LIVING LIVER DONORS' EXPERIENCES FOLLOWING LIVER TRANSPLANTATION SURGERY

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FOLLOWING LIVER TRANSPLANTATION SURGERY

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I hereby declare that all information in this document has been obtained and presented in accordance with academic rules and ethical conduct. I also declare that, as required by these rules and conduct, I have fully cited and referenced all material and results that are not original to this work.

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ÖZET

CANLI KARACİĞER NAKLİ DONÖRLERİNİN

KARACİĞER NAKLİ AMELİYATI BOYUNCA

YAŞAM DENEYİMLERİ

Tankurt, Aslı

Psikoloji Bölümü Yüksek Lisansı

Süpervizör: Prof. Rita Krespi

Eylül 2014, 193 sayfa

Karaciğer nakli, karaciğerle alakalı bir çok hastalıklar için bir tedavi seçeneğidir. Naklin amacı, bakım maliyetleri ve hastalığın etkilerini minimize ederken yüksek yaşam kalitesini hedeflemektir. Nitel metodoloji, canlı donörlerin bir donor olma olgusunu yaşama deneyimini anlamak için benzersiz bir yol sunar. Fakat Türkiye'de detaylı bir örnek çalışma bulunmamaktadır. Bu çalışmanın amacı, transplantasyon boyunca karaciğer nakli canlı donörlerin nakil deneyimini keşfetmektir. Bu çalışmanın örneklemini 16 canlı donörler oluşturmaktadır. Gömülü teori methodu kullanılmıştır. Yaşam deneyimlerini detaylı bir şekilde keşfetmek için yönlendirmeler kullanılmıştır. Nitel methodoloji kullanılarak, ameliyat sonrası görüşmeler kopya edilip ve analizleri yapılmıştır. Bu çalışmanın temelinde, donörler canlı karaciğer bağışı ile ilgili hem kendilerinin hem de alıcıların yaşam deneyimlerini anlattılar. Deneyimleri çeşitli alanları içerir; donor inançları, karaciğer yetmezliği, donor olma, nakil ameliyatı ve organ bağışına yönelik inançlarda gruplanabilir. Donörlerin yaşamlarının değerlendirilmesi, karaciğer yetmezliğine ve nakil ameliyatına bağlı sınırlamalar, gerekli yaşam tarzı değişikliğine karşı bilinçlenme, duygusal değişimler, karakter değişimleri ve karışık ilişkiler olarak gruplandırılabilir. Donörler, hastaların karaciğer yetmezliği teşhisi ve nakil ameliyatı boyunca yaşam deneyimlerini sınırlamalara, karışık ilişkilere, duygusal değişimlere ve yaşam içindeki gelişimlere dayandırarak değerlendirdi. Bulgular donörler için psiko-eğitici müdahaleler amaçlamanın yanı sıra onlarla birebir klinik danışmada yol gösterici olarak kullanılabilir.

Anahtar kelimeler: Karaciğer nakli, canlı karaciğer donörleri, deneyim

ABSTRACT

LIVING LIVER DONORS' EXPERIENCES

FOLLOWING LIVER TRANSPLANTATION SURGERY

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Liver transplantation is the treatment of choice for a number of liver related diseases. Transplantation aims to achieve maximal quality of life while minimizing the effects of disease and the costs of care. Qualitative methodology offers a unique way to understand the ways in which the live donors experience the phenomenon of being a donor. However, there is no such detailed study. The aim of this study was to explore liver live donors' experience following transplantation. The sample of this study was 16 live donors. Grounded theory method was used. Prompts were used when appropriate to explore areas of interest in detail. The post-operative interviews were transcribed and analyzed using qualitative methodology. On the basis of the present study, donors recounted their own and recipients experiences about living liver donation. The experiences include various domains: beliefs of donors can be grouped into beliefs about liver failure, being a donor, transplantation surgery and organ donation. Donors' evaluation of their life can be grouped into limitations brought by liver failure and the transplantation surgery, awareness of the need for lifestyle changes, emotional changes, changes in character and mixed relationships. Donors evaluated patients' experience of life following the diagnosis of liver failure and transplantation surgery in terms of limitations, mixed relationships, emotional changes and improvement in life. Findings could be used guide one to one clinical consultations with donors as well as providing targets for psycho-educational interventions.

Keywords: Liver transplantation, living liver donors, experience

This thesis dedicated to my family and my close friends

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CHAPTER 1

INTRODUCTION

Living donor liver transplantation (LDLT) is a new chance for patients and families. Organ transplants have increased worldwide whereas the number of organ donors has not increased. Follow-up reports concerning living donor experiences are short-term, and they initially focus on medical outcomes.

The current study examines the psychological aspects of the donors' experiences. This study provides a better understanding of their experiences, their beliefs about their illnesses and their treatment. It gives a better understanding with reference to their adjustment.

The first section of the present study explains the nature and prevalence of the organ transplantation, together with the varieties of organ transplantation. In the second section, the physical and psychological outcomes of LDLT have been examined. In the sections that following, the nature of the qualitative research and previous qualitative research related to donors' experiences have been presented and the last section discusses the findings.

1.1. Nature of Organ Transplantation

Organ transplantation is generally the only treatment for organs in their final stages of failure such as liver, health, lung, pancreas or kidney. Organ transplantation is preferred by patients for both the quality of life that it gives and for its cost effectiveness (Platt, 1998). Organ transplantation is a medical procedure that includes the transfer of a healthy organ from a donor (usually a close relative such as a parent or a sibling) or a cadaver into a patient who has a dysfunctional organ (Akış, Katırcı, Uludağ, Küçükkılıç, Gürbüz, TürkerKayacan, Öngel, & Gül, 2008). Organ transplantation has increasingly become the preferred treatment for several life threatening childhood and adulthood disorders (Clavien, Camargo, Croxford, Langer, Levy, & Greig, 1994).

1.1.1. Prevalence of Organ Transplant

Success in organ transplantation has increased in the last decade; since 1990, about 10,000 kidneys, 2700 livers, 200 hearts, 500 pancreases and 260 lungs have been transplanted in the United States (Clavien et al., 1994). Every day, approximately, 77 people receive organ transplants; but about 18 people die each day while waiting for an organ transplant due to the shortage of donated organs (Clavien et al., 1994). In 2010, the list of Canadians waiting for an organ transplant increased to over 4,000 people, additionally, 195 Canadians died while waiting for an organ transplant in 2009 (Preiksaitis et al., 2010). From April 2011 to March 2012, about 1,817 organ transplants were performed successfully (Kotton et al., 2013).

1.1.2. Types of Transplants

1.1.2.1. Lung Transplant

Lung transplantation is a successful treatment method for patients with terminal lung disease. Since the early 1990s, lung transplantation (LTx) has proved to be an effective treatment for the final-stage of pulmonary failure which is caused by a variety of etiologies, such as obstructive lung disease, cystic fibrosis (CF), pulmonary hypertension or idiopathic pulmonary fibrosis (Ullrich, Schmidt, Scharf, Penkert, Niedermeyer, Schulz & 2010). The survival rate one year after transplantation is 80–85%, compared to 65–70% three years later (ISHLT, 2008).

1.1.2.2. Kidney Transplantation

Kidney transplantation is a result due to final-stage renal failure (ESRF) and it is defined as the impairment in renal functions, chronic renal insufficiency (Renal Association, 1995). It also results from the loss of 70 to 80% of renal function (Berkow, 1977; Frohlich, 1985).The first adult-to-adult kidney transplant was conducted in Boston, 1947 (Akış, et al. 2008). Furthermore, the first successful kidney transplantation between mother and son was performed by Dr. Mehmet Haberal in Hacettepe University of Medicine Faculty Hospital, 3rd of November, 1975 (Akış, et al., 2008). The same transplant team conducted the first cadaveric kidney transplantation in 1978 (Akış, et. al. 2008). ESRF is a very common chronic physical illness and there are more than 24,000 people affected by it in the UK (Isles and Carson, 1995). Out in one million people, between 100 and 130 people aged 15-17 develop ESRF (Cameron, 1996; Gabriel, 1990). The best achievement is seen in renal transplantation. The survival rate for children who received transplants between November 1968 and December 1987 was 79% after 14 years, and for those who received transplants after October 1983, was 94% after four years (Bradford and Tomlinson, 1990).

1.1.2.3. Heart Transplantation

Heart failure (HF) refers to a complex clinical syndrome which can result from any structural or functional cardiac disorder that impairs the ability of the ventricle to fill with or to eject blood (Harris and Heil, 2013). Between 2008 and 2009, 7462 adult heart transplantations were performed from more than 200 centers in the world (ISHLT, 2012). In the USA, About 1 in 100,000 children are diagnosed with symptoms of cardiomyopathy each year. Dilated cardiomyopathy (DCM) is the primary indication, accounting for 65% of heart transplants in children 11-17 years of age (Park, Sandres, Smith, Ryan, Plasencia, Osborn, Wellnitz, Southard, Pierce, Arabia, Lane, Frakes, Velez, Pophal, & Nigro, 2014).According to the Organ Procurement and Transplantation Network, approximately 375 heart transplants were performed in pediatric patients in 2011 (Park, et al., 2014). The first successful heart transplant was conducted by Dr. Christian Barnard in 1967 (Akış, et al., 2008). In Turkey, the first heart transplant was performed by Dr. Kemal Beyazıt who was a doctor in Ankara Yüksek İhtisas Hospital on 22 November, 1968 (Akış, et al., 2008).

1.1.2.4. Pancreas Transplantation

Pancreatic transplantation refers to the treatment for select patients with diabetes. Diabetic patients and many of those with adult-onset diabetes develop severe complications. These include capillary lesions in the eyes leading to loss of vision, capillary lesions in the glomeruli of the kidney leading to renal insufficiency, and accelerated atherosclerosis throughout the body (Clark, Makoff, Weısman, Kemp, & Mullen, 1978). Total transplant of adult patients with diabetes has indicated that the longest survival time of an organ was about 4 years (Clark, et al., 1978). Since early 2004, over 21 000 pancreas transplants have been performed in the world. In Australia and New Zealand, there are three pancreatic transplant centers where over 300 pancreas transplants have performed so far. The Monash Medical Centre (MMC) is responsible for 27% of these (Kave, Yii, Bell, Kanellis, Scott, & Saunder, 2010).

1.2. Liver Disease and Liver Failure

The liver plays an important role in the digestion, metabolism and storage of nutrients. Liver failure is the inability of the liver to perform as part of normal physiology. There are some symptoms related to liver failure such as digestive problems, blood sugar problems, immune disorders and metabolism disorders. Liver failure causes liver disease (Mezey, 1978). There are several liver diseases which might require liver transplantation. Moreover liver transplantation is a treatment of choice for a number of liver related diseases such as liver cancer, patients with pre-transplantation diagnoses of cholesteric liver diseases, alcoholic caused diseases, cirrhosis, chronic hepatitis B and hepatitis C (Charlton, Kasparova, Weston, Lindor, Kendler, Wiesner, Rosen, & Batts, 2003). According to the WHO Report of 2002, in 2001, 1.4 million people died from chronic liver diseases, including 796 000 due to cirrhosis and 616 000 due to primary liver cancer.

1.2.1. Causes of Liver Failure

1.2.1.1. Hepatitis C

1.2.1.1.1. Nature of Hepatitis C

Hepatitis C virus is usually chronic and asymptomatic causing viral infection. It is a liver disease caused by the hepatitis C virus (Poynard, Yuen, Ratziu, & Lai, 2003). It has no specific symptoms and causes mild to severe chronic liver disease. Patients with Hepatitis C have generally mild fatigue, lethargy, nausea, reduced appetite, abdominal pain and jaundice (Poynard et al., 2003). Hepatitis C is a blood borne virus and the most common modes of infection are through unsafe injection equipment, inadequate sterilization of medical equipment in health care services and unscreened blood and blood products (Bowen et al., 2005). Furthermore, Hepatitis C can cause cirrhosis, which results in liver transplantation in Europe and the USA. However, Hepatitis C can recur after liver transplantation (Garcia-Retortillo et al., 2002).

1.2.1.1.2. Prevalence of Hepatitis C

The USA has the highest prevalence of Hepatitis C in the general population between the ages of 40-59 years, especially in African Americans (6.1% prevalence) (Poynard, et al., 2003).

At least 20% of these deaths are probably attributed to HCV infection—more than 280 000 deaths. (Poynard, et al. 2003). 15%-50% Hepatitis C virus (HCV) rates among the homeless and incarcerated persons (Augenbraun, Goedert, Thomas, Feldman, Seaberg, French, Robison, Nowicki, & Terrault, 2003). The major risk factor shown to be in those with current or past drug use which was reported to be 86% with and 22% without incident HCV (Augenbraun, et al., 2003).

1.2.1.2. Hepatitis B

1.2.1.2.1. Nature of Hepatitis B

Hepatitis virus is a viral infection and can be either an acute or a chronic infection. Acute HBV is self- limiting and it can cause both chronic liver disease and chronic infection in most adults. In addition Hepatitis B has a higher risk on people's life such as the risk of death from cirrhosis of the liver and liver cancer (Lok and McMahon, 2009). Generally, Hepatitis B has no specific symptoms but some people with acute illness of Hepatitis B have some symptoms such as yellowing of the skin, dark urine, extreme fatigue, nausea, vomiting and abdominal pain (Lok and McMahon, 2009). Chronic HBV infection is more likely to develop in children who are infected during the perinatal period (Ioannou, MS, 2011). However, it can be a major cause of cirrhosis and hepatocellular carcinoma (Ioannou, et al., 2011).

1.2.1.2.2. Prevalence of Hepatitis B

Approximately, 45% persons worldwide live in regions highly endemic for chronic hepatitis B (prevalence > 8%). In 2%-7% countries with intermediate endemicity, the multiple modes of transmission that are responsible include:

(a) Perinatal

(b) Household contacts

(c) Sexual

(d) Injection drug use

(e) Health care related (Ioannou, et al., 2011).

1.2.1.3. Cirrhosis of the liver

1.2.1.3.1 Nature of the Cirrhosis of the Liver

There are several causes of cirrhosis. One of the most important causes is acute liver failure that is coagulating abnormality plus any degree of mental alteration in patients with newly-onset liver disease. It can take more than 26 weeks in order for cirrhosis to be diagnosed. (Moss, Chen, & Yi, 2007). In adult-to-adult liver transplantation, cholesteric disease due to liver cirrhosis is the most common reason for transplantation (Fujita, et al., 2004). Another important reason is alcoholic cirrhosis. Alcohol disorder maybe defined as alcohol abuse, alcohol dependence or hazardous drinking. It is also defined that a person who drinks more than the recommended daily, weekly or per-occasion amount has an increased risk of health consequences (Moss, et al., 2007). Alcohol use disorder is when men drink over 14 drinks per week and women drink more than 7 drinks per week (Moss, et al., 2007).

Alcohol abuse leads to major recurrent failures in home, work, or school responsibilities. The individual also uses alcohol in physically hazardous situations, and this it leads to alcohol-related legal or social problems (Moss, et al., 2007).

Alcohol dependency is represented as physical cravings, withdrawal symptoms and a frequent consumption of alcohol in larger amounts over longer periods. In addition the need for increased amounts of alcohol to achieve intoxication shows dependency also (Moss, et al., 2007).Nonalcoholic and alcoholic cirrhosis are measured for two thirds of the adult indications (Todo, Fung, Starzl, Tzakis, Demetris, Kormos, Jain, Alessiani, Takaya, & Shapiro, 1990).

1.2.1.4. Biliary Atresia

1.2.1.4.1. Nature of Biliary Atresia

Biliary atresia is seen among children and it is a neonatal disorder with obliteration or abnormality of extra hepatic biliary system resulting in the obstruction of the bile flow (Haber et al., 2008) which leads to persistent direct hyper bilurbinema beyond the first two weeks of life in a natal (Nio, Ohi, Miyano, Saeki, Shiraki, & Tanaka, 2003). During the newborn period, most patients can be treated surgically. Patients with biliary atresia consist of 2 distinct groups; one which is isolated biliary atresia, postnatal form and the other being fetal, embryonic forms (Haber et al., 2008). In Taiwan, it is a significant cause of childhood deaths and the most common reason for liver transplantation (Ho, 2003).

1.2.1.4.2. Prevalence of Biliary Atresia

It is more common in girls than boys (Nio, et al., 2003). The prevalence of biliary atresia is much higher in Asian children, between 1 per 3500-1 per 20.000 (Chou, et al., 2008). According to the Japanese Biliary Atresia Society, in 1989, 1,381 patients, (863 girls) were recorded between 1989-1999; 164 (12%) had type I atresia of the common bile duct, 34 (2,5%) had type II atresia of the hepatic ducts, 1,162 (84%) had type III atresia of the porta hepatitis (Nio, et. al. 2003). The disease is generally seen in about 1 in 15,000 live births, and presents itself with jaundice, alcoholic stool, and hepatomegaly in the neonatal period (Chin et al., 2004).

1.2.2. Physical Effects of the Liver Failure

Patients with liver failure experience physical problems such as tiredness, lack of vitality, itching, headaches, fatigue, pain and difficulties in performing daily activities (Bryan et al., 1998; Hellgren et. al. 1998). Furthermore, Brown et al. 2006 explained the impact of the final stage of liver disease patients experience poor appetite, nausea, weight loss, jaundice and abdominal swelling caused by fluid retention. It can also lead to mental confusion with memory loss and eventual coma. Patients were described in a study that extreme tiredness was the major physical limitation and it is the most overwhelming change in their waiting time (Wainright, 1997). In addition, they develop many serious symptoms like edema, vertical bleeding and encephalopathy (Huang et al. 2011).

1.3. Liver Transplantation

Due to advances in liver transplant procedures and immunosuppressive therapies, one year allograft survival rates are currently over 85 %- 90 %. (Keeffe, 2001). The major goal of transplantation is the achievement of maximal quality and quantity of life while minimizing the effects of disease and the costs of care (Keeffe, 2001). Liver transplantation can be performed in the basis of cadaveric and living-donor transplantation.

