



Beliefs of Living Donors About Recipients' End-Stage Liver Failure and Surgery for Organ Donation

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ABSTRACT

Background. The concept of beliefs could provide a basis for how donors may perceive recipients' end-stage liver failure (ESLF) and surgery for organ donation. However, there is no such quantitative study. Therefore, the objective of this study was to explore beliefs of living donors about recipients' ESLF and surgery for organ donation.

Methods. The sample comprised 16 living donors who donated a part of their liver to a patient who had ESLF. The data were analyzed by following established procedures for inductive qualitative analysis.

Results. Analysis showed that donors' beliefs can be viewed in a number of groups. Beliefs about recipients' ESLF included diverse explanations for ESLF (blaming oneself and physicians) and physical symptoms (developmental slowing down). Beliefs about being a donor included reasons for being a donor (performing a good deed, being healed), barriers to being a donor (other people being ignorant and selfish), ways to manage these barriers (following one's gut feeling), and factors facilitating being a donor (the feeling that one does not have many people to leave behind). Beliefs about surgery for organ donation included physical effects (pain, feeling stiff). Beliefs about organ donation included views that general organ donation should be encouraged and that people's awareness should be raised.

Conclusions. Existing psychological perspectives could help to interpret some beliefs. Nevertheless, other beliefs, not previously reported, could be considered as targets for individual consultations/psycho-educational programs for fostering emotional well-being.

LIVER transplantation is the choice of treatment for patients with end-stage liver failure (ESLF). This can be either cadaveric or living donor transplantation. The main aim of transplantation is the achievement of maximal quality and quantity of life [1]. The construct of beliefs could provide a basis for understanding how the donors may perceive recipients' ESLF and surgery for organ donation. Nevertheless, there is no such quantitative study. The Self-Regulatory Model of Illness [2], also referred to as Personal Models of Illness [3], was developed by means of interviews with patients with a range of chronic physical illnesses. This model postulates that each individual has his/her own ideas about his/her illness along a number of dimensions including identity, cause, consequences, control, and timeline [2]. This postulation highlights the notion that beliefs about ESLF will vary from one patient to another.

Following from this, it can be argued that living donors' beliefs about recipients' ESLF and their own surgery for organ donation will vary from one donor to another.

An alternative approach to studying donors' beliefs is to be guided by qualitative research. Some qualitative studies have examined the beliefs of donors of liver transplantation. Findings have shown that donors become a donor automatically and perceive this as an opportunity to help the loved one [4,5]. During this process, donors prioritize the recipient's life, perceive liver transplantation as the last chance for the recipient and her family, and feel obligated

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to save the recipient [6]. Donors give 3 types of consent, including unconditional consent, pressured consent, and ulterior-motivated consent, referring to the situation when the donor has a hidden motive [7].

Previous qualitative work can be used as an evidence base for clinical consultations and/or psycho-educational interventions. However, this may be limited in terms of the range and commonality of beliefs held by donors. Therefore, to understand how living donors naturally think about ESLF of recipients and their own surgery for donating a part of their liver, more qualitative research must be undertaken. Therefore, the present study aimed to explore these views.

METHODS

Participants

The use of purposeful sampling helped to gather detailed information regarding the aim of the present study [8]. In the present study, as a type of purposeful sampling, typical sampling procedure was used to select donors. This contributed to making sure the transferability of the findings to other living donors of liver transplantation [8]. The typical living donor of liver transplantation was one who has been referred to a donor and who has given a part of his/her liver to someone who needed liver transplantation for a common cause of ESLF. The coordinator of the Liver Transplant Unit selected typical donors as defined above from all living donors who underwent surgery for liver donation in a private hospital in Istanbul. After organ donation surgery, these donors were approached while they attended the clinic and were asked to take part in an interview. Donors who had a medical condition preventing participation were excluded from the study.

