



# Liver Transplantation: Recipients' Evaluation of Life From the Perspective of Living Donors

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## ABSTRACT

**Aim.** Liver transplantation affects not only recipients and living donors' lives, but also the nature and quality of their relationship. Moreover, the ways in which recipients of liver transplant experience life and views of living donors on how recipients experience life may differ. These differences may account for relational changes. It is also important to understand how recipients and their living donors' views differ if the aim is to devise psychoeducational programs for recipients and living donors. Therefore, the present study examined the recipients' experience of life after a diagnosis of end-stage liver failure (ESLF) and transplantation surgery from donors' perspective.

**Methods.** The sample consisted of 16 living donors who donated a part of their liver to a patient with ESLF. Thematic analysis was undertaken in parallel with interviews during which an interview guide was followed.

**Findings.** Donors felt that recipients evaluated life after the diagnosis of ESLF and transplantation surgery in terms of limitations, mixed relationships, emotional changes, and improvement in life.

**Conclusion.** Experience of social limitations, negative emotions, and the feeling that one is supported by others could be interpreted in terms of existing psychological theory. Some ways of adjusting that have not been reported before within the context of ESLF extended the literature. These included others being frightened of being infected by ESLF and being insensitive, experience of positive emotions, and ways of improving. Overall, compared with findings of previous qualitative work among recipients, our findings suggest that donors' evaluation of recipients' lives converge with that of recipients.

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**E**ND-STAGE LIVER FAILURE (ESLF) is the inability of the liver to perform its roles in relation to digestion, metabolism, and storage of nutrients resulting in digestive, immune, and metabolic disorders [1–4]. The most common causes of ESLF include chronic hepatitis, cholestatic liver diseases, alcoholic liver disease, metabolic diseases, liver cancer, fulminant hepatic failure, and other diseases such as polycystic liver disease, cryptogenic cirrhosis, and amyloidosis [5–7]. Liver transplantation, including cadaveric and living-donor transplantation, is the only treatment for ESLF. Living donor liver transplantation involves a healthy family member or somebody else decided by the ethical committee donating a part of his or her liver to a patient.

The ways in which donors think about recipients' ESLF and surgery for organ donation could be understood on the

basis of the construct of beliefs. However, no quantitative study has been carried out to understand the nature of these beliefs and their effects on adjustment among living donors of liver transplantation. Studies carried out within the context of chronic physical illnesses other than ESLF suggest that all these approaches define, on theoretical grounds, the beliefs that patients are presumed to hold. However, common sense studies of illness [8,9] and other qualitative studies [10] in different types of chronic illnesses have shown that patients often hold beliefs that are greatly

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at variance with either medical knowledge or psychological theory. Therefore, living donors may hold beliefs that are not described by theoretically based approaches and that in turn might influence adjustment.

Qualitative findings can help clinicians to identify specific targets for clinical consultations and/or psychoeducational interventions to improve poor outcomes among recipients. In qualitative studies, recipients of liver transplant recounted experiencing fear, fluctuations in mood, lack of energy, pain, discomfort, physical changes, inactivity, guilt, anxiety, frustration, embarrassment, and uncertainty [3,11–16]. Patients complained of social isolation, stigma, dependence on caregivers, disruption to lifestyle and interactions, parental overprotection, and peer rejection [11,13,16].

These qualitative findings can help clinicians to identify specific targets for clinical consultations to improve poor outcomes among donors. However, owing to the small number of studies, there is limited evidence to provide a basis for such interventions. Further qualitative research is necessary to understand in detail donors' views of recipients' ESLF and surgery for organ donation. Therefore, the aim of this study was to explore these views of donors.

## METHOD

### Participants

In the present study, as a type of purposeful sampling typical sampling procedure was used to ensure transferability of the findings to other living donors of liver transplantation [17]. Typically, "living donor" in liver transplantation refers to a donor who donated a part of his or her liver to somebody who needed a liver transplantation owing to a common cause of ESLF. On the basis of this definition, the coordinator of the Liver Transplant Unit identified typical living donors from a pool of living donors who had surgery for liver donation in one of the private hospitals in Istanbul. The final sample consisted of 16 living donors of liver transplant (6 males and 10 females; mean age, 30 years [range, 23–41]). The mean duration of time that elapsed from organ donation surgery was 4.47 months (range, 3 days–7 months). Ten donors were first-degree relatives, 3 donors were second-degree relatives, and 3 donors were unrelated and approved by the ethical committee.