1.3.1. Cadaveric Liver Transplantation (CLT)

Cadaveric liver transplantation has become widely preferred as an alternative treatment for the final-stage of liver disease (ESLD). There biggest challenge of CLT is the increased waiting time for patients and this can affect the mortality of the patients awaiting a liver transplant. In addition, CLT generally requires inpatient treatment which leads to decreased survival chances (Sagmeister et al., 2002).

1.3.1.1. Prevalence of CLT

According to the study of Lo et al. (1999), in Hong Kong, the average waiting time for a cadaveric graft was between 18 and 24 months and out of all of the patients who were on the urgent waiting list, only 10 % received a cadaveric liver transplant within 7 days of the listing. In India, between 1995 and 2001 there were 12 cadaveric liver transplants (Shroff et al., 2001). Out of the 6.8 million population in Switzerland, CLT tripled from 24 to 75 in 1999 (Sagmeister et al. 2002). In Taiwan, there were 7,176 patients on the transplant waiting lists for liver, but only 205 cadaveric donors reported in 2011 (Huang et al., 2011).

1.3.2. Living Donor Liver Transplantation (LDLT)

Traditionally, liver transplants have been performed by using a liver donated by someone who has died, but there are several problems with that, especially the rarity of the organ itself. Therefore, until a suitable liver is found many patients either have to be removed from the list due to significant deterioration in their health, and therefore perhaps miss an opportunity for a new liver or die. (McGregor, Swanson, Hayes, Forsythe, & O'Carroll 2008). In order to reduce the risk of death and amount of time patients must wait for a liver, living donor liver transplantation (LDLT) has been increased. LDLT allows a healthy family member to donate part of their liver to a relative on the transplant waiting list. Living liver donors consist of related (siblings, parents, spouse) and unrelated donors. Being a related liver donor means that the donor and recipient are from the same family and mainly there has been consanguinity from one another or it can also be a spouse (Weng, et al., 2011).

Unrelated living donors are decided mostly by the ethical committee. LDLT is beneficial for the recipients because of the decrease in waiting time and the increase of the survival rate in contrast to CLT (Marcos et al., 2000).

Adult-to-adult transplant is a more complicated procedure as normally the right lobe of the donor liver is required which constitutes approximately 60% of the donor's entire liver mass (Renz and Roberts 2000). In Japan, living donor liver transplantation was first reported to have been performed on children in 1989 (Raia, et al., 1989) and in adults in 1994 (Hashikura, et al., 1994). According to the Japanese Liver Transplantation Society report, (2005) among 3218 LDLT cases until 2004, the recipient 1- year survival rate is 81%, 3-year survival rate is 78%, 5-year survival rate is 76% and 10-year survival rate is 72%.

1.3.2.1. Prevalence of LDLT

In Taiwan, Ho and Lee in 2002 managed the first successful LDLT, which opened new hopes for children with biliary atresia and their families (Chen et al. 2006). In addition, between the period of 1997-2007 in Taiwan, 1097 patients experienced a liver transplantation procedure, including both cadaver and living related (Weng et al., 2011). According to the Scientific Registry of Transplant Recipients (2009), in 2008, there were approximately, 6318 cases of liver transplantation in which249 were from living donors (Weng, et al., 2011). In Turkey, Prof. Dr. Mehmet Haberal conducted the first living donor liver transplant in 1990 and the first cadaveric transplantation in 1988. In Norway, between 2004 and 2005, the number of liver transplantations was 38 and 45 (Newsletter Transplant 2005, 2006).

1.3.2.2. Selection of the LDLT Donor Candidate

The person must be suitable medically and psychologically in order to become a living donor. Donors are well informed of the risks and benefits of the study and thus make an autonomous decision (Brown, 2008). Children under 18 generally are not suitable to be living donors; the suitable age is between 21-55 years old. Donors should not have any liver disease or other significant disease such as cardiovascular or diabetes. In addition donors should not be obese or underweight, if a donor is over-weight; he/she must wait until they have lost enough weight in order to undergo the transplant (Brown, 2008).

Moreover, potential donor candidates should undergo a medical evaluation like recipients with serologic testing for viral hepatitis, HIV antibody and other chronic diseases (Trotter, et al. 2000). All living donors should also undergo a psychosocial evaluation and between 15%-45% of living donor candidates are accepted for liver transplantation (Brown, et al., 2003).

1.4. Physical Outcomes of LDLT

While some donors after transplantation, totally recover, some of them also suffer from persistent post-operation symptoms such as abdominal discomfort, fatigue, chronic pain and scar itching, albeit mild (Trotter et al. 2001; Fukunishi et al. 2003; Chen et al., 2011). According to the Japanese Liver Transplantation Society report (JLTS), 10% of donors had suffered from physical symptoms one year after transplantation (Ishizaki, et al., 2012). Ran et al (2009) found that 14 patients of 105 living donors had postoperative complications, 11 of them experienced incursive treatment or re-operation. Biliary problems are the most common medical complications. Out of 202 donors, 3% of have suffered from bile leak (Adcock, et al.2010). Furthermore, another study demonstrated that 82 donors had biliary complications including cholestasis (7.3%), bile leakage (6.1%) and bile duct stricture (1.1%) (Lo, 2003).

1.5. Psychological Effects of LDLT

Little research has been done so far on the psychological impacts of LDLT. Patients, who had undergone liver transplantation due to liver disease, can have very several psychological and psychiatric problems (Grover, et al., 2012). Adult patients with transplanted livers are more likely to have psychiatric disorders before (15-54%) than recipients of other organs (Noma et al., 2008). To understand the psychological effects of liver transplantation on patients and donors, a number of constructs, which are adjustment and beliefs, have been proposed.

1.5.1. Adjustment

Liver disease is by nature similar to a number of chronic illnesses. One is the final stage of renal disease. Another one is diabetes as both have psychologically debilitating outcomes. Liver transplantation is also by nature similar to other types of transplantation such as pancreatic, heart and lung. Therefore, in the following sections, when there are limited numbers of studies in liver disease and/or liver transplantation, findings of studies related to final-stage renal disease, diabetic and heart transplantation have been reported.

1.5.1.1. Nature of Adjustment

In order to understand the effects of liver transplant, literature has focused on the concept of adjustment. There is no well-established definition of adjustment. However, in general terms it has been described as an individual's ability to manage his/her symptoms, treatment regimen and life style changes inherent in living with a chronic condition (Barlow, Cullen, & Rowe, 2002). Furthermore, Shontz (1975) said that patients adjust to their illness in a dynamic way in a number of three stages. Shock phase, patients experience confusion and separate from what is happening. Encounter phase, patients have experienced of extreme emotional distress and feelings of loss and hopelessness. In the retreat phase, it stated that patients have denied the reality and seriousness of the illness, which ends when the patients acknowledge illness. Bowling (1991) explained the poor adjustment as the presence of psychological or social difficulties. Baker and McWilliams's (2003) adjustment rule that major stress and limitation to patient's freedom in relationship to non-adherence and this might cause the loss of transplant candidacy.

Adjustment has been defined much clearer in renal transplantation. For example, Reichsman and Levy (1972) asserted that End Stage Renal Failure (ESRF) patients adjust to their illness in three stages different. The ''honeymoon'' stage begins 1 to 3 weeks after the beginning of dialysis treatment and patients generally deny the treatment and disturbance caused by ESRF. The ''disappointment'' stage, patients have experienced emotional problems as realization of the adjustment that is required to their past life and activities. Final stage, ''long-term adaptation'' involves accepting illness and treatment; and physical limitations caused by ESRF. Nonadherence is related to inadequate regimen knowledge, depression and anxiety, low social support, substance abuse, life stress, barriers to medication access and a poor relationship between physician and patient (Lisson et al., 2005).

Kubler-Ross (1969) explained adjustment as ''modeling of grief''. People with chronic illness are dying; they have a tendency to use denial as a way to protect themselves from the painful inevitability of death. Denial is the early response to grief; anger, bargaining and depression follows in this order. Acceptance is the last stage of model of grief. In her model, denial is expected to decrease gradually and replaced with acceptance, which is the final stage before death (Telford, et. al., 2006).

To understand adjustment, literature also focused on the construct of depression, anxiety and quality of life.

1.5.1.1.1. Nature of Depression

A depressed mood refers to severe states of negative effect on people that are often depressed but not necessarily pathological. People with depressive mood have several symptoms such as sadness, grief, demoralization, guilt and boredom (Nesse, 2000). When the depressed mood is excessive and prolonged, it is considered to be pathological depression, so it might be explained by DSM criteria. According to DSM-IV-TR (2000), Depressive disorders consist of a Major depressive disorder which is diagnosed when a person experiences either a depressed mood or loss of energy in daily activities, and at least four other symptoms (cognitive and behavioral) chronically for at least two weeks.

Dysthymic disorder is diagnosed when a person experiences both depressive mood and two other symptoms (cognitive or behavioral symptoms) for at least two years. In addition, bipolar disorder is diagnosed when a person experiences elevated, expansive or irritable mood for at least one week. Cyclothymia occurs between episodes of hypomania and moderate depression chronically over at least a two-year period. Depression has many symptoms such as fatigue, impaired concentration, irritability, sleep disturbance and somatization (Kerry, J. et al., 2000). According to DSM-IV, symptoms of depression consist of emotional, physiological and behavioral and cognitive symptoms. Emotional symptoms are classified as sadness, depressive mood, anhedonia and irritability. Physiological and behavioral symptoms are classified as sleep disturbances, appetite disturbance, fatigue and loss of energy. Cognitive Symptoms are classified as poor concentration, poor self-esteem and hopeless. Depression is more likely to be secondary to other illness such as cancer or organ transplantation (Khantzian, 1985). This belongs to a disorder due to a general medical condition and substance-induced mood disorders (Dunn, et al., 2001).

1.5.1.1.2. Nature of Anxiety

Barlow (2002) defined anxiety as a future-oriented emotion. It can be described as concerns about unpredictability or perceptions of loss of control over aversive events. It is also characterized by a ‘’shift in attention to the focus of potentially dangerous events or one’s own affective response to these events’’ (p.104). May (1977) defines anxiety as a human response directed toward reducing or destroying forces such as aggression, fatigue, boredom and death. When anxiety is excessive and prolonged, it becomes pathological anxiety, so it might be explained by DSM criteria.

According to DSM-IV (2000) criteria, there are several kinds of anxiety disorders. One of these is panic disorder, which is demonstrated by fear of dying, heart palpitations, sweating and sensations of shortness of breath. Another anxiety disorder is posttraumatic stress disorder, which is demonstrated by the symptoms of re-experiencing the traumatic events, emotional numbing, detachment and hypervilance and chronic arousal. Another anxiety disorder is social phobia that includes the fear of being judged by others. Acute stress disorder is another anxiety disorder is, which includes the symptoms of avoidance of stimuli that arouse recollections of the trauma and anxiety symptoms, which is mentioned below. Another anxiety disorder is the obsessive compulsive disorder that includes recurrent and persistent thoughts and repetitive behaviors. The final anxiety disorder is specific phobias, which are concluded as the fear of specific objects, places or situations. (DSM-IV-TR, 2000). There are several symptoms of anxiety. One is emotional symptoms, (sense of dread, terror, restlessness, irritability. The second symptom is cognitive (fear of dying, sense of unreality, fear of losing control). The other type of symptom is behavioral (escape, avoidance, aggression). Generalized anxiety included of symptoms of nervousness, worry and restlessness (Ninan, 1999). People with generalized anxiety disorders demonstrated excessive anxiety and worry, difficulty in controlling the worry, easily fatigued, irritability, muscle tension, sleep disturbance and difficulty in concentrating (DSM-IV-TR, 2000).

1.5.1.1.3. Quality of Life (QOL)

There is no well-established definition of quality of life. The term is frequently used in relation to health in general, but is not often defined. According to Calman (1984), quality of life is explained as a present lifestyle, past experience, hopes for the future, dreams and ambition. It is expected that quality of life includes all areas of life and experience and takes into consideration the effect of illness and treatment. A good quality of life occurs when the hopes of an individual meet with experience. Furthermore, it is described as a satisfaction, contentment, happiness and fulfillment and the ability to cope (Calman, 1984). Gough (1994) explained quality of life as the perceived discrepancy between the realities of what one has, and what one wants, or expects or has had. The concept of the definition is based on gap theory and demonstrates the difference between expectations and present experience, and perceived and actual goals (Calman, 1987). According to Fraser (1993), quality of life is more than just a reflection of health status (physical, psychological and social well-being) because it incorporates other life experiences such as economic, occupational and family domains. The definition of quality of life by the WHO in 1995 is the most accepted. According to the WHO (1995), QOL refers to "an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns" (p.1403).

1.5.1.1.3.1 Nature of Health Related Quality of Life (HRQOL)

The World Health Organization describes that HRQOL is a state of well-being instead of presence of disease (Nicholas, et al., 2010).WHO (1994) also defined as ''the personal perception of an individual of his situation in life, within the cultural context and values in which he lives, and in relation to his objectives, expectations, values and interests''. Health Related Quality of health consists of several factors such as physical health, psychological state, level of independence, social relationships and relationship with the environment and religious belief (Ortega et al., 2007). This means that illness is effected not only the physical domain but also the psychological and social state of the individual as well (Orley et al., 1994).

1.5.1.2. Level of Adjustment

There have been a small number of studies among liver transplant patients or donors. These studies can be reviewed on the basis of the course of illness that is before and after transplantation. Some studies have shown that donors are faced with adjustment problems after transplantation, which are conceptualized as adjustment disorders (Lam, et. al., 2000).

Patients with chronic liver diseases are more likely to have poor social adjustment (Lang et al.1997). Patients' waiting time for transplantation also affects the psychosocial adjustment. Studies have shown that patients' social network and social activities have decreased because of physical problems such as itching growing encephalopathy and tiredness (Wainwright, 1997 and Robertson 1999). Blanch (2004) found that female patients showed a poorer overall psychosocial adjustment before liver transplantation.

In terms of adjustment, research has focused more on renal transplant and diabetic patients. Keogh et al. (1999) found that adjustment and acceptance of illness of patients who had a functioning renal transplant were higher than patients who were on hemodialysis, were employed or study full-time, and also in whites rather than in Asians. The impact of the final-stage renal disease on peoples' adjustments is dramatic (Orr et al., 2007), although returning to physical activity, social relationships and work requires consistent adjustment (Muehrer and Becker, 2005). However, after KT (kidney transplantation), patients have a significantly and substantially better adjustment (Purnell et al., 2013; Tonelli et al., 2011).

Furthermore, according to a study by Prabhu (2007), people without diabetes had better psychosocial adjustment than people with diabetes.

The most commonly studied criterion of adjustment is the presence of psychological problems. In order to understand patients and donors' psychosocial adjustment to a chronic illness (types of organ transplantation, diabetes), literature has focused on the level of depression, anxiety and quality of life.

1.5.1.2.1. Level of Depression

Though there are successful outcomes of LDLT, psychiatric symptoms especially depression are more likely to occur in LDLT (Fukunishi et al., 2001). There have been a small number of studies among liver transplant patients or donors. These studies can be reviewed on the basis of the course of illness that is prior and post transplantation.

1.5.1.2.1.1. Donors' Level of Depression

There has been a small number of studies have shown donors' depressive symptoms. Fukunishi et. al. (2001) explained that around 10 % of donors have been diagnosed with depressive disorders before transplantation. While some potential donors had been highly motivated before surgery, some donors demonstrated extremely depressive attitudes (Walter, et. al., 2002). He also found that some donors' depression levels were markedly higher than healthy group. After transplantation, depression symptoms of donors lower and had better psychosocial outcome (Walter et al., 2012).

In addition, in kidney transplantation, before surgery 16.3% of donors had moderate/serious depression. There were no significant changes in donors' depression levels; the differences were no longer significant. There was an increase among severely depressed donors (Lopes et al., 2011).

1.5.1.2.1.2. Patients' Level of Depression

The most commonly reported psychological problem is depression (Grover, et al., 2012) and patients experience depression before transplantation (Drotar, 1999; Keller, Nicolls, 1990; Stawski et al., 1995; Trzepacz et al., 1989).

Studies have found that pre transplant, the rate of depression among patients increased (Ishizaki et al., 2012; Ortega et al., 2007; Rogal et. al., 2011). For example, according to Rogal et al. (2011) reported that diagnosis of depression was common among patients awaiting liver transplantation; it was higher than 36%

Literature has focused more on depression level of kidney transplant and diabetic patients because there has been a limited study related with depression level of the liver transplant patients. In kidney transplantation, before surgery 38.7% of recipients had moderate/serious depression. There were no significant changes in recipients' depression levels; the differences were no longer significant. There were less severely depressed recipients but severe depression was seen more in female recipients (Lopes et al., 2011). In addition, among both type 1 and type 2 diabetic patients, it has been estimated to be around 40% (Von Dras and Litchy, 1990) and 60 % (Padgett, 1993). Egede and Ellis (2008) reported that diabetes patients have seen depression-related symptoms, such as loss of interest, reduced decision-making ability and fatigue.

After transplantation, some studies demonstrated that the depression level of patients decreased (De Bona et al., (2000; Sargent et al., 2006). For example, Sargent et al., 2006 conducted a study that patients improved psychologically after acute liver failure and liver transplantation. Other studies showed that there was no significant difference between depression levels in recovering post-operation and pre-operation period (Ishizaki et al., 2012).

Moreover, in kidney transplantation, there have been some studies to demonstrate that depression levels of patients after transplantation were lower that of before transplantation (Szeifert et al., 2010; Akman, 2004). According to a study by Akman (2004), the depression level of the renal transplant recipients was significantly lower than that of hemodialysis patients with chronic allograft rejection. In heart transplantation, Fusar-Poli et al. (2005) found that thirty-two percent of patients experienced mood depressive symptoms in the long term after transplantation.

