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Psychosocial Aspects of Liver Transplantation and Liver Donation

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Abstract

The construct of adjustment may help to understand the demands of end-stage liver failure (ESLF) and liver transplantation. Adjustment can be operationally defined on the basis of whether or not recipients and donors suffer from psychological problems and the ways in which they perceive their quality of life. For recipients of a transplant, evidence suggests that ESLF is related to the experience of psychological problems and poor quality of life, whereas transplantation is associated with less psychological problems and improvement in quality of life. Among donors, there is some evidence to suggest that organ donation surgery is associated with deterioration in quality of life and high levels of psychological problems. However, findings have been contradictory regarding the extent of these difficulties. Attempts to predict these outcomes are limited. More research is therefore needed. The construct of beliefs in general and the self-regulatory model of illness and qualitative research in particular could guide future attempts to explain these outcomes. Qualitative findings suggest that recipients and their donors experience ESLF and/or transplantation surgery or organ donation surgery in ways that are not identified by quantitative research. These findings can be used not only to develop ESLF-specific quality of life or emotional well-being questionnaires but also patient- or donor-derived interventions to improve poor outcomes.

Keywords: liver transplantation, liver donation, adjustment, quality of life, mood and anxiety disorders

1. Introduction

Two concepts including disease and illness can be differentiated. The concept of disease refers to changes that occur in the structure or functions of bodily systems, whereas the concept of

illness refers to patients' perception of their symptoms and their own and their significant others' reactions to these symptoms [1].

In medicine, the concept of 'chronic patient' is a relatively recent concept [2]. Approximately, in the last 3 decades, a considerable amount of attention is given to chronic physical illnesses for two main reasons. First, medicine can effectively control infectious diseases [2]. Second, the number of patients with a chronic physical illness is increasing. A chronic physical illness refers to a long-lasting and incurable physical illness, although patients may not experience the symptoms all the time [2]. Currently, in developed countries, common causes of death are chronic physical illnesses [3]. Healthcare professionals dealing with patients with a chronic physical illness need to pay attention to both concepts of disease and illness if the aim is to provide a high quality of care which is responsive to all the needs of the patients and their significant others.

The treatment of chronic physical illnesses aims to slow down their course as well as to reduce distress resulting from associated physical symptoms. In many cases, medicine is uncertain about the mechanisms of cause and cure of these illnesses [2]; as a result the growing number of patients with a chronic physical illness presents themselves as a big challenge to healthcare professionals. In general, treatment involves changes in lifestyle (such as dietary restrictions), dependence on medical technology such as the use of medication and artificial means to replace bodily functions.

The main characteristic of the ESLF is the liver failing to execute its main functions of digesting, metabolizing and storing the essential nutrients [4]. ESLF occurs due to a number of causes. Hepatitis, liver diseases, metabolic conditions and cancer of the liver constitute some causes of ESLF [5]. Cadaveric and living donor transplantations are the main choices of treatment. Transplantation not only aims to achieve maximal quality and quantity of life but also to minimize the effects of illness and its costs [6].

Cadaveric transplantation is preferred over living donor transplantation, but the former has a number of disadvantages including long waiting time and low chance of survival [7]. In addition, cadaveric liver transplantation generally requires inpatient treatment and care which may also decrease the chances for survival [7]. The waiting time of the cadaveric liver transplantation is generally long, but available cadaveric donors are scarce [7–10].

In living donor transplantation, a healthy individual related by blood or an individual who is considered by the ethical committee as suitable to donate, although not related by blood, provides a transplant. This form of transplantation has the advantage of decreasing the time that candidates wait for a transplant and increasing the survival rate [11]. However, adult-to-adult transplantation is a complicated procedure because approximately 60% of the liver of the donor, in other words the entire right lobe, is used [12].

Due to advances in liver transplant procedures and immunosuppressive medications, the prognosis following transplantation is good, and the survival rate after 1 year and 8 years of transplantation is approximately 85–90 and 61%, respectively [6, 13]. Some donors are likely to develop complications after organ donation surgery such as biliary problems, reoperation and persistent physical symptoms [9, 14–16]. Donor mortality ranges from 0.1 to 0.3% [17].

