



## ARAŞTIRMA / RESEARCH

# Living with a foreign organ: counselling needs of living liver transplant recipients

Yabancı bir organ ile yaşamak: canlıdan karaciğer transplantasyonu yapılan alıcıların danışmanlık gereksinimleri

Özge Pekin İşeri<sup>1</sup>, Özgül Karayurt<sup>2</sup>, Sezai Yılmaz<sup>3</sup>

<sup>1</sup>Gaziosmanpaşa University, Health Science Faculty, Surgical Nursing Department, Tokat, Turkey

<sup>2</sup>İzmir Ekonomi University, Health Science Faculty, Surgical Nursing Department, Izmir, Turkey

<sup>3</sup>İnönü University, General Surgical Department, Malatya, Turkey

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### Abstract

**Purpose:** Liver transplantation can be a lifesaving option for people with acute/chronic liver failure. Although liver transplantation has positive outcomes, the recipients experience many physical, psychological and social problems. It is of great importance to satisfy their needs for counselling so that they can overcome these problems. The aim of the study was to describe the counselling needs of living liver transplant recipients.

**Materials and Methods:** A descriptive qualitative research design was used. The study was conducted between November 2012 and December 2012. In-depth interviews were performed with sixteen participants who had experiences of living liver transplantation. Data were analyzed with inductive content analysis.

**Results:** The liver transplant recipients' counselling needs were categorized into two main themes: "pre-transplantation period counselling needs" and "post-transplant period counselling needs". Subthemes were also identified and described. The first main theme had three subthemes (causes and symptoms of liver failure, treatment process, living donors) and the second main theme had four subthemes (medications used, possible complications, sexuality and body image and life after transplantation).

**Conclusions:** The results indicate that the living liver transplant recipients' currently have insufficient knowledge about transplantation periods and they need counselling.

**Key words:** Counselling, liver transplant recipient, qualitative research, nursing.

### Öz

**Amaç:** Karaciğer transplantasyonu son dönem akut ve kronik karaciğer yetmezliği olan hastalar için yaşam kurtaran bir tedavi yöntemidir. Karaciğer transplantasyonunun her ne kadar olumlu sonuçları olsa da alıcılar fiziksel, psikolojik ve sosyal açıdan birçok sorun yaşamaktadırlar. Bu nedenle alıcıların yaşanan sorunlarla baş edebilmesi için danışmanlık gereksinimlerinin karşılanması oldukça önemlidir. Bu çalışmanın amacı canlıdan karaciğer transplantasyonu yapılan alıcıların danışmanlık gereksinimlerinin belirlenmesidir.

**Gereç ve Yöntem:** Bu çalışma tanımlayıcı kalitatif bir araştırmadır. Çalışma Kasım-Aralık 2012 tarihlerinde yürütülmüştür. Veriler canlıdan karaciğer transplantasyonu olan 16 alıcı ile derinlemesine görüşme yöntemiyle toplanmıştır. Verilerin değerlendirilmesinde içerik analizi yöntemi ve tümevarımcı yaklaşım kullanılmıştır.

**Bulgular:** Alıcıların danışmanlık gereksinimleri "transplantasyon öncesine ilişkin danışmanlık gereksinimleri" ve "transplantasyon sonrasına ilişkin danışmanlık gereksinimleri" olmak üzere iki ana temadan ve tanımlanan yedi alt temadan oluşmaktadır. Birinci ana temanın üç alt teması (karaciğer yetmezliğinin nedenleri ve belirtileri, tedavi süreci, vericiler); ikinci ana temanın (kullanılan ilaçlar, oluşabilecek komplikasyonlar, cinsel yaşam ve beden imajı ile yeni yaşamları) ise dört alt teması bulunmaktadır.

**Sonuç:** Canlıdan karaciğer transplantasyonu olan alıcıların transplantasyondan önce ve sonrasında bilgilerinin yetersiz olduğu ve danışmanlık gereksinimlerinin olduğu saptanmıştır.

