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Attitude towards related living donation among candidates on the liver transplant waiting list

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ABSTRACT

Objective: to analyze attitude of patients on the liver transplant waiting list toward living donation (LD).

Design and patients: patients on the transplant waiting list —2003-2005 (n = 164)— were selected. Attitude was evaluated using a validated questionnaire, completed by an independent healthcare professional.

Results: the questionnaire completion rate was 97% (n = 159). A total of 87% (n = 138) of patients stated that they would donate an organ while alive if a family member needed one. However, only 39% (n = 61) would be prepared to receive a liver donation from a living relative and 50% would prefer to wait on the list (n = 80). 90% accepted that living liver donation involves a certain amount of risk. This assumption was not associated with a willingness to accept related LD (p = 0.170). A willingness to accept LD was related to patient's knowledge of his or her family's attitude toward donating an organ to the patient (p = 0.027).

Conclusions: patients had a favorable attitude toward living liver donation. When there was a family base that is in favor of LD then this encouraged acceptance, and therefore, it is essential to carry out family screening of patients to detect those cases in which this type of LD can be successfully requested.

Key words: Living liver donation. Patients. Liver transplant waiting list. Attitude.

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INTRODUCTION

In spite of the highest level of cadaveric donation in the world, in Spain there is not enough donations to cover transplant needs. Furthermore, given the good results of liver transplantation, it is being increasingly recommended and therefore the number of patients on the waiting list is continually increasing. This means that, for a vital organ such as the liver, mortality on the transplant waiting list is constantly increasing (1). This fact has made it necessary to develop other ways of obtaining organs that are different from cadaveric donation, such as living donation, asystole donation, split liver transplantation, domino transplantation and suboptimal donation (2,3). The development of living liver donation in Spain has meant that there is a living liver donor transplant program in some transplant centers. However, the percentage of these transplants compared to all transplants continues to be minimal and insufficient for avoiding mortality on the waiting list (1). This is a matter of concern, especially if we take into account the favorable attitude of the general public (4,5) and of healthcare workers (6). One fact that could prevent the development of living liver donation is the attitude of patients on the transplant waiting list who might not be in favor of members of their family being subjected to living donation (7). This is a situation that has been seen in Spain in those patients who are on the waiting list for a kidney transplant (8).

Our hypothesis is that the attitude of patients on the liver transplant waiting list is not favorable toward living liver donation by their family members thus making it difficult to develop this type of donation. Therefore the objectives of this study are to: a) analyze the attitude of patients on the liver transplant waiting list toward related living liver donation; and b) determine the factors affecting this attitude so that we can define a group of patients who are more in favor of this kind of donation.

PATIENTS AND METHODS

Study population

The patients who were included on the liver transplant waiting list between January 2003 and December 2005 (n = 164) were selected prospectively in a hospital in the Southeast of Spain. In this institution, the mean time on the liver transplant waiting list is seven months and an annual mean of 40 liver transplants are carried out (range in the last 5 years: 36-50 transplants/year). The patients were selected for the study at the time when they were added to the waiting list. The procedures were approved by the Ethics Committee of Human Experimentation in the hospital.

Questionnaire and variables analyzed

Attitude toward living donation was evaluated using a psychosocial questionnaire about organ donation and transplantation that was validated in our local area (7,8). This questionnaire was used by an independent healthcare professional from the Transplant Coordination Center, using a direct personal interview in the liver post-transplant consultation dedicated to Liver Transplantation.

An attitude in favor of receiving a donated living liver by a family member or friend was used as the dependent variable (living related donation). The independent variables analyzed were; age; sex; marital status; level of education; having descendents or not; expectations of receiving a re-transplantation; attitude toward cadaveric donation; attitude toward the donation of a family member's organs; knowledge of the risks involved in living liver donation; having had a family discussion about the possibility of donating an organ to the patient; and whether or not the physician had proposed living donation as an option to the patient.

Sample description

Of the 164 patients on the waiting list, 159 could be interviewed (questionnaire completion rate: 97%). The mean patient age was 50 ± 12 years. A total of 67% (n = 106) were men; 77% (n = 122) were married and 89% (n = 141) had children. With respect to level of education, 47% (n = 74) either had no studies or had only studied at primary school. 11% (n = 17) were waiting for a re-transplant.