This means that transplantation has the possibility of endangering the health of donors. Therefore, in order to maintain their health, they are asked to go through an interdisciplinary

preoperative evaluation involving a series of medical as well as psychosocial assessments. This evaluation aims to ensure that they made autonomous and voluntary decisions to donate, and they can cope with the requirements and/or outcomes of organ donation surgery [18–20]. In general, medical inclusion criteria for liver donation include being between the age of 21 and 55, being within the normal weight range, the absence of any liver disease or any other significant disease such as cardiovascular diseases or diabetes and being free of any viral infection such as viral hepatitis or HIV [21, 22].

Recipients of a liver transplant and their donors are required to change their behavior or lifestyle to meet the demands brought by ESLF and transplantation or surgery for liver donation. Therefore, they both tend to face adaptational difficulties. The construct of adjustment may help to understand these difficulties. Adjustment can be defined in different ways depending on different assumptions. One way of defining adjustment involves whether or not the recipients or donors experience psychological problems (such as depression, anxiety or distress) or difficulties in overall functioning. Another way of defining adjustment is to do it in global terms by, for example, in terms of overall quality of life.

The impact of chronic illness in general and ESLF in particular goes beyond the patient himself or herself to all individuals who the patient is interacting with [1]. In general, a chronic illness can potentially influence various dimensions of life including interpersonal relationships, economic conditions and daily as well as social functioning [1]. Therefore, it is essential to understand the ways in which transplantation or surgery for liver donation influences both recipients and donors in order to formulate appropriate criteria for selecting suitable donors and promote donors and recipients' adjustment.

While reviewing the adaptational difficulties of recipients and their donors, it is important to review the difficulties experienced at pre-transplant and the ways in which these difficulties change across different time points following transplantation or organ donation surgery. Moreover, the adaptational difficulties will be reviewed on the basis of the construct of adjustment. For the purpose of this chapter, the construct of adjustment will be operationally defined on the basis of whether or not recipients and donors suffer from psychological problems and the ways in which they perceive their quality of life.

To that effect the search strategy aimed to identify all studies relevant to the experience of adaptational difficulties by recipients of a liver transplant and their donors. A number of databases were searched from 1985 to 2017. These databases included Medline, Embase, Psycinfo, PsycArticles and the Cochrane Library. A number of keywords were used. These keywords included chronic liver disease, ESLF, adjustment, quality of life, anxiety, depression, emotional well-being, mood disorders, psychological distress, psychological problems and psychiatric problems.

2. Recipients' experience

Both quantitative and qualitative studies have aimed to understand the adaptational difficulties experienced by the recipients.

2.1. Quantitative research

2.1.1. *Psychological problems*

Among candidates of liver transplant, reviews [23] have shown that the most common psychological problems at pre-transplant period include delirium, alcohol and substance misuse, anxiety and depressive disorders. In particular, the rates of depression, anxiety and delirium have varied from 4.5–64%, 20–50% and 50–56%, respectively [24–32].

Suitability of candidates with major mental illnesses for liver transplantation is subject to controversy. It has been argued that the presence of a major mental illness should not be an automatic exclusion criterion. Indeed evidence suggests that candidates with schizophrenia can be successfully transplanted [33]. It has been found that 27% of the sample had a severe personality disorder and 40% of this subsample were put on the transplantation list [34]. Therefore, specific exclusion criteria for those who suffer from a major mental illness may include poor compliance with medical and psychiatric follow-up appointments and poor quality of social support [33].

At post-transplantation, psychological problems experienced by the recipients include delirium, anxiety, depression, dysthymia, adjustment disorder, psychosis, post-traumatic stress disorder (PTSD) and substance related disorder [35–38]. Eighteen to twenty-seven percent of recipients report at least one disorder [38–40]. For example, it was reported that 23% of recipients experienced symptoms of PTSD, and among these recipients, 50% also experienced major depression [38]. However, the rate of depression has ranged from 5–46% across different studies [38, 41]. Nevertheless, the rate of psychological problems was the same as the general population [38].

Some studies have examined whether or not at post-transplant, the rate of psychological problems changes compared to that of pre-transplant. For example, while within 3 months post-transplant, the rate of these problems has been estimated to be 54% [36] at 1- and 3-year follow-up this rate has been estimated to be 7 and 2%, respectively [42]. Research has also shown that levels of different mood problems such as depression and anxiety have got reduced after transplantation [43]. In contrast another study found that there was no difference in terms of depressive symptoms prior and following transplantation [44].

Recipients also tend to experience different psychological problems at different time periods following transplantation. For example, it was found that recipients experienced depressive symptoms more commonly while they were in the intensive care unit, whereas they experienced anxiety symptoms more commonly after discharge from hospital [45].