**Anahtar kelimeler:** Danışmanlık gereksinimi, karaciğer transplantasyonu alıcısı, kalitatif araştırma, hemşirelik.

Yazışma Adresi/Address for Correspondence: Dr. Özge Pekin İşeri, <sup>1</sup>Gaziosmanpaşa University, Health Science Faculty, Surgical Nursing Department, Tokat, Turkey E-mail: ozgepekiniseri@gmail.com  
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## INTRODUCTION

Liver transplantation (LT) can be a lifesaving option for people with acute/chronic liver failure<sup>1,2</sup>. The number of people receiving liver transplants is growing each year. Six thousand seven hundred and twenty-nine patients in the USA<sup>3</sup> and 5995 patients in Europe had LT in 2013<sup>4</sup>. In Turkey, 2254 patients need LT<sup>5</sup>. There are 41 LT centers and 1215 LTs were reported to be performed in these centers by 2015<sup>6</sup>. It is anticipated that LT increases survival of patients and grafts, reduces morbidity and mortality and improves quality of life<sup>7</sup>. According to data from the ELTR, with which seven liver transplant centers from Turkey are affiliated, one-year patient survival was 82% and graft survival was 76% between 1988 and 2011<sup>8</sup>. In Turkey, one-year survival was 77%<sup>9</sup>.

Unlike European Union countries and the USA, Turkey has a very low number of deceased donors and an increased number of living donors, which is considered as one of the most important problems concerning organ transplantation<sup>9,10</sup>. The number of deceased donors per 1 million is 5.3 in Turkey and 20-25 in European Union countries<sup>11</sup>. In fact, in Turkey, of 1248 liver transplants, 959 were obtained from living donors in 2013<sup>6</sup>. Reasons for the low number of deceased donors in Turkey have been reported to be lack of knowledge of organ donation, religious beliefs and distortion of body integrity<sup>12</sup>.

The advantages of living donor liver transplants (LDLT) are a shorter period of time elapse between donation and transplant, a decreased cold ischemia time and a lower rate of rejections<sup>7,13</sup>. Despite of the great number of prosperities of liver transplantation, there are many important and critical issues about it. LDLT recipients have been reported to experience many physical problems such as rejection, infection and diabetes; social problems such as inability to work and changes in familial relationships<sup>2,14,15,16,17</sup>.

The recipients may suffer from more severe pain and have a poorer quality of life<sup>17,18</sup>. These complications should be recognised as pertaining to LTs in general. And also different from deceased donor transplant psychological problems such as anxiety and depression due to the feeling of guilt can be seen. The studies conducted so far have examined LT recipients' experiences<sup>16,17,18,19,20,21,22,23</sup> and contents and methods of education to be offered to the recipients<sup>24,25</sup>. To maintain liver function and avoid complications, LT recipients

need to engage in a self-management behaviors<sup>26,27</sup>. For this reason proper education and counselling is essential for patients to enhance these behaviors<sup>28</sup> and control over diseases<sup>26,29</sup>. And also it is important to better understand their situation to provide holistic nursing care and to improve their quality of life. But there is lack of sufficient research about counselling needs of LT recipients in Turkey and in the world. We can find only one study about this topic<sup>30</sup>. The aim of this study was to investigate counselling needs of LDLT recipients' in a single centre in Malatya, Turkey

## MATERIALS AND METHODS

The study design was descriptive, qualitative, and focused on counselling needs of LDLT recipients. We used this approach for three reasons. First, its exploratory open nature is well-suited to understanding the counselling needs of recipients. Second, the flexibility of the study design gives an opportunity for further investigation. Third, a qualitative approach allows for new perspectives to emerge.

The study was conducted in an organ transplantation centre of a university hospital in Malatya, Turkey. There were 17 transplant surgeons, 11 transplant assistants, one organ transplantation coordinator and 15 nurses in the organ transplantation center. This is the center where the highest number of organ transplantation is carried out in Turkey.

Approval was obtained from the ethical committee of the University (2012/222) where the study was conducted and permission was taken from the institution where the data were collected. The study was performed in accordance with the Declaration of Helsinki. The LDLT recipients included in the study were informed about the aim of the study, and both oral and written informed consent was obtained from all of the participants. They were also informed that participation in the study was voluntary and that they could withdraw from the study at any time without giving a reason.