Statistical analysis

All the data were added to a database and analyzed using the Spss 11.0 statistical package (SPSS, Inc. Chicago, IL, USA). Descriptive statistical analysis was carried out on each of the variables, Student's t-test was applied and the χ^2 test complemented by an analysis of remainders. Fisher's exact test was also used if it were necessary. Values of $p < 0.05$ were considered as being statistically significant.

RESULTS

General attitude toward cadaveric organ donation

Most of the patients interviewed (91%) (n = 145) would donate their organs upon death, compared to 3% (n = 5) who stated that they would not and 6% who were unsure (n = 9). About half of the respondents (48%) (n = 76), indicated that their attitude toward organ donation had changed in a favorable way since becoming ill or being added to the transplant waiting list.

Acceptance of related living liver donation (from a family member)

39% (n = 61) of patients on the waiting list would be willing to accept a related liver donation compared to 50% (n = 80) who would prefer to wait on the list until it were their turn to receive a cadaveric organ, and 11% (n = 18) were unsure about the matter.

When we analyze the many factors affecting the attitude of being willing to accept an organ from a family member, it has been seen that attitude was affected by the family's attitude toward donating an organ to the patient ($p = 0.027$) (Table I). However, only 51% of patients interviewed (n = 72) knew the attitude of their family toward the matter. In 92% of cases (n = 66), the family were in favor of this kind of donation, whereas only 8% (n = 6) were against. As shown in figure 1, when the family is in favor and the patient knows this, 56% (n = 37) of patients would be willing to accept this kind of donation, compared to just 30% (n = 19), when their family's attitude is not known or the family is against this type of donation ($p < 0.05$).

It should be noted that 90% of respondents stated that there is a risk in living liver donation. However, this assumption of a greater or lesser risk for their family members was not associated with a greater or lesser acceptance of related living liver donation ($p = 0.170$).

Finally, only 19% (n = 26) of respondents stated that their physician offered them living donation as a possible treatment option. As shown in table I, it has been observed that among those respondents who were offered this living liver donation option by their physician, there was not a more favorable attitude ($p = 0.146$).

Personal attitude toward related living donation

A total of 87% (n = 138) of patients on the waiting list had a favorable attitude toward related living donation

Table I. Variables that affect attitude of liver transplant patients on the waiting list toward accepting related living liver donation

Variable	*Yes, they would n = 61 (39%)*	*They would wait n = 80 (50%)*	*p*
Mean age (51 ± 11 years)	50 ± 11	51 ± 11	0.851
Sex:			
Male (n = 98)	45 (46%)	53 (54%)	0.337
Female (n = 43)	16 (37%)	27 (63%)	
Marital status:			
Single (n = 13)	4 (31%)	9 (69%)	0.451
Married (n = 111)	51 (46%)	60 (54%)	
Separated/Divorced/Widowed (n = 17)	6 (35%)	11 (65%)	
Level of education:			
None/Primary (n = 66)	25 (38%)	41 (62%)	0.226
Secondary/Further/University (n = 75)	36 (49%)	39 (51%)	
Infection from the hepatitis C virus:			
No (n = 104)	41 (39%)	63 (61%)	0.123
Yes (n = 37)	20 (54%)	17 (46%)	
Descendents:			
Yes (n = 130)	58 (45%)	72 (55%)	0.187
No (n = 11)	3 (22%)	8 (78%)	
Re-transplantation:			
Yes (n = 13)	7 (54%)	6 (46%)	0.419
No (n = 128)	54 (41%)	74 (59%)	
Organ donation after death:			
Yes (n = 132)	54 (41%)	78 (59%)	*0.004*
No (n = 2)	0 (0%)	2 (100%)	
Doubts (n = 5)	5 (100%)	0 (0%)	
DK/NA (n = 2)	2	-	
Assessment of the risk of living liver donation:			
A lot (n = 71)	27 (38%)	44 (62%)	
Some (n = 50)	26 (52%)	24 (48%)	0.170
None (n = 14)	4 (29%)	10 (71%)	
DK/NA (n = 6)	4	2	
Knowing that one's family is in favor of donating an organ to the patient:			
Yes, in favor (n = 66)	37 (56%)	29 (44%)	*0.027*
Yes, against (n = 6)	3 (50%)	3 (50%)	
No (n = 63)	19 (30%)	44 (70%)	
Doubts (n = 6)	2 (20%)	4 (80%)	
Living donation proposed by the patient's physician:			
Yes, as a first option (n = 4)	0 (0%)	4 (100%)	0.146
Yes, as a second option (n = 22)	9 (41%)	13 (59%)	
No (n = 109)	51 (47%)	58 (53%)	
DK/NA (n = 6)	1	5	
Donation of organs while alive (donation to a family member):			
Yes (n = 126)	57 (45%)	69 (55%)	0.377
No (n = 3)	1 (33%)	2 (67%)	
Doubts (n = 12)	3 (25%)	9 (75%)	