1.5.1.2.1.3. Primary Caregivers' Level of Depression

Primary caregivers are also affected by liver transplantation. Some studies demonstrated that caregivers of a liver or kidney transplantation candidate show depressive symptoms (Bolkhir et al., 2007; Malik et al., 2013). For example according to the study of Bolkhir et al., 2007, approximately 19% of the caregivers had depression, so the prevalence rate is significantly higher than in the general population (19% vs. 3,85%).

1.5.1.2.2. Level of Anxiety

There have been a small number of studies among liver transplant patients or donors. These studies can be also reviewed on the basis of the course of illness that is before and after transplantation.

1.5.1.2.2.1. Donors' Level of Anxiety

There is no study that has shown donors' level of anxiety before and after liver transplantation but it has been examined among other type of organ transplantation studies. For example, before kidney transplantation, 64.4% of the donors showed higher anxiety levels in all dimensions. Male donors showed greater cognitive anxiety at both times (Lopes, 2011).

1.5.1.2.2.2. Patients' Level of Anxiety

A limited number of studies show that anxiety problems are common in patients before and after liver transplantation (Trzepacz et al., 1989; Junior et al., 2008; Rogal et al., 2011). For example, according to a study by Rogal et al., 2011, a diagnosis of anxiety disorder is common for patients awaiting liver transplantations; it is higher than 36%.

Anxiety symptoms are also common in the final-stage of renal diseases (Weisbord, 2007; Akman, 2004; Lopes et al., 2011). For example, Lopes et al. (2011) found that before kidney transplantation 100% of the recipients presented total anxiety, with higher anxiety levels in all dimensions. Men showed higher levels of cognitive anxiety before transplantation.

However, when anxiety levels have been compared before and after transplantation, the results have been mixed. Some studies have shown that anxiety levels of recipients one year after transplantation was worse compared to before transplantation, but better results have been observed up to three years post-transplant (Leyendecker et al., 1993) whereas other studies have shown no significant difference in terms of anxiety during the post-operative, recovery period (Ishizaki et al (2012). Moreover, in kidney transplantation, according to a study by

Pascazio et al. (2010), transplanted patients scored significantly lower than control subjects in anxiety scales and in general negative emotions. Transplant recipients did not display any symptoms of anxiety.

1.5.1.2.3. Level of HRQOL

Liver transplant affects both patients' and donors' psychological wellbeing. Transplantation has an impact on quality of life among transplant recipients and donors (Tong, et al., 2009). Studies can be also viewed in terms of quality of life before and after transplantation.

1.5.1.2.3.1. Donors' Quality of Life

There have been a limited number of studies that reported the health quality of life among donors before transplantation. According to Walter et al. (2003) study, before LDLT donors' quality of life was significantly low. Constantly, other studies have shown that health related quality of life after liver transplantation was higher among donors (Zhang et al., 2005; Chen and Yan, 2011; Feltrin et al., 2008). However, De Bona et al. (2000) studied that HRQOL is significantly worse during the second year after liver transplantation than during the fifth year. More specifically, Walter et al. (2003) conducted a research about quality of life of living donors before and after living donor liver transplantation. According to the result of this study, before LDLT the donor quality of life (QOL) is high, after LDLT the reduction in the QOL that appears in the areas of 'physical health' and 'living condition' is significant. Furthermore, post operation complications had no significance influence on QOL of donors after transplantation.

There have been also such studies about the effect of HRQOL on living kidney donors and some theorists have proved longer improvement in living donor recipients after kidney transplantation (Kizilisik et al., 2003) but others did not find any differences in the HRQOF of living or deceased-donor recipients (Lima et al., 2006).

1.5.1.2.3.2. Patients' Quality of Life

There is little data published on the HRQOL of pre-LT and post-LT patients. A quantitative study has shown that just before the transplant, prevalence of quality of life is higher in adult LDLT recipients than in adult living-donor kidney transplantation recipients (Fukunishi, Sugawara, Takayama, Makluuchi, Kawarasaki & Surman 2001). Some studies found a significant improvement in the quality of life after transplantation (Junior et al. (2008; Ortega et al., 2007; Wang et al., 2012). For example, Junior et al., 2008 examined that a significant quality of life improvement after transplantation for the following categories: functional capacity, physical aspects, pain, overall health status and social aspects. Adult patients with transplanted livers are more likely to have psychiatric disorders after surgery (61%).

There have been also such studies about the effect of HRQOL on other types of organ transplantation. In heart transplantation, Grady et al. (2003) reported that patients were significantly more satisfied and had a higher HRQOL in their lives 3 months after heart transplantation in contrast to 3 months after a left ventricular assist device (LVAD). Johnson et al. (1982) reported that successful transplant and hemodialysis patients were similar in reporting a normal quality of life, but failed transplant patients showed a lower quality of life. Similarly, some studies have shown significant improvement after renal transplantation compared with before transplantation (Dew, et al., 1997; Davison et al., 2013). For example, Davison et al. (2013) found that patients had highly HRQOL account for 29% and 27% of the variance in physical and mental HRQL scores, respectively than before transplantation.

The effects of living liver transplantation on patients have been examined on the basis of the construct of adjustment in general and the presence of depressive and anxiety problems and quality of life in particular. In particular, some studies have shown depressive and anxiety symptoms are much more common before transplantation than after transplantation whereas other studies have shown no significant difference in terms of anxiety or depression before and after transplantation. In terms of quality of life, studies have shown improvement in quality of life after transplantation whereas other studies have found poor quality of life in patients with before transplantation in particular decrease in social activities and social network.

1.5.2. Beliefs

There are different models of beliefs to explain how beliefs affect adjustment of donors. A number of studies have postulated the effects of beliefs on adjustment. These include Theory of Planned Behavior (TPB) (Ajzen, 1988), Health Belief Model (HBM) (Rosenstock, 1966), Attribution Theory, Social Learning Theory, Self-Regulatory and Social Cognitive Model.

1.5.2.1. Nature of the Beliefs

1.5.2.1.1. Attribution Theory

According to Kelley (1967), attribution theory refers to the peoples' explanations of causes of events. These attributions help the understanding and management of causal events (Turnquist et al., 1988). Different kinds of attributions have been outlined. Internality refers to the notion that cause is related to peoples' own behavior whereas externality states that external factors cause the illness. Stability states that the cause may be long lasting whereas it may be unstable. Globosity refers to cause as being global whereas it is specific. An event can also occur because of universal or personal factors and finally the cause can be controllable or uncontrollable for the people (Krespi, 2001).

1.5.2.1.2. Social Learning Theory

According to Rotter's theory (1954), the likelihood of a given behavior depends on the perception that this behavior will guide to desired outcomes. Locus of control is one of the constructs of social learning theory. Locus of control indicates whether people perceive events as controllable by them or uncontrollable by them, in other words they are the internal or external locus of control (Rosenbaum and Ben-Ari Smira, 1986). It is commonly thought that patients having internal locus of control over one's health are more likely to be related to health seeking behaviors (Mastroyannopoulou et al., 1998).

Wallston and Wallston (1982) stated that health locus of control refers to peoples' beliefs that their health is or is not determined by their own behavior. Health locus of control shows the health or sick-role behavior. In addition, in order to measure health behavior, Wallston and Wallston (1982) developed a measure of the health locus of control that assesses whether an individual regards their health as controllable by them (''I am directly responsible for my health''), whether their beliefs are not controllable by them and in the hands of fate (''whether I am well or not is a matter of luck'') or whether they believe that their health is under the control of powerful people (''I can only do what my doctor tells me to do''). Pucheu, et al., 2003 said ''Health-related locus of control (HRLOC) is a way of describing how an individual considers his/her participation in maintaining or not his/her health and refers to the type of attributions, internal or external (chance or medical power), of each individual'' (p.318).

According to the learned helplessness model, there have been a variety of responses to uncontrollable negative events (Abramson, Seligman, & Teasdale, 1978). People are likely to have psychological reactions such as depression, helplessness and hopelessness when the absence of a relationship between one's behaviors and consequent outcomes occurs (Seligman, 1975). A person who explains his/her illness with stable, global and internal causes demonstrates much more severe helplessness deficits than a person who explains them with unstable, specific and external causes (Peterson, et al., 1988).

1.5.2.1.3. Theory of Planned Behavior

According to Ajzen's theory (1988), behavioral intention is conceptualized as the outcome of a combination of several beliefs. Intention is affected by attitudes toward the behavior and subjective norms that refers to social norms and pressures to perform behaviors and beliefs. Perceive control affects behavior through its impact on intentions and behavior that postulates internal and external factors (Stroebe and Stroebe, 1995). Perceived control also refers to how much control people have over a given situation depending on their awareness of their capabilities (Bandura, 1977).

1.5.2.1.4. Health Belief Model (HBM)

HBM was developed by Rosenstock (1966) in order to explain preventive health behaviors and later modified by Becker and Maiman (1975). There are five components of HBM; one is susceptibility to illness(''My chances of getting lung cancer is high''), second is severity of the illness (''Lung cancer is a serious illness''), third costs involved in carrying out the behavior (''stopping smoking will make me irritable''), fourth is the benefit involved in carrying out the behavior (''stopping smoking will save me from cancer''), and fifth component is cues to action that may be internal (the symptom of breathlessness) and external (information in the form of health education leaflets) (Becker and Maiman, 1975).

1.5.2.1.5. Self-Regulatory Model

According to this model, patients' perception of their illness is generic and there are organized cognitive representations or schemata that are formulated as personal models of illness (Hampson, 1997a). In addition, each patient has his/her own ideas about the identity, cause, consequences and timeline of his/her illness in the SRM (Leventhal et al., 1984a; 1984b and Meyer et al., 1985). Identity is defined as the nature of an illness or symptoms of an illness; cause refers to bio psychosocial factors of the illness, consequences refer to the short term or long lasting physical, economic, social and emotional costs of the illness and the final factor, the timeline is defined as an acute, episodic or chronic of illness (Ogden, 1996). Furthermore, Lau and Hartman (1983) added the cure and controllability into the SRM and it is defined as the beliefs about the degree to which and the ways patient cope with their illness.

In SRM, the patient perceives illness as a problem and manages this problem through cognitively, and emotionally parallel and interactive processes (Hampson, 1997a; Leventhal et al., 1984a &Horne, 1997). First, people try to make sense of an illness by cognitive processes; second they develop a coping strategy in order to manage treatment, third, they assess the outcome and usefulness of the coping strategies.

1.5.2.1.6. Social Cognitive Theory

According to Bandura's social cognitive model (1977), there are three constructs which assist in the understanding of adjustment. These include situation expectancies that have referred to the behavior which may be dangerous (''smoking can cause lung cancer''), outcome expectancies have been explained that behavior can reduce the harm to health (''Stopping smoking can reduce the chances of lung cancer'') and efficacy expectancies have been defined as the individual's capability of carrying out the desired behaviors (''I can stop smoking if I want to'').

1.5.3. Coping

1.5.3.1. Nature of Coping

Coping generally refers to cognitive and behavioral efforts in order to cope with internal and external factors presented as threatening (Lazarus and Folkman, 1984).

There are two main coping strategies. One is problem-focused coping refers to how it provides in taking action to reduce stressors or to increase the resources available to manage it (Lazarus, 1993). Second is emotion-focused coping that have provided as management of the emotions evoked by the stressful event. Problem-focused coping is related to more favorable outcomes in illnesses that offer the most opportunities for control, whereas emotional-focused coping is adopted in less controllable illnesses (Felton and Revenson, 1984).

1.5.4. Social Support

1.5.4.1. Nature of Social Support

There is no well-established definition of social support. It has been defined differently. Some investigators have tried to explain social support in terms of perceived availability of general social support which determines how the perception of support protects one from pathogenic outcomes (Wilson et al., 1986; Connell et al., 1994), emotional appraisal which involves the provision of information that is useful for the self-evaluation process (Glanz, et al., 2002), and this is also linked with social comparison theory, which suggests that the existence of other people enables individuals exposed to a stressor to choose an available coping strategy by comparing themselves with others (Hammer, 1981). Appraisal model of social support involves the view of how interpersonal relationships interfere with the pathological influences of a stressful event (Cohen and McKay, 1984). Lazarus (1966) explains the appraisal model in terms of cognitive model of stressor appraisal. A person perceives the stimuli as threatening when one experiences psychological stress depends on potentially threatening. Social support effects the individual's appraisal of the potential stressor. Social support is also explained in terms of illness-specific social support (Wilson et al., 1986) by some investigators. Support given by the family is a general definition of social support (Parkerson and Gutman, 1997). Family support has been composed while being together with family cohesion, expressiveness and conflict (Christensen et al., 1992). Social support is generally used to refer to the perceived comfort, caring, esteem or help one individual receives from others (Wallston et al., 1982).

Community support plays very supportive roles in people's lives. A sense of community support evokes the perception of willingness to help on the part of various types of organizations and those who staff them (Sarason and Sarason, 2009). Community support has included police and fire departments, hospitals, schools and social agencies. This is called social integration of social support.

Wills (1985) has defined several types of social support, one which is esteem support and refers to one's own self-esteem that has been increased by other people. The second one is companionship, which involves support through activities and other type of social support is instrumental support involving physical help.

Two models have been proposed to understand social support. The first one is that support is perceived as a main effect that occurs in the generalized group like a large social network (Cohen and Wills, 1985). Relationship in a social network may help one to avoid negative experiences because in a contrasting situation, psychological and physical disorders are more likely to be developed by people. This view of support is related to sociological perspectives as ''regularized social interaction'' or ''embeddedness'' in social roles (Cassel, 1976; Hammer, 1981). The second model of social support is that support is perceived as a stress buffer. Support may protect persons from the potentially pathogenic effect of experiencing stressful events (Cassel, 1976; Hammer, 1981).

1.6. The Effects of Beliefs on Adjustment among Patients and Donors

Beliefs have an important affect on patients' adjustment and quality of life. However, there have been a small number of studies that examined the effects of beliefs on adjustment among liver transplant patients or donors. These studies can be reviewed on the basis of the course of illness that is before and after transplantation.

There has been no study about the effect of causal attributions on adjustment among living donors and patients. However, only a few studies have examined the effect of attribution theory on adjustment among other chronic illness. For example, Witenberg et al. (1983) concluded that haemodialysis patients with ESRF who had a causal attribution are more likely to show better adjustment although there was no relationship of the specific causal attributions of self-blame and blaming other people with adjustment whereas in a study by Ahola and Groop (2013), self-blame was found to be associated with lower diabetes self-efficacy and nonadherence to the illness and its treatment. Other studies have found that patients with hemodialysis or diabetic show more depressive symptoms when they explain their illness as stable, global and internal (Seligman 1975; Cristovao 1999). For example a study by Cristovao (1999) found that hemodialysis patients with overall, internal, unstable and controllable attributions were indirectly associated with good psychological adjustment through the use of emotion-focused coping.

Despite the increasing use of living donor liver transplantation, there is also no information about the effect of locus of control and perceived control on adjustment among liver transplant patients and living donors. However, a number of studies have examined the effect of locus of control and perceived control on adjustment among other physical illnesses. Some studies found that patients with hemodialysis who had an internal locus of control, developed less depression and worse adjustment (Bremer et. al. 1995; Devins et. al., 1983; Rothbaum, et al., 1982; Devins et al., 1981). For example, a study by Devins et al., 1981 found that patients who believed that they could control their disease were more likely to adhere to treatment and to be less depressed whereas some studies found that there was no relationship between health locus of control and emotional adjustment (Devin et al., 1983)

In addition, internal locus of control has been associated with better outcomes and quality of life among diabetic patients (Pucheu, et al., 2003; Poll and De Nour, 1980; Sloan et al., 2009; Peyrot and McMurry 1985).

Moreover, White et al. (2007) studied whether perceived control were related to physical activity. In terms of the physical activity level, differences were observed in perceived control. Compared with the less active, those highly active were more likely to think that exercising makes them feel healthy and less likely to anticipate that exercise would make them feel sore afterwards. Additionally, those less active more likely reported that laziness prevented them from being physically active.

There have been no studies about the effects of HBM on adjustment among liver transplant patients and donors. However, there is a limited study that has been conducted about the effects of health beliefs on adjustment among patients with other chronic illnesses. Friend et al. (1997) found that health beliefs were not related to depression and anxiety among hemodialysis patients whereas Di Matteo et al. (2007) reported that adjustment was significantly positively correlated with patients' beliefs in the severity of the disease to be prevented or treated.

Furthermore, people with diabetes who reported more depression and anxiety did report more barriers to treatment and more vulnerability to complications and also perceived their illness as more severe (Lewis et al., 1990).

There have been no studies that have examined the effects of SRM on adjustment among liver transplant patients and donors. However, a few studies have been reported the effects of SRM on adjustment among other chronic illnesses such as diabetes and hemodialysis. Hampson et al. (1995) demonstrated that patients who reported greater outcomes of their diabetes had poorer quality of life and emotional adjustment. A study related to hemodialysis patients demonstrated that patientswitha high risk of anxietyordepression had a negativeperception of illness (Yıldırım et al., 2013).

There have been limited studies about the effect of self-efficacy on adjustment among liver patients, although not among liver living donors. Gutteling, (2010) researched into psychosocial factors of patients with chronic liver disease. According to findings, depression was largely determined by low self-efficacy due to using of maladaptive coping strategies and also decreases quality of life. However a few studies have examined the effects of self-efficacy or outcome expectancy on adjustment among other chronic illness such as type 2 diabetic patients. Posadzki et al. (2010) conducted research about the relationship between self-efficacy and health behaviors of physical illness such as adjustment to illness. The result of this study indicates that the healthier the behaviors the stronger the self-efficacy. Furthermore, type 2 diabetic patients who have greater self-efficacy to continue treatment demonstrate less depression (Padget, 1991). In contrast, Connell et al. (1994) stated that self-efficacy and outcome expectancy were not significant predictors of depression among type 1 and type 2 diabetic patients.