### Procedure

Each interview, which was undertaken individually in a private room, lasted for 60–90 minutes. Donors' views of recipients' experience of life after the diagnosis of ESLF and transplantation surgery was queried. Donors were also prompted to describe recipients' ESLF and transplantation surgery, the process of being a donor, the effects of each for themselves and the recipients, their understanding of how these effects arose and the difficulties that they and the recipients experienced, and to describe their own experience of life. However, the findings were not reported here. The interviewer (A.T.) encouraged the donors to talk in their own way and avoided closed questions. Interviews were transcribed anonymously after audio-taped recordings.

### Data Analysis

Thematic analysis was undertaken in parallel with interviews. The inductive analysis of the anonymized interview transcripts followed

established conventions to ground the analysis in data rather than preexisting ideas [18–20]. Preliminary analysis by 1 author (A.T.), based on reading 10 transcripts, was developed by discussion with a second author (R.K.) and the other authors, who also read the transcripts. Recurrent patterns were tested and modified by cycling between additional data and the ongoing analysis. Procedures are not sufficient to guarantee helpful findings [21].

In the present study, attention was paid to consensus, trustworthiness of data, and trustworthiness of the analysis. Consensus was achieved by following established conventions [22,23]. Recurrent patterns were identified, then tested and modified by cycling between additional data gathered during the second set of interviews and on the developing analysis. The trustworthiness of data was shown by providing sufficient transcript material to illustrate the themes identified in the analysis. Coherence and theoretical validity and catalytic validity formed the basis of the criteria for assessing the trustworthiness of the analysis [20]. In particular, catalytic validity [23] of the analysis (ie, the potential of the analysis to influence clinical practice and research) was also considered important. Analysis continued until no further changes emerged from this process and all relevant text was accommodated by the analysis. Each category of the final analysis was defined by several donors' data. In the findings discussed herein, illustrative quotes demonstrate the range and commonality of content of each category.

## RESULTS

Before transplantation, in addition to experiencing social limitations, donors recounted that recipients were subject to mixed relationships. On one hand, there were negative experiences with other people. Donors felt that recipients perceived others as being frightened of being infected by ESLF:

Oh! take her away, we will get jaundice. But [the recipient's name]'s illness ... is nothing like infectious, and as being insensitive people in our society, our social networks are very insensitive. ... They come to pay a visit to my mother, and you know, they say 'such and such person's daughter died of that illness.'

On the other hand, there was the view that one was supported by others. My mother is liked by quite a lot of people; God bless them. ... we saw that we were not alone.

Donors felt that the recipients experienced emotional changes. According to donors, recipients experienced different emotions both negative and positive in relation to the diagnosis of ESLF. Fear was an important aspect of the recipients' experience according to donors. In particular, fear of death because of ESLF:

I mean think of a person who is waiting for his time to come. His execution is close, as well as transplantation surgery.

We thought it well over in Cyprus, with fear of course. Both me and my mother, after all it is a surgery.

According to donors, recipients needed their loved ones' blessing before they went into surgery.

We went down to the theatre, my mother said “give me your blessing, daughter!”.

There were also other negative emotions, including feeling down, feeling hopeless, feeling worn out, having low morale, feeling exhausted, being embarrassed, as well as feeling like a loser:

When she went to the park or anywhere she attracted attention at once. They said, “Ah! You are too yellow! Is your hair dyed?” She ... was upset, “Mother, I am yellow, everybody will laugh at me.” There was this feeling of being a loser, feeling uncertain:

She said “Will I become white? Will I be a white girl? Will I recover? My mother will give me her liver, and then it will be very easy. The doctors will open my belly, they will fit my mother’s..., and I’ll get better.

There was also a feeling that one is a burden to others:

She said, “You’re always looking after me. You can’t go to work because of me. Others can’t do what they want to do, no one can do his/her work because of me.”

There was concern that one is going to leave others bereaved:

An honest person doesn’t feel sorrow because that he/she will die but thinks of his/her family he/she will leave behind. He/she thinks of the agony he/she would give to them.

As the original prospective donors had given up to be a donor, some donors mentioned the disappointment that the recipients experienced, which was extended to the feeling of being driven to the edge for some recipients: “They were very upset, they were incredibly upset. I mean they were almost driven to the edge.”

After surgery, donors recounted that the recipients experienced improvement in mood: “The support we give as a family improves my big brother’s psychology. Psychology is very important. ... Goodwill is important”; felt happy: “Now he is very happy. He has a job here which he likes”; relaxed: “He eats and drinks better. The way he talks, walks got better”; refreshed: “she is free of burden now, she is now all refreshed and growing! She has started walking”; improved physical status, including becoming fit and active, skin getting white: “Her color is white, very beautiful. You know, when I saw that color I couldn’t believe to my eyes. The kid seemed like a stranger to me, because I always saw her yellow for 4, 5 months;” growing up: “She blossomed out and grew up, she grew up very fast after the surgery”; putting on weight: “She put on 800 gram in 2 weeks”; feeling rejuvenated: “My mother is 52 years old now. She changed as much as a 70 year-old person does when he/she returns back to 40 years old”; and not itching: “She is not itching anymore.”