The final sample consisted of 16 living donors. There were 6 male and 10 female living donors. The mean age of the sample was 30 years (range, 23–41); the mean duration of time after surgery for

organ donation was 4.47 months (range, 3 days to 7 months). Three donors were approved by the ethics committee (patient's third-generation relative, colleague), 10 donors were first-degree relatives, and 3 donors were second-degree relatives. For more details, refer to Table 1.

Procedure

After informed consent was given, living donors were interviewed individually in a private room for 60 to 90 minutes and were prompted by means of adopting an interview guide approach. The interviews were audio-recorded anonymously. Before the interview started, an outline of topics was prepared. The flow of the interview with each participant determined the sequence of the questions as well as how the questions were worded [8,9]. Donors were questioned about recipients' ESLF, transplantation surgery, the process of being a donor, the effects of ESLF and transplantation surgery for themselves and the recipients, their understanding of the ways in which these effects came about, and the difficulties that they and the recipients experienced. Donors were also prompted about recipients' and their own experience of life. Some of these findings were reported elsewhere [10].

Data Analysis

Grounded theory [11], which helps to understand and formulate a theory that is based on the participants' views [8] about the processes involved in a phenomenon [9,12], was considered in the present study because this approach includes some specific data analysis strategies [11]. These strategies specify systematically the ways in which qualitative data are analyzed [11,13,14]. This broad approach, which has been used in similar ways in chronic illness including end-stage renal failure [15,16] and in other areas [17], was adopted in the present study.

The analysis of the anonymized interview transcripts followed established procedures for inductive qualitative analysis, which helped to base it on the present data instead of a priori theoretical or professional ideas [8,11,18,19]. One author (AT) engaged in a

Table 1. Demographic Characteristics of the Participants

Patient No.	Age, Years	Sex	Marital Status	Education	Occupational Status	Relationship of Donor to Recipient	Duration After Transplantation
1	30	Male	Single	High school	Had medical report for 6 months	Son	2 Months
2	40	Female	Married	Primary school	Housewife	Mother	2 Years
3	23	Female	Single	University	Housewife	Daughter	8 Months
4	26	Female	Married	Primary school	Housewife	Mother	1.5 Years
5	27	Male	Single	University	Employed	Son	1 Month
6	24	Female	Engaged	Primary school	Housewife	Niece \ uncle	3 Weeks
7	23	Female	Married	Secondary school	Housewife	Mother	2.5 Months
8	30	Male	Single	High school	Gave up work until recovery	Patient's colleague (accepted by the Ethics Committee)	2.5 Months
9	35	Male	Married	High school	Gave up work for transplantation	Nephew \ uncle	12 Days
10	40	Female	Married	Primary school	Housewife	Wife	3 Days
11	29	Male	Married	Primary school	Employed	Son	1.5 Months
12	27	Female	Widowed	Primary school	Housewife	Third-degree relative (accepted by the Ethics Committee)	1.5 Months
13	28	Female	Married	Primary school	Housewife	Mother	1.5 Months
14	25	Female	Married	Secondary school	Employed	Mother	1 Week
15	30	Female	Married	High school	Housewife	Third-degree relative (accepted by the Ethics Committee)	15 Days
16	41	Male	Married	Secondary school	Employed	Brother	7 Months

preliminary analysis of 10 transcripts. This analysis was developed by discussion with the other authors. Recurrent patterns were changed by gathering additional data and continued data analysis. Data analysis procedures are insufficient to come up with useful findings [20]. In the present study, attention was paid to consensus, trustworthiness of data, and trustworthiness of the analysis. Consensus was ensured by adopting established procedures of data analysis [21,22]. Ensuring that sufficient transcript material was provided to illustrate the themes identified in the analysis satisfied the criteria for the trustworthiness of data. Coherence, theoretical validity, and catalytic validity were considered in assessing the extent to which the analysis was trustworthy [19,23]. Coherence is defined as whether the analysis includes elaborate interpretations of the data and whether the themes identified accommodate the data [9,18,19]. Theoretical validity is defined as whether the conclusions that are drawn are related to existing theories or constructs [9,18,19]. Catalytic validity [22] of the analysis relates to the potential of the analysis to have an impact on future interventions and studies. Analysis was stopped when no further changes were obtained as a result of the analysis. Each theme of the analysis was described by many donors' accounts. In the findings discussed herein, transcripts are given in italics to illustrate the content of themes. Numbers given in parentheses refer to numbers that identify participants.