According to Nickel et al. (2002) study; patients who have poor coping strategies are more likely to take a high score for anxiety and depression. These factors are related to a poor physical and mental quality of life also. According to the Stilley et al. (2010) study, patients with liver transplant who use avoidant coping and affective dysregulation, have poor clinical and mental health outcomes.

The effects of coping strategies on adjustment have been examined among other chronic illnesses such as diabetes and renal disease. Sherbourne et al. (1992) stated that type 1 and type 2 diabetic patients and ESRF patients who were used avoidant or defensive strategies were related with poor emotional well being (White et al., 1992; Dew et. al., 1996) and self-esteem and social adjustment (Blodget, 1985). Some studies stated that using emotive coping strategies have been associated with negative quality of life of HD and diabetic patients (Lindqvist et al., 1998; Pucheu et al., 2003). For example, Lindqvist et al. (1998) found that HD patients who use emotional coping strategies extensively seem to be less effective at handling their illnesses.

The effect of social support on psychosocial functioning has not been widely examined among living liver donors but a few studies have examined among patients. Studies have shown that patients who were perceived to have less social support were more likely to develop depression (Junior et al. (2008; Noma et. al., 2008). On the other hand, some studies have failed to demonstrate a relationship of social support with depression or anxiety in ESRF (Parkerson and Gutman, 1997). For example, Palmer et al. (1983) posited that hemodialysis patients who receive greater support from dialysis team have poorer adjustment. According to a study by Pucheuet al. (2003), hemodialysis patients' mental component score of QOL was negatively associated with seeking social support. Kimmel et al., 1995 reported that perceived quality of social support has been related with more favorable psychological adjustment among ESRD patients. In a study by Tang et al. (2008) among Type 2 diabetic patients, the attending physician was most frequently (43% of the respondents) identified as the primary source of support, followed by the spouse (20%) or another family member (19%) and this population has better coping strategies and adjustment than those receiving no support. On the other hand, Hagedorn et al. (2006) investigated that high level of social support might be related to overprotection which communicates low trust in ones' abilities. Therefore, social support negatively influences psychosocial wellbeing in diabetic patients.

In summary, beliefs are important to understand donors and patients' thought about liver failure and its treatment. There are number of studies which have examined the effect of beliefs on adjustment. These beliefs contain patients' locus of control, perceived control, health beliefs, causal attribution, self-efficacy and self-regulatory. Many studies have shown that patients who perceive their illness as internal, unstable, specific and controllable by them, they have better adjustment and quality of life to their illness, higher self-efficacy to cope with their illness and show less depression and anxiety after liver transplantation. On the other hand, there have been also some studies showing that before transplantation, patients who have a lack of social support demonstrate a low quality of life, worse adjustment and higher level of depression or anxiety symptoms toward their illness. Furthermore, some studies have found that patients who had poor coping strategies were more likely anxious and depressed and reported that after transplantation patients who used avoidant coping and affective dysregulation had negative clinical and mental outcomes.

Even though many variables have been examined which can help to identify patients, who are at risk, they give limited information on the possible targets for education or psychological interventions in the literature and no quantitative study has been carried out to understand the nature of these beliefs and their effects on adjustment among living donors of liver transplantation. Studies carried out within the context of chronic physical illnesses other than liver failure suggest that all these approaches define, on theoretical grounds, the beliefs that patients are presumed to hold. An in depth understanding of psychological process of patients and donors is also needed, so the next section will outline qualitative methodologies which provide an avenue to understand liver transplant patients and donors' experience of liver failure.

1.7. Qualitative Research in Liver Transplantation

1.7.1. Nature of Qualitative Research

Besides quantitative studies, in order to understand patient's adjustment and to explore patients' experiences by liver transplantation, qualitative methodology has been used. It is a field of inquiry in its own right that privileges no single methodology over any other (Denzin and Lincoln, 1994). Furthermore, it emphasizes description and explanation more than on measurement and prediction (Fitch, 1994a). This method also provides an answer questions about the ''what, how'' or ''why'' of a phenomenon rather than questions of quantitative methods about the ''how many'' and ''how much'' (Bricki and Green, 2007). What clinicians need to know is how patients are influenced by the illness and its treatment in order to make interventions. Therefore, qualitative methodology aims to ensure that patients' and donors' beliefs about their illnesses and its treatment and their views of adjustment are captured and qualitative methodology identifies patient-derived targets of educational or psychological interventions to improve poor adjustment (Krespi, 2001). Qualitative research is also neutral which refers to the researchers' attitudes towards the participants of the study. In addition, qualitative research is empathic which refers to convey interest and caring (Patton, 1990).

1.7.2. Aim of the Qualitative Research

In fact, qualitative methodology generally aims to offer a unique opportunity for identifying targets for patient-derived psychological interventions and to understand the experiences and attitudes of patients, the community or health care worker. Qualitative methods are naturalistic and because of being naturalistic, they aim to obtain the insider's view of a phenomenon (Henwood and Pidgeon, 1992). Furthermore, they aim to explore naturally occurring beliefs about illness within the real-life context in terms of the individuals who experience the illness (Henwood and Pidgeon, 1992).

Qualitative methods are inductive and due to being inductive, they aim to discover and explain the situation in more detail. They also aim to develop theory inductively (Carr, 1994). This helps to understand how phenomena change into general ones from specific ideas (Henwood and Pidgeon).

Qualitative methodology also aims to understand and describe the participant's feelings, experiences and opinions with the full empathy of the researchers (Patton, 1990).

Beyond that, qualitative research aims to gather information on each part of phenomenon of the study and gives attention to contextual issues about social, cultural or political factors (Patton, 1990).

1.7.3. Theoretical Orientation in Qualitative Research

A number of theoretical orientations have been followed in the qualitative approach (Patton, 1990). These orientations have included in ethnographic inquiry, phenomenological inquiry and Grounded Theory. Ethnographic inquiry aims to understand standards and meanings within a specific group of behaviors, patterns, values and beliefs (Miller and Crabtree, 1992), and then constitutes new theoretical models about this group (Searight and Campbell, 1992). Phenomenological inquiry aims to describe the ways in which people experience the world and interpret it (Patton, 1990).

Other theoretical orientation is Grounded Theory, which includes some data analysis and has been greatly contributed to the literature of medical sociology and nursing (Miller and Crabtree, 1992). Qualitative research is the source of well-Grounded Theory illustrated with rich description and explanation of processes that occur in an identifiable local context (Miles and Huberman, 1994). Data analysis consists of a gradual understanding of a phenomenon through a repeated cycle of data collection, then a multi-step process of coding the data and comparative analysis (Glaser and Strauss, 1967). In order to take information from the participants open-ended questions have been used without placing a study in a pre-existing theoretical framework (Patton, 1990) because Grounded Theory aims to generate a descriptive or explanatory model of an area that has previously not been well understood (Patton, 1990).

1.7.4. Previous Qualitative Studies among Liver Transplant Patients, Donors and Caregivers

1.7.4.1. Qualitative Studies on Donors' Beliefs

In the following section, findings related to donors' experiences of liver failure and its treatment will be outlined. These findings can be grouped into beliefs about being a donor, liver transplantation, recipient's health and post-operation duration.

Many qualitative studies, based on grounded theory, have shown that donors become a donor as an automatic response and perceive this an opportunity to help the loved one to survive (McGregor et al., 2008; Walter et. al. 2004) and also donors feel that they wish to help their loved one from deterioration (McGregor et al., 2008). Fujita et al. (2006) found that donors have no choice and decide to be a donor because they prioritize the recipient's life, and they perceive liver transplantation as the last chance for the recipient and her family and feel obligated to save the recipient.

More specifically, Fujita et al. 2004 in a qualitative study was based on grounded theory and several nuances of voluntary consent consisting of three patterns. ''Unconditional consent'' is consent from the bottom of one's heart to save family members' life, ''pressured consent'' is donor feels a pressure from inside to donate although he/she feels fear. ''Ulterior-motivated consent'' is that the donor has a hidden motivation. According to this theme, if the donor's recipient dies after donation, the donor is rewarded with the estate, however, if he survives, he is more than likely to feel indebted to donor for life.

Some qualitative studies, based on grounded theory, have shown that donors feel motivated for an operation and idealize the relationship with the recipient (Walter et al., 2004) whereas some studies have shown that donors feel ambivalent for an operation, fear of surgery and experience a poor relationship with the recipient during transplantation (Papachristou et al., 2010; Walter et al., 2004) and difficulties in accepting liver failure, denial, fatalism (Papachristou et al., 2010).

Relatedly, Fujita et al. (2006) asserted that decision-making process for transplantation included 5 stages. One is recognition, (learning of LDLT from recipients, family, doctors or media). The second is digestion (realizing seriousness of LDLT), and some donors want to save recipients from suffering and avoiding guilt. The third is decision making, the fourth is reinforcement, donors reinforce themselves psychologically. The final stage is resolution (preparedness and acceptance of donation). Stages 2 and 3 donors have reached a decision and experienced anxiety and conflict. Stage 4 and 5 donors have become impatient and nervous.

In a study by Walter et al. (2006), sadness toward the organ rejection and death of the recipient were important themes. During the post-operative period, two donors were extremely sad because of recipients' dying. Another theme was the anxiety toward the recipient and their own health because donors have an uncertainty about whether their liver health will recover.

Walter et. al. (2006) stated that donors were frustrated and had anger toward the medical system and social environment. They reported the need for more post-operative medical and family support but they were frustrated.

1.7.4.2. Qualitative Studies on Recipients' Beliefs

In the following section, findings related to recipients' of liver failure and its treatment will be outlined. These findings can be grouped into donors' and their own health, organ donation, liver transplantation and psychosocial effect of liver transplantation

Some qualitative studies, based on phenomenological approach, have shown that patients feel ambivalent and worry. The worry is related to whether or not the potential donor will change his/her mind and cost of liver transplant (Watanabe et al., 2010). Patients are worried about also donors' physical health because some studies have shown that many recipients perceive LDLT as a risk for their donors' quality of life, family strains, employment, financial and general health and LDLT includes extreme physical and mental pain for the donor (McGregor et al., 2008; Watanabe et al., 2010).

Some studies have shown that their relationships with donors got strengthened following transplantation (Tong et al., 2009) and felt guilt when thinking about survival by hurting a potential donor and problems associated with donor (Tong et al., 2009; McGregor et al. 2008; Watanabe et al., 2010). For example, Tong et al. (2009) conducted research about recipients who underwent organ transplantation by searching a systematic review of qualitative studies. The findings have shown organ donation as a theme. The attitude toward the donor consists of obligation of gratitude, strengthen relationship, concerns about risks to donor, regret, fear, guilt.

Many qualitative studies have shown that patients avoided transplantation because of death risk and fear of losing their physical capability (McGregor et al.

2008; Brown et al., 2006), they also felt the burden of new body and experience difficulties in adapting to post transplant lifestyle (Watanabe et al., 2010) whereas some studies stated that patients managed these negative emotions by leaving it to the fate (Watanabe et al., 2010) and adopting a positive attitude (Tong et al., 2009), perceiving transplantation as a last option (McGregor et al., 2008), focusing on the benefits of transplantation including getting rid of the final-stage liver disease, avoiding a hopeless sense of life with psychological effects of a waiting death (Huang, et al., 2011), redefining identities, seeking normality and achieving independence (Tong et al., 2009) and trusting of the transplant team (doctor and nurse) (Brown et al., 2006).

Relatedly, Huang et al. (2011) described the process of decision-making, the process and recipients' motivation of liver transplantation by using an explorative qualitative methodology. According to the result of this study, patients' decision making process of liver transplantation is consisted of several phases (the degree of patients' understanding, the degree of faith, support from relatives and friends, hope for post-LT) and these phases consist of transplant data evaluation and every phase have unique contents, factors and dilemmas.

Some studies have found that patients were socially isolated and socially stigmatized (Tong et al. (2009; Sargent 2007) in that there was the view that liver failure was infectious (Sargent 2007), parental overprotection, peer rejection, struggle to maintain school work, participation in physical activities and managing medical demands, dependence on formal and family caregivers, disruption to lifestyle and vigilant adherence for survival (Tong et al., 2009) whereas a study by

Sargent (2007) found that following transplantation, patients felt optimistic and willing to help others.

Some qualitative studies, based on exploratory design, have shown that patients reported some physical limitations involving lack of energy, physical inactivity and physical changes before transplantation (Bjork and Naden 2008; Sargent 2007), they reported also their uncertainty towards life and death (Bjork and Naden 2008). Three to six months after transplantation, patients reported better physical outcome and they adapted post-transplant life styles easily (Sargent 2007).

1.7.4.3. Qualitative Studies on Primary Caregivers and Families' Beliefs

In the following section, findings related to the primary caregivers and families' experiences of liver failure and its treatment are outlined. These included beliefs about liver transplantation, donors and recipients' health, psychosocial effect of liver transplantation and role function.

A qualitative study, based on thematic content analysis, by Weng et al. (2011) found that caregivers and families recounted experiencing unstable feelings towards liver transplantation.

Furthermore, Chou et al. 2009 investigated family experience of waiting for living donor liver transplantation using descriptive phenomenological approach. Findings showed that surgery was perceived as hope of rebirth, although surgery was a threat for donors and recipients' health, parents reaffirmed their decision.

Following transplantation, caregivers were embarrassed from the burden of care (Weng et al. (2011) and they saw themselves as a protector of recipients' medical needs (Weng et al., 2011).

There was the view that when non-synchronized family interaction, caregiver had more stress and patients felt that the medical terminology caused the caregivers anxiety and stress (Weng et al. (2011). Chou et al. (2009) examined that caregivers and families were anxious towards surgery.

1.7.5. Summary Results of Qualitative Research about Liver Transplantation

In an attempt to understand liver transplant patients and donors' experience during their illness and post-transplantation process, some qualitative studies have been carried out. The results have demonstrated that patients and donors think about their illness and treatment and also their experiences in ways that are not found by previous quantitative studies.

Previous qualitative studies have studied experiences of donors, recipients and families because recipients and families have strong influence on LDLT and family studies focus on donor-parental relationship and the ongoing interaction between the donor, recipient and family members (Chou et al., 2009). Studying the recipients' perspectives is also an extremely important issue because recipients have strong effects on LDLT donors. Inter-relationship study provides a better understanding of the psychosocial effects of LDLT. Many qualitative studies demonstrate that there have been several themes related with donors and recipients' experience during their illness. Donors recounted a number of beliefs in relation to being a donor. These included feeling obligated to change the situation, feeling that one needed to help the loved one to survive, wishing to help their loved one from deterioration and feeling fear of death of recipients. Donors recounted also a number of beliefs in relation to liver transplantation surgery. These included feeling fear of surgery, having risk of surgery, feeling motivated and ambivalent for an operation.

After transplantation the relationship between recipient and donors and difficulties of liver failure, were also recounted by donors.

Some donors and recipients receive good social support from their family whereas some have lack of social support. Recipients recounted some beliefs related to donors' health. Most of the recipients thought that surgery had a risk to the donor's health and life. Recipients recounted also some beliefs related to organ donation. They described the relationship between recipients and donors and described their guilt if anything happened to the donor following transplantation. Recipients recounted some beliefs related to psychosocial effects of liver transplantation. They reported that recipients experienced socially isolation and stigmatization before liver transplantation. All recipients and donors suffer from physical complications related with liver transplantation. Finally, all individuals are related with liver transplantation (patients, donors, primary caregivers and families) perceive surgery as hope of rebirth.

All these qualitative findings can help clinicians to identify specific targets for clinical consultations and/or psycho-educational interventions to improve poor outcomes among patients following diagnosis of liver failure and transplantation surgery.

1.8. Importance of the Study

This study is important for two reasons. One is that there are limited qualitative findings to devise psycho-educational programs and second is that no study has been carried out in Turkey. Qualitative methods offer an alternative to understand patients' experience of liver failure and its treatment without imposing professional and/or theoretical ideas. This may help to understand the process of how donors decide to be a donor or how they feel when being a donor or what difficulties that has to cope with. These methods can minimize the extent to which theoretical or professional assumptions shape this understanding.

Qualitative findings can help clinicians to identify specific targets for clinical consultations and/or psycho-educational interventions to improve poor outcomes among patients following diagnosis of liver failure and transplantation surgery. On the other hand, there is limited evidence to provide a basis for such interventions. Previous qualitative work identified themes of being a donor that were a great variance with the findings of quantitative work among patients with liver transplantation. For example, McGregor (2008) found that obligated to change the situation, feeling that one needed to help the loved one to survive; wishing to help their loved one from deterioration and feeling fear of death of recipients are the contributor factors of being a donor. Therefore the present study explores donors' experience of life following diagnosis of liver failure and transplantation surgery.

Relatedly, ''common sense'' studies of illness (Leventhal et al., 1984; Meyer et al., 1985) and other qualitative studies (Krespi et al., 2004) in different types of chronic illnesses, have shown that patients often hold beliefs that are greatly at variance with either medical knowledge or psychological theory. All theoretical approaches define the beliefs which patients are presumed to have and then assess them in patients. Therefore, the content of measurement instrument has been shaped by authors' prior decisions with regards to what should be measured (Krespi, et al., 2004), so the present study holds beliefs that are not described by theoretically based approaches and that in turn might influence adjustment.