It is not quite possible to determine the sample size in qualitative studies before they are started<sup>31</sup>. Therefore, until concepts and processes which can be considered as responses concerning counselling needs emerged repeatedly, participants were registered in this study. A total of 16 LDLT recipients were included in the study. We used a

purposive sampling strategy, which is commonly used in qualitative research to select study participants. Criterion sampling was used. Inclusion criteria were as follow: Having LT for the first time, having LT from a living donor, going through the post-transplantation period at the time of the study, volunteering to participate in the study, not having any hearing or speech problems and being able to understand and speak Turkish. Exclusion criteria were: Giving consent first for being included into the study but declining later and becoming ill during data collection which required stopping interviews.

The study was conducted between November 2012 and December 2012. In-depth interviews were used to collect data. The interviews continued until a point at which no new information was obtained. Sixteen LDLT recipients were enrolled in the study. In-depth semi-structured face-to-face interviews were conducted in a quiet, well-lit, and well-air-conditioned room and were tape recorded. During the interview, the researcher asked follow-up questions such as 'Can you please tell me more about that?'. The researcher also took notes about the participants' tone of voice, mimics and gestures during interviews. All participants were encouraged to contribute and sufficient time was allowed for the participants to express themselves. Each interview lasted for approximately 30 minutes.

All data were collected by one researcher using a demographic and clinical data form and a semi structured interview form. The demographic items included questions about sociodemographics of the LDLT recipients. The semi structured interview form included one open-ended question about what the recipients wanted to consult about liver transplantation during the hospital stay and after discharge. Exploratory questions were used when necessary during interviews. Caution was exerted to ask questions which can be understood easily and which should not influence the participants' opinions.

Four experts experienced in qualitative research were requested to offer their opinions about the form. Afterwards the form was piloted on ten patients followed in a liver transplantation outpatient clinic of a hospital in İzmir, Turkey and fulfilling the inclusion criteria to test understandability of the questions. Data obtained from the piloting study were not included into the analysis. Since all the questions were understood

easily, no changes were made in the form.

Criteria recommended by Lincoln and Guba were used to estimate the validity and reliability of the study<sup>32</sup>. Lincoln and Guba use the terms credibility, transferability, dependability, and confirmability instead of internal validity, external validity, internal reliability, and external reliability, respectively<sup>32</sup>. In terms of validity (credibility), data were collected during in-depth interviews and were analyzed by two independent researchers. The interviews were recorded by one researcher, who also took notes during interviews. The researchers examined the findings to determine whether the findings accurately reflected the reality described by participants by questioning themselves critically. To achieve transferability, content analysis and purposeful sampling were used. The content analysis allowed transferring data without adding any comments, and the purposeful sampling helped to reveal situations in accordance with their nature<sup>31,32</sup>. To achieve dependability, the questions asked by the researcher at each interview were based on a similar approach, and two researchers independently examined the data. To achieve confirmability, findings were expressed clearly so that readers could understand them easily. In addition, recordings of the interviews, notes taken during interviews, verbatim transcriptions of the recordings, and analyses were retained for future confirmation use<sup>31,32</sup>.

### Statistical analysis

Inductive content analysis, in which obtained data were continuously compared by two researchers, was used to analyze the data. This analysis is a systematic approach to describe a phenomenon extensively and to create new knowledge on the phenomenal concept for action<sup>33</sup>. Concepts derived from the coding became subthemes. Subthemes were combined to create themes (Figure 1).

The recorded interviews were transcribed verbatim, and main themes and subthemes were determined independently by the two researchers. The two researchers subsequently compared their coding and reached consensus on them. The themes were next analyzed and confirmed by another researcher (investigator triangulation)<sup>31,34</sup>. The field notes taken by the researcher during the actual interviews were also taken into consideration in the analysis process.