RESULTS

Beliefs About Recipients' ESLF

Donors attempted to explain recipients' ESLF in a variety of ways. In many explanations, there was no tangible cause, in that for some donors, the causes of ESLF were unknown. In the face of no tangible, medically explained cause, these donors used their own judgment and interpreted the information available to them in idiosyncratic ways to account for what happened to the recipients' liver. One donor (patient 14) recounted that somehow the recipient's liver failed spontaneously as follows: *A cheerful child changed over time.* Another participant (patient 7) expressed that the recipient's liver *got rotten* like a piece of meat would.

In the absence of concrete medical explanations, donors also provided less tangible psychological causes for the recipients' liver failure. These included worry, stress, senseless drug use, and blaming oneself. Indeed, one donor (patient 13) said that *I wonder if it is because of me.* Another less tangible cause included blaming doctors. One donor (patient 3) pondered whether the liver failed *because of the doctor's mistake.* Yet again, other donors thought that it was God's will. One donor (patient 13) explained this as follows: *Everything comes from God, fate.*

However, many beliefs identified medically tangible causes including complications at birth, cirrhosis, liver cancer, and genetic disorders including hepatitis, oxalosis, glycogen storage disease, and Crigler Najjar and biliary atresia. Many donors explained the complex processes involved in the development of liver failure caused by these factors. These explanations reflected their interpretation of the content and quality of the consultations with their surgeons. For example, one donor (patient 13) explained glycogen storage disease as follows: *They said to me and to*

my husband that we could be carriers, they said, 'your chromosomes interfere with each other'. Biliary atresia was explained by one donor (patient 4) as follows: *They said that her (the recipient's) gallbladder had not fully developed, her bile ducts were narrow, and that's why her liver was damaged.*

Donors associated some physical symptoms with recipients' ESLF. These reflected commonly mentioned physical symptoms in that donors recounted cramps, itching, swelling, weakness, tiredness, loss of weight, bleeding, vomiting, pain, shortness of breath, deterioration of other organs, and not being able to eat. Donors also described some physical symptoms in idiosyncratic ways such as "yellowing." One donor (patient 7) commented that *she (the recipient) turned yellow, it was not like a lemon yellow you know, but like orange.* Donors also felt that recipients also slowed down developmentally and described it also in idiosyncratically vivid ways. One donor (patient 12) described this as follows: *the baby could not even hold his head upright up to 4 months. I mean, he was like a newborn.*

Beliefs About Being a Donor

Donors perceived the risk involved in being a donor as small. One donor (patient 15) described this perception as follows: *I mean we agreed as there was one percent, two percent danger.* Some donors said that they did not hesitate to be a donor and donated part of their liver, based on their (patient 1) *free will*, and asserted that others should not also hesitate. However, donors also recounted that other potential donors gave up after deciding to be a donor. One donor (patient 15) recounted that his niece *wished to donate but his father discouraged him.*

Donors recounted a number of reasons for being a donor. One reason involved being related by blood. One donor (patient 9) described this as follows: *You either donate to your mother or to your child, to your next of kin. ... as they say, blood is thicker than water.* For one donor (patient 9), this extended to the idea that the recipient resembled to the relative of the donor that passed away and described this as follows: *My father passed away at my uncle's age, I, for example, wanted to donate more to my uncle as I didn't have a father.* On the other hand, other donors emphasized that they could be a donor even if they were not related to the recipients by blood. One donor (patient 11) expressed that she *can donate to any one, towards whom she feels close.*

