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ARAŞTIRMA / RESEARCH

Expectations of liver transplantation candidates and their relatives and difficulties they experience

Karaciğer transplantasyonu adaylarının ve yakınlarının beklentileri ve yaşadıkları güçlükler

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Abstract

Purpose: The aim of this study is to investigate LTCs' and Relatives' LTCRs' expectations and experienced difficulties during the liver transplantation waiting process

Materials and Methods: This descriptive and single-center study was performed in the Transplantation Polyclinic of a public hospital in Ankara. The sample consisted of 170 liver transplantation candidates and 170 patient relatives. Data were collected through face-to-face interviews with participants.

Results: This study reveals that the most important expectation of liver transplantation candidates during the waiting period is "a transplant operation with successful results" (70.0%), whereas liver transplantation patients' relatives are primarily concerned with the expectation that their sick relative will "regain her or his health" (80.0%). Almost all (97.1%) of the patients had physical problems, and the majority of them(87.1%) struggled with activities of daily living and experienced psychological (85.3%) and socio-economic problems (81.8%). Patients' relatives also had problems associated with activities of daily living (80.6%) and experienced psychological (81.8%) and socio-economic (73.5%) difficulties.

Conclusion: The results of this study confirm that liver transplantation candidates and their relatives experience many difficulties that impact their activities of daily living, as well as psychological and socio-economic problems. In order to provide relief from these difficulties, liver transplantation candidates and their relatives should be given training and counseling.

Key words: Liver transplantation, transplant recipients, caregivers.

Öz

Amaç: Bu araştırma, karaciğer transplantasyonu için bekleyen hastaların ve yakınlarının beklentilerini ve yaşadıkları güçlükleri belirlemek amacıyla yapılmıştır.

Gereç ve Yöntem: Tanımlayıcı ve tek merkezli bu çalışma, Ankara'daki bir kamu hastanesinin Transplantasyon Polikliniğinde yapılmıştır. Örnekleme 170 karaciğer transplantasyonu adayı ve 170 hasta yakınını dahil edilmiştir. Veriler katılımcılar ile yüzyüze görüşülerek toplanmıştır.

Bulgular: Araştırmada, karaciğer transplantasyonu bekleyen hastaların bekleme süreci sırasında en büyük beklentisinin "başarılı bir nakil ameliyatı olma" (%70.0), hasta yakınlarının en önemli beklentisinin ise "hastalarının eski sağlığına kavuşması" (%80.0) olduğu belirlenmiştir. Hastaların tamamına yakını (%97.1) fiziksel sorunlar, büyük çoğunluğu da günlük yaşam aktiviteleri (%87.1) ile ilgili, psikolojik (%85.3) ve sosyo-ekonomik (%81.8) güçlükler yaşamaktadır. Hasta yakınları da günlük yaşam aktiviteleri ile ilgili (%80.6), psikolojik (%81.8) ve sosyo-ekonomik (% 73.5) güçlükler yaşamaktadır.

Sonuç: Bu araştırmanın sonuçları karaciğer transplantasyonu bekleyen hastaların ve yakınlarının günlük yaşam aktivitelerini etkileyen birçok güçlüğün yanı sıra, psikolojik ve sosyo-ekonomik güçlüklerle karşılaştıklarını desteklemektedir. Yaşanan bu güçlüklerin azaltılabilmesi için karaciğer transplantasyonu bekleyen hasta ve hasta yakınlarına eğitim ve danışmanlık verilmesi önerilmektedir.

Anahtar kelimeler: Karaciğer transplantasyonu, transplantasyon bekleyen hastalar, bakım verenler.

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INTRODUCTION

Liver transplantation is the most basic, economical, and commonly successful treatment for patients diagnosed with chronic liver disease[1,2]. Liver transplantation has thus become a widely-preferred treatment and has been accepted as the gold standard in the treatment of chronic liver disease [3,4]. An increasing number of liver transplantation candidates (LTCs) has led to the formation of waiting lists onto which patients are placed after being evaluated by transplantation centers.According to the Turkish Ministry of Health (2013), at the time of this study, there were 2,068 patients on the liver transplantation waiting list (LTWL); however, liver transplantation could only be performed for 581 patients in the first six months[5].

Being placed on an LTWL awakens new expectations both in LTCs and in liver transplantation candidates' relatives (LTCRs). A study by Aras (2006) showed that, during the waiting process for liver transplantation, 85.4% of patients expected to regain their health, 7.3% expected their deteriorating condition to improve, 4.9% expected prospects for a better life, and 2.4% expected that their relatives and close friends would no longer be in distress. Similarly, 81.8% of LTCRs members expected that the deteriorating condition of their loved ones would improve, whereas 18.2% of them expected that their relatives would regain their health[6]. Due to such expectations, the patients and their relatives experienced difficulties during the waiting process.

In cases when the waiting time on the LTWL is extended, complications can arise, and the condition of patients waiting for liver transplantation can deteriorate, which can also lead to potentially fatal conditions.The study by Dalgıç et al. (2001) carried out on 25 patients waiting on an LTWL showed that liver transplantation was performed in only four (16%) of the patients,whereas one patient (4%) who responded well to the treatment was taken off of the list, 12 patients (48%) died during the waiting process,and the remaining eight patients (32%) still continued to wait[7]. On the other hand, the results of another study carried out in the US between 2005 and 2006 using the records of the Organ Procurement and Transplantation Network showed that 13,940 patients were placed on the waiting list, and at the end of two years, a transplant was performed in 38% of the patients, 6% of them died while waiting[8]. These studies give the impression that waiting lists have turned into "lost lists" for patients.

When no appropriate donor organs can be found, it becomes increasingly difficult and stressful for patients with every day that passes. The physical problems due to illness not only lead to difficulties associated with activities of daily living (ADLs) such as insufficiency in personal care, difficulties in moving, fatigue, insomnia, and forgetfulness but also give rise to psychological and socio-economic problems[9–12]. The waiting process for liver transplantation causes patients to increasingly experience negative emotions, such as exhaustion, anxiety, depression, fear, and anger[6,13–15]. Due to the psychological problems that arise during the waiting process, the coping abilities of patients decline, their bodies and identity perceptions change, and their social life is negatively affected[16]. In addition, the insidious and life-long nature of chronic liver disease has a negative effect on patients' economic situations[17].

