donor's family should be possible in the Netherlands, only 19% of the respondents actually favored direct contact with their donor's family (Figure 2). Forty-nine percent indicated that they did not wish to contact the donor's family, and 32% had doubts about direct contact.

**Table 2.** Percentage of agreement with reasons in favor or against anonymity of organ donation in general, and in relation to the opinion on the principle of anonymity of organ donation.

Statement	% Agreement overall (n = 177)			% Agreement in relation to opinion on anonymity <sup>a</sup>			X <sup>2</sup> test, P
	Agree	Neutral	Disagree	Agree with anonymity (n = 94)	Neutral about anonymity (n = 53)	Disagree with anonymity (n = 30)	
1 I think that the principle of anonymity of organ donation is an expression of mutual respect	66%	21%	13%	83%	50%	43%	<0.001
2 I have feelings of guilt towards the donors and the donor's family	6%	10%	84%	6%	6%	7%	0.284
3 I would like to support the family of the donor	15%	35%	50%	7%	10%	47%	<0.001
4 I feel obliged to do something in return	9%	25%	66%	7%	8%	17%	0.118
5 Anonymity of the donor should not be imposed by law but should be decided upon by the transplant recipient and the donor's family	54%	18%	28%	38%	64%	87%	<0.001
6 I am afraid to become emotionally involved with the donor's family	42%	26%	32%	49%	41%	23%	0.101
7 I am afraid to cause additional grief to the donor's family	27%	27%	46%	27%	24%	33%	0.167
8 I am afraid that the donor's family might have expectations of me that I cannot live up to	36%	24%	41%	42%	28%	30%	0.202
9 I am worried about differences in social, political, or moral background between myself and the donor	19%	24%	58%	15%	22%	22%	0.313

<sup>a</sup> only the percentage of respondents who agreed with the statements is shown

**Table 3.** Percentage of agreement with reasons in favor or against direct contact in general, and in relation to the wish for direct contact with the donor's family

Statement	% Agreement overall (n = 177)			% Agreement in relation to wish for direct contact <sup>a</sup>			X <sup>2</sup> test, P
	Agree	Neutral	Disagree	Wish for direct contact (n = 33)	Doubt about direct contact (n = 57)	No wish for direct contact (n = 87)	
1 I want to express my gratitude directly towards the donor's family	28%	30%	42%	79%	33%	4%	<0.001
2 Contact with the family of the donor would help me to cope with the transplant experience	5%	16%	79%	18%	4%	0%	<0.001
3 I want to personally share the result of the transplantation with the family of the donor	19%	28%	53%	70%	12%	4%	<0.001
4 I am afraid that I will have feelings of guilt when I am confronted with the donor's family	26%	20%	54%	12%	23%	33%	0.062
5 I am afraid of the emotional consequences of contact with the family of the donor	38%	22%	40%	24%	36%	46%	0.001
6 Direct contact between transplant recipients and family of the donor can stimulate people to become an organ donor	34%	40%	26%	69%	39%	16%	<0.001
7 I doubt if I can handle the situation when I have contact with the family of the donor	39%	24%	37%	14%	36%	50%	<0.001
8 I find it difficult to be confronted with the grief of the donor's family	40%	29%	31%	21%	39%	49%	0.001

<sup>a</sup> only the percentage of respondents who agreed with the statement is shown

In Table 3, reasons to be in favor or against direct contact are presented. No distinct reasons for respondents to be in favor of or against direct contact could be identified (Table 3). However, respondents who favored direct contact with the donor's family differed significantly from respondents who doubted about or did not favor direct

contact on almost all reasons mentioned. Respondents who liked to get in touch with the donor's family reported significantly more often that they wanted to express their gratitude personally ( $P < 0.001$ ), that they would like to share the result of the transplant personally ( $P < 0.001$ ), that it would stimulate organ donation ( $P < 0.001$ ), and that contact with the donor's family would help them to cope with the transplant experience ( $P < 0.001$ ). Respondents who doubted about or did not favor direct contact reported significantly more often that they were afraid of the emotional consequences of contact with the donor's family ( $P = 0.001$ ), found it difficult to be confronted with the grief of the donor's family ( $P = 0.001$ ), or doubted if they could handle the situation ( $P < 0.001$ ). No additional reasons for wanting direct contact or not were mentioned, but a substantial part of the respondents stressed that direct contact should only be considered if both the recipient and the donor family have a wish for direct contact. Respondents with more feelings of guilt toward the donor doubted more about direct contact with the donor's family ( $P = 0.018$ ). This ambivalence is reflected in the underlying reasons. On the one hand, they indicated more often that they would like to express their gratitude directly ( $P = 0.028$ ). On the other hand, they indicated more often that they doubted if they could handle the situation ( $P = 0.002$ ), found it difficult to be confronted with the grief of the donor family ( $P = 0.011$ ), and that they were afraid of the emotional consequences ( $P = 0.044$ ). Respondents with a higher educational level ( $P = 0.003$ ) felt significantly less need for direct contact with the donor's family, mainly because they felt no need to share the result of the transplant personally ( $P = 0.039$ ). Respondents transplanted for alcoholic liver disease ( $P = 0.007$ ) reported significantly more often that they felt no need for direct contact with the donor's family. Mainly because they felt no need to express their gratitude directly ( $P = 0.003$ ) or to share the result of the transplant personally ( $P = 0.011$ ). Also, they were more afraid of the emotional consequences ( $P = 0.003$ ).