2.1.2. *Quality of life*

Reviews [46] have shown that quality of life of candidates is poor at pre-transplantation. Indeed, the extent of impairment is greater than that of hospitalized patients with pneumonia, outpatients with rheumatoid arthritis, patients with minor nonacute conditions and the general population but similar to those of patients with peripheral vascular illness and osteoarthritis [47, 48].

After transplantation, systematic reviews and individual studies [44, 49–52] have shown that recipients have better quality of life. Studies indicate improvement in many areas including emotional, cognitive, social, behavioral, vocational, domestic and sexual areas [53]. A review showed that transplantation improved many dimensions of quality of life. These dimensions included physical health, sexual and social functioning, daily activities as well as overall quality of life [46]. Most positive changes were reported in physical, sexual and daily functioning and overall quality of life, whereas less positive changes were reported in psychological and social areas.

Prospective studies have also shown similar findings. One such study showed that recipients' general well-being was improved and the experience of physical symptoms (including tiredness, exhaustion and weakness) got reduced 1 year post-transplantation [54]. Similarly another prospective study reported improvements in cognitive areas and overall quality of life [55].

In contrast, evidence also suggests that observed positive changes in quality of life disappear when this is adjusted for those who died and that at a follow-up of 10 years, recipients' cognitive functioning and quality of life are poor [56, 57].

In addition, some systematic reviews and individual studies [51, 52] have shown that recipients have poorer quality of life in most dimensions of quality of life than healthy controls. In contrast, other studies have shown that quality of life of recipients is not different from or is higher than those of general population and patients with chronic liver disease at 1 year post-transplantation [58, 59].

Other studies have shown that high levels of psychological difficulties such as anxiety and depression reduce quality of life directly or as a mediator. For example, it was found that at pre-transplant, 31.1 and 25.8% of recipients were clinically significant for anxiety and depression, respectively, as compared to the rates observed in the general population (12.6 and 3.6% for anxiety and depression, respectively [59]). Those recipients with anxiety and depression within clinically significant levels also reported worse quality of life at post-transplantation. Similarly, following transplantation quality of life gets improved, and improvement in mood following transplantation is also related to improvement in quality of life [4, 43, 46, 54, 60, 61]. For example, one of these studies found that recipients without anxiety or depression symptoms at pre-transplant reported quality of life within the normal range at post-transplantation [60].

2.2. Qualitative research

Studies have shown that patients with ESLF experience their illness by going through two stages including 'becoming ill' and 'not living' [62]. Accordingly, the stage of 'becoming ill' includes interpreting the illness as an illness which develops insidiously, doubting the illness in the absence of experiencing its signs and managing the illness (such as by being positive, independent and supported by the family and friends) and managing its physical symptoms (such as tiredness). The stage of 'not living' includes losing independence due to deterioration in physical functioning, becoming disabled and wishing to return to a normal life by regaining independence. Other studies have provided specific information on the ways in which recipients of a transplant progress from physical, social and psychological dependence to independence [63]. The same study also showed that at pre-transplant period, recipients

recounted that their quality of life was poor and their physical problems prevented their independence, their social activity, the fulfillment of personal goals and management of psychological issues. At post-transplant period, recipients recounted that they wished to socially integrate and achieve control but significant others limited their independence by overprotecting them. A principled personality, optimistic outlook, incentives and professional support helped toward independence.

Candidates or recipients of liver transplant reported that they not only experienced negative emotions (such as fear, guilt, anxiety, frustration, embarrassment and uncertainty), mood fluctuations, lack of activity and energy and physical symptoms (such as pain and discomfort) but also negative social changes such as isolation, stigma, dependence on carers, carers' overprotection and restrictions in lifestyle [64–69].

Only one study examined the views of donors on the ways in which recipients evaluated their life as a result of the diagnosis of ESLF and transplantation [70]. Accordingly, donors felt that prior to transplantation in addition to experiencing social limitations, recipients experienced others both negatively (such as being frightened of getting infected by ESLF and others being insensitive) and positively (such as being supported by others). The experience of negative (such as feeling down, hopeless, like a loser) and positive feelings (such as feeling happy and relaxed) as well as improvement in life characterized recipients' experience according to donors. Improvement in life included not only physical and social improvements but also altering life perspective (such as appreciating that ESLF is serious and holding onto life).