Exhausting and long-lasting treatments also cause LTCRs, who are obligated to support LTCs, to experience difficulties and become exhausted. Aras (2006) has shown that the relatives of patients cannot cope with the problems they experience (75.8%); they need psychological support (42.4%), and they experience difficulties in the procurement of drugs and materials (42.4%), in finding accommodation (24.2%), and due to lack of persons who can assist with caretaking responsibilities (39.4%)[6]. The family member who takes over caretaking for the patient must deal with their own changing role within the family, increasing responsibility and stress, and decreased quality of life[18]. LTCs and LTCRs should therefore be informed—especially about the process of the illness, the drugs used, diets, problems that can occur in patients, emergency procedures, and routes to the hospital and they should be followed at regular intervals and given the opportunity to share their problems and emotions[19,20].

The transplantation nurses who assume an important role in the transplantation team should provide consultations and education to LTCs by adopting an holistic approach, being informed about the difficulties experienced by LTCs and LTCRs, and providing support to relieve these difficulties[20–22]. For this reason, nurses should fulfill their roles in terms of care, training, and consultation.

Although there are studies available in the literature on the general expectations and difficulties experienced after liver transplantation, we have found no studies addressing the expectations and difficulties of LTCs and LTCRs during the waiting process for transplantation. The aim of this study is to investigate LTCs' and Relatives' LTCRs' expectations and experienced difficulties during the liver transplantation waiting process. This is the first study in which the expectations and difficulties experienced by patients waiting for an liver transplantation and their relatives are examined in an integral manner. This study will therefore provide important insights to transplantation nurses and transplantation teams. We believe that this study will also provide effective support in matters such as defining the needs of LTCs and their families, providing holistic nursing care before transplantation, and increasing the quality of health services.

Research questions in the study were; what are the expectations from liver transplantation of the patients during the liver transplantation waiting process?; what are the expectations from liver transplantation of the patient' relatives during the liver transplantation waiting process?;what are the experienced difficulties of patients during the liver transplantation waiting process? And what are the experienced difficulties of patients' relatives during the liver transplantation waitingprocess?

MATERIAL AND METHODS

This descriptive study was carried out in the Transplantation Polyclinic of a public hospital in Ankara between 29 December, 2011 and 29 March, 2012. Organ transplantations have been performed in the hospital since 1998. LTCs are regularly assessed and followed up in the Transplantation Polyclinic by a Transplantation Working Group.

The universe of the study was composed of 274 LTCs waiting on the waiting list of the hospital in the period during which the study was carried out and their relatives. As the number of patients in the universe is known in the study (N = 274), the following formula was used to determine the sample size.

$$n= \frac{Nt^2pq}{d^2(N-1)+ t^2pq}$$

The minimum number of patients and patient relatives to be included in the study was calculated with the formula and was determined as 160. We interviewed all the LTCs and LTCRs in the order of the appointments made, and those who agreed to take part in the study were included in the sample group. The sample of the study consisted of 170 patients and 170 patients' relatives. The sample of the study consisted of 170 LTCs and 170 LTCRs.

Prior to the study, written consent was obtained from the Directorate of Treatment Services in the Ministry of Health and the hospital (Dated: 29.12.2011-Number:17054). All patients and relatives gave informed consent, and the study was approved by the ethical review board (Dated 14.12.2011-Number:360) and conducted in accordance with the Declaration of Helsinki.

Data collection and procedure

In data collection, two separate questionnaire forms were used. These forms were developed by the researchers based on the current literature[2,4,6,11-19,25-27,30,35,38-44]. The LTCs form includes three sections. The first section covers sociodemographic characteristics, chronic liver disease information, and liver transplantation waiting time (31 questions). The second section covers the expectations of LTCs (six questions), and the third section contains questions about the experienced difficulties of LTCs concerning ADLs (20 questions), psychological problems (14 questions), and socio-economic difficulties (16 questions).

The LTCRs form consists of three sections. The first section covers the socio-demographic data of LTCRs and their status as caregivers (33 questions). The second section covers the expectations of LTCRs (six questions), and the third one includes questions about the difficulties LTCRs encounter in terms of ADLs (24 questions), psychological difficulties (16 questions), and socio-economic difficulties (10 questions).

Prior to the initiation of the study, transplantation coordinators, doctors, and nurses at the Transplantation Polyclinic were informed about the study. The data of the study were collected via face-to-face interviews; each interview lasted 15–25 minutes.

Statistical analysis

Statistical evaluation of the study data was performed using the Statistical Package for Social Sciences, version 16.0 (SPSS Inc., Chicago, IL, USA). Figures, percentage, average, chi-square and Fisher's exact chi-square tests were used in the evaluation of the data. P values of ≤0.05 were accepted as statistically significant in the evaluation of the results.

RESULTS

The mean age of the LTCs was 46.18±12.33, 59.4% were men, 77.6% were married, and 58.8% of them had insufficient income (Table 1). The average time the patients survived with chronic liver disease was 7.57±5.95 years, with viral hepatitis (62.9%) and cirrhosis (27.6%) beingthe two most frequent causes for liver failure. 35.2% of the patients had been waiting for an liver transplantation for less than two years, 32.4% for 3–5 years, and 32.4% for more than six years (the average waiting time was 4.10±2.81 years). Although the expectations of patients during the waiting period were mainly (70.0%) focused on a "successful transplantation", the largest number of patients (98.8%) hoped that there would be "a decline in complications" during the post-liver transplantation period (Table 2).