Some fundamental reasons for being a donor involved (patient 5) *saving a life*, being (patient 8) *dependent on* and wanting the recipient to (patient 10) *come back to life.* The idea of saving a life extended to the idea of not committing a sin. One donor (patient 1) expressed herself as follows: *Imam said there is nothing wrong. Saving a life is a unique experience which is not comparable to anything.* However, other donors recounted that organ donation might be perceived as a sin. One donor (patient 5) pondered that *there is this folkloric thing, you see, when people resurrect in*

afterlife, how will resurrection take place when they have no liver, no kidney, ... when they have no eye?... Maybe they stay out of donation because of this. Still others were indecisive. One donor (patient 1) wondered *whether or not it is written in the Koran*.

Donors also described a number of idiosyncratic reasons for being a donor. These included avoiding the feeling that one is indebted to distant relatives—feeling upset and conscientiously uncomfortable. One donor (patient 12) explained the latter reason as follows: *if I didn't donate, I would feel very uncomfortable, conscientiously I mean*. Other reasons included (patient 1) *doing the right thing* or (patient 12) *a good deed*, and being healed. One donor (patient 11) recounted that she *felt as if she was very ill and needed to be healed*.

Donors also recounted barriers to being a donor. Some barriers were related to practicalities including losing one's job and health-related issues such as pregnancy, obesity, (patient 15) *jaundice*, being (patient 3) *underage*, and medical incompatibility. One donor (patient 12) recounted that *her father's blood type wasn't compatible*. However, other barriers were more psychosocial in nature. In particular, donors felt that significant others were (patient 11) *senseless*, (patient 5) *ignorant*, and (patient 2) *selfish*—frightened and critical of them. In particular, donors felt that others were critical of them through, for example, frequent questioning as to why they donated part of their liver. One donor expressed (patient 3) that this made getting the consent of significant others difficult: *After all he was my sister's husband and he did not allow her to have surgery*. On the contrary, another barrier was more altruistic in that some donors' relatives opposed to liver donation because of the wish to protect the donors. One donor (patient 15) recounted that she *can't have my all grown up child go under the knife*.

Donor experience also suggested that overcoming these barriers was also important. For some donors, getting their loved ones' consent was the only way to overcome these barriers. One donor (patient 8) described her journey as follows: *It took me a while to persuade them but they got convinced eventually*. For other donors, overcoming these barriers independently or against the wishes of significant others was necessary, in that some donors were left to decide on their own by their significant others. Still others overlooked loved ones' wishes to protect them. One donor (patient 12) expressed herself as follows: *The only answer my mother and father gave me was this: 'You have a 5 years old daughter, so give it a second thought, can you risk everything?' ... I risked everything*.

There were also some factors that facilitated being a donor. These included not having any (patient 1) *responsibility* and not having many people to leave behind if things went wrong. One donor (patient 3) pondered as follows: *I have neither a wife nor children, if I die my mother, father and sister will grieve but if anything happens to my mother, my grandmother, my grandfather, my uncles, her child, my elder sister will*.

Beliefs About Organ Donation and the Surgery

As well as viewing organ donation more positively, donors stated that organ donation that is done for money should be legalized and organ donation should be encouraged. One donor (patient 5) recounted that he is *planning to push whoever for organ donation*. Donors envisaged that they could do this not only through non-governmental organizations, magazines, physicians, newspapers, media, and Internet but also by giving (patient 9) *speeches* or targeting TV programs, writing books, and changing legislation. One donor (patient 5) expressed his views as follows: *If I were the government, of course it is against human rights but I would make ... organ donation compulsory*.

Donors recounted some physical effects of surgery for organ donation including (patient 7) *pain*, opening of stitches, (patient 2) *putting on weight*, and (patient 1) *feeling stiff*.