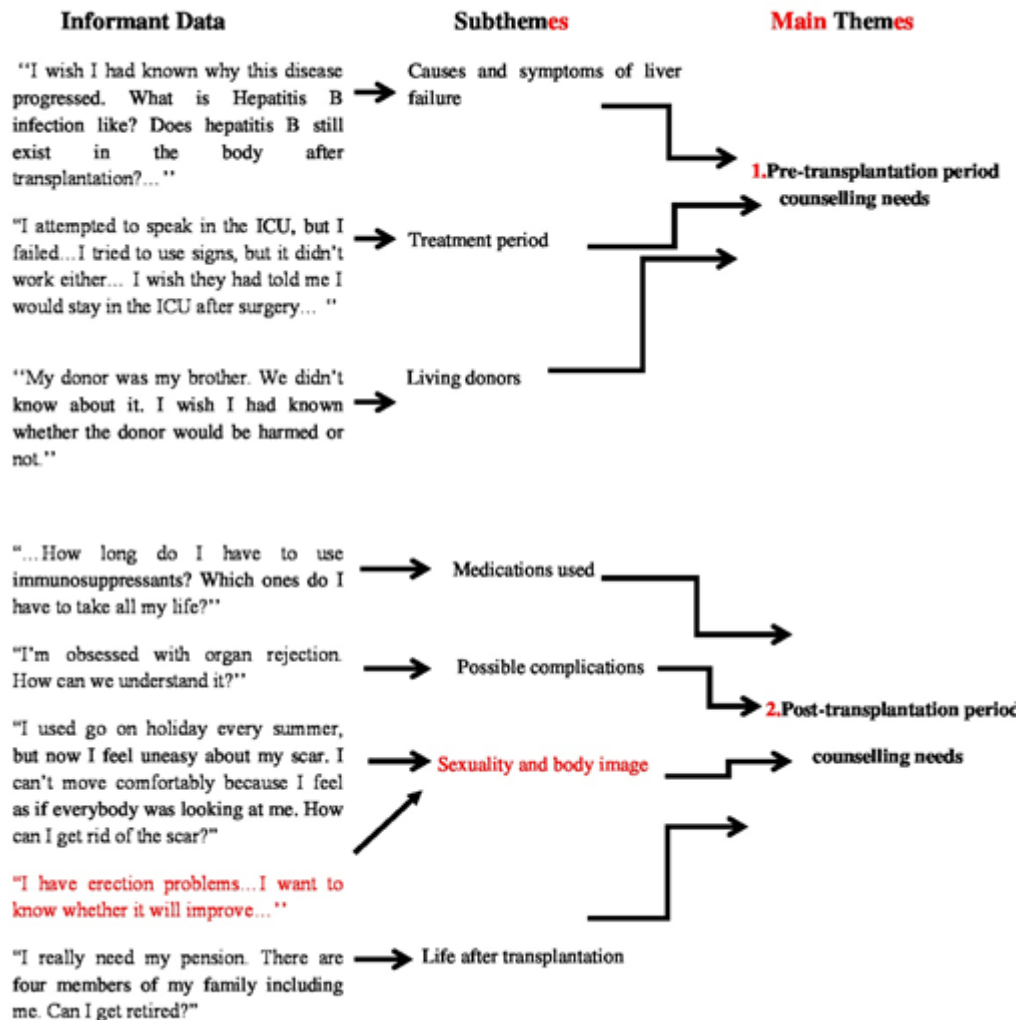


Figure 1. Example of subthemes and main themes about counselling needs of living liver transplant recipients

**RESULTS**

The LDLT recipients participating in the study were aged 19-58 years with a mean age of 41.43±14.87 years. Of all the recipients, 43.75% were secondary school graduates. Fifty-six point twenty five percent of the recipients had liver transplantation due to hepatitis B and 68.75% of the donors were the recipients' relatives (Table 1). The recipient's

counselling needs were classified into two main themes and subthemes (Figure 2).

**Main theme 1: Pre-transplantation period counselling needs**

The first main theme was divided into three subthemes. The recipients stated that their counselling needs must be met at an appropriate time in the clinic prior to surgery.

### Causes and symptoms of liver failure

The LDLT recipients reported that they needed counselling about causes of liver failure such as hepatitis B, hepatitis C and symptoms of liver failure such as ascites, jaundice and weakness. "I wish I had known why this disease progressed. What is Hepatitis B infection like? Does hepatitis B still exist in the body after transplantation?..." {5<sup>th</sup> interviewee aged 19yrs; donor: mother} "There was jaundice in my eyes and my body before surgery. I didn't know about jaundice..." {14<sup>th</sup> interviewee aged 19yrs; donor: father}