Table 1. Sociodemographic characteristics of LTCs and LTCRs

Sociodemographic Characteristics	LTCs† n (%)	LTCRs† n (%)
Age		
≤45	78 (45.9)	96 (56.5)
≥46	92 (54.1)	74 (43.5)
Mean Age ($\overline{X}$ ± SD)	$\overline{X}$: 46.18 ± 12.33	$\overline{X}$: 41.82±13.30
Min- Max	19-80	18-77
Gender		
Female	69 (40.6)	80 (47.1)
Male	101 (59.4)	90 (52.9)
Marital status		
Married	132 (77.6)	129 (75.9)
Single	38 (22.4)	41 (24.1)
Having child(ren)		
Yes	145 (85.3)	130 (76.5)
No	25 (14.7)	40 (23.5)
Educational Status		
Illiterate/ Literate	20(11.8)	10(5.9)
Primary school	100 (58.8)	90 (52.9)
High school and upper	50 (29.4)	70 (41.2)
Occupation		
Housewife	59 (34.7)	57 (33.5)
Worker	20 (11.8)	26 (15.3)
Retired	43 (25.3)	17 (10.0)
Self-employment	17 (10.0)	16 (9.4)
Officer	8 (4.7)	13 (7.6)
Farmer	9 (5.3)	8 (4.7)
Others	14 (8.2)‡	33 (19.4)§
Employment status		
Working	22 (12.9)	58 (34.1)
Not working	97 (57.1)	89 (52.4)
Not working due to disease	51 (30.0)	23 (13.5)
Income level		
Adequate	11 (6.5)	17 (10.0)
Moderate	59 (34.7)	76 (44.7)
Inadequate	100 (58.8)	77 (45.3)
Social security		
Yes	153 (90.0)	146 (85.9)

No	17 (10.0)	24 (14.1)
The perception of current status		
Poor	63 (37.1)	73 (42.9)
Average	57 (33.5)	71 (41.8)
Good	50 (29.4)	26 (15.3)

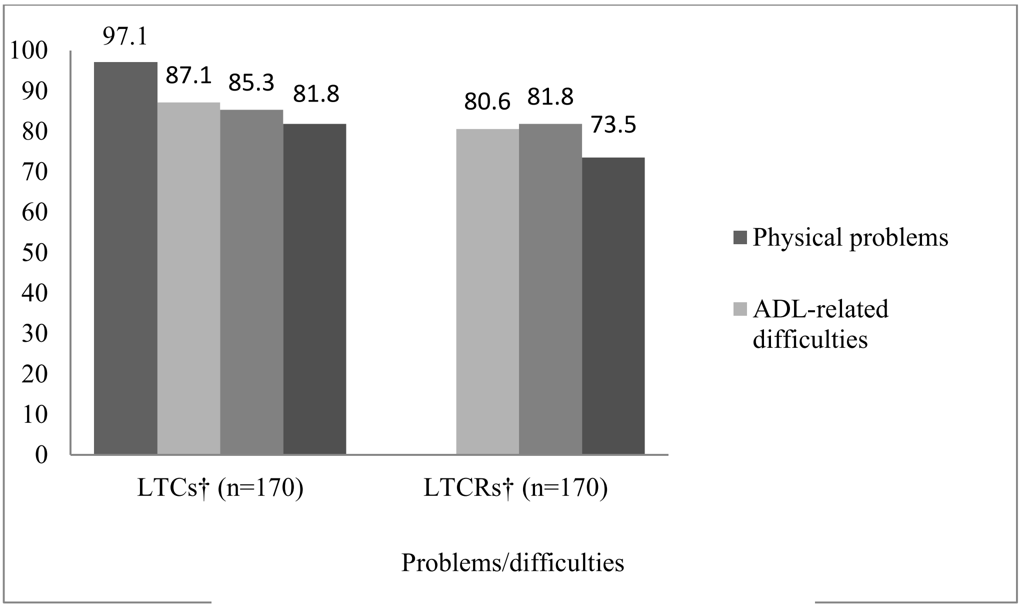
LTCs, Liver transplantation candidates. LTCRs, Liver transplantation candidates' relatives.; ‡Driver (7), student (3), jurnalist (1), draftsman (1), janitor (1), unemployed (1).; §Unemployed (18), service man (7), student (3), craftsman (1), accountant (1), greengrocer (1), operator (1)

Table 2. The expectations of LTCs and LTCRs concerning the waiting process for liver transplantation and life after transplantation

Expectations†	**LTCs‡ n (%)**	**LTCRs‡ n (%)**
Expectations Concerning the Waiting Process		
A successful transplantation surgery	119 (70.0)	80 (47.1)
An experienced/successful team	87 (51.2)	28 (16.5)
Regaining health	79 (46.5)	136 (80.0)
Availability of proper cadaver/living organ	65 (38.2)	127 (74.7)
A team who takes special care of patients/takes time for them	40 (23.5)	44 (25.9)
Hope	34 (20.0)	19 (11.2)
A decline in complications	14 (8.2)	-
No expectations	13 (7.6)	5 (2.9)
Being informed by the healthcare team about the transplant	12 (7.1)	17 (10.0)
Undergoing a surgery as soon as possible and rehabilitation	-	55 (32.4)
Fear/anxiety/despair	-	13 (7.6)
Expectations in respect of the life after liver transplantation		
A decline in complications/problems	168 (98.8)	-
Regaining health	151 (88.8)	65 (38.2)
Reduced frequency of hospital visits	101 (59.4)	-
Increased life span	99 (58.2)	-
Increased life quality	97 (57.1)	-
Being able to fulfill the roles/duties in the family	92 (54.1)	4 (2.4)
Being able to plan for the future	83 (48.8)	45 (26.5)
Walking freely in the street	75 (44.1)	-
That the patient can meet her/his own personal needs	74 (43.5)	2 (1.2)
A better functional condition	72 (42.4)	-
Being able to perform sportive activities	65 (38.2)	-
A reduction in expenses of the patient	65 (38.2)	1 (0.6)
A better outer appearance	64 (37.6)	-
Psychological relief	-	60 (35.3)
A more safe and hopeful future	-	25 (14.7)
Ability to take time for oneself	-	10 (5.9)
No expectations	-	5 (2.9)
An increase in responsibilities	-	1 (0.6)

†Percentage was taken over n because more than one answer was given.

‡LTCs, Liver transplantation candidates. LTCRs, Liver transplantation candidates' relatives.