DISCUSSION

Existing psychological perspectives could help to interpret some beliefs identified in the present study. Nevertheless, in the context of these psychological perspectives, beliefs are defined in rather general terms. Moreover, these perspectives fail to predict the ways in which these beliefs will show themselves in any donor. More importantly, some beliefs were not reported previously.

Beliefs About Recipients' ESLF

Although in several explanations of the participants, there was no tangible causal agent such as spontaneous failure of the liver, donors recounted diverse explanations for recipients' ESLF, including complications at birth, genetic disorders, cirrhosis, and liver cancer. Donors blamed themselves and physicians for recipients' ESLF. Senseless drug use, stress, worry, and God's will were also mentioned as causes for recipients' ESLF. Although some causes have been reported by previous qualitative studies including hepatitis, primary biliary cirrhosis, or cancer [24], some causes such as God's will and blaming oneself or physicians have not been reported previously either by recipients or donors. These could be understood on the basis of the Attribution Theory.

Blaming physicians and God's will illustrate the specific ways in which blaming external factors for traumatic events can take shape, especially within a religious context, whereas blaming oneself illustrates the specific ways in which people can attribute the causes of ESLF to internal factors.

Blaming oneself reflects the emphasis on personal responsibility for health [25], which can be constructive if this motivates the donor to find a meaning in this. This explanation can be destructive if this stimulates lifestyle changes that interfere with treatment recommendations and fuels negative emotions such as guilt and depression [15]. Blaming physicians, on the other hand, can also be destructive because it can damage the relationship with the

physicians and therefore hinder adherence [15]. These causes should be targets for individual consultations whereby depressive symptoms [26–29] and low levels of quality of life [30–33] reported within the context of organ donation can be ameliorated.

Donors reported a wide range of physical symptoms associated with recipients' ESLF. These included shortness of breath, yellowing, vomiting, having pain, swelling, itching, and deterioration of other organs. Similar symptoms including itching, nausea, vomiting, and pain have been reported by quantitative and qualitative studies [32–34]. The experience of physical symptoms may influence emotional well-being and/or quality of life; therefore, this also must be a target for clinical consultations if the aim is to promote adjustment.

Beliefs About Being a Donor

Some donors donated a part of their liver on the basis of their free will, whereas other donors donated because others gave up being a donor. Donating on the basis of free will is consistent with previous findings [35].

Donors recounted a number of reasons for being a donor, which formed a number of continua. One continuum involved whether or not a donor was related by blood to the recipient; that is, there was the idea that recipients and donors should be related by blood, which also extended to the idea that the donor resembled the relative of the recipient that passed away. On the other hand, there was the idea that one could be a donor regardless of whether or not one was related by blood. Previous qualitative and quantitative studies have reported this continuum [36] and showed that most participants showed a willingness to donate their organs to their close relatives and friends [37].

Another continuum was related to whether or not being a donor involves committing a sin. This finding is consistent with the findings of both quantitative and qualitative studies among the general population, medical students, and health workers that indicate cultural issues and religion beliefs and/or traditions as barriers to organ donation [38–41] and reflects the role of religion in shaping the beliefs toward organ donation. In fact, it has been found that although 88.2% of imams and educators of Koran reported that organ donation was appropriate for Muslims, only 1.4% of them reported that they agreed to donate organs [42]. These findings suggest that officials of religion may play a pivotal in organ donation and therefore training on organ donation is appropriate if the aim is to promote organ donation in Turkey.

Previous qualitative and quantitative studies have shown a number of reasons for being a donor [4,6] similar to those reported in the present study, such as saving a life. However, the present study provided a wider range of reasons for being a donor. Some reasons may be potentially burdening and destructive (such as the view that organ donation is a sin) because they may go against individual needs and in turn may foster the feelings of guilt and depression. Other

reasons such as doing the right thing, performing a good deed, and being healed may foster a sense of happiness and well-being. Therefore, during clinical consultations, attempts should be made to help donors identify reasons for organ donation that foster a sense of well-being if the aim is to promote emotional well-being after surgery for organ donation.