3. Donors' experience

Both quantitative and qualitative studies have aimed to understand the adaptational difficulties experienced by donors.

3.1. Quantitative research

3.1.1. *Becoming a donor*

The experience of becoming a donor was characterized with ambivalence. There are two different types of ambivalence [71]. Residual ambivalence comprised uncertainty feelings and hesitation about the process of donation (such as being frightened of going through with donation) that continue to be present after medical assessments. Acute ambivalence refers to feelings of indecision present during the psychosocial assessment which prevent the prospective donor to give informed consent [18]. Acute ambivalence is uncommon (less than 2%) [72–74], whereas residual ambivalence is common (75%) [75–79].

Studies suggest that donors tend to make decisions that are not informed. A systematic review showed that a high percentage (89–95%) of donors felt they comprehended medical information provided by healthcare professionals regarding drawbacks and benefits of donation, although they reported that their needs for information and knowledge regarding the risks and possible complications were not met [80].

Although a small minority of donors (less than 5%) report to regret their decision to donate [81–84], the majority (80–100%) of donors report to be willing to donate again [77, 84–87]. Those donors who are hesitant or regret donating explain this on the basis of the specific characteristics of their situation (such as risky behaviors of the recipient) rather than the characteristics of the donation process (such as medical risks). Relatedly, donors who believe that the recipient is healthy are willing to donate again, whereas donors who believe that recipients risk their transplant are not willing to donate again.

3.1.2. *Psychological problems*

Compared to studies which examined the extent of psychological problems among candidates or recipients of liver transplant, not many studies have examined the extent of these problems among donors.

At pre- and/or post-donation periods, psychological problems that are experienced include low self-esteem, stress and low confidence [88, 89] and mood and anxiety disorders [37, 38, 90–92].

Although some studies suggest that donors' mental health gets improved at post-donation period [88, 93–95], other studies report that the extent of psychological distress is one in every four donors [85, 95, 96].

3.1.3. *Quality of life*

As in the case of candidates or recipients of liver transplant, the findings regarding to quality of life of donors have been mixed both at pre-donation and post-donation.

Before liver donation, evidence has suggested that quality of life of donors is low [97]. Yet many studies have suggested that the levels are better than that of general population [87, 92, 98, 99], whereas other studies have shown that donors report poorer quality of life based on mental dimensions [100] as compared to healthy controls.

After donation quality of life has been found to be high among donors [15, 94], and physical and mental aspects of quality of life are equivalent to and even higher than that of general population [81, 84, 86, 87, 90, 100–102]. Recent systematic reviews [103] have shown similar findings.

Evidence suggests that prior to organ donation, quality of life of donors is good, but following donation quality of life gets reduced particularly with regard to physical aspects and activities of daily living [99]. Compared to general population, evidence suggests that prior to donation, quality of life of donors is equal to and in some cases higher but following donation the physical but not mental dimensions of quality of life deteriorate, and this level returns to starting levels at 6-month to 1-year follow-up [87, 100]. More specifically, in one of these studies, donors returned to work at 1 year post-donation, but their levels of physical functioning contrasted with those of mental functioning [87]. With regard to social aspects, most donors do not report any changes in their relationship with recipients or report that their relationship gets improved post-donation [84, 87]. However, closer relationships including relationship with the spouse get worsened [81, 101, 104].

Relatedly, studies show that donors rate their physical health as fair to poor or worse following donation [77, 95, 101, 105]. More specifically, it was shown that quality of life was worse at 2-year than 5-year follow-up [106]. Donors also suffer from debilitating symptoms including pain around the scar, fatigue and poor body image [84, 87–89, 94–96, 105, 107]. In particular, difficulties in quality of life are related to financial difficulties, negative changes in employment status or social relationships as indicated by reviews [15].

As in the case with recipients of transplant, reviews [15] show that donors who report poor quality of life also report psychological problems.

3.2. Qualitative research

More qualitative research has been undertaken to examine the experience of donors than that of recipients.