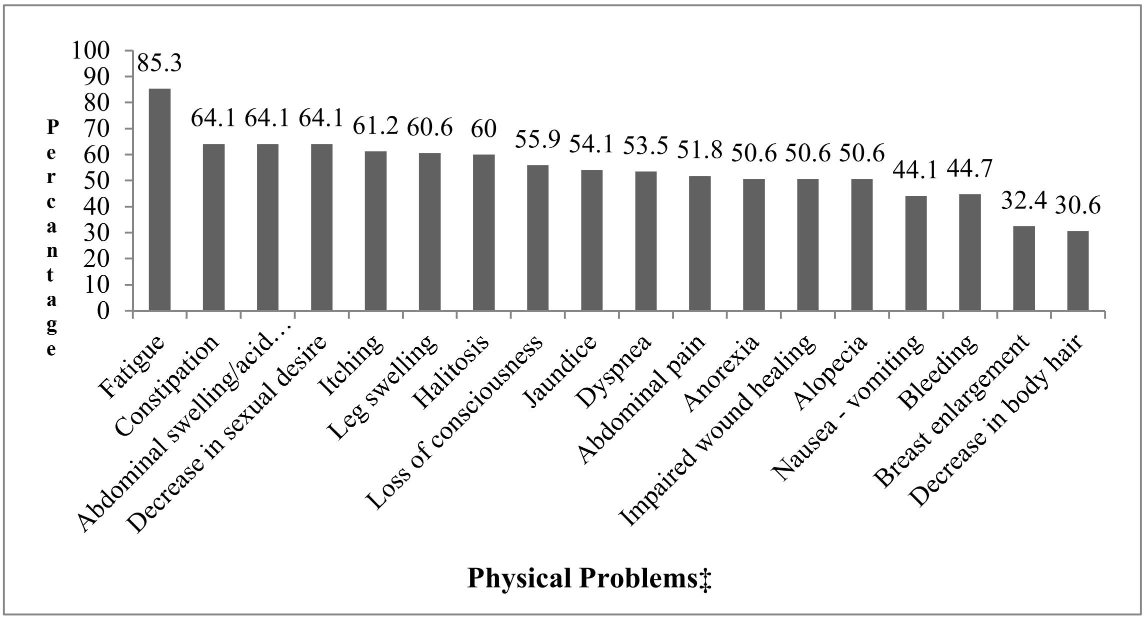
†LTCs, Liver transplantation candidates. LTCRs, Liver transplantation candidates' relatives. ADL Activities of daily living.

Figure 1. Distribution of the physical, ADL-related, psychological, and socio-economic difficulties experienced by LTCs and LTCRs

This study has shown that almost all the patients experienced physical problems;most of them faced problems associated with ADLs, as well as psychological and socio-economic difficulties (Figure 1).The physical problems the patients primarily experienced were fatigue (85.3%), constipation (64.1%), abdominal swelling/acid deposition (64.1%), and decrease in sexual desire (64.1%) (Figure 2).As far as ADLs are concerned, this study has confirmed that LTCs experienced the most difficulties in climbing up and down the stairs (64.1%), compliance with diet (56.5%),and breathing (51.8%). LTCs also cited psychological difficulties—such as uncertainty/concerns about the future (57.1%)—and socio-economic difficulties, such as inability to meet treatments costs (51.8%), as the problems that disturbed them most (Table 3).

This study has confirmed that women experienced more problems than men in connection with ADLs in a statistically significant manner (p=0.022). Another statistically significant result of this study is that patients who do not work (85.8%) experienced more socio-economic problems than those who are employed (54.5%) (p=0.001) (Table 4).

According to the results of this study, patients suffering from respiratory disorders experienced more psychological and socio-economic problems in connection with ADLs than those who did not have such disorders (p<0.05). Patients diagnosed with vascular, gastrointestinal, and neurological disorders also experienced more difficulties in terms of ADLs (p<0.05). Patients with skin disorders (88.1%) experienced more psychological difficulties than those who did not suffer (70.4%) from such disorders (p<0.05). In addition, the great majority of the patients who experienced problems associated with their sexual lives also experienced psychological (89%) and socio-economic (83.5%) problems and difficulties associated with ADLs (89%) (p>0.05) (Table 5). Although this information is not included in the table, this study has revealed that whereas 68.9% of married patients experienced sexual problems, only 47.4% of single patients experienced such problems, which is a statistically significant difference (p=0.015).



†LTCs, Liver transplantation candidates.; ‡Percentage was taken over n because more than one answer was given.

Figure 2. Distribution of the physical problems experienced by LTCs during the waiting time on the Waiting List

Table 3. Difficulties experienced by LTCs.

Difficulties	**Yes**
	n (%)
Difficulties related to ADLs	
Climbing up and down stairs	109 (64.1)
Compliance with diet due to illness	96 (56.5)
Breathing problems due to abdominal swelling	88 (51.8)
Walking	81 (47.6)
Falling asleep	81 (47.6)
Carrying objects	81 (47.6)
Needing assistance when going up and down stairs	67 (39.4)
Performing the domestic works by oneself	64 (37.6)
Shopping by oneself	53 (31.2)
Preparation of own food	52 (30.6)
Taking care of children	51 (30.0)
Needing tools when walking	42 (24.7)
Taking one's drugs by oneself on time and in the right dosage	40 (23.5)
Getting dressed by oneself	36 (21.2)
Bathing by oneself	36 (21.2)
Performance of personal care by oneself (washing hands and face, brushing teeth, combing hair)	35 (20.6)
Getting in or off a car/bus	35 (20.6)
Eating by oneself	32 (18.8)
Going to toilet by oneself	31 (18.2)
Sitting on and standing up from bed/chair by oneself	28 (16.5)
Psychological Difficulties	

Uncertainty/anxiety about the future	97 (57.1)
Decline in self-confidence	87 (51.2)
Difficulties in sexual life	78 (45.9)
Anxiety due to unavailability of proper donor organ	78 (45.9)
Fear of being excluded from the liver transplantation waiting list	77 (45.3)
Thinking that one's family is emotionally affected in a negative way	70 (41.2)
Difficulties controlling one's emotions	68 (40.0)
Feelings of inadequacy in meeting one's needs	62 (36.5)
Difficulty adapting to the disease process	62 (36.5)
Getting annoyed due to changes in outer appearance and fear of being isolated	61 (35.9)
Difficulties coping with problems	57 (33.5)
Difficulty responding to questions about one's illness	55 (32.4)
Difficulty sharing feelings/emotions/anxieties/worries	54 (31.8)
Fear of being abandoned/left alone due to disease progression	44 (25.9)
Socio-economic Difficulties	
Difficulties covering treatment expenses	88 (51.8)
Difficult4y in fulfilling responsibilities in family	75 (44.1)
Changes in working life due to illness	72 (42.4)
Problems with social security	70 (41.2)
Difficulty taking part in social activities	67 (39.4)
Inability to cover expenses not reimbursed within the social security system	67 (39.4)
Feeling inadequacy due to inability to fulfill responsibilities in family	57 (33.5)
No possibility of having support/assistance from other people due to illness	56 (32.9)
Not being able to vacation due to illness	53 (31.2)
Getting annoyed when people look at one	51 (30.0)
Feeling suffocated due to interest of others in providing support/assistance	51 (30.0)
Difficulty in social relationships due to changes in outer appearance	50 (29.4)
Feeling social isolation due to illness	44 (25.9)
Difficulties in relations with relatives/friends	42 (24.7)
Difficulty in looking into a mirror due to changes in outer appearance	41 (24.1)
Difficulties in relations with spouse/family	39 (22.9)

†LTCs, Liver transplantation candidates. ADL, Activities of daily living.