Donors also recounted barriers to becoming a donor. Apart from patients wanting not to harm or make their healthy family members suffer because of them [4] and fear of loss and working disablement [30], these barriers have not been reported before. In the present study, most donors returned to work 3 to 6 months after surgery, consistent with previous studies [43]. Some barriers (such as being criticized by people and not getting consent of significant others) can be potentially burdening and can compromise adjustment. Other barriers (such as other people being senseless, ignorant, and selfish) can be also burdening and can deteriorate relationships with other people and may foster alienation and isolation from others. Clinical consultations should include these barriers as targets if the aim is to promote organ donation and emotional well-being after surgery for organ donation.

Donors managed to overcome these barriers by forming a continuum involving whether or not one should get their loved one's consent. This continuum can be understood on the basis of 1 of 3 patterns of voluntary consent, including "unconditional consent" reported by a previous qualitative study [7]. "Unconditional consent" refers to the consent that is sincere to save close relatives' life. Clinical consultations should foster "unconditional consent" if the aim is to help donors adjust to recipients' ESLF and surgery for organ donation and manage its after-effects. Donors also recounted some factors that facilitated being a donor. These factors included the feelings that one has few responsibilities and does not have many people to leave behind. These have not been reported before. Although these seemingly facilitate organ donation, they may be destructive because they may foster a sense of low self-worth, security, and well-being. These should also be targets of clinical consultations. These barriers to and factors facilitating being a donor can be understood on the basis of the Health Beliefs Model [44], by reflecting the specific ways in which these benefits and barriers can take shape within the context of recipients' ESLF.

Beliefs About Organ Donation and the Surgery

Raising awareness on organ donation through not only non-governmental organizations, magazines, physicians, newspapers, media, and Internet, but also through giving speeches, targeting TV programs, writing books, and changing legislation, has not been reported before. However, this reflects the general attempts to promote organ donation and indicates donors' willingness to help others by sharing their experiences. Research has shown that although organ donation is preferred by healthcare professionals in

surgical departments and departments unrelated to transplantation [45,46], a lack of knowledge on organ donation negatively influences their attitudes [47]. In fact, research has shown that one reason for not agreeing to donate included a lack of knowledge of the donation process and procedures [40,41] and that being a living donor is not considered as viable, partly because of physicians' views [48]. If the aim is to promote transplantation and organ donation, campaigns should be initiated nationwide, especially in hospitals.

Legalization of organ donation for money carries the risk of abuse of socio-economically disadvantaged people, and therefore this should also be a target of clinical consultation. These findings are consistent with the view that medical costs and lack of social security challenge the decision of being a living donor and this, especially organ donation by someone who is not related to the recipient by blood, runs the risk of commercialization of organ donation [49]. To avoid these pitfalls, it is necessary to raise public awareness through training.

Donors recounted some physical effects. Apart from chronic chest pain [50], the physical effects of surgery for organ donation such as opening of stitches, putting on weight, and feeling stiff have not been reported before. Clinical consultations should target these if the aim is to increase organ donation and facilitate adjustment.

CONCLUSIONS

Existing psychological perspectives could help to interpret some beliefs identified in the present study such as barriers to being a donor and factors facilitating being a donor. Nevertheless, these perspectives provide general definitions of beliefs. On the other hand, the present findings showed the specific ways in which these beliefs are held in donors of liver transplantation. Some beliefs were not reported previously, within the context of organ donation. Of particular importance were God's will, blaming oneself, and blaming physicians as causes for recipients' ESLF and reasons for being a donor such as doing the right thing, performing a good deed, and being healed. These beliefs represent themselves as targets for individual consultations for promoting organ donation and fostering emotional well-being after surgery for organ donation.

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