DK/NA: does not know/no answer.

being carried out, compared to 4% (n = 6) who would not be prepared to donate while alive, and 9% (n = 15) who stated that they were unsure about the matter.

The following factors have been seen to affect attitude: a) sex (women were more in favor) (89 *vs.* 86%; p = 0.057); b) marital status (those who are married were more in favor than single people (89 *vs.* 72%; p = 0.023); c) having descendents (91 *vs.* 56%; p = 0.000); d) having a favorable attitude toward cadaveric donation (90 *vs.* 77%; p = 0.000); and e) knowing the attitude of one's

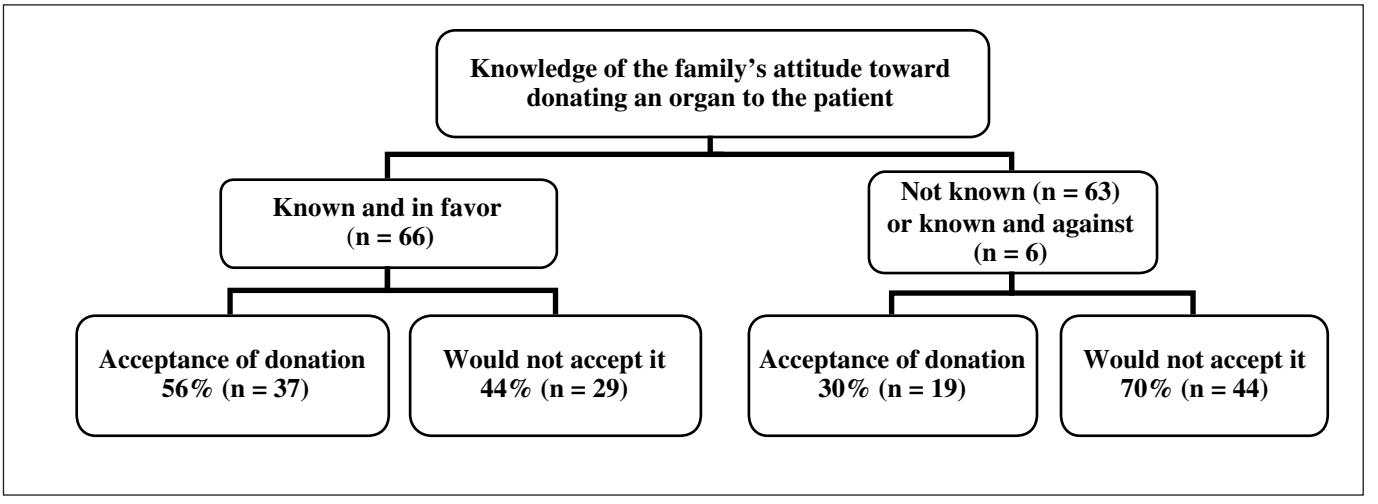

Fig. 1. Patients' attitudes toward living liver donation according to knowledge of his or her family's attitude toward living donation.

family toward donating a living organ to the patient (97 *vs.* 84%; p = 0.000) (Table II).

DISCUSSION

In Spain the high rates of deceased donation have overshadowed living donation. However, in the last decade, an effort is being made to encourage this type of donation to avoid mortality on the waiting list (1). Living kidney donation has a low morbidity and mortality rate and provides good results in the recipient. Living liver donation, however, is more controversial because it involves greater risks for the donor and the results are worse for the recipient than in deceased organ donation. In spite of these limitations this kind of therapy is defended by several groups especially in the USA and Japan.

In Spain there is a favorable attitude toward related living donation (4) in the public, as well as among healthcare employees across various job categories (6). What is more, as seen in this study, the attitude of patients on the waiting list is also favorable: 87% would donate to a family member while alive if an organ were needed. However, only 41% would be prepared to receive a donated organ.