### Treatment period

The LDLT recipients commented that they needed counselling about physical features of the operating room, the method of transplantation used, the

amount of blood lost, the size of the graft placed and the exact place of the surgical incision. Also they want to learn the possibility to stay in the intensive care unit (ICU), ICU environment, drainage catheters including the cause and place of drainage and reasons for investigations and tests their relatives and themselves were exposed to. "I wish I had known what kind of surgery I would undergo. It was very important for me to feel safe. I wish I had known about the environment of the operating room." {14<sup>th</sup> interviewee aged 19yrs; donor: father} "I attempted to speak in the ICU, but I failed...I tried to use signs, but it didn't work either... I wish they had told me I would stay in the ICU after surgery..." {2<sup>nd</sup> interviewee aged 58yrs; donor: nephew/niece} "... Who is exposed to drainage? Why?" {6<sup>th</sup> interviewee aged 55yrs; donor: spouse}

**Table 1. Socio-demographic and clinical features of live donor liver transplantation recipients' (n: 16)**

Features	$\pm$ SD (min-max)
Age (years)	41.43 $\pm$ 14.87 (19-58)
Sex	
Female	11 (68.75%)
Male	5 (31.25%)
Education	
Not literate	2 (12.5%)
Primary school	3 (18.75%)
Secondary school	7 (43.75%)
University or higher education	4 (25%)
Marital status	
Married	12 (75%)
Single	4 (25%)
Occupation pre/post	
Same	5 (31.25%)
Changing position or job	3 (18.75%)
Resignation	8 (50%)
Etiology of liver transplantation	
Hepatitis B	9 (56.25%)
Hepatitis C	1 (6.25%)
Hepatitis B + Hepatitis C	1 (6.25%)
Budd Chiari syndrome	2 (12.5%)
Idiopathic liver failure	1 (6.25%)
Cryptogenic liver failure	1 (6.25%)
Wilson's Cirrhosis	1 (6.25%)
Time after liver transplantation	
0 month-1 year	9 (56.25%)
2-3 years	4 (25%)
4 years or more	3 (18.75%)
Relationship to donor	
Mother/ Father / Sibling	11 (68.75%)
Cousin/ Nephew	3 (18.75%)
Spouse	2 (12.5%)

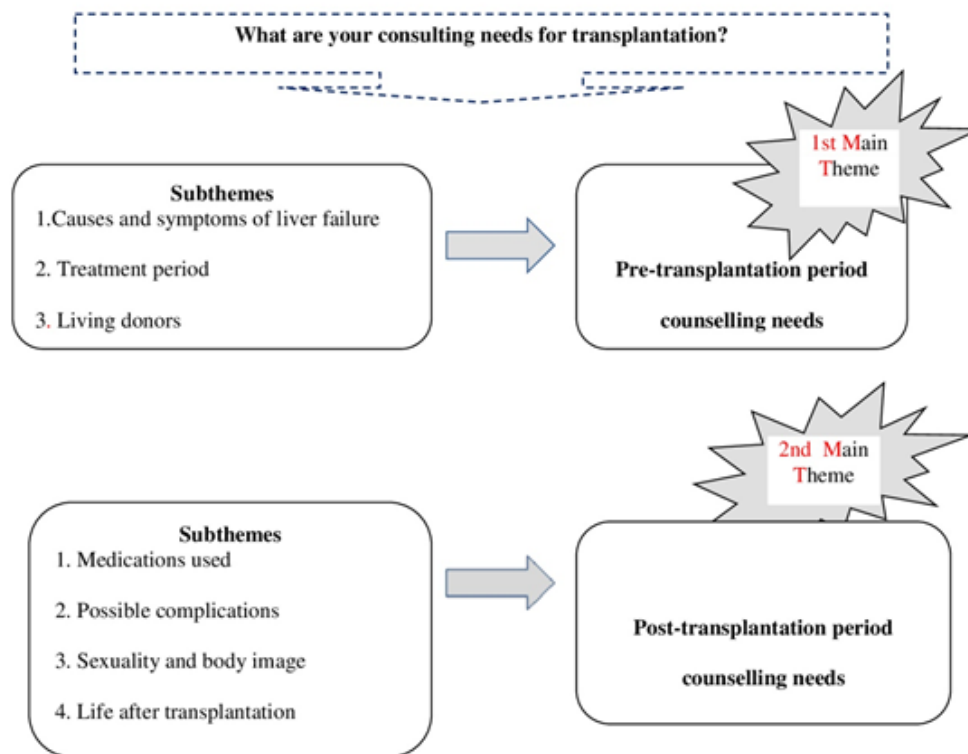


Figure 2. Main themes and subthemes associated with liver transplant recipients counselling needs.