While in the previous studies experiences of donors and recipients are examined, they studied generally following titles: (a) A decision-making process of donors in adult-to-adult living donor liver transplantation, (b) Examination of psychosocial aspect of the donors' decisions in adult-to-adult liver transplantation, (c) Study of risk assessment patterns of living liver donors and assess whether the principles of informed consent and decision autonomy are being met, (d) Investigation the circumstances for impaired psychosocial outcome in donors after LDLT, (e) Reconstructing the determinants of willingness to donate before transplantation, (f) Psychosocial aspects of the donors' decision in adult-to-adult living transplantation, (g) Exploring the transformational experiences of adult-to-adult living donor liver transplant recipients, (h) Experiences of the recipients who undergo organ transplantation, (I) Exploring patients' quality of life following an emergency liver transplant for acute liver failure, (j) Exploring the motivation and dilemmas in the decision-making process by liver transplant patients, (k) Exploring the stress experiences of primary family caregiver during post-operative stage, (l) Investigation from the perspectives of the donor parents of children with biliary atresia during the period of waiting for a living donor liver transplant.

1.9. Aim of the Study

There has been no qualitative research on the donors' experiences of LDLT in Turkey and there are limited qualitative findings to devise psycho-educational programs. Therefore, the aim of the present study is to explore the donors' beliefs of being a donor and experiences of life following diagnosis of liver failure and transplantation surgery and to provide a basis for psycho-educational interventions. It is known how and if these findings converge with the view of Turkish patients with liver failure who had living donor transplantation.

Furthermore, existing findings pertain to patients' views about their experience of life. The ways the patients think that they experience life following transplantation may differ from the ways the donors think how the patients experience life following transplantation. It is important to understand how patients and their donors' views differ if the aim is to devise psycho-educational programs for this group. Therefore, other aim of the current study is to explore donors' view of the patients' experiences of life following diagnosis of liver failure and transplantation surgery. However, there is limited evidence to provide a basis for psycho-educational interventions. According to psychological outcome of donors and patients, it is aimed to enlarge the facilities for them in the hospital before and after transplantation.

CHAPTER 2

METHOD

2.1 Participants

Typical sampling procedure was used to select participants. This sampling procedure helped to ensure transferability of findings to other living donors of liver transplantation (Henwood and Pidgeon, 1992).Typical living donor of liver transplant refers to a donor who has given part of his/her liver to a relative who needed a liver transplantation due to a common cause of liver failure such as Hepatitis C, alcoholic liver disease, nonalcoholic fatty liver disease, and liver cancer. This donor can be a sibling, parent or partner. Following the interviews with 10 living donors, the interview transcripts were analyzed. These analyses were tested with another 6 donors. The final sample consisted of 16 living donors of liver transplant(6 males and 10 females; see table 2.1). These donors were identified by the coordinator of the liver transplant unit of a private hospital in İstanbul. These donors were asked for consent to interview. Recruitment of participants continued until no new data was gathered during interviews. Exclusion criteria were the presence of a medical condition preventing participation. Basic demographic information was also taken from the donors.

Table 1

Sample Description

No	Age	Gender	Marital Status	Education	Occupation	Relationship of donor to recipient	Duration after transplantation
1	30	Male	Single	High School	Medical reported for 6 months	Patient's son	2 months
2	40	Female	Married	Primary School	Housewife	Patient's mother	2 years
3	23	Female	Single	University	Housewife	Patient's daughter	8 months
4	26	Female	Married	Primary School	Housewife	Patient's mother	1,5 years
5	27	Male	Single	University	Journalist	Patient's son	1 month
6	24	Female	Engaged	Primary School	Housewife	Patient's niece\uncle	3 weeks
7	23	Female	Married	Secondary School	Housewife	Patient's mother	2,5 months
8	30	Male	Single	High School	Gave up working until recovery	Patient's collegue\ethical comitte approved	2,5 months
9	35	Male	Married	high School	gave up working for transplantation	Patient's nephew\uncle	12 days
10	40	Female	Married	Primary School	Housewife	Patient's wife	3 days
11	29	Male	Married	Primary School	employed	Patient's son	1,5 months
12	27	Female	Widowed	Primary School	Housewife	patient's third generation\ethical committe approved	1,5 months
13	28	Female	Married	primary School	Housewife	Patient's mother	1,5 months
14	25	Female	Married	Secondary School	employed	Patient's mother	1 week
15	30	Female	Married	High School	Housewife	patient's third generation\ethical committe approved	15 days
16	41	Male	Married	Secondary School	employed	patient's brother	7 months

All of the donors accepted to participate in the study except one donor. She refused to take part due to the use of audio-recording. In the present study, non-relative donors were interviewed unlike previous studies. Especially for these donors who were accepted by ethical committee, participation of this interview may represent a particular perspective associated with the procedure; as a result present study found that they did not want to share their experience with his recipient and they also did not want to talk about the financial issues of donation in detail.

2.2. Procedure

Ethical approval was obtained from the hospital. All participating donors received an information sheet which gives a full explanation of the study *(Appendix A).* The consent form has included that what was expected of the participants, the risk benefit information and researcher's contact details. A set of topics and issues were determined in the form of an outline before the interview begins, however the sequence and the wording of the questions depend on the flow of the interview (Patton, 1990). An interview guide was designed which consist of a list of themes that would be explored.

Donors were prompted to describe liver failure, (its development and causes), transplantation surgery, being a donor, the effects of each, their understanding of how these effects arose the difficulties that they experienced. Donors' experience of life and donors' views of recipients' experience of life following the diagnosis of liver failure and transplantation surgery were also prompted but the findings were not reported here. Donors determined the pace and the sequencing of the interview. The interviewer (AT) encouraged to talk the donors in their own way and avoided closed questions. Participants were interviewed individually in a private room lasted for 60-90 minutes. The interviews were audio-recorded with the participants' permission and transcribed anonymously and verbatim.

2.3. Data Analysis

This study is based on Grounded Theory (Glaser and Strauss, 1967). This theory aims to develop a theory about the main psychological processes of a phenomenon, which is grounded in the views of the participants being studied (Patton, 1990; Millerand Crabtree, 1992). Established conventions to ground analysis in data rather than pre-existing ideas (Glaser and Strauss, 1967; Patton 1990; Stiles 1993) were followed for analyzing anonymised interview transcripts inductively. Thematic analysis was undertaken in parallel with interviews.

Each recording were analyzed by two independent investigators. Preliminary analysis by one author (AT), based on reading 10 transcripts was developed by discussion with the supervisor (RK), who also read the transcripts. The analysis of the interviews generally followed the recommendations of Stiles (1993). In addition, the transcripts were read in full several times to allow familiarization with content. The identification of recurrent patterns that were identified, were tested and modified by cycling between additional data and the developing analysis. Procedures are insufficient to guarantee useful findings (Barbour 2001). In thematic analysis, Initial codes are generated using detailed quotes to provide evidence for subsequent interpretation. These codes are then grouped into themes (Walker, James, and Burns, 2012). After discussing similarities and differences of the initial codes and themes, it is given a definition of the naming themes and codes and finally, it is highlighted that how the themes and codes were inter-related (Braun and Clarke 2006). Once the analysis was complete, six final interviews were undertaken which required no significant further new information of the analysis.

In a qualitative study, reliability refers to the trustworthiness of data gathered from information about the observations or interviews, and involves helping the reader to understand the data (Stiles, 1993). Generalization is very difficult in qualitative research; because very detailed and rich data can be tried to gather from a small number of patients groups (Miller and Crabtree, 1992). Therefore, instead of generalization the term of transferability was used. Transferability refers to the ability to use the findings of a study in contexts that are similar to those from which they were originally derived (Henwood and Pidgeon 1992).

On the other hand, reliability refers to trustworthiness of the interpretations and conclusions. Coherence is important factor of trustworthiness (Stiles, 1993). It shows the comprehensiveness of interpretations, how the categories fit the data and the degree of the categories' meaningful related to the phenomenon being studied. The trustworthiness of interpretation can be achieved by paying attention to the coherence and integrity of analysis. Integrity also refers to the organizing the data in order to achieve the best fit between data and interpretation (Patton, 1990). Trustworthiness is also related to being analyzed the negative cases which refer to the categories that do not fit the data during analyzing. On the other hands, negative cases help to wide or amend the definition of existing categories about their validity (Patton, 1990). The study focuses on both theoretical and catalytic validity. Theoretical validity refers the ways in which the findings relate to theoretical ideas whereas catalytic validity refers to the ways in which the findings contribute to future practice and research (Krespi, Bone, Ahmad, Worthington, &Salmon, 2004). Previous studies have also used in catalytic validity in order to show more broadly to the clinical utility of the analysis in informing the literature about outcomes which can be subject to empirical test (Salmon et al., 1999). Analysis was stopped when no further amendments emerged from this process and when all relevant text was coherent with it. Each category of the final analysis was defined by several donors' data. In the results that follow, illustrative transcript (in italics) demonstrates the range and commonality of content of each other. Omitted text is indicated by the ellipsis.

CHAPTER 3

RESULTS

3.1. Beliefs of Donors about Liver Failure and its Treatment

3.1.1. Beliefs about Liver Failure

Donors' beliefs about liver failure are summarized in Figure 1. Donors recounted diverse explanations for liver failure and physical symptoms with liver failure. In the following sections, accounts that illustrate the beliefs are in italics. Superscripts describe the donor. Refer to Appendix C for extracts of interviews that were annotated to show the analysis.

3.1.1.1. Causes of Liver Failure

Donors recounted diverse explanations for liver failure. A tangible causal agent was absent for several explanations. Even though the illness that causes liver failure was not known for some donors,[7]*the cause is not known.,* and for others the liver failed spontaneously[14]*A mirthful children changed in a while. He started to have fever. Day after day he disappeared before our eyes. We took him to 3 different hospitals. Liver test values turned out to be very high in all of them, we couldn't believe,* most donors recounted that the liver got rotten[7]*His liver got rotten.,*

Figure 1

Beliefs about Liver Failure

Causes of Liver Failure
- Unknown cause
- Liver failed spontaneously
- The liver got rotten
- Complications at birth
- Genetic illness
- Other illnesses
- Donors' blaming themselves
- Blaming doctors
- Senseless drug use
- Stress
- Worry
- God's will

Physical Symptoms with Liver Failure
- Cramps
- Swelling
- Weakness
- Tiredness
- Losing weight
- Bleeding
- Vomiting
- Pain
- Shortness of breath
- Yellowing
- Not being able to eat
- Itching
- Developmental slowing down

Deterioration other Organs

However, many beliefs identified causes including complications at birth[15]*shehad liver failure from birth.,* due to genetic illnesses including *CriglerNajjar*[2]*A genetic illness from birth, an illness called Crigller Najjar, we are* *relatives, uncle's/aunt's children. ... Her liver lacked an enzyme, an enzyme that helps through jaundice out through urine, jaundice goes directly into blood, cannot be thrown out through urine. As a result, they linked this to kin-marriage.,* and hepatitis[5]*Our family has got chronic hepatitis B illness, which seems to be due to genetic factors. It is not the kind that can be caught from outside, my sister also has it...my father also has it for instance. ... but because my sister has it. 8 years ago my sister gets married, so she had blood test and it came out. Besides, it also started to show itself in other members, for instance my uncle, of the family. We have it in our family genetically;* biliary atresia[4]*My daughter suffers from this illness from birth. ... She was diagnosed with biliary atresia. They said that her gallbladder had not fully developed, her bile ducts were narrow, and that's why her liver was damaged,* and ofzonesnimi[12]*There is this illness which starts in the liver, then spreads down to the kidneys...Ofzonesnimi or something like that,* glikoojedepa[13]*they said glikoojedepa illness. I really don't know. They said to me and to my husband that we could be carriers, they said, 'this may be coming from you, your chromosomes interfere with each other. I really don't know anymore, but, um, metabolism, whatever, um, metabolism damages all organs. ,* cirrhosis [6]*My brother's liver had failed; he had cirrhosis, something like that. Tests and all were done, and then cirrhosis was found,* and liver cancer[5]*Ultrasound imaging revealed a mass in her liver, 5 cm in diameter, it is then called as HCC that is liver cancer.*

Donors blamed themselves[13]*'I wish I didn't do it...is it because of me? I wonder if it is because of me. When she gets older, is she going to tell me 'did you give me birth in spite of knowing this?'* and doctors for liver failure[3] *Because of the doctor's mistake, which shouldn't be made, she* (the patient)*had a surgery which* *caused her liver to fail. My mother... had a surgery… about this gynecologist...then it turned into cirrhosis.*

Senseless drug use[1]*senseless and long-term use of pills or drugs and wrong treatments produce this illness. If, during this while, it is used or taken from doctors I can say OK, but senseless use of pills are very harmful. This affects the liver very badly,* stress[1]*Stress really affects. He* (the doctor) *said so. I don't know but I think emotions that develop within you, emotions that you suppressed, I don't know either, when you cannot throw them out, something, I don't know, maybe develops within you,*worry[3]*Then that surgery period, then my sister's despair. You see my mother didn't have only one problem, there was already this cancer thing, which could also be triggering as they said…I mean lots of things that come along with worry, my sister, you see, she experienced a great deal as she was worried about different things., and God's will* [13]*Everything is from God, fate, God's destiny, will of God; after all it is out of my hand. I am already doing my best. The rest is up to God…after all it is not me who created the child. I am already doing whatever I can, the rest is up to God's will... I said everything is from God, God gives and God takes back,* were also mentioned as causes for liver failure.

3.1.1.2. Physical Symptoms with Liver Failure

Donors associated some physical symptoms with liver failure. These includedyellowing[7] *she turned yellow, it was not like a lemon yellow you know, but like orange,*cramps[10]*Cramps was awful,* swelling [9]*my uncle's abdomen swelled very much, then they drew water from his abdomen,* weakness[7]*the kid was always weak,* tiredness[7]*there was this weariness. He always tended to sleep,* losing weight [7]*He was* *slimming down, he was losing weight.,*not being able to eat [4]*His gall bladder pushed him hard, he got starved as he could not digest. He got starved for weeks and days.*

Shortness of breath[9]*He had difficulty in breathing,*bleeding[4]*He had this massive bleeding, again bleeding because of his illness.,* vomiting[12]*He vomited continuously and cried,* itching,[15]*His skin was scabbed because of continuous scratching. .... we could not sit and have a word or two with him, he even scratched between his nails and made them bleed. His itching was severe. His skin was scabbed, became very hard because of scratching,* developmental slowing down[12] *the baby could not even hold his head upright up to 4 months. I mean, he was like a new-born. His head fell aside, I held his head, I mean the child was not like an upright child, it seems as if you took an ordinary pillow in your hand and walked around a pillow* and pain, Donors also recounted that treatment of pain was impossible. [6]*Doctors prescribed him medication in Çapa. He took the medication. He did everything; his pain did not go away. ... He got ill badly once or twice a week, we took him to hospital, pain killer was administered.*

Donors emphasized that illness causing liver transplantation might get worsened day by day and might deteriorate other organs [11]*At the beginning we experienced certain difficulties, there was no heart disease, heart-related problems occurred during the last examination, we overcame this. Then there was this weight related problem. During this period, he had a disorder called strangled hernia. I mean, because of the weight of the water accumulated in the abdomen he suffered from strangled hernia and then we got hospitalized again and stayed for about a month… After all it is an organ that gives blood to the body. You went to hospital and they say we have to operate this patient within 3-3,5 hours, otherwise the* *strangled hernia will spread throughout the body and he will become gangrenous... His kidneys because of his bowels, the routine of the body was broken down.*

3.1.2. Beliefs about Being a Donor

Donors' belief about being a donor is summarized in Figure 2. They expressed a number of feelings in relation to being a donor, reasons for being a donor, barriers to being a donor and factors that facilitated being a donor. In the following sections, accounts that illustrate the beliefs are in italics. Superscripts describe the patient. Refer to Appendix C for extracts of interviews that were annotated to show the analysis.