## DISCUSSION

Our results show that the majority of the Dutch liver transplant recipients agreed with the principle of anonymity of organ donation, only a minority (17%) opposed to the principle of anonymity. Nevertheless, most recipients did express the wish to receive some general information about their donor. Only a small proportion (19%) of the Dutch liver transplant recipients was in favor of direct contact with the donor's family, whereas 32% had doubts about direct contact.

The reason to be in favor of or against anonymity of organ donation was based on personal values of either mutual respect or autonomy to make your own decisions. Recipients who favored direct contact mainly based this wish on positive expectations, such as showing gratitude and sharing the result of the transplantation. Whereas recipients who did not favor direct contact had negative expectations, such as being afraid of emotional consequences or of not being able to handle the situation.

Our study is the first to examine variables that are of influence on the opinion of transplant recipients regarding anonymity of organ donation and their wish for direct contact with the donor's family. Regarding demographic variables, we found that living situation and age were both of influence on the opinion on anonymity of organ donation. However, no distinct underlying reasons were found. Respondents with a higher educational level and those transplanted for alcoholic liver disease felt a less need to get in touch with the donor's family, mainly because they felt no need to express their gratitude or share the result of the transplantation personally. Although it was expected beforehand, the opinion of recipients transplanted for alcoholic liver disease was not related to feelings of guilt. Regarding emotional variables, we found that transplant recipients with a higher level of positive affect opposed more to anonymity of organ donation, mainly based on the moral value of autonomy to make their own decisions. Respondents with more feelings of guilt towards the donor doubted more about direct contact with the donor's family. This ambivalence is reflected by the underlying reasons indicated: they would like to express their gratitude personally, but were also afraid of the possible negative consequences.

Our findings are in line with the results from the study of Dobbels et al.<sup>2</sup> among Belgian liver transplant recipients, in which also the majority (60.5%) was satisfied with the principle of anonymity of organ donation and a minority (36%) favored the possibility of direct contact with the donor's family. However, our findings differ from the results of American studies.<sup>5,6,8</sup> Their results showed that majority of transplants recipients (52%-77%) favored direct contact with the family of the donor. This could be because of cultural differences between American societies, in which individual opportunities are highly appreciated, and European societies, in which collective norms play a more important role.<sup>10</sup>

A result that needs to be mentioned is that most respondents (65%) reported that they would like to receive at least some general information about their donor, such as age, sex, and health status. However, uniform guidelines about the type and amount of information which can be given to transplant recipients have not yet been established in the Netherlands. Providing this information to transplant recipients would not only satisfy their need for information, but could also facilitate the search for the donor's family. Therefore, when providing general information health care workers should be aware of the wish for direct contact of the transplant recipient and discuss the expectations of the recipient regarding direct contact, as well as the possible psychological strain and (dis)advantages of direct contact for both the transplant recipient and the donor family.

A limitation of our study is that the study was only performed among liver transplant recipients. Although the sample size was adequate and the response rate (73%) was reasonable, the results may be different for transplant recipients who had other types of organ transplants. In addition to this, only a small percentage of liver transplant recipients with a foreign descent were included in the study. Therefore, future research on this topic should focus on the opinion of heart, kidney, and lung transplant recipients, and transplant recipients with a foreign descent. Additionally, it would be interesting to assess the opinion on anonymity of organ donation and direct contact from

the perspective of the donor family, as this study only focuses on the perspective of transplant recipients.