### Living donors

The LDLT recipients explained their counselling needs about employment status of donors and risks donors likely to suffer. "My donor was my brother. We didn't know about it. I wish I had known whether the donor would be harmed or not." {3<sup>rd</sup> interviewee aged 34yrs; donor: sibling} "...I have greater difficulty because the donor is my spouse (swallowing and not talking). My husband couldn't go to work for six months after transplantation. I wish I had known all about them." {15<sup>th</sup> interviewee aged 29yrs; donor: spouse}

### Main theme 2: Post-transplantation period counselling needs

The second main theme was divided into four subthemes. The recipients stated that their counselling needs must be met in the clinic before their discharge.

### Medications used

It turned out that most of the recipients needed counselling about duration of immunosuppressive drugs including the mode of action and side-effects and uses of other medications such as painkillers. "...How long do I have to use immunosuppressants? Which ones do I have to take all my life?" {9<sup>th</sup> interviewee aged 50yrs; donor: sibling} "I had the diagnosis of diabetes two months ago. I haven't been informed that the immunosuppressants cause diabetes or hypertension (Her tone of voice has risen)." {4<sup>th</sup> interviewee aged 34yrs; donor: sibling} "I feel really worried when I have to take another medication such as painkillers. I wonder whether they affect my liver." {14<sup>th</sup> interviewee aged 19yrs; donor: father}

### Possible complications

The LDLT recipients noted that they wanted to

receive counselling about complications of transplantation including infections, rejections and biliary problems.

“...I keep away from people to avoid contacts with microorganisms...How does a person contract microorganisms?” {5<sup>th</sup> interviewee aged 19yrs; donor: mother} “I’m obsessed with organ rejection. How can we understand it?” “...I have some problems related to bile...What should I do to prevent them?” {11<sup>th</sup> interviewee aged 56yrs; donor: sibling}

### Sexuality and body image

The LDLT recipients reported that they experienced decreased sexual arousal and impotence. Patients also wondered whether a sexual relationship damages their liver and when they can start it. They expressed their worries about getting married and having children and explained that their surgical scar had a negative effect on their body image.

“I have erection problems...I want to know whether it will improve...” {10<sup>th</sup> interviewee aged 56yrs; donor: son} “Can I get married? Can I become pregnant?” {5<sup>th</sup> interviewee aged 19yrs; donor: mother} “I used go on holiday every summer, but now I feel uneasy about my scar. I can’t move comfortably because I feel as if everybody was looking at me. How can I get rid of the scar?” {14<sup>th</sup> interviewee aged 19yrs; donor: father}

### Life after transplantation

The LDLT recipients noted that they needed counselling about life at work, retirement, medical reports to prove their disability, financial problems, nutrition, physical activity, travelling, social life and frequency of follow-ups.

“I really need my pension. There are four members of my family including me. Can I get retired?” {16<sup>th</sup> interviewee aged 52 yrs; donor: sibling} “What should I wear? I don’t know whether I should follow a diet.” {5<sup>th</sup> interviewee aged 19yrs; donor: mother} “...I used to do sports regularly, but I don’t know whether I can do it now...” {1<sup>st</sup> interviewee aged 48yrs; donor: son}

## DISCUSSION

Although there have been studies on causes and symptoms of liver failure in Turkey and other parts

of the world<sup>35,36</sup>, there have not been any studies on LDLT recipients’ counselling needs. The finding that the recipients insisted on receiving counselling about causes and symptoms of liver failure although they went through the post-transplantation period indicates the staffs not spending sufficient time on offering education and counselling to the patients.

Fulfilling patients’ needs for counselling about transplantation and the operating room will help them to feel safe and overcome the fear of surgery. Unfortunately, in Turkey nurses are not offered education about transplantation nursing after undergraduate education and there are not any certificate programs about transplantation nursing. Consistent with the results of the present study, it has been reported in the literature that LDLT recipients experienced loss of control, insufficiency in their ability to speak, pain, anxiety and fear in the ICU<sup>21,37</sup>. Actually, informing patients and counselling them about ICUs, nursing interventions and treatments offered by nurses may reduce their fear and anxiety.