The risk involved in being a donor as small[15] *we talked with doctors and all, and then we made this decision after we got relieved. First we came and talked, already existing dangers and all. I mean we agreed as there was one percent, two percent danger. There is this danger anyway in every surgery, even in tonsil surgery, for each human being… In general donors are less at risk than recipients. They are said to recover quicker, and death is said not to have occurred up to now, so it wasn't difficult to be convinced.*

Figure 2

Beliefs about Being a Donor

The risk involved in being a donor as small
Not hesitate to be a donor
Potential donors had given up after they had decided to be a donor
Free will
Reasons for being a donor
- Being related by blood
- Donor resembles to the relative of the recipients that passed away
- Becoming a donor even if they were not related to the recipients by blood
- Saving life
- Bringing a person back to life
- Doing the right think
- Performing a good deed
- Being healed
- Recipients are dependent on the donors
- Not committing a sin
- Some donors perceive organ donation as a sin
- Being indifferent
- To avoid feeling upset
- Conscientiously uncomfortable
- Indebted
- Others had given up to be a donor

Barriers to being a donor
- Not getting consent of significant others
- Being criticized by others
- Donors' relatives wishing to protect the donors
- Being senseless
- Being ignorant
- Being selfish
- Fear of deterioration of their job
- Fear of losing their job
- Health problems
- Deciding on their own for some donors
- Getting consent of their loved ones'

Factors that facilitated being a donor
- Having few responsibilities
- Having not many people to leave behind

Some donors said that they had not hesitated to be a donor [13]*I never thought as to donating or not donating,* and asserted that others also should not hesitate [2]*they should not refrain and donate their liver. If they don't have a physical, health problem, then they should donate, and let them get well soon, they shouldn't let them suffer from such misery in hospitals*. On the contrary, the same donors said that potential donors had given up after they had decided to be a donor[15]*My uncle's son wished but his father discouraged him, he used this very bad word you know.... for his mother, 'If he dies, she will deliver another' .... 'But I will not have a son again.'*

Some donors said that they donated their livers based on their free will[1]*I believe I did it based on my own free-will, voluntarily, and this makes me very happy.*

3.1.2.1. Reasons for Being a Donor

Donors emphasized that this decision regarding being a donor was influenced by the fact that the donors and the recipients were related by blood. These donors said that they became a donor as they were first degree relatives and they did not want to donate their organ to strangers [9]*Iwill do this, you know, for a person I know. You cannot do this for an unfamiliar person, as you don't know him/her. You are not supposed to save a passerby; I mean you do not give consent for transplantation for a passerby. You either donate to your mother or to your child, to your next of kin. I gave to my uncle. … if one looks at transplantations in general, ninety nine percent of donors donated to their relatives, such as mother to her son, son to his mother or nephew or brother. An outsider is said to donate very rarely you know, maybe, as they say, blood is thicker than water, such stuff you know.*

The idea that donors and recipients are related by blood extended to the idea that the donor resembles to the relative of the recipients that passed away[9]*My father* *passed away at my uncle's current age, I, for example, wanted to donate more to my uncle as I didn't have a father, I mean maybe this is the reason.*

On the other hand, other donors emphasized that they could be a donor even if they were not related to the recipients by blood[11]*Iwould donate not only to my mother, but also to a very close relative of mine suffering from the same troubles. Should it necessarily be your mother, your father or your brother/sister? No of course not. I can donate to any person, towards whom I feel close, if I see him/her in this situation, if it will do any good; I mean it's not a difficult thing to do.*

Other reasons for being a donor included saving a life[5]*You save a life you save a soul. After all you die and disappear but you leave a life behind.,* bringing a person back to life[10]*I really wanted to donate to him* (her husband), *I wanted him to come back to life.,* doing the right thing [15] *I believe that I did good, I believe I did the right thing.,* performing a good deed[12]*It is a very nice feeling, I mean, I don't know ,the good deed is enough for you.,* and being healed[11]*It was a great thing for us, for me, when I was to be a donor, I mean, let me put it this way, I felt as if I was very ill and I who was to heal, I mean it was not my mother who was ill, my mother would donate to me and I would recover.* There was also the thought that the recipients are dependent on the donors [8]*They depended on me and here the matter is the life of a human being, I mean you gave hope to a human, giving up is wrong… It depended on my decision… From a human being, if you fell into someone's hand, someone who comes after the Maker, it is then our duty to fulfill that task.*

Donors said that they had accepted to be a donor as it was not a sin from a religious point of view[12]*I asked preachers and all, religiously, as I have a strong religious faith. We asked.' You see, preacher, there is this matter, okay I volunteer, I* *want but will the Allah question me in the afterlife? Why give your organ while you are all healthy, I mean, donating organ, would you make it clear to me?' Then the preacher said' There is nothing wrong. Saving a life is a unique experience which is not comparable to anything. I don't know how to put it, I mean, like a plant blossoms and becomes lovely when you water it, it is just like that.'*

On the contrary some donors also recounted that others might perceive organ donation as a sin [5]*I mean this may be due to people's religious ignorance. I mean there is this folkloric thing, you see, when people resurrect in afterlife, how resurrection will take place when they have no liver, no kidney, how they will come to… well… whatever… when they have no eye, there are such common rumors. I don't know it is a sin you know when you do this to another person; among folk there are some superstitions and rumors you know. Maybe they stay out of donation because of this.* Others on the contrary were indifferent[1]*I don't know whether or not it is written in Koran, or whether or not it is forbidden, I don't know this either.*

On the other hand, some donors recounted that they would otherwise feel upset [8]*I was upset because of his illness; this was why I wanted to donate.*[15] *I was very sad, if I did not donate, he would die maybe*, conscientiously uncomfortable [12] *I am not sure, I mean I would conscientiously be very uncomfortable. For example, if I didn't donate although I was able to, then I would feel very uncomfortable, conscientiously I mean.*, and indebted[2]*I thought, I mean, after all he was my uncle but still I would feel indebted to him, I would feel like a looser., I would always feel the need like stroking his ego.*

Some donors accepted to be a donor as other potential donors had given up[15]*they told me with their faces blushing all red, 'You have a little child.', so on so* *forth 'would you accept it?' I already directly accepted. You can't stand when you see how they are, you really can't. When my 66 years old uncle cried his heart out in front of me ... they suffered a lot, I mean actually they literally collapsed during the process of giving up. If not...it would have been long since he had recovered.*

3.1.2.2. Barriers to Being a Donor

Some donors mentioned that they were criticized by people because they wanted to be a donor [9]*People, I mean everybody,' why did you donate?,' I mean this is how they see it, but this thought is wrong. I mean, you maybe get angry, after all it is your uncle who is in front of you, I mean, I say 'Look, you speak like that but it may happen to your partner, may happen to, I don't know, your father, you will then get your answer when it happens to your siblings, relatives, someone close.'*, not getting consent of significant others [3]*After all he was my sister's husband and he did not allow her to have surgery, which worn my mother away pretty much, I mean in emotional sense, she had already have some issues with my sister's husband, and her not donating pretty much affected her.*

Donors' relatives at first did not want them to be a donor as they did not want to put their life in danger and wished to protect them [5]*You see, after all there is this instinct to protect your child, which mothers and fathers, particularly mothers, have. I mean, I prefer not to take from you as you are young. Maybe something happens during the rest of your life, if we can find another one, from our relatives, let us take from them.*

For some potential donors this was effective in giving up to be a donor [15] *'I can't have my all grown up child go under the knife to make her half human.' This put her off from being a donor..*

Donors recounted a number of factors that led people refuse to be a donor. These included being senseless [11]*people are definitely senseless, … all young people have high educational levels, they all think the same, either ignorant or educated all think the same,* being ignorant[5]*it is nothing but ignorance, you see, I mean what else could it be,* and being selfish [5]*Human selfishness*, [2]*my father was a self-loving, self-centered and a little selfish person. My mother would give her life but my father didn't do it. We as parents for example would give our lives, but there are those who, are scared for, love and treasure their lives.*

Some donors stated that potential donors might refuse to be a donor as they fear of deterioration of their health [9]*people may be scared of this and that, I mean, you will stay ill for life, this is what I guess, I mean, this is why they are scared* and of losing their job[9] *People might be afraid of this job losing thing, because they say two months, three months, I mean even under good conditions two months I guess, but this may go up to four, five months they say. So they are scared, they think 'I will lose my job, my job will go wrong,'*

Other factors included health problems such as obesity[12]*Baby's mother got fat,* and jaundice[15] *She* (the mother) *wanted to donate but there was this thing that she had jaundice, I mean at advanced age, therefore I mean she can donate, but after donation there may be the risk of developing cirrhosis.,* medical incompatibility [12]*Her father's blood type wasn't compatible. Her aunt's liver was said to be suitable for an adult, she can't donate to the little baby,* pregnancy [11] *there were three donors, my big sister, me and my little sister. They got married and I donated because they got pregnant,* and age [3]*my sister was underage anyway.*

Some donors managed to overcome these barriers. In that some donors managed to get their loved ones' consent[8]*Truly, my family didn't take it well, nobody did anyway, it took me a while to persuade them but they became convinced eventually. I wouldn't have attempted anything like that without their consent* or were let other let to decide on their own [6]*I already asked my fiancée, 'I will donate, what you say?' He said 'If you are donating willingly, then do it, I will support you. After all he is your brother.* Still others overlooked loved ones' wish to protect them and took every risk[12]*The only answer my mother and father gave me was this ' You have a 5 years old daughter, so give it a second thought, can you risk everything? ', this was their only answer. Of course I risked everything.*

3.1.2.3. Factors that Facilitated Being a Donor

Donors mentioned some factors that facilitated being a donor. These factors included having a few responsibilities [1]*my sister, brother is married, has children, my big sister, brother likewise, so, as a single person, I said to myself that it should be me who should embark. I didn't have any responsibility, I mean, I didn't have a private job, nor did I have my own job or a career, or, how do I put it, it was my family, since I didn't have s spouse or children, I believed that I could do it. This happened that way because I was free*., and having not many people to leave behind[3]*I have neither a wife nor children, if I die my mother, father and sister will grieve but If anything happens to my mother, my grandmother, my grandfather, my uncles, her child, who is responsible for her care, my elder sister, I mean, my mother being alive was more important if I may put it that way.*

3.1.3. Beliefs about Transplantation Surgery

Donors’ belief about transplantation surgery is summarized in Figure 3. They recounted some feelings about physical effects in relation to transplantation surgery. In the following sections, accounts that illustrate the beliefs are in italics. Superscripts describe the patient. Refer to Appendix C for extracts of interviews that were explained to show the analysis.

Figure 3

Beliefs about Transplantation Surgery

Physical Effects of Transplantation Surgery
- Pain
- Opening of stitches
- Putting on weight
- Feeling stiff

3.1.3.1. Physical Effects of Transplantation Surgery

After transplantation, donors stated that they had some physical problems including pain[7]*I started to have pain, I said ‘what is happening to me‘, I mean, I felt very bad for some time. They give me pain killers; I really had a lot of pain at first,* opening of stitches [13] *there were some openings, you know, tiny openings. Big ones emptied themselves, discharge came out I mean. They said ‘You should dress the wound every day,’* putting on weight: [2]*That’s why I put on weight, as I avoided moving I think. I put on some weight after surgery,* and feeling stiff [1]’*there was muscle stiffness because of not moving.*’

3.1.4. Beliefs about Organ Donation

Donors' beliefs about organ donation are summarized in Figure 4. In the following sections, accounts that illustrate the beliefs are in italics. Superscripts describe the patient. Refer to Appendix C for extracts of interviews that were explained to show the analysis.

Figure 4

Beliefs about Organ Donation

More positively after transplantation

Organ donation should be legalized for money

Organ donation should be encouraged

Awareness should be raised in others

- Non-governmental organizations
- Magazines
- Doctors
- Newspaper/media
- Internet
- Interviewing with patients
- Books
- Laws

Donors stated that they thought of organ donation more positively after transplantation[1]*'You know, as they say, you'll know when it happens to you, so we started to think stuff like that as it happened to us, and frankly, I started to show interest in such things, because it is a good thing. Organ donation is a good thing,'* and that organ donation done for money should be legalized [2]*'I think, It should be* *legal even if it is for money... I think, if donating his/her liver does not cause any physical harm to a person then this should also be done for money,*

General organ donation should be encouraged organ donation [5] *'I will direct whoever I have around to organ donation, because, you know as they say you'll never know unless it happens to you, when I see the patients here, because you don't need your organs after you die but with the liver you donate maybe two people will hold on to life again. So, also transplantation, I am planning to push from now on. I am planning to call whoever I see for organ transplantation I mean* and awareness should be raised in others [16] *'This time they start to feel guilty. You know, why didn't we donate back then? We should donate from now on. So maybe you provided them with something. I mean, an opportunity. You provided them with courage'.*

Donors envisaged that they could do this through non-governmental organizations [1]*For instance I can join non-governmental organizations, I can provide emotional and financial support*, magazines [4] *'Something for example, they said, an interview an all in a magazine,. If there was something like that before, I would accept it.'*, doctors [9]*I wanted to talk with doctors about this anyway, I mean If there will be anything I could do for help.,* articles on the Internet [9] *I, for example read the articles of Mr.* (the name of the doctor) *on the Internet, I mean, I felt relieved very much.',* interviews with patients[9]*People should read it, they should give interviews, they should be on television more often, they should look for the programs which listened by most, I think, they can explain it,'*, books [2]*I want to turn what I experienced into a book, I want everybody to read and be inspired by what I experienced.',* newspaper/media[5]You know, *I am a journalist. I work for*(name)*newspaper. Apart from that, a plan is needed for what can be done through* *media,* 'laws [5]*If I were the government, of course it is against human rights but I would make a new law about transplantation. And I would, if um, make organ donation compulsory, I mean this is a little fascistic but after all you save the life of a human.*

3.2. Living Donors' Evaluation of Life Following Liver Transplantation Surgery

Donors' evaluation of life is summarized in Figure 5. Donors recounted a number of feelings in relation to evaluation of life following diagnosis of liver failure and transplantation surgery. These included limitations brought by liver failure and the transplantation surgery, awareness of the need for lifestyle changes, emotional changes, changes in character and mixed relationships. In the following sections, accounts that illustrate the beliefs are in italics. Superscripts describe the patient. Refer to Appendix C for extracts of interviews that were explained to show the analysis.

3.2.1. Limitations brought by Liver Failure and the Transplantation Surgery

Donors were aware of the physical limitations brought by liver failure and the transplantation surgery [12]*I experienced some difficulties after the surgery, how, I mean, while standing up, lying down… my mother helped me with everything, bring this, bring that, say my child's medications, those of mine, with setting and clearing the table. You know, not to be able to help made me very… say physically … collapsed.*

Figure 5

Evaluation of Life

Limitations brought by liver failure and the transplantation surgery

  Physical limitations

  Social Limitations

Awareness of the Need for Lifestyle Changes

  Lifestyle changes

  Put on weight after surgery

Emotional changes

  Negative Emotions

  Positive emotions

Changes in character

  Negative changes

  Positive changes

Mixed relationships

  Getting support

  Not having support

  Forming a special bond between donors and recipients

  Relationships getting worse

Donors were also aware of the limitations brought to their social lives [4]*we were always in the hospitals, we went back and forth between home and hospital, we didn't have any social life.* These social limitations led to quitting one's job [9]*You need to be careful while standing, even lifting…. I quit my job because I didn't know when I can work.*

Especially, donors recounted that they avoided social gatherings [2]*I did not want to visit my relatives and all nor to wedding ceremonies. I didn't feel like to have fun as the kid was ill at home. … I shut out the social life for sure. I didn't do anything only dealt with* (the child). *I fed and watered him.* Behind this, there was the feeling that they dedicated their lives to the ill person[3]*There was my mother's illness* *since I was a child. When I was at primary school, my mother and my big sister used to be at hospital when I came home with my brother. I mean this didn't occur recently, always with illnesses from the very beginning*.

Donors recounted that because of the illness process they neglected the other family members including the spouse, children, siblings [2]*We have one more, you know, 12 years old, I think we neglected her while dealing with this one… Our daughter had chicken pox last year. Upstairs is our relative you know, we left our other daughter with them. We didn't let the kid come in the house for 10 days as she* (the patient) *might be infected. ... Do you know what she said to us? She is very smart, you know, a mature kid. She said, ' Mom, you never were sorry that I had chicken pox. You, both my father and you, only worried that ………* (the patient) *might be infected… I felt so sorry, I said to myself that how discriminative we had been, I felt very sorry for her.,* This neglect was also felt by the neighbors [2]*Even the neighbors said ... that I mean she is very sorry, ... You show too much interest in* (the patient) *You aren't taking care of this girl,* and the doctors[2]*There is this children's doctor, to whom we take both kids together. He said, 'I will make a complaint about you. You don't spend the money, time for* (patient's sister) *you spent for this one, our doctor said, so also he realized.*

There was also disruption in plans [3]*My brother had this 8th grade SBS exam. He wanted to be a police. His score for that year was good ... I took my brother to the exam. You see, everybody had come with their parents, we went into the school yard and I started to cry there. Supposedly I was there to support him ... 'Don't cry sister,' and all. He did the exam, you see, there I say, 'I wish, I held my temper and I didn't cry, I controlled myself'. He could not get the score he wanted in that exam.*

3.2.2. Awareness of the Need for Lifestyle Changes

Donors were also aware of the need to make lifestyle changes[1]*the doctors took me in the room 'Are you sure of what you are going to do, is your decision firm, are you confident of yourself, aren't you scared, it'll be like this and that, anything can happen anytime, you shall not drink alcohol, you shall not smoke, there will be some constraints in your private life, do you accept all of these?' We accepted everything.*' As a result some donors changed their lifestyles [9]*I am not smoking anymore,* [1]*this thing happened after the surgery. I was a drinker and smoker, not that alcoholic thing and all of course, I was a social drinker. I stayed away from these* whereas others did not change their lifestyles [16]*he (brother) is better than me. I smoke, I couldn't quit smoking, but he did, touch wood!.*

Donors said that it is important for them to put on weight after surgery [1] *my eating and drinking habits changed, I am trying to eat well… After the surgery, you know, during the surgery period, I went down to 68 kg. Now I weigh 70-71kg. I mean I put on 2-3kg and I think I need to put on 5-6 kg more. ..... If you don't put on weight, then it means that there is something wrong with this illness.*

3.2.3. Emotional Changes

3.2.3.1. Negative Emotions

Donors experienced different emotions about liver failure, transplantation surgery and during convalescence period. These included getting confused[1]*we were confused when we heard. The cirrhosis we knew, we said 'we know that cirrhosis occurs because of smoking and drinking, how could it be for God's sake?'* being unable to face [5]*I did not believe, I didn't accept it. ... I mean, if I put it this way, they said 'cirrhosis,' I said ' there is no such thing, they must have misdiagnosed.' We had* *never thought that the illness could be cirrhosis. Then, we went back and forth when all doctors said the same thing; made the same diagnosis, then we had to accept it. We had to accept.* Feeling shocked [2]*we were shocked at first. I said 'let's have this surgery and be saved, rather than seeing my kid like that,* feeling down[2]*prior to transplantation, ..., tears, sadness, refraining from going anywhere, like what happened, what's going to happen,* feeling unhappy[11] *I was not happy, my husband took it personally he said 'Is it because of me?', unhappiness brought by illness was felt all around the house,* feeling helpless [7]*I said my child will die he is dying in front of me and I can't do anything' . ... Not to be able to do anything, okay, I take him to the doctor and back, give him his drugs but the transplantation was the most important thing and we accept it," There isn't anything else to do, it is our last resort, and we accepted everything. ... I was desperate;* being hopeless[4]*I was hopeless, very hopeless.*

Feeling uncertain [4]*this is such an illness that you are not certain what is going to happen to you tomorrow. You may have bleeding again, you may fall and something may happen to you, it is a risky illness.,*[4] *A new bleeding may or may not occur any moment, He said 'There is no need of course to feel down. But we'd better consider it to be a volcano which is about to explode. There may or may not be a new bleeding, we shall pay attention to. We shall keep monitoring continuously'. He said 'We shall attach great importance on everything,'* feeling angry [16]*you know people who were burdened, you know they bully someone or something to explode. They are angrier,* being collapsed [7]*I collapsed when I learned his illness,* feeling distress [4]*I was in agony, I always cried, always distressed. He cried and I cried. The more the child felt pain and cried, the more I wore out. ...I experienced great distress,* and being sleepless[2]*We didn't sleep in our bed with my husband for 4 years. He snuggled on one end of a sofa bed and I on the other… we stayed wherever we sleep just like that. Lying down, cover myself up, make myself comfortable…. Never, I never slept.*

Donors recounted fear as an important aspect of their experience in relation to transplantation surgery; [4]*Frankly, I was frightened if anything might happen or not, I was scared. He says 'His veins get blocked', 'this is the end' There was the fear of losing, it was a serious illness. The fear that he will die, I was not able to do anything. The fear that he would die right before my eyes was ruining me,* fear of losing the recipient[3]*I was wondering if anything would happen to my mother; I mean I didn't worry about myself that I would have a surgery. What I had in mind was only the thought that anything would happen to my mother,* and/or themselves, [2]*Of course I was scared for one month or so. It is terrifying, while you are healthy then all of a sudden; I mean something will happen to you. You go to surgery when you are ill and you say 'I will get better", you go with joy. But me, I wonder what will happen? I have two kids, will I be able to raise them* (she is crying).[15]*I mean I was not anaesthetized, not anything. I had worries related to this. We got over it because of them, I mean, there was a little fear. After all you can't help being frightened. It is not an easy operation. I didn't know what transplantation was until I came to hospital, frankly, I was scared.*[1] *I was of course a little scared, because about something, which, it will not somewhat, um, I mean, how should I say, be experienced, there we talked about all possibilities… The fear, okay we are now going to have a surgery, but what if something goes wrong and I lose my mother or something bad happens and my mother loses me! It is very painful, really one losing the mother or the mother losing her son, I thought it would be very bad when you* *knew it later or when you woke up and learned. No one wants it to go like this. May God never let it happen to anyone,* because of the transplantation surgery itself.