Table 4. The distribution of physical problems and difficulties experienced by LTCs and LTCRs according to sociodemographic characteristics

Sociodemographic Characteristics	**LTCs†**				**LTCRs†**		
	Physical Problems	**ADL-related Difficulties**	**Psychological Difficulties**	**Socio-economic Difficulties**	**ADL-related Difficulties**	**Psychological Difficulties**	**Socio-economic Difficulties**
	Yes n (%)	Yes n (%)	Yes n (%)	Yes n (%)	Yes n (%)	Yes n (%)	Yes n (%)
Gender							
Female	68 (98.6)	65 (94.2)	63 (91.3)	59 (85.5)	65 (81.3)	66 (82.5)	59 (73.8)
Male	97 (96.0)	83 (82.2)	82 (81.2)	80 (79.2)	72 (80.0)	73 (81.9)	66 (73.3)
Statistical analysis	p=.649‡	X^2=5.261 **p=.022** §	X^2=3.345 p=.067 §	X^2=1.091 p=.296 §	X^2=0.042 p=.837 §	X^2=0.055 p=.815 §	X^2=0.004 p=.951 §
Marital status							
Married	129 (97.7)	115 (87.1)	112 (84.8)	108 (81.8)	108 (83.7)	111 (86.0)	97 (75.2)
Single	36 (94.7)	33 (86.8)	33 (86.8)	31 (81.6)	29 (70.7)	28 (68.3)	28 (68.3)
Statistical analysis	p=.311‡	p=1.000‡	X^2=0.093 p=.760 §	X^2=0.001 p=.973 §	X^2=3.355 p=.067 §	X^2=6.577 **p=.010** §	X^2=0.761 p=.383 §
Having child(ren)							
Yes	142 (97.9)	127 (87.6)	124 (85.5)	119 (82.1)	108 (83.1))	111 (85.4)	98 (75.4)
No	23 (92.0)	21 (84.0)	21 (84.0)	20 (80.0)	29 (72.5)	28 (70.0)	27 (67.5)
Statistical analysis	p=.157‡	p=.746‡	p=.767‡	p=.783‡	X^2=2.187 p=.139 §	X^2=4.856 **p=.028** §	X^2=0.977 p=.323 §

Employment status							
Working	20(90.9)	**17(77.3)**	16(72.7)	12(54.5)	15(25.9)	12(20.7)	40(69.0)
Not working	145(98.0)	131(88.5)	129(87.2)	127(85.8)	18(16.1)	19(17.0)	85(75.9)
Statistical analysis	p=.126‡	p=.170‡	p=.101‡	**p=.001‡**	X^2=2.341 p=.126 §	X^2=0.356 p=.551 §	X^2=0.942 p=.332 §
Income level							
Inadequate	96 (96.0)	87 (87.0)	86 (86.0)	85 (85.0)	70 (90.9)	67 (87.0)	64 (83.1)
Moderate and adequate	69 (98.6)	61 (87.1)	59 (84.3)	54 (77.1)	67 (72.0)	72 (77.4)	61 (65.6)
Statistical analysis	p=.407‡	X^2=0.001 p=.978 §	X^2=0.096 p=.756 §	X^2=1.705 p=.192 §	X^2=9.58 **p=.002 §**	X^2=2.600 p=.107 §	X^2=6.647 **p=.010 §**
Social security							
Yes	148 (96.7)	133 (86.9)	129 (84.3)	124 (81.0)	118 (80.8)	123 (84.2)	109 (74.7)
No	17 (100.0)	15 (88.2)	16 (94.1)	15 (88.2)	19 (79.2)	16 (66.7)	16 (66.7)
Statistical analysis	p=1.000‡	p=1.000‡	p=.473‡	p=.741‡	p=.787‡	**p=.048‡**	p=.456‡

†LTCs, Liver transplantation candidates. LTCRs, Liver transplantation candidates' relatives. ADL, Activities of daily living. ‡Fisher's exact chi-square test. §Chi-square test.

Table 5. ADL-related, psychological, and socio-economic difficulties according to physical problems

Physical Problems	**Difficulties**		
	ADL-related Difficulties	**Psychological Difficulties**	**Socio-economic Difficulties**
	Yes n (%)	**Yes n (%)**	**Yes n (%)**
Respiratory problems			
Yes	86 (94.5)	84 (92.3)	83 (91.2)
No	62 (78.5)	61 (77.2)	56 (70.9)
Statistical analysis	X2=9.638 p=.002‡	X2=7.679 p=.006‡	X2=11.714 p=.001‡
Circulatory problems			
Yes	96 (93.2)	92 (89.3)	86 (83.5)
No	52 (77.6)	53 (79.1)	53 (79.1)
Statistical analysis	X2=8.759 p=.003‡	X2=3.378 p=.066‡	X2=0.525 p=.469‡
Gastrointestinal problems			
Yes	134(89.9)	129 (86.6)	123 (82.6)
No	14 (66.7)	16 (76.2)	16 (76.2)
Statistical analysis	p=.008 §	p=.202 §	p=.545 §
Hematologic problems			
Yes	131 (89.1)	128 (87.1)	122 (83.0)
No	17 (73.9)	17 (73.9)	17 (73.9)
Statistical analysis	p=.086§	p=.114§	p=.381§
Sexual problems			
Yes	97 (89.0)	97 (89.0)	91 (83.5)
No	51 (83.6)	48 (78.7)	48 (78.7)
Statistical analysis	X2=1.006 p=.316‡	X2=3.310 p=.069‡	X2=0.604 p=.437‡
Skin problems			
Yes	128 (89.5)	126 (88.1)	120 (83.9)
No	20 (74.1)	19 (70.4)	19 (70.4)
Statistical analysis	p=.054 §	p=.033 §	p=.107 §
Neurological problems			
Yes	88 (92.6)	83 (87.4)	79 (83.2)
No	60 (80.0)	62 (82.7)	60 (80.0)
Statistical analysis	X2=5.936 p=.015‡	X2=0.739 p=.390‡	X2=0.280 p=.596‡
Endocrine problems			
Yes	51 (92.7)	47 (85.5)	44 (80.0)
No	97 (84.3)	98 (85.2)	95 (82.6)
Statistical analysis	X2=2.319 p=.128‡	X2=0.002 p=.967‡	X2=0.170 p=.680‡