Donors also felt that recipients started to socialize again: “She could go out, play with her friends, I mean, you know, she is going to outings”; changed their perspective on life including appreciating the seriousness of ESLF: “At least

she has now learned to take illnesses more seriously, because this was because of her lack of care”; holding onto life: “she will hold on to future, life more seriously”; and allocating time for oneself: “I think she will make time for herself, enjoy life more, she will slow down a bit and become more serene.”

## DISCUSSION

Living donors evaluated recipients’ life in terms of limitations, mixed relationships, emotional changes, and improvements. Some findings could be interpreted in terms of existing psychological theory about adjustment. However, these theories define components of adjustment in general terms, cannot predict the form that adjustment will take in any recipient of a liver transplant. Some ways of adjusting were not reported before within the context of ESLF and therefore, they extended the literature.

Donors felt that, before transplantation, recipients experienced limitations in their social life consistent with the findings of previous qualitative findings suggesting that patients were socially isolated and socially stigmatized [13]. These findings suggest that recipients’ evaluation of their life converge with donors’ evaluation of recipients’ life. According to donors, there was a continuum in relation to the ways in which recipients perceived other people. Donors recounted that recipients had negative experiences of others, including others being frightened of being infected by ESLF and others being insensitive. However, donors also felt that recipients were supported by others. These findings are consistent with the qualitative findings among recipients indicating experience of negative emotions, such as fear of being infected by ESLF and being bullied and rejected by peers [11,13,16]. This suggests that recipients’ evaluation of their life converge with donors’ evaluation of recipients’ life. It is well-accepted that social support in chronic illness can have adverse effects on adjustment [24]. Overall, the present findings suggest mechanisms by which social support can compromise adjustment in ESLF. Clinical consultations need to pay attention to these negative aspects of social context.

The experience of both negative and positive feelings was an important aspect of recipients’ experience according to donors. The negative feelings not only involved fear, feeling down, hopelessness, worn out, exhausted, embarrassed, and uncertain, but also feelings such as feeling like a loser, feeling of being a burden to others, and being driven to the edge. Similar findings have been reported by previous qualitative studies among patients with ESLF [3,11,12,14,16]. These findings indicate that ESLF has worsened patients’ emotional state and that donors’ evaluation of recipients’ lives converges with recipients’ evaluation of their own life. Positive feelings included feeling happy, relaxed, and refreshed, and feeling an improvement in mood. These findings have not been reported before. Clinical consultations need to aim to reduce the experience

of these negative feelings and foster the positive feelings if the aim is to promote recipients' adjustment.

Based on donors' evaluations, improvement in life was also an important aspect of recipients' experience. These involved becoming physically improved, socializing again, and a changing perspective on life. Physical improvement included becoming fit and active, the skin growing white, growing up, putting on weight, feeling rejuvenated, and not itching. These ways of improving after transplantation have not been reported previously. Clinical consultations need to foster these to help patients manage the whole process of transplantation. Previous qualitative studies have shown that itching was the most frequently mentioned problem for recipients [12]. The present finding on physical improvement, particularly not itching, stresses the healing effect of transplantation surgery as evidenced by the disappearance of a symptom that is the characteristic of ESLF. There were also changes in perspective on life. In particular, after transplantation surgery donors felt that recipients appreciated the seriousness of ESLF, held onto life, and allocated time for themselves. Similar findings have been reported in other chronic illnesses [25]. Clinical consultations need to foster these ways of finding meaning within the context of ESLF. Overall, these findings suggest that donors' evaluation of recipients' lives converge with recipients' evaluation of their own life.

Donors evaluated recipients' life in terms of limitations, mixed relationships, emotional changes, and improvements. Some findings, including social limitations, being supported by others, and experience of negative emotions, could be interpreted in terms of existing psychological theory. However, these theories define components of adjustment in general terms and cannot predict the form that adjustment will take in any recipient. Some ways of adjusting that have not been reported before within the context of ESLF extend the literature, including others being frightened of being infected by ESLF, others being insensitive, experience of positive emotions, and ways of improving. Overall, our findings suggest that, compared with previous findings, donors' evaluation of recipients' lives converge with those of recipients' evaluations of their own life. However, these findings should be interpreted with caution owing to methodological and cultural issues. Future studies need to further compare donors' evaluation of recipients' life and recipients' evaluation of their own life in a way that overcome methodological and cultural problems. Nevertheless, the present findings provide an evidence base for targets of individual consultations and/or psychoeducational programs for recipients and their donors.

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