A number of qualitative studies have explored the donors' views on becoming a donor. Accordingly, donors perceive the process of becoming a donor as an automatic response and as an opportunity to help the loved one [67, 108, 109]. The donors felt that they had no choice and decided to be a donor by prioritizing the recipient's life, viewing transplantation as the last chance for the recipient and her family and feeling obligated to save the recipient [110]. More specifically, this study showed that donors decided on becoming a donor by going through five stages [110]. The first stage, recognition, involves learning of liver transplantation from recipients, family, doctors or media; the second stage, digestion, involves realizing the seriousness of liver transplantation and wanting to save recipients from suffering and avoiding the guilt; the third stage consists of making a decision; the fourth stage, reinforcement, involves the donors reinforcing themselves psychologically; the final stage, resolution, involves preparedness and acceptance of donation. Relatedly, it was also reported that donors give three types of consent [111]. 'Unconditional consent' is a voluntary consent to save family members' life; 'pressured consent' is a consent whereby the donor feels pressurized to become a donor but he/she feels frightened. 'Ulterior-motivated consent' refers to the situation when the donor has a hidden motive.

Relatedly, other studies have shown that donors consider donation to cope with guilt regarding their own health and to reduce the responsibility for the ESLF of the recipient [112]. In the same study, donors recounted that they would only donate to certain family members or close friends [88]. By contrast, in another study donors recounted that they would donate to people who were related by blood as well as to anybody whom they felt close to regardless of whether or not they were related by blood [113].

Only one study explored donors' beliefs of the ESLF of the recipients, their transplantation and their own organ donation surgery [113]. This study found that donors' beliefs could be viewed in a number of groups including beliefs about recipients ESLF, beliefs about being a donor, beliefs about surgery for organ donation and beliefs about organ donation. Beliefs about recipients' ESLF included diverse explanations for ESLF (such as spontaneous failure of the liver, worry, stress, senseless drug use, blaming oneself and physicians) and physical symptoms (such as cramps, itching, weakness, developmental slowing down). Beliefs about being a donor consisted of reasons for donating (such as being related by blood, saving a life, doing the right thing, being healed), barriers to being a donor (such as pregnancy, obesity, other people being senseless and selfish), ways of managing these barriers (such as getting

significant others' consent and acting on one's gut feeling) and factors helping toward donation (such as the feeling that one does not have any responsibility). Beliefs about organ donation surgery included physical effects (such as pain, opening of stitches, putting on weight). The views that it is necessary to encourage organ donation and to raise people's awareness made up beliefs about organ donation.

In other qualitative studies, donors reported various feelings related to being a donor including not only negative emotions but also positive emotions. The former included feeling frightened, sad, anxious, angry and disappointed as well as feeling of being a failure, whereas positive emotions included feeling motivated and certain [109, 114, 115]. There was also the feelings of disappointment and anger toward medical system and insurance and the views that donation was not valued, that one is not supported and is not taken seriously by the medical staff [115]. Another study found that when the transplant did not fail, donors felt happy for having saved life. When the transplant failed, donors comforted themselves by the fact that they did everything they could [108].

On the other hand, a recent study found that donors experienced not only emotional changes but also changes in character. The former consisted of both negative (such as feeling angry, hopeless, down and helpless) and positive emotions (such as feeling appreciated, reputable, conscientiously comfortable). Changes in character were characterized by both worsening of (such as changing into an aggressive person) and positive changes in character (such as turning into a believer and stronger) [116].

The relationship of the donor with the recipient has been idealized [109], and difficulties about accepting recipients' ESLF have been experienced [114]. Research has also shown that there is a special bond between the recipient and the donor [116], in that the donor and the recipient become closer and donation is considered as a "proof of love" and the scar as a symbol of a special experience shared by the recipient and the donor only [117]. Moreover, the latter study also found that donation enhanced the positive or conflicting characteristics of the donor recipient relationship and there was not any deterioration in this relationship. Donors sometimes minimized the negative characteristics of this relationship and emphasized the improvements [117]. Similarly, another study reported that the extent of marital breakdown was lower than the general population. In the case of no marital breakdown, marital relationship has become stronger because of donation. In the case of marital breakdown, causes were independent of transplantation or donation process [108]. By contrast, another study reported that donors recounted mixed relationships. These included not only a continuum of feeling supported by significant others/doctors and not feeling supported by mothers or spouses but also formation of a special bond and worsening of close relationships [116]. Relatedly, it was reported that donors tend to postpone their personal needs such as emotional needs associated with rehabilitating oneself [108].