†LTCs, Liver transplantation candidates. ADL, Activities of daily living.;‡Chi-square test. §Fisher's exact chi-square test.

37.1% of the LTCs stated that they perceived their health condition as "poor" (Table 1). In addition, 46.3% of the patients with neurological problems, 42.7% of those with skin disorders, and 40.9% of those with gastrointestinal system disorders defined their current health condition as “poor.” It has also been confirmed that there is a statistically significant relationship between the existence of neurological, skin, and gastrointestinal systems disorders and the current health condition of LTCRs ($p<0.05$).

LTCRs

The family members who participated in the study are spouses (43.5%) and children (21.2%) of LTCs. The average age of the LTCRs was 41.82±13.30; among them, 52.9% were men and 75.9% were married (Table 1). 65.9% of the LTCRs lived with the patient in the same house, and 88.2% directly gave care to the patient. 63.3% of those who directly cared for the patient stated that they had been doing it for more than six years. The most frequently cited caretaking activities were taking the patient to the hospital and helping him or her during examinations (52%). 49.3% (n=74) of those who personally assumed the care of an LTCs experienced difficulties providing care. These difficulties mainly involved providing transport to the hospital (31.1%), financial problems (28.4%), and coping with thenegative effects of the illness on the patient (18.9%). The majority of the patients’ relatives obtained no financial or moral support (77%), and they often needed financial support (37.8%), a helper with whom to share responsibilities (16.2%), and/or assistance providing transportation to the hospital (14.9%). 42.9% of LTCRs perceived their own current health condition as “poor,”and 35.3% had health problems, which mainly included endocrine (26.7%), cardiovascular (26.7%), and musculoskeletal disorders (26.7%).

This study has shown that the main expectation of LTCRs with respect to the waiting process and the period after liver transplantation is that the patients will regain their health (80% and 38.2% for the waiting period and the post-LT period, respectively) (Table 2).

The majority of LTCRs had problems associated with ADLs (90.5%), as well as psychological (89.2%) and socio-economic (86.5%) difficulties. LTCRs stated that they primarily had trouble keeping up with ADLs due to fatigue (54.1%), feelings of uneasiness that the patient's psychological condition would deteriorate (70%),and financial difficulties due to the needs of the patient (50%)(Table 6).

Table 6. Difficulties experienced by LTCRs

Difficulties	**Yes**
	n(%)
Difficulties related to ADLs	
Fatigue	92 (54.1)
Forgetfulness and distractibility	82 (48.2)
Headache and tension	79 (46.5)
Postponing own needs to meet the needs of the patient	73 (42.9)
Postponing own activities due to fatigue	70 (41.2)
Waking up in the morning	57 (33.5)
Falling asleep	57 (33.5)
Having no time for personal care	56 (32.9)
Lack of appetite or excessive eating	53 (31.2)
Interruption of sleep due to providing care to the patient	52 (30.6)
Helping the patient go up and down stairs	51 (30.0)
Performing domestic activities	47 (27.6)
Helping the patient walk	46 (27.1)
Helping the patient to get in/out of a car/bus	45 (26.5)
Experiencing health problems due to providing care to the patient	45(26.5)
Shopping	42 (24.7)
Preparing food for the patient	39 (22.9)
Dressing the patient	31 (18.2)
Feeding the patient	31 (18.2)
Helping the patient to sit in/on and stand from bed/chair	28 (16.5)
Taking the patient to the toilet	26(15.3)
Bathing the patient	24 (14.1)
Performing personal care for the patient (washing face, brushing teeth, etc.)	23 (13.5)
Giving the patient his/her drugs	23 (13.5)

Psychological difficulties	
Anxiety due to possible worsening of the patient's condition	119 (70.0)
Anxiety due to unavailability of proper donor organ for the patient	107 (62.9)
Anxiety for the future for oneself and the patient	107 (62.9)
Anxiety about lack of knowledge of proper course of action in emergency situations associated with the patient	93(54.7)
Fear of exclusion of the patient from the waiting list	89 (52.4)
Feeling despair due to the condition of the patient	88 (51.8)
Difficulty in sharing emotions/feelings/anxieties/worries	68 (40.0)
Feeling guilty due to inability to help the patient	59 (34.7)
Being uneasy due to changes in the patient's outer appearance	59 (34.7)
Strain due to inability to fulfill responsibilities in the family	56 (32.9)
Difficulty fulfilling responsibilities in the family	55 (32.4)
Difficulties coping with problems	55 (32.4)
Feeling weariness, fatigue due to providing care to the patient	46 (27.1)
Fear of contagion when caring for the patient	40 (23.5)
Considering caretaking a burden	37 (21.8)
Feeling angry due to the requirement to provide continual care for the patient	26 (15.3)
Socio-economic difficulties	
Having no possibility to make savings due to satisfying patient's needs	85 (50.0)
Thinking that one has more responsibilities due to caring for the patient	81 (47.6)
Economic difficulties covering patient's expenses	75 (44.1)
Difficulties covering the care/treatment expenses of the patient	73 (42.9)
Feeling uneasy when everybody talks about the health condition of the patient in social surroundings	67 (39.4)
Having no time for family, relatives, and friends due to caretaking responsibilities	60 (35.3)
Changes in working life due to patient care	58 (34.1)
Difficulties in relationships with relatives/friends	55 (32.4)
Difficulty taking part in social activities	53 (31.2)
Inability to vacation due to caretaking responsibilities	45 (26.5)
†LTCRs: Liver transplantation candidates' relatives. ADL, Activities of daily living.	