In short, the findings of our study suggest that, from the perspective of transplant recipients, there is no need to change the current legislation regarding anonymity of organ donation in the Netherlands. A minority (17%) of the respondents opposed to the principle of anonymity of organ donation, whereas a small majority was in favor of anonymity of organ donation. The opinion of liver transplant recipients is based on the moral values of mutual respect (in favor of anonymity) or autonomy (against anonymity) and is influenced by age, living situation, and level of positive affect. A small percentage (19%) of the liver transplant recipients favored direct contact with the donor's family. The wish for direct contact is related to expectations, either positive or negative, recipients carry and is influenced by educational level, primary disease, and feelings of guilt. However, most liver transplant recipients would like to receive some general information about their donor. Therefore it is important to establish guidelines about the type and amount of information that can be given within the boundaries of the law.

## MATERIALS AND METHODS

### Participants and procedure

A cross-sectional study was performed among liver transplant recipients from our center in November and December 2012. Recipients were eligible for inclusion if they had undergone transplantation in our center between 2000 and 2010, were 18 years or older at the time of the survey, and still received post-transplant care at our center. Exclusion criteria were: not being able to fill in a Dutch questionnaire, having had a retransplantation after 2010, or being enlisted for retransplantation at the time of the survey. Eligible transplant recipients (N = 244) received an information letter explaining the purpose of the study, a questionnaire and a pre-addressed and stamped return envelope. Questionnaires were coded to guarantee confidentiality. After 4 weeks, a reminder was sent to nonrespondents and another 4 weeks were allowed for completion. The study met the criteria for an exemption from institutional review board approval (approval letter METc2012.306).

### Measures

The questionnaire was composed for the purpose of the study under guidance of an experienced health psychology researcher (A.V.R.). Questions were based on questions from previous studies on this topic.<sup>2,5,11,12</sup> Firstly, recipients had to answer five questions regarding anonymity of organ donation and direct contact (Materials and Methods, SDC, <http://links.lww.com/TP/B48>). Next, the recipients were asked to report their level of agreement with nine statements with reasons in favor or against anonymity of organ donation and eight statements regarding direct contact. All statements could be answered on a five-point Likert scale (strongly agree to strongly disagree). A full description of all statements can be found in Tables 2 and 3. Additionally, respondents

had the possibility to add reasons for being in favor or against anonymity, regarding their wish for direct contact, or other comments.

To measure emotional variables two research instruments were used:

(1) *Transplant Effects Questionnaire (TxEQ)*. The TxEQ is a 23-item self-report instrument measuring the emotional response of transplant recipients to the receipt of a transplant organ.<sup>13</sup> In this study, four subscales of the TxEQ were used: worries about the transplant, feelings of guilt toward the donor, disclosure about having undergone a transplantation, and perceived responsibility toward others. Items are scored on a five-point Likert scale (strongly disagree to strongly agree). A mean score is computed for each subscale. On the subscales “Worry” and “Guilt,” a higher score indicates a problematic response. On the subscales “Disclosure” and “Responsibility,” a lower score indicates a problematic response.<sup>14</sup> The Dutch version of the Transplant Effects Questionnaire (TxEQ-NL) showed acceptable internal consistency scores (0.66-0.79) and confirmatory factor analyses revealed an adequate fit of the TxEQ-NL with the original version.<sup>15</sup> In this study Cronbach’s  $\alpha$  ranged between 0.69 and 0.85.

(2) *Positive And Negative Affect Schedule (PANAS)*. The PANAS is a 20-item self-report measure of positive affect (PA) and negative affect (NA) reflecting positive mood and pleasurable engagement with the environment (PA), and subjective distress and unpleasurable engagement with the environment (NA).<sup>16</sup> Each emotion is rated on a five-point Likert scale (very slightly or not at all to extremely). Higher scores indicate higher levels of PA or NA. Cronbach’s  $\alpha$  of the PANAS in the present study was 0.86 for the PA scale and 0.90 for the NA scale.

The questionnaire ended with questions about demographic characteristics. Transplant-related variables were retrieved from the hospital’s liver transplant database.

### Data analyses

Descriptive data are presented as means and standard deviations or percentages of respondents. The Pearson Chi-square test was used to examine differences between groups regarding categorical variables. Because the data were not normally distributed nonparametric test were used to examine differences in continuous variables; the Mann-Whitney *U* test to examine differences between two groups, and the Kruskal-Wallis test to examine differences between more than two groups. Questions and statements with answering categories with a five-point Likert scale were compiled into a three-point Likert-scale (Agree/Neutral/Disagree) to facilitate analyses of the relation between the opinion of transplant recipients and demographic, transplant-related, and emotional variables. *P* value was set at 0.05 two-sided. All analyses were performed using IBM SPSS statistics 20 (IBM SPSS Inc., Chicago, IL).

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