Similarly, donors fear of hurting their dependents[2] *I have two more children. I said for them ' if I die, who will look after them',* and scared of leaving them alone[15]*After all, I have a child too. I was scared very much of losing him or him loosing me.* Donors felt that they needed their loved ones' blessing before they went into surgery[1] *I summoned all of the family elders, and I told them 'talk, because the doctors said that it would take 45 minutes or 1 hour.' I summoned my brothers and all so they didn't say afterwards 'why didn't you let us know since there was such a thing.' I called them to say goodbye, I mean, I said 'At least see yourself and don't say then why you didn't let us know since there was such a thing, don't put the responsibility in this on me also.'*

However, other donors asserted that they did not experience any negative feelings including fear [4]*While I was going to have surgery; I was not frightened at all or anything. I went OK, I mean, I went happily, as it would be good for my daughter. ...It was nothing to be afraid of. When you come to the hospital and see people around, you start to feel strong, fear fades away, and you get courageous. This is what happened to me. I came to hospital. I thought it was only me who would have transplantation until I came here. I thought it happened to nobody but us. Bu when I came and saw those in the hospital I said to myself 'it is not us only but everybody'. Until I came to the hospital, I felt alone as a patient. ... I said 'If It were such a bad thing, an impossible thing, why would this many people come, why doctors would insist on transplantation. So there is a remedy, there is recovery otherwise they wouldn't do it.'* Some donors found a way to comfort themselves by focusing on destiny[12]*If I die, I have a 5 years old daughter, I am separated from my husband. I said 'to my child, ' what happens then? '. I thought of my child, I mean, I thought of only of him, what happens. I said 'If the Allah… its destiny, then it would happen somewhere out there if not here. If my child would end up losing her mother, he would anyway. So I considered this as a self-comfort.*

Donors also recounted a number of negative feelings after transplantation. The predominant negative feeling was worry. Sources of this worry about the health of recipients included the necessity of using prescribed medications regularly[7]*There is this drug which she is to use lifelong.… I mean, in the end, she shall use it for her entire life, I mean will she remember? Will she forget? Will she take it by herself when she grows up?… I wonder if anything happens if I don't give it to my child, for example I jump out of the bed in some mornings saying 'Oh God, I forgot!.',* side effects of the medication [7]*That drug has side effects, I mean side effects to the extent of causing cancer.',* recurrence of liver failure [2] *When his enzyme levels goes up that fear, you know, that will something happen? Are we going to go through all of this suffering again. When his enzymes come up to be normal, then no problem, it's very well then. But even f they are elevated, if anything happens afterwards, this is what should be done,* and fear of rejection of the liver [3]*It is an uncertain process, if it is rejected or not, I mean you are joyful and ask yourself on the other hand whether her body will accept it, as there is the risk of rejection.*

Another worry centered around the possibility of infertility caused by liver failure [2]*Everything went through our minds, I mean, will the girl be able to get pregnant, can she have a baby, how she can, will it be like this or like that,* and the occurrence of the liver failure in the offspring of the recipients [13]*she'll get married in* *the future, will her baby have it, you see, will the baby carry it? ... Won't she get married? If she get married, will her kids have it?... I think of these a lot. I am obsessed with them*, and in the offspring of the donors [7]*Because if I have a baby, what if he/she gets sick, I mean losing him/her is a very bad thing, these thoughts went through my mind a lot, especially at nights, I felt very bad when it went through my mind. If anything happened to this kid, I could never fill her place with anyone ..., besides, I would be afraid if he/she got ill. I mean I wouldn't do it because of fear.*

Donors also said that they experienced some negative feelings after transplantation. These included being stressed [2]*She had a second surgery which was also troubling and stressful*; being tired [4]*It gave me a little tiredness and stress, naturally made me angry. The hard times I had worn me out deeply*, feeling down [7] *I lost a lot of children in the hospital environment. Seeing children, my head was full of children's cries. Even when sleeping with such voices of children in my sleep, always crying sounds,* feeling angry [12]*I get angry even with the smallest thing, for example when my daughter did something.,* being irritable[6]*I had too much pain therefore I was irritable.,* and feeling inadequate[2]*I will get ugly, I won't be able to handle all the chores I used to do at home, will I fall short in taking care of my children? ... I wonder if I will be inadequate in handling them. Will my body become deformed? Will my liver work?* Furthermore, some donors experienced lack of appetite due to feeling down [3]*I could not eat, this was due to my nerves, I could not eat.* Donors also recounted losing self-confidence [12]*the waiting period seemed too long to me, I mean, um, I lost my confidence. ... I called Mr.* (the doctor's name)*....I said. 'I lost my confidence Mr.* (the doctor's name), *please take us into the surgery,' Your confidence is broken, you can't help it.,* and courage[12]*The more the time goes* *on, the more you lose your courage.* As the original prospective donors had given up to be a donor, some donors mentioned the disappointments that they experienced[2]*you know he (*the uncle) *said 'I will donate it and save you' and when he gave up afterwards, I was disappointed.*

Donors stated that relatives of the patients, including father and siblings, also experienced a number of negative feelings including feeling down [1]*He*(the father) *also felt down, because the phones ring, how is my brother?, how is my son?, how is that?, how is this?, he continuously tried to explain to all… as such he fell into depression?,* feeling upset[2]*Our father is very, um, caring, concerned person anyway, he is a perfectionist, we did this together that is standing shoulder to shoulder. I donated my liver, but he was more upset, more worn out than me, He lost 20kg in weight in the meantime. He was deeply affected, I mean, he said 'two surgeries in one house, how should I manage this?, He* (the brother)*has been crying since yesterday* (brother), *for example ... he*(the patient)*will go to get tested, what will happen? His sister, she doesn't care at all, I mean, she is somehow, um, cool. He was upset .... What will the results of test be? He cried a lot, he told me so.*

Wetting themselves [13]*The kid, who never wet his clothes, started to do so.,* vomiting, having fever and headache [15]*I always sleep cuddled with my daughter. I was hospitalized and next day they hospitalized my daughter. Psychological vomiting, fever and all, the doctors couldn't find anything. ... This I related this to, um, because my daughter was separated from me, because I also was like that. When I was separated from my father, I got fever straightaway, vomiting for no reason, headaches and all. My daughter is like me.*

Donors also said that there were economic factors behind the negative feelings that they felt[1]*I mean, we also have some financial problems. These can happen because of our financial problems, this unhappiness and this down feeling may arise from this. We are in fact a middle income family. As we came here through the institution, and at least the money is provided by the government, we covered some expenses. ... If anything happens, we know we won't be able to do anything, we may have financial difficulty and will not be able to do anything, and frankly we have this fear. ... What shall we do if we really have to face such a situation? Shall we sell our house or shall we sell our car, I don't know.*

On the contrary, some donors overcame these negative feelings by focusing on the end result, the recovery [2]*You suffered both financially and spiritually, your body became deformed, stitches and all, no matter at all, I mean, I say, I am so glad I donated to my child so he recovered, I always thank God that ....recovered. We trust this place yes we never worried about money. Normally you worry, but we pushed, got into debt, so that our child could have the best treatment.*

3.2.3.2. Positive Emotions

Donors experienced positive feelings towards being a donor. These included feeling proud of themselves[5] *I am proud of myself...You of course feel the pride and honor of it,* feeling appreciated [4]*they appreciated me. Nobody knows organ transplantation in my country, my village for example. The elders who heard this said 'We appreciate, No mother would do what she did.* ',

[16] *'For example, I mean, as what, you know, as they speak back then., 'well done, a sibling donates her liver to her sibling,* feeling strong [14] *They said 'you are strong'.,* becoming reputable [16]*It reflects on our family, relatives and even*

neighbors'. ... These people are talking about us ...what do they say for example? They say 'Well done, a sibling donated his liver to his sibling, and feeling conscientiously comfortable[11]*I feel conscientiously comfortable. I did my best. If anything happened to my mother after surgery, I'd say 'I did what I had to but it didn't work. I did my best.' But if anything happened to her before I donated, then I'd be conscientiously uncomfortable,* feeling joyful [3]*there was joy, my mother would be free of pain she had been suffering,* and excited [1]*I was excited. I waited for the phone to ring sooner rather than later. 'Okay ... today you will have an operation, please come within a week. 'Frankly, this was what I always waited for. There was excitement in me, there was such a heart, 'let me go right away and give life to my mother.*

Some donors recounted some feelings in relation to post transplantation surgery, feeling happy [10]*This is a bliss, a great happiness. When I gave birth to a child, I experienced great happiness, really, during the motherhood, I mean, this something close to that,* feeling relieved [16]*I was relieved from the tiredness of forty years, I mean, this is the most important effect of it, you relax psychologically,* feeling comfortable[5] *I am psychologically comfortable.,* in particular morally [5]*My conscience is clear, It was like I carried a burden on my back, now I am relieved. ... I am relieved conscientiously.* This state of clear conscience extended to the feeling like rewarded in afterlife[12] *I mean, I have my place already prepared in the next world. I mean, I will be given a medal in the next world.* [16]*I can say that I have guaranteed half of the heaven. I mean I can say that. I have more emotional profit than that of material. You know, as I said that I guaranteed half of the heaven, I can guarantee the other half thanks to my mother's prayers.* In addition, the donors recounted that transplantation surgery increased their confidence [14] *It is gorgeous, I feel confident and I am forgetting all the suffering that I experienced,* and helped them to avoid the feelings of guilt [16]*This time they start to feel guilty. You know, why didn't we donate back then? We should donate from now on. So maybe you provided them with something. I mean, an opportunity. You provided them with courage.'*

Other important feelings experienced postoperatively included feeling like being born again [4] *It is a like new world for both her and me, we are like newborns, I mean we are newborns. ... Now she is 4 years old, but she seems to me as if she is 2 years old. With the transplantation we were born again and started a new life.,* saving the world [16]*It felt as if saving the world, I mean your chest, your hunch back is fixed a little, you stand a little bit more upright. Then I will be moved well into profit,* and paying off the debt of conscientious [5]*I guess this is the greatest duty you would fulfill for your mother, I mean, there is no other duty, after all you ensure your mother's life to continue. I believe that this is a great pleasure*.

3.2.4. Changes in Character

3.2.4.1. Negative Changes

Donors recounted worsening of character. These included becoming half human [3]*I guess I became half human in his eyes. Therefore he distanced himself from me after the surgery*, turning into an aggressive person [1]*I can say that some aggressiveness occurred. Sometimes I can get angry for no reason. I can get angry with trivial things, which didn't happen before. I was quite relaxed previously. I was an easy-going person. Now I became a little aggressive, which I don't know why, because of nicotine, of the cigarettes I smoke or maybe alcohol, I don't know either, I don't know if the body freshens itself up*and experiencing the bitterness of life [1]*I* *learned how bitter life could be. In fact all these existed for me, they were not something that I learned recently, life is hard.*

One donor later on felt that being a donor is difficult and giving up was understandable[2] *I was mad at her uncle previously. ... I said, 'I will not talk with him again so on ' but then I absolutely changed my mind, this is turned out to be a very difficult issue. Parents donate, child after all, they donate to each other, and uncle is also close, but only if he is a very devoted uncle, when there are strong bonds, then maybe.*

Similarly, donors also reported worsening of character in the siblings of the recipients[12]*My daughter's psychology essentially worsened. ... Her character changed a little when her grandmother was with me, when she was left alone. She always wanted to throw herself out. She always wanted to play, to stay out. Normally she was not like this; she always wanted to stay with me,* becoming disobedient[13] *He is disobedient, after all he is not grown up, and he is a 5 year-old kid. I am here, his dad is here, and you know he is at home alone with his grandmother. I mean it is difficult,* aggressive [14]*I have another son who is 6 years old. He is little aggressive since he is left alone, he fight with other children outside. I am sorry for him, he is asking after his brother, and he is curious about his brother. He was left alone, we could not look after him.,* andjealous[14]*I think, he is little jealous of his brother. But there is a little time left. When we are discharged from hospital, we will all be together again. When the school breaks up, my other son also will be with us,*

3.2.4.2. Positive Changes

The donors mentioned some positive changes in their characters, including becoming more of a believer[2] *We learned the facts of life, we learned pain, sorrow, and thus I mean I started to become more of a believer. I believed in God more. Because I saw my child living many things thanks to prayers and all. ... I saw the benefits of praying the God. Now I think differently, as such everything is possible with prayers. You should take your measures. Sure you take him to the best hospital, you find the best physician, you take your precautions, yes but, it is very important to pray for the will of God.',* being grateful [2] *Now whenever I look at my child, I say thank you God for your granting such thing to me so that I can do something good for my child. You gave me such a good liver that it also did good to her. Is that why you granted mea large liver? Because, someone said, 'my liver is small so it didn't fit to my daughter.'' So you created mine bigger so it can do well to her too'. I am grateful.*

Becoming a stronger person[11] *Bits and pieces like that there is work or not do not upset you. They don't shake me up as I have seen worse, because consequently if you like it or not you grow stronger.*, becoming a humanist[16] *in an instant you can see that the world can go to an end. You can see that it is pointless ... I mean you start to think in a more humanistic way ... To value human, as you know the world was created for mankind, be it green plants, animals. ... But now, we have learnt to value human.*

3.2.5. Mixed Relationships

In addition to improvement in social life following transplantation[2]*Now we go to the shopping malls comfortably. I am now going out after the surgery, because there is a very big problem back at home, I mean, you can't forget him at home and have fun elsewhere. Part of you always feels bruised,* donors remarked that they were supported by people around them [2] *we did this standing shoulder to shoulder with him* (husband). *I donated my liver but he was more upset and more worn out than me. Plus, my friends said to me 'you take care of yourself, help yourself so that you can help your children‘, there is this very understanding friend of mine, I sometimes have a heart to heart talk with her, she is somewhat like a psychologist. She said you know, 'If you don't look after yourself. How could you do any good to your children?',*

Donors said that they received financial support from within and out of the family during transplantation surgery [2] *as my husband is a teacher, our grandpa helped, husband's father. He helped during the surgery, he didn't help afterward. We try to afford it with our regular salaries. He helped also God bless him, if it wasn't for him we would have difficulty or we would have the surgery in a state hospital which I never wanted there.* For some donors financial support of the government was an important factor [7]*The Ministry of Health helped. I mean, no money was asked here anyway, they had already said us, they took some amount at the beginning, and they took when we came for pre-diagnosis. Then we said, you know, 'if it goes beyond that much we can't pay, because we are a middle income family. We said 'we aren't in a very good shape, we can't afford.' Then, as the government would cover the transplantation surgery,' they said 'no money will be asked after the surgery'.*

Donors also recounted that they got support from doctors and their trust were important [2]*I trusted the doctors so much… I trusted Mr.* (doctor's name) *and Mr.* (doctor's name) *so much… I trusted so much… They both turned out as I trusted, I mean, Mr.* (doctor's name) *consoled us very much. He cheered us up, He said 'relax, and don't be sad. You will get ill too,* [4]*we trusted doctors. We came to the hospital trustfully and in peace, everything is covered and done for us, we have good news and leave. This makes us happy…. After all we are in* (the hospital's name) *hospital and in the hands of the professor who is the best in this in Turkey. If there is anything that can be done medically then it will be done, dealt with. As such we made him relieved a little.*

On the other hand some donors felt not supported by potential supporters like mothers, or spouses[13]*My father and mother are very old, they are in the country. When I had this operation, they weren't here. Only this winter, they came to stay for one to two months. I was again in the hospital anyway, and I couldn't see them. They came to the hospital twice, when I moved back home, they had come again to see me. The following day they went back. I mean I can't say that I saw my parents. You know they are very old.*

But for some donors, this turned out to be something that reduced the general burden felt[7]*I mean she wouldn't be interested… My mother couldn't stand, you know, my mother couldn't even come to surgery because she has hypertension; even if she came she wouldn't be able to stand. I think of myself, but I thought of my mother more than myself. It was better for me that my mother didn't come, because she will fall faint and cry, I mean she never stops … I was kind of relieved when she didn't come… I asked after my father when I came out from the surgery 'did he* *come?' He said when later we talked 'he would have, but he didn't. I couldn't stand it my daughter. To see you like that, I don't know, you care for your child and donate your liver, and you are our baby, we think about you of course, we certainly think about our grandchild but we also think about you'.*

On the contrary, particularly mother donors felt that they were the sole care throughout the whole illness period and found this very wearing[4]*Nobody supported me. I didn't have anyone with me. I was worn out too much as I took care of everything. There was no one to visit and see us. They called only, my mother and father couldn't not come to see us. The grandmother and grandfather* (of the patient) *are very old, so they couldn't come. My husband worked, he couldn't come often. I mean we spent the day together whether we cry, we sleep or not. I suffered too much at that time. I had nobody to satisfy my needs, I did everything by myself.*

During this process a special bond was formed between some donors and recipients[5]*It creates a different bond between you, I mean, you donating your organ, your liver to your mother is an entirely different thing, it creates a completely different bond I mean. Between you, there is something different from mother-son relationship; after all, a piece of your body is in your mother's body. In the end, it is a very different thing, different feeling for the person who gave you birth, it cannot be expressed it is experienced.* Other donors, on the other hand, mentioned that close relationships got worse[3]*In fact this surgery turned out to be a major thing that would affect the course of my life, let me put it this way, there was a person who I had been seeing for 5-6 years I mean a person with whom you would go as far as marriage. His attitude changed right after the surgery, I mean, you put that person in a place in* *your eyes, you say 'perfect sweet heart' but then you realize that it's nothing but an appearance.*

3.3. Living Donors' Views of Recipients' Evaluation of Life

3.3.1. Limitations

Donors felt that patients experienced limitations in their social life [2]*'She didn't want to enter the room when everyone was in there. I said to her 'Why don't you come? Come in'. She always said. 'Mother, I won't come in that room because everybody will say how yellow you are.' She said 'Little kids say 'inside your ayes are very yellow.'*

3.3.2. Mixed Relationships

Patients' mixed relationships are summarized in Figure 6. Donors recounted a number of feelings in relation to patients' both negative and positive experiences with other people following diagnosis of liver failure and transplantation surgery. In the following sections, accounts that illustrate the beliefs are in italics. Superscripts describe the patient. Refer to Appendix C for extracts of interviews that were explained to show the analysis.