This study also shows that married LTCRs (86.0%) experienced more psychological problems than those who were single (68.3%). Similarly, those who had children (85.4%) experienced more psychological problems than those who had no children (70%), and those receiving social security (84.2%) experienced more problems than those who were not covered under the social security system (66.7%) ($p<0.05$). In addition, LTCRs who had insufficient income experienced more socio-economic and ADL-related problems than those who had sufficient income ($p<0.05$) (Table 4). In addition, LCTRs who experienced difficulty associated with caretaking experienced significantly more psychological, socio-economic, and ADL-associated difficulties ($p=0.024$, $p=0.002$, and $p=0.003$, respectively).

DISCUSSION

This study was carried out as a descriptive to investigate LTCs' and Relatives' LTCRs' expectations and experienced difficulties during the liver transplantation waiting process. The findings of the study were discussed under two headings: expectations and experienced difficulties of the patients and their relatives waiting for liver transplantation.

Two-thirds (64.8%) of the LTCs who participated in this study had been waiting on an LTWL for more than three years. Previous studies indicate different time spans in this respect. Telles-Correia et al. (2009) found an average waiting time of one year[23].According to the Organ Procurement and Transplantation Network (2016), the waiting time for

60.1% of the 14,603 surveyed patients was zero to two years[24]. Although the average waiting time for organ transplant candidates is not officially published in Turkey, the results of this study confirm that the average waiting time for LTCs is four years. We believe that the relatively long waiting time in Turkey is due to insufficient donation of cadaveric organs in our country. Due to this long waiting time and insufficient organ donations, the general health condition of LTCs can deteriorate, and they can also be taken off of the waiting list.

The recording of patients with chronic liver disease on an LTWL awakens many expectations in association with the liver transplantation process and life in the post-liver transplantation period. Our study has shown that whereas about two-thirds of patients expect to have "a successful transplantation" during the waiting period, their expectation for the post-transplantation period is that the period will bring about "a decline in the complications/problems" caused by the disease. The patients also stated that they hoped they would regain their health parallel to a decline in complications and better life quality. These findings are a reflection of patients' desire to return to their normal daily life. Holzner et al. (2001) also carried out a study about the expectations of patients awaiting liver transplantation surgery and found that 60% of the patients expected to lead a "normal" life in the post-transplantation period[25].

The waiting process for liver transplantation raises expectations not only for patients but also for their relatives, who are always with them and support them in difficult times. The main expectation of LTCRs during the waiting time for an organ is that "their patient will regain his or her health". LCTRs also hope that their relative and themselves will begin to lead a normal life after the transplantation. Meltzer and Rodrigue (2001) reported that LTCRs felt useful because of the assistance they provided to their sick relatives; however, during the waiting period, they also experienced negative, stress-causing emotions, such as uncertainty and fear[26]. Claar et al. (2005) carried out a study on people who provided care to LTCs and discovered that caretakers experienced high levels of anxiety and depression[27]. The results of other studies confirm that the waiting process negatively affects the psychology of LTCRs. Naturally, our findings about the expectations of LTCRs for the post-liver transplantation period support this observation. In this study, we have found that patients' relatives expect psychological relief and to be able to plan for the future in the post-liver transplantation period (Table 2).

The results of this study indicating that LTCs and LTCRs have different expectations for the post-liver transplantation period is remarkable. Whereas the patients expect to become more healthy and social individuals able to perform their ADLs, fulfill their responsibilities, and plan for the future, their relatives expect to obtain psychological relief, have time for them selves, be hopeful, and make plans for the future. These results show that although patients and their relatives have similar expectations during the waiting process, their expectations in respect to the post-liver transplantation period vary.

Irrespective of the cause of development, chronic liver disease typically has a bleak prognosis and negative effects on physical health[10]. It has also been confirmed in this study that almost all LTCs experience physical problems. There are many studies available that address the physical problems patients encounter during the waiting process on a LTWL.Younoussi et al. (1999) have found that LTCs most commonly experience general fatigue and fatigue upon awakening in the morning in particular[28]. Gündoğdu (2007) has revealed that pain, irregular sleep schedule, and impairment in physical activities are also problems that most LTCs face[10]. Khan (2007) has confirmed that the majority of patients also experience abdominal acid deposition and Can (2010) has discovered that LTCs experience more sexual problems than those who have already undergone organ transplant surgery[29,30]. Similar to the results obtained in previous studies, we have found in this study that patients primarily experience fatigue, decreased sexual desire, constipation, abdominal swelling/acid deposition, and itching.

The physical problems that patients experience make it more difficult for them to perform ADLs. This study has confirmed that the majority of patients experience difficulties associated with ADLs. The patients in this study also had movement problems associated with ADLs (such as climbing up and down the stairs, walking, and carrying objects), diet, breathing, and sleeping, which is partly due to the fatigue that they experience. A study carried out by Rakoski et al. (2012) on patients diagnosed with cirrhosis and their families found that patients have trouble performing ADLs, such as walking, using the bathroom, shopping, eating, and taking their medications, and are therefore dependent on caretakers[31]. These ADL-associated difficulties are exacerbated by other symptoms, such as hypoalbuminemia, anemia, joint and muscle pain, muscle atrophy, edema in the legs, fatigue, and abdominal acid deposition[32–34].

This study has shown that women experienced more difficulty performing ADLs than men ($p<0.05$). There are no studies specifically addressing this difference, but we presume that this result is associated with the Turkish culture, in which women generally perform domestic tasks. This may exacerbate feelings of inadequacy and lead to higher levels of anxiety and depression in female LTCs.

In this study, the primary psychological difficulties LTCs experienced were uncertainty/anxiety about the future, a decline in self-confidence, anxiety arising from the unavailability of proper donor organs, and the fear that they would be taken off of the waiting list. Similarly, Lasker et al. (2010) found that the pre-liver transplantation period causes a feeling of uncertainty in patients, and that this feeling can be more intense in patients with advanced disease due to the probability of a lengthy wait for liver transplantation and declining quality of life[35]. In addition, Maikranz et al. (2006) have shown that hope and uncertainty are associated with depressive symptoms and anxiety, and that depressive symptoms are associated with the seeking of therapy[36]. Another study carried out on LTCs showed that the fear of "it being too late for a transplant" is the biggest source of stress for patients[37].