Therefore, it should be noted that most of the studies about the attitude of patients on the waiting list toward living donation have been carried out on kidney patients, although there are no differences between the two largest groups that have been analyzed: North Americans (from the USA and Canada) and Europeans (from Holland and Spain). In both cases, most studies conclude that there are considerable difficulties when the topic brought up in conversation and students are not very willing to talk about it (Table III).

Living donation of the kidney is different from that of the liver. In the current bibliography, most studies focus their analysis on the donor's attitude rather than the recipient's. With regard to the liver, only two studies have been carried out to analyze the attitude of patients on the waiting list toward living donation (possible recipients of a living donor organ). In an American study (9), where the possibility of achieving a donor was investigated, only 29% of potential recipients were prepared to look for one. However, the attitude of these patients toward this kind of treatment has not been investigated. Another study which analyzed the situation of these patients in Spain (10) concluded that 30% of the subjects would refuse to accept an organ from a family member if one were offered to them (Table IV).

In this respect, it is important to search for patients who have a favorable attitude toward this type of living donation (10,11), given that we have found that the most important factor is having a family unit that is in favor of donation. For example, those patients who had a family that is in favor and who knew that their family was in favor were more prepared to accept this type of donation than those who did not know their family's attitude or who had a family that is against (56 *vs.* 35%) ($p < 0.05$). Therefore, it is necessary for there to be a favorable attitude and for the patient to have knowledge of this favorable attitude. In fact, it should be noted that more than half of patients did not know their family's attitude toward the subject. Thus, prior screening at the consultation stage for detecting favorable family units would be a good option if we want to increase donation. It has been reported that when patients have a favorable predisposition to this treatment option, it is easier to increase this type of donation. By analyzing the results obtained, it would be interesting not only to inform the patient about this therapeutic option, but also to spread knowledge about living donation and related aspects to the families.

This situation is different to the one reported among patients on the waiting list in our local area. An analysis of the attitude of kidney patients has shown that patients are not

Table II. Variables affecting the attitude of patients on the liver transplant waiting list toward living donation for a family member

Variable	*In favor n = 138 (87%)*	*Against n = 6 (4%)*	*Doubts n = 15 (9%)*	*p*
Mean age (49 ± 12 years)	50 ± 11	41 ± 16	48 ± 16	0.127
Sex:				
Male (n = 106)	91 (86%)	2 (2%)	13 (12%)	*0.057*
Female (n = 53)	47 (89%)	4 (7%)	2 (4%)	
Marital status:				
Single (n = 18)	13 (72%)	0 (0%)	5 (28%)	*0.023*
Separated/Divorced/Widowed (n = 19)	16 (84%)	0 (0%)	3 (16%)	
Married (n = 122)	109 (89%)	6 (5%)	7 (6%)	
Level of education:				
None/Primary (n = 74)	60 (81%)	5 (7%)	9 (12%)	0.087
Secondary/Further/University (n = 85)	78 (92%)	1 (1%)	6 (7%)	
Infection from the hepatitis C virus:				
No (n = 115)	99 (86%)	4 (4%)	12 (10%)	0.755
Yes (n = 44)	39 (89%)	2 (4%)	3 (7%)	
Descendents:				
Yes (n = 141)	128 (90%)	3 (2%)	10 (8%)	*0.000*
No (n = 18)	10 (50%)	3 (19%)	5 (31%)	
Re-trasplantation:				
Yes (n = 17)	14 (82%)	0 (0%)	3 (18%)	0.346
No (n = 142)	124 (87%)	6 (4%)	12 (9%)	
Organ donation after death:				
Yes (n = 145)	131 (90%)	3 (2%)	11 (8%)	*0.000*
No (n = 5)	0 (0%)	3 (60%)	2 (40%)	
Doubts (n = 9)	7 (71%)	0 (0%)	2 (29%)	
Assessment of the risk from living liver donation:				
A lot (n = 75)	63 (84%)	3 (4%)	9 (12%)	0.235
Some (n = 51)	47 (92%)	0 (0%)	4 (8%)	
None (n = 17)	17 (100%)	0 (0%)	0 (0%)	
DK/NA (n = 16)	11	3	2	
Knowing that one's family in favor of donating an organ to the patient:				
Yes, in favor (n = 70)	67 (96%)	1 (1%)	2 (3%)	*0.000*
Yes, against (n = 7)	4 (57%)	0 (0%)	3 (43%)	
No (n = 70)	59 (84%)	2 (3%)	9 (13%)	
Doubts (n = 12)	8 (64%)	3 (27%)	1 (9%)	
Living donation proposed by the patient's physician:				
Yes, as the 1st option (n = 5)	5 (100%)	0 (0%)	0 (0%)	0.770
Yes, as the second option (n = 22)	21 (96%)	0 (0%)	1 (4%)	
No (n = 124)	105 (85%)	6 (5%)	13 (10%)	
Doubts (n = 8)	7 (86%)	0 (0%)	1 (14%)	