4. Correlates

A small number of quantitative studies have examined the effect, of a number of factors on outcomes among recipients of a liver transplant and their donors. For example, it was found that that 51–58% of the variance in quality of life was explained by a number of factors [60]. After

transplantation among recipients, employment, age, and depression predicted physical aspects, whereas anxiety and depression predicted mental dimensions of quality of life. Transplant-related factors such as rejection of the transplant, the number and length of hospital stays, effectiveness of the medication and complications did not predict anxiety symptoms. However, more patients suffering from anxiety and/or depression went through re-transplantation.

Studies have shown that the experience of feelings including ambivalence about donation, hesitation and uncertainty are important predictors of poor adjustment and quality of life at post-donation period among donors [76, 86]. Moreover, it was also shown that donors who were concerned about their own health, finances and close relationships at pre-donation period had a history of psychiatric illness or present psychiatric illness and held a graduate degree reported poorer quality of life, although donors' medical complications were unrelated to their quality of life [86].

5. Conclusion

To date, there are numerous studies among candidates or recipients of a liver transplant and their donors on their adjustment. Evidence suggests that ESLF is associated with adjustment difficulties including experience of psychological problems and poor quality of life among candidates or recipients of a liver transplant. However, findings have been contradictory regarding the extent of these difficulties partly due to different approaches that studies have taken to defining and measuring psychological problems and quality of life. Transplantation is associated with less psychological problems and improvement in quality of life, with more improvements in physical functioning and less improvements in psychosocial areas. However, although it can be argued that quality of life improves after transplantation, the ways in which this improvement continues over time are not clear. Some studies show that quality of life remains similar during follow-up, whereas other studies show subsequent deterioration. In studies which examine quality of life across different time points following transplantation, recipients with high mortality rates need to be accounted for to avoid bias.

There is also some evidence to suggest that contrary to recipients of a transplant, organ donation surgery is associated with deterioration in quality of life, particularly in physical functioning among donors and experience of psychological problems and poor quality of life among donors. However, findings have also been contradictory regarding the extent of these difficulties partly due to different approaches that studies have taken to defining and measuring psychological problems and quality of life.

As mentioned above, contradictory or inconsistent findings may be due to methodological problems. More specifically, studies have mainly used generic measures of quality of life [81, 85, 101]. Such measures may not be specific and sensitive enough to understand adjustment-related issues among recipients of a transplant or their donors. Moreover, studies which examined the long-term implications of liver transplantation and donation have assessed recipients and donors at different times after surgery [19, 84].

Evidence also suggests that high levels of psychological problems such as anxiety and depression negatively influence quality of life directly or as a mediator among recipients of a liver

transplant and their donors. One explanation for this evidence is that high levels of these problems impair quality of life directly or as a mediator by, for example, maintaining the sick role [60]. Another explanation is that anxiety and depression may reduce compliance with treatment, and this in turn reduces quality of life [61].

Despite numerous studies on the extent of psychological problems and quality of life, attempts to predict these outcomes have fallen short. There is little evidence to conclude from quantitative studies that particular factors predict outcome. Therefore, more research is needed. The construct of beliefs could guide future attempts to explain these outcomes. A review on adjustment in end-stage renal failure (ESRF) [118] shows that although the variance explained in outcomes by beliefs is small, beliefs have been more consistent in predicting these outcomes than other variables such as social support. One exception for these small effects is the beliefs postulated by the self-regulatory model of illness [119, 120] which is developed on the basis of interviews with patients suffering from different types of chronic physical illnesses. This model includes beliefs about identity, cause, consequences, timeline and cure or controllability of a particular chronic physical illness. Future research may examine the ways in which these beliefs predict these outcomes.

An alternative approach to better understand these outcomes is to be guided by qualitative studies. In terms of beliefs, only one qualitative study [113] examined donors' beliefs about ESLF, transplantation and organ donation surgery. More qualitative research is needed, in particular about recipients' beliefs about ESLF and transplantation.

Overall, qualitative findings suggest that candidates or recipients of a liver transplant and their donors experience ESLF and/or transplantation surgery or organ donation surgery and the process of organ donation in ways that are not identified by quantitative research. God's will, blaming oneself, blaming physicians as causes for recipients' ESLF, doing the right thing, being healed as reasons for being a donor, the views that others are frightened of getting infected by ESLF and insensitive, experience of positive emotions, ways of improving, worsening aspects of character and close relationships are among findings which extend quantitative findings. These findings can be used not only to develop ESLF-specific quality of life or emotional well-being questionnaires but also patient- or donor-derived interventions to improve poor outcomes.

Conflict of interest

There is no conflict of interest.

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