The physical problems that patients experience lead to changes in their outer appearance, and as a result they feel isolated[38]. Gündoğan (2006) found that changes occur in the outer appearance of 97.8% of patients diagnosed with cirrhosis in the first two years after the diagnosis, which leads to further agitation[38]. Studies have also shown yellowing of the eyes and the skin, abdominal swelling, itching, loss of body hair, weight loss, and deformities, as well as psychological problems[10,17,38,39]. The patients in our study also worried about changes in their outer appearance and feared that as a result of these changes, they could be isolated and experience difficulty sharing their emotions.

Over time, the psychological problems that patients experience negatively affect communication and social relations within their families and negatively affect their work and social lives. Patients also encounter financial trouble due to the needs for continual monitoring of their condition and frequent hospitalization, as well as expenses that are only partly reimbursed within the social security system[12,40]. Our study has also revealed that the majority of patients have socio-economic problems due to treatment expenses, inability to fulfill responsibilities within the family or lead a normal working life, and being in the social security system.

The difficulties patients experience during the waiting process for liver transplantation increase their need for caretakers. Almost half of the patients who participated in this study obtained support from their spouses. This finding of our study is similar to the results of studies carried out by Meltzer and Rodrigue (2001) and Miyazaki et al. (2010), who also found that spouses are the primary caretakers for most patients awaiting liver transplantation[19,26].

This study has revealed that almost half of LTCRs who provided care encountered difficulties in fulfilling this duty, and the majority of them received no support. In addition, health problems such as fatigue, stress, and depression affect LTCRs because of their obligation to fulfill diverse roles and responsibilities[19,41–43]. Of the LTCRs who participated in this study, 35.3% had health problems, and almost half perceived their current health condition as "poor". Several studies have come to the conclusion that there is a significant relationship between the health condition of LTCRs and the stress they experience, and providing long-term care to patients triggers physical and psychological problems[42,43]. Rodrigue et al. (2007) state that LTCRs experience strain during the waiting process related to the care time, low quality of life, low mood, and limited social lives of their patients[44].

We have found in our study that the majority of LTCRs have difficulties associated with ADLs. The main causes of this are fatigue, forgetfulness and distractibility and headaches and tensions. This study has also shown that almost half of LTCRs prioritize caretaking over their own needs and activities. Taşdelen et al. (2012) have confirmed that patients cared at home are usually completely dependent on their relatives for assistance in performing ADLs[11]. In addition, Atagun et al. (1998) have found that LTCRs undergo role changes in the family, as well as changes in their social lives, leading to fatigue and boredom[45]. Kara (2008) has shown that LTCRs cannot take time for themselves and have difficulty performing their own ADLs[46]. We have also found that LTCRs experienced more caretaking difficulties in association with assisting LTCs with ADLs. This is a statistically significant finding similar to other findings in the literature. It is thought that the difficulties that LTCRs experience in association with ADLs emerge from their responsibility to provide care to their relatives and the lack of sufficient financial or moral support.

In addition to the changing roles of LTCRs in the family, their health problems and the difficulty of looking after themselves bring about psychological problems. In this study, 81.8% of LTCRs experienced psychological disorders. LTCRs experienced anxiety that the condition of their relative would deteriorate, uneasiness about the non-availability of proper donor organs, anxiety about lack of knowledge of the proper course of action in an emergency, and fear that their relativewould be taken off of the WL. Miyazaki et al. (2010) have also found that LTCRs do not know how to performing an emergency situation[19]. Aras (2006) has shown that the waiting process affects the psychological health of LTCRs and that they experience sadness, anger, and insomnia[6]. In addition, Domínguez-Cabellob et al. (2010) have confirmed that LTCRs experience more psychological difficulties and much higher anxiety levels than LTCs[47].

The results of this study also reveal that LTCRs who are married and have children experience more psychological complications than unmarried and childless LTCRs. This is likely due to the fact that LTCRs must assume the role of a caretakering addition to that of a parent. Hacımusalar (2005) has revealed that LTCRs are expected to perform tasks such as “caring for patient, shopping, domestic tasks, caring for children”[48]. Increasing dependence of patients, poor prognosis, changes in the priorities of LTCRs, and inability to fulfill primary responsibilities are factors that exacerbate psychological difficulties. Mollaoğlu et al. (2011) found that patients are dependent on caretakers for ADLs, caregivers who have health problems have more caretaking burdens, and that there is a positive significant relationship between the dependence level of patients and the care burden of care givers[49].

In this study, 73.5% of LTCRs experienced socio-economic difficulties. There are no studies available that specifically address the socio-economic difficulties experienced by the relatives of the patients waiting for liver transplantation; however, Yun et al. (2005) have shown that patients with chronic diseases and their families must pay large expenses and therefore cannot accumulate savings[12]. Meltzer and Rodrigue (2001) have confirmed that LTCRs experience financial difficulties and that they have concerns regarding covering the expenses of drugs and treatments[26]. These results from the literature confirm that caregivers providing care to individuals with chronic disease experience many difficulties and need support, irrespective of the disease group. However, the provision of this support is often hindered due to non-reimbursement of healthcare expenses within the social security system and other economic problems within the family.

As a conclusion, LTCs and LTCRs have expectations from the moment the patients are recorded on the WL, including that “a donor organ will be found as soon as possible” and “the patient will regain their health and return to a normal life”. However, both LTCs and LTCRs experience many difficulties surrounding ADLs and psychological and socio-economic conditions. The physical problems experienced by LTCs increase these difficulties. In this waiting process marked with so many difficulties, it is of great importance that patients and their relatives be provided with care services, treatment, training and consultation in a multi-disciplinary team approach.

Yazar Katkıları: Çalışma konsepti/Tasarımı: TAY; Veri toplama: TAY; Veri analizi ve yorumlama: TAY, SGD; Yazı taslağı: TAY, SGD; İçeriğin eleştirel incelenmesi: SGD; Son onay ve sorumluluk: TAY, SGD; Teknik ve malzeme desteği: TAY; Süpervizyon: TAY, SGD; Fon sağlama (mevcut ise): yok.
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