Although the incidence of biliary conditions varies widely (5-25%), the mortality due to these conditions is 2-7%<sup>38</sup>. In the present study, the recipients reported that they had problems due to biliary complications and drainage tubes. Consistent with the results of the present study, Stivetti et al. (2013) reported that 15.5% of the individuals receiving liver transplantation had difficulty related to T tubes<sup>39</sup>. It is clear that the recipients should be informed about biliary complications and drainage tubes.

In transplantations, living donors can also be at risk of surgical complications. Since the number of deceased donors is low in Turkey, living donors are preferred<sup>10</sup>. It has been reported in the literature that the risk of death in donors for LT is 0.2%-0.5%<sup>36,40</sup> which is very high compared to the risk in donors for renal transplantations (0.013%)<sup>41</sup>. It is clear that being a LDLT is risky. In this study, all of the donors were the recipients’ first or second degree relatives and naturally the recipients wanted to know the risks the donors were exposed to. In one study, 86% of the donors completely recovered in the first 3.8 months after transplantation<sup>42</sup> and in another study, the donors returned to work 2.5 months after the operation. Sharing the evidence about the donors with LDLT recipients may prevent them from feeling guilty.

It has been noted in the literature that immunosuppressive medications create problems such as infections, diabetes and hypertension<sup>2,43</sup>. In a qualitative study, it has been emphasized that offering information about medications played an important role in problem solving strategies concerning treatment compliance<sup>44</sup>. It is required that side effects of immunosuppressants should be monitored and managed well to improve survival and quality of life in the long-term and to prevent rejection<sup>45</sup>. In the first two weeks after transplantation, most frequently bacterial infections occur and in the 3<sup>rd</sup>-8<sup>th</sup> weeks fungal infections become frequent<sup>15,45</sup>. In the present study, the recipients wanted to know causes of infections and rejections and ways to prevent them. Education about the risk of infections and rejections after LT should be based on signs, symptoms and ways to prevent them<sup>45,46</sup>.

In one study, 44% of the recipients were found to have decreased satisfaction with their sexual life after LT<sup>47</sup>. In the other studies, one third of LDLT recipients reported to have sexual dysfunctions after transplantation<sup>48</sup>. The recipients reported sexual dysfunctions emerging after transplantation and originating from immunosuppressants and psychological and social problems<sup>45,49</sup>. Sexuality, which is considered as private in general and can be seen as a taboo in Turkish society, should be dealt with carefully and recipients should be informed about it.

It is reported that LDLT recipients have difficulties in their physical, social, emotional, economical and mental roles<sup>14,23,50</sup>. The recipients' needs for counselling about retirement and disability suggest that LDLT recipients should be questioned about their financial status and health insurance and that appropriate long-lasting programs supported by social workers should be designed to solve their financial and insurance related problems<sup>19</sup>. However, a low number of social workers and nurses' lack of appropriate knowledge about these issues cause problems in Turkey. There is also evidence in the literature that LDLT recipients have the fear of infections and resultant rejections and therefore are isolated from social life consistent with the findings of this study<sup>22</sup>. For these reasons, transplantation nurses, who will offer counselling to LT recipients continuously and regularly, are required. In the transplantation center where this study was conducted, the recipients were followed

by a gastroenterologist, a general surgeon and an assistant in the outpatient clinic, but there was not a specialist transplant nurse. There is not any literature about transplantation nurses' counselling in Turkey because of there aren't specialized transplantation nurses in our country which could be a limitation of this study.

The results indicate that recipients currently have insufficient counselling about transplantation process. For this reason the study has provided new data about liver transplant recipients' pre and post transplantation counselling needs. Pre and post-transplantation care is a job of a multidisciplinary team and transplantation nurses are important members of this team. Education programs in which nurses and other health professionals are educators and counselors can fulfill LDLT recipients' need for counselling and improve their quality of life. It can be recommended that transplantation nurses' roles should be determined and that certificate programs for transplantation nursing should be designed in Turkey. Outpatient clinics where short-term and long-term follow-ups of LDLT recipients are performed by transplantation nurses should also be opened. In addition, experimental studies on fulfillment of recipients' counselling needs with education booklets and interactive education CDs and on effects of education programs on patient outcomes are required, and based on the results of this study, an experimental study has been designed to be conducted in the present study setting.

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