DK/NA = Does not know/ No answer.

very willing to accept a related living organ given that most patients on the kidney transplant waiting list are not particularly in favor of accepting living donation for themselves, even when an organ is offered to them (only 35% would be prepared to accept one, compared to 60% who would prefer to wait on the list for a deceased organ transplant). The factors that affect this attitude are different from the factors that affect liver patients, therefore, the actual profile of a patient who is in favor of receiving a living related donor organ is a young, single person with a high level of education.

It also has to be taken into account that the position of Spanish patients on the waiting list is different to that of patients in America, in the rest of Europe and Japan (12,13), where the possibility of a transplant is more remote. Most Spanish patients are aware that receiving a deceased organ transplant, given donation rates, is a question of time and, therefore, they frequently prefer to wait before subjecting a family member or a friend to a "mutilation" or putting their life at risk.

Table III. Summary of the articles that analize the attitude in patients towards living kidney donation

Author	*Year*	*Country*	*Attitude*	*n*
Kranenburg LW, et al.(21)	2009	The Netherlands	Many found it very difficult to ask a potential donor directly.	84
Rodríguez JR, et al. (22)	2008	USA	56% had a low willingness to talk about living donation. White race, more education, less concern about LDKT, and poorer perceived health are associated with greater willingness to talk to others about living kidney donation.	132
Waterman AD, et al. (23)	2008	USA	Recipients who received LDKT were more interested in information about donors' evaluation, surgery, medical tests, and donation concerns than the other recipients. Recipients evaluated who had living donors were more comfortable accepting family members or friends who volunteered rather than asking potential donors because of concerns about pressuring donors (85%), harming their health (83%), or causing them pain or inconvenience (76%).	304
Reese PP, et al. (24)	2008	USA	51% reported initiating a conversation with at least one potential donor. Domains associated with initiating a conversation included: preference for LDKT, willingness to ask for help, and female gender.	96
Young A, et al. (25)	2008	Canada	Potential recipients were the most averse to donor risk. Whereas potential donors were significantly more willing to accept greater long-term donor risks than potential recipients and transplant professionals.	111
Kranenburg LW, et al. (26)	2007	The Netherlands	78% of the patients were willing to accept the offer of a living donor. Reluctance to discuss the issue with the potential donors is the reason for not pursuing LKD.	91
Lunsford SL, et al. (27)	2007	USA	Education is the best way to reach living donors and dispell fears. Promoting general health of African Americans may increase their willingness to be a living donor.	18
Lunsford SL, et al. (28)	2007	USA	Only half of patients were willing to ask for a living organ donation, and those patients that were single/never married were less likely to ask for a living donation.	328
Martínez-Alarcón L, et al. (8)	2006	Spain	35% would accept a related living kidney if it were offered to them, 60% would prefer to wait on the waiting list and the remaining 5% are undecided.	214
Waterman AD, et al. (29)	2006	USA	Recipients reported that they might not pursue living donation because they felt guilty and indebted to the donor, did not want to harm or inconvenience the donor, did not want to accept a kidney that a family member might need later, and did not want to disappoint the donor if the kidney failed. They thought that training on how to make the donation request and education about living donors' motivations for donation and transplant experience could help more renal patients pursue living donation.	26
Zimmerman D, et al. (30)	2006	Canada	Employment status and number of close relatives, willingness to consider an LDKTx was independently associated with a lower perceived risk of peri-operative complications to the donor, the perception that the recipient would live longer following LDKT and greater perceived appropriateness of asking a family member to donate a kidney.	214
Gourlay WA, et al. (31)	2005	Canada	All patients could identify at least one family member who might serve as a live kidney donor. Less than 13% of these potential donors have actually undergone an evaluation.	414
Kranenburg L, et al. (32)	2005	The Netherlands	61% of the patients preferred living kidney donation to postmortal donation. Their main motivation for this choice was the better quality of the living kidney.	61
Álvarez M, et al. (33)	2005	Spain	Parents and brothers were considered the best match between donor and recipients and non genetically/emotionally-related donors were accepted by only 2.5%. 60% considered that time in the waiting list is to long and 59% didn't have any information about LDKT.	416
Pradel FG, et al. (34)	2003	USA	All had a positive attitude toward LDKT. Potential recipients and recipients found it difficult to ask for a kidney and worried about the consequences of a kidney removal on their donor's health.	25
Pradel FG, et al. (35)	2003	USA	Recipients identified 2 barriers to accepting LDKT: they were unwilling to accept a kidney if it meant this would financially burden their donors, and they worried that their donors might succumb to a future kidney problem.	244

LDLT: living donor liver transplantation; LDKT: living donor kidney transplantation.

It should be noted that as opposed to living kidney transplantation that has a low morbidity rate in the donor and good results in the recipient (14-16), in liver transplantation there is a higher morbidity rate in the donor and in the recipient. Due to the greater level of risk involved than in kidney donation we should make extra ef-

Table IV. Summary of the articles that analyze the attitude in patients towards living liver donation

Author	*Year*	*Country*	*Attitude*	*n*
Rudow DL, et al. (9)	2003	USA	29% (n = 60) of potential recipients had at least one living donor volunteer for evaluation. No analysis of attitude.	204
Rimola A, et al. (10)	2005	Spain	21 (17%) patients underwent living donor liver transplantation. 50% (n = 60) no living donor for reasons concerning the patients themselves, especially their refusal to receive LDLT from a relative (30%). 33% (n = 40) did not undergo LDLT for reasons concerning potential donors.	121

LDLT: living donor liver transplantation.

forts to overcome two aspects: firstly, the possible mortality and morbidity in healthy donors; and secondly, the mortality of patients on the waiting list. Accordingly, we consider that in Spain, it would be ethically acceptable to increase living transplantation to 10% of overall liver transplantation in order to prevent waiting list mortality (currently about 10%), although this would mean the acceptance of greater mortality in the recipient and the donor. It should also be taken into consideration that morbidity is directly related with experience in the transplant center, so that it is necessary to be very selective when these centers are accredited. The proof of this is that in recent years, several centers from many countries have closed their living liver donor transplant programs (17).

It should not be forgotten that this ethical situation could possibly affect the attitude of healthcare professionals, causing uncertainty toward this type of donation. This could be the reason why this type of donation is not being offered systematically. Only 19% of patients state that living liver donation has been offered to them as an alternative. It seems clear that even if there is an ongoing living transplant program, if living liver donation is not offered on a greater scale it will be difficult to encourage this type of donation. Therefore, it is essential to raise awareness among the professionals involved in living donation that this type of donation should be offered (5,18-20).

Finally, it should be taken into account that living liver donation can have a dual impact, both positive and negative. Accordingly, for the donor, it is well-known that there is an increase in self-esteem and personal worth in the socio-family setting, as well as closer personal relationships. However, it also involves associated morbidity and mortality in a considerable percentage of patients which usually leads to temporary or permanent incapacity at work, and consequent economic repercussions for the family. For the recipient, there is also a positive and negative impact, in which the recipient is the clear beneficiary, of reductions in the mortality rate on the waiting list, and therefore a longer working life, improved quality of life and social relations. However, it is also recognized that the results are somewhat worse than those achieved in deceased donation due to the size of the graft. In the cases in which there is morbidity and mortality the donor has feelings of guilt and associated psychological disorders.

To conclude, we could say that patients in the waiting list for a liver transplant have a favorable attitude toward being living liver donors, although, they are not very willing to be recipients of related living donation. The existence of a family unit that is in favor of living donation helps to encourage acceptance toward this type of donation, therefore, it is essential to carry out family screening on patients to detect those cases in which this type of living donation can be successfully requested. It should be considered as a real healthcare objective, increasing living liver donation in order to prevent mortality on the waiting list. However, living liver donation should not be increased indiscriminately in view of the fact that there is already a large pool of deceased organs and when these are used we do not expose the living donor to a risk of morbidity and mortality.

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