Figure 6

Mixed Relationships

Fear of being infected by liver failure
Insensitivity
Supported by others

Donors expressed that patients had negative experiences with other people. Others were said to be frightened of being infected by liver failure[2] '*Oh! Take her, we will get jaundice.' But*(the patient's name)*'s illness has got nothing to do with jaundice, it is nothing like infectious.',* and to be insensitive[3] *'one more thing, You know, people in our society, our surroundings are very insensitive, senseless that is. They come to pay a patient visit to my mother, and you know, they say 'such and such person's daughter died of that illness; we lost her because of that.' I mean what people say have a great effect. After all she had a surgery and you come there to pay a visit to a patient… Look at what you're saying, the thoughtlessness'.*

On the contrary other donors felt that the patients were supported by others[5]*Here there is also this thing which is very important, I mean, for the recipient, her friends calling her, being with her is very important, I mean, this is really the most important part of treatment. My mother is liked by quite a lot of people; God bless them, they called and we saw that we were not alone. This is very important, they loved so much that you then see how good friends you have, you feel happy.*

3.3.3. Emotional Changes

Patients' emotional changes are summarized in Figure 7. Negative feelings were generally directed to liver failure and to being a donor whereas positive feelings were more to do with the transplantation surgery. In the following sections, accounts that illustrate the beliefs are in italics. Superscripts describe the patient. Refer to Appendix C for extracts of interviews that were explained to show the analysis.

Figure 7

Emotional Change

Negative feeling
- Fear
- Fear of death
- Feeling down
- Feeling hopeless
- Feeling worn out
- Having low morale
- Feeling exhausted
- Feeling Embarrassed
- Feeling like a loser
- Feeling uncertain
- Feeling of being a burden to others
- Feeling that one is going to leave others bereaved
- Disappointments
- Feeling extended to the feeling of being driven to the edge
- Need their loved one's blessing

Positive feelings
- Recovering and feeling happy
- General improvement in mood
- Getting relaxed
- Being refreshed

3.3.3.1. Negative Feelings

Liver failure, According to donors, patients experienced different emotions in relation to the diagnosis of liver failure. These included fear: [1] *'We thought it well over in Cyprus, with fear of course. Both me and my mother, after all it is a surgery,* especially fear of death[16] *'I mean think of a person who is waiting for his time to come. His execution is close. Think of a person in jail who thinks 'I will be executed after 1 year. I will be executed after 2 years. What do you expect from this person?. I* *mean as if he let go off everything without showing that he is in agony, he speaks as if he let it go, but it is not so,* feeling down [4]*'We had been through very hard times. She continuously cried.',* feeling hopelessness [11]'*She is not able to think anything about the future, she can't think of tomorrow, because she doesn't have any hope anymore*.', feeling worn out [11]'*I mean there was this time that you reached the end of your patience. At one stage she said 'I don't want it. Regardless of what you do, I don't want it. I have enough of myself,* having low morale[16]*She had low morale before.,* feeling exhausted[16]*She was psychologically exhausted anyway*.

Being embarrassed [10]*I mean she was shy about going out in public. She was ashamed. She felt uncomfortable by the glances of people,* feeling like a loser[2]*When she went to park or anywhere she attracted attention at once. They said 'Ah! You are too yellow'. Is your hair dyed?' She felt she had failed, for example, and she was upset, 'Mother, I am yellow, everybody will laugh at me.' There was this feeling of being a loser,* and feeling uncertain [2]*She said 'Will I become white? Will I be a white girl? Will I recover? My mother will give me her liver, and then it will be very easy. The doctors will open my belly, they will fit my mother's, and I'll be better.'*

Donors also felt that patients experienced the feeling of being a burden to others [11] *She said 'You're always dealing with me. You can't go to work because of me. Others can't do what they want to do, no one can do his/her work because of me.',* the feeling that one is going to leave others bereaved [16] *An honest person doesn't feel sorrow because that he/she will die but thinks of his/her family he/she will leave behind. He/she thinks of the agony he/she would give to them, one does not get scared of death., and the feeling that* organ transplantation was not for them[5]*He felt that it was not for him and he said 'it can be resolved with surgery or anything* *else. But when we said, 'There you will have organ transplantation, and besides in a very short time. She cried when we came back home.'*

Being a donor, As the original prospective donors had given up to be a donor, some donors mentioned the disappointments that the patient experienced [9]*I mean, my uncle's second wife somewhat pressurized her daughter, like 'I do not let my daughter go under the knife at a young age'. She looked as if she gave up when she was put under pressure. Making her give up thing made my uncle feel down. It was a disappointment for him.* According to donors for some patients this feeling extended to the feeling of being driven to the edge [15]*They were very upset, they were incredibly upset. I mean they were almost driven to the edge. Another thing if she hadn't accepted it initially, it would have not been a problem within the family, but all tests and everything were done, and when gave up all of sudden while everything was all right, the family naturally collapsed.*

Transplantation surgery Donors felt that the patients need their loved ones' blessing before they went into surgery[3]*We went down to the theatre, my mother said 'give me your blessing daughter'.*

3.3.3.2. Positive Feelings

Transplantation surgery, Donors recounted that the patients anticipated that they would recover following surgery and were happy for this [9]*She was glad, I mean, that she would recover. Of course she does after all, She didn't say it exactly to me but she expressed to her children, to my brother that she was glad,* and experienced general improvement in mood following transplantation surgery [16]*The support we give as a family improves my big brother's psychology. Psychology is very important. ... Goodwill is important.*

Post transplantation surgery, According to donors, following transplantation surgery patients recounted feeling happy [2] *'Now he is very happy. He has a job here which he likes*', getting relaxed[9] *'He eats and drinks better. The way he talks, walks got better.'* and being refreshed[4] *'she is free of burden now, she is now all refreshed and growing! she has started walking*.'

3.3.4. Improvement in Life

Patients' improvements in life are summarized in Figure 8. Donors reported that recipients improved physically, socialized again and changed their perspective on life. In the following sections, accounts that illustrate the beliefs are in italics. Superscripts describe the patient. Refer to Appendix C for extracts of interviews that were explained to show the analysis.

Figure 8

Improvements in Life

Becoming Physically Improved
- Becoming fit
- Active
- Skin growing white
- Growing up
- Putting on weight
- Getting rejuvenated
- Body balancing itself
- Stopped itching

Socializing Again
- Going out in public
- Getting socialized

Changing Perspective on Life
- Understanding of seriousness of the illness
- Holding onto life
- Allocated time for oneself

3.3.4.1. Becoming Physically Improved

According to donors, most patients became fit [16]*You know, my brother's current mood, the way he talks, eats, walks, his work, the way he looks are great. Besides, he is better than me. I smoke, I couldn't quit smoking, but he did, touch wood! He runs faster, walks faster than us* ,and active[11]*He can do all the chores on his own for 1.5 months. ... now he does his chores by himself... He doesn't have any pain,* their skin grew white[7]*My baby is good right now. ...Her color is white, very beautiful. You know, when I saw that color I couldn't believe my eyes. The kid seemed like a stranger to me, because I always saw her yellow for 4, 5 months. I ever saw her white*, their body balanced itself [3]*My mother is well, even very well and her diabetes and all is now balanced.'*

They grew up [2]*She blossomed out and grew up, she grew up very fast after the surgery,* they put on weight [7]*My baby is good right now, her weight and everything. Her weight is good right now. She put on 800 gram in two weeks.* They gotrejuvenated[11]*My mother is 52 years old now. She changed as much as a 70 year-old person does when he/she returns back to 40 years old.*', , and they stopped itching [15]*' Thank God it is all over now. She is not itching anymore. She beat hepatitis.*

3.3.4.2. Socializing Again

According to donors, after transplantation surgery patients started going out in public and getting socialized [4]*She e was able to go out in the neighborhood, out in the street. She could go out, play with her friends, I mean, you know, she was going to outings, everything is normal. We live our same normal life now, like human, beautifully.*

3.3.4.3. Changing Perspective on Life

According to donors, patients changed their perspective on life [16]*'In the end, the perspective is changed I mean.'* In particular, after surgery for transplantation the donors felt that the patients appreciated the seriousness of the illness [5]*At least she has now learned to take illnesses more seriously, because this was because of her lack of care.*', they held onto life [5]*she will hold on to future, life more seriously,* and allocated time for oneself [5]*I think she will make time for herself, enjoy life more, she will slow down a bit and become more serene.*

CHAPTER 4

DISCUSSION

This is the first qualitative study which examined donors' experience of life following the diagnosis of liver failure and transplantation surgery. Although many studies have focused on the health status of donors, there have been few studies which provide crucial information about life experiences of donors and patients in relation to diagnosis of liver failure and transplantation surgery.

In addition, qualitative methodology has provided a more in-depth investigation than standardized questionnaires. As a server to current study's purpose, this also provides a richer understanding of the impact of living liver organ donation.

On the basis of the present study, donors expressed their own and recipients experiences about transplantation surgery. The experiences include various domains: beliefs of donors can be grouped into beliefs about liver failure, being a donor, transplantation surgery and organ donation. Donors' life of evaluation can be grouped into limitations brought by liver failure and the transplantation surgery, changing lifestyle, emotional changes, changes in character and mixed relationships. Donors evaluated patients' experience of life following the diagnosis of liver failure and transplantation surgery in terms of limitations, mixed relationships, emotional changes and improvement in life. Some of these findings in the present study could be interpreted in terms of existing psychological theory about adjustment and beliefs. However, these theories define beliefs and adjustment in very general terms and cannot predict the form that they will take in any patient group. Some beliefs and ways of adjusting were not reported before, so they extent the literature.

4.1. Beliefs of Donors about Liver Failure and its Treatment

4.1.1. Beliefs about Liver Failure

Donors recounted a number of causes of liver failure. Some of them were not a tangible causal agent such as unknown and spontaneous failure of the liver whereas some were a tangible causal such as genetic illnesses, complications at birth, cirrhosis and liver cancer. Donors also added to these causes, senseless drug use, stress and worry. Some causes of the present study findings are consistent with those of previous qualitative studies including hepatitis, primary biliary cirrhosis or cancer (Bjork and Naden, 2008). Previous qualitative studies in other chronic illnesses such as end-stage renal disease have suggested that clinical consultations should help patients to identify a cause in order to promote better adjustment (Krespi et al., 2004). Therefore, donors' adjustment could also be facilitated by helping them to find a cause during the clinical consultations with the hospital team.

As a different from previous qualitative studies, God's will, blaming oneself and blaming doctors were reported as causes for liver disease by donors in the present study. These causes have not been reported before and extent the literature. This means that donors preferred to explain causes of illness based on external or internal factors that could be understood on the basis of Attribution Theory. Donors attributed the causes of liver failure to external factors, including blaming doctors and God's will whereas blaming oneself illustrates the specific ways in which people can attribute the causes of liver failure to internal factors. God's will reflects donors' religious faith and demonstrates the ways in which blaming external factors for traumatic events can take shape within a religious context. External factors can be constructive if it motivates the donor to find a meaning in the traumatic events and this way also helps donors to manage the stressful event (Kelley, 1967) whereas they can be also destructive because they may cause the feelings of anger or disruptions in relationships with others. For example blaming doctors can be also potentially destructive in that it carries the potential to damage the relationship with the doctors and therefore hinder adherence (Krespi et al. 2004). Internal factors including blaming oneself reflect the contemporary cultural emphasis on personal responsibility for health (Brownell, 1990) and an increasingly critical attitude to health care. These internal factors can be destructive because they may lead to feel of guilt and depressed (Krespi et al., 2004). Therefore, these causes of liver failure should be targets for individual consultations and/or psycho-educational programs.

While donors recounted beliefs in relation to liver failure, they also reported some physical symptoms of the liver failure. Major symptoms related with liver failure in the present study was the overwhelming experiences of shortness of breath, yellowing, vomiting, having a pain, swelling, itching and deterioration of other organs. These findings are consistent with the symptoms identified in previous qualitative and quantitative studies including itching nausea, vomiting, pain (Bjork and Naden 2008; Brown et al., 2006; Bryan et al., 1998; Hellgren et al., 1998; Huang et al., 2011; Baker and McWilliam, 2003; Wainright (1997). Physical symptoms of liver failure may influence the donors’ emotional well-being or quality of life, so these physical symptoms should be targets in order to promote adjustment within the context of liver failure for individual consultations and/or psycho-educational programs.

4.1.2. Beliefs about Being a Donor

Donors reported a number of reasons for being a donor. One of them is that for donors, the recipients and donors must be related by blood which also extended to the idea that the donor resembles to the relative of the recipient that passed away because hey reported that they did not want to donate to unfamiliar people. According to similar study results of Papachristou and his colleagues (2004) that all donors mentioned that they would not agree to donate to a non-relative patient, but only for a limited group of close family members or friends.

According to donors, another reason for being a donor, because of the fact that donation was not a sin from a religious point of view, they accepted to be donor. Religious tradition needs to be taken into consideration. On the other hand, some donors said that most of the people do not want to be a donor because they thought that donation might be perceived as a sin. These findings have not been reported before and reflect the complexities involved in deciding to be a donor and role of religion in shaping the beliefs towards organ donation.

Most donors donated their liver on their free will and asserted that others should not hesitate to donate. In addition there were donors who decided to be a donor because others gave up being a donor. These findings are similar to McGregor (2010) and Walter’s study (2008) which showed that the donors accepted to donate ‘automatically’.

Other reasons for being a donor included saving a life, bringing a person back to life, doing the right thing, performing a good deed, being healed, being dependent, avoiding feeling upset, being conscientiously uncomfortable and being indebted. Like previous study of Papachristou, et al. (2004), donation was a way of coping with guilt for donors' own health or sharing the responsibility for the recipient's disease. Previous qualitative and quantitative studies have shown similar reasons for being a donor like the current study, including helping the loved one and saving the recipient (McGregor et al., 2008; Fujita et al., 2006; Walter et al., 2004; Goldman 1993). The current study provided a number of reasons for being a donor. Some of these reasons may be potentially destructive because they may go against individual needs and may foster the feelings of guilt and depression. For example, a strong wish to help and save the loved one may contradict with the idea that organ donation is a sin or the loved one is not related by blood. On the other hand, reasons of doing the right thing, performing a good deed and being healed may foster a feeling of happiness and emotional well-being. Therefore, during clinical consultations, the aim should be helped patients identify reasons for being a donor which can foster a sense of happiness and well-being if the aim is to facilitate psychologically sound decision making process and to promote emotional well-being following transplantation surgery.

Donors also reported a number of barriers to becoming a donor. These included being criticized by people, donors' relatives wishing to protect the donors, other people being senseless, ignorant and selfish. Relatedly, some donors needed to get permission from their significant others in order to be a donor. They reported also some potential donors do not want to be a donor because they fear of deterioration in health status and of losing one's job and these barriers are consistent with previous qualitative study (Walter et al., 2003) that has shown the barriers to becoming a donor included fear of loss and working disablement after surgery. In the present study, most of the donors returned their work after the breaking for 3-6 months. According to Kousoulaset al. (2011) study, almost all donors were able to return to their previous job after the liver donation. Other barriers of becoming a donor were health problems such as obesity and jaundice, medical incompatibility, pregnancy and age. Barriers of patients wanting not to harm or make their healthy family members to suffer in any way due to them (McGregor et al., 2008) have been reported before but others have not been reported previous literature. Moreover, being criticized by people and not getting consent of significant others can be burdening and can compromise adjustment. However, other people being senseless, ignorant and selfish can be also burdening and can deteriorate relationships with other people and may foster alienation and isolation from others. Clinical consultations and/or educational interventions should include these barriers as targets if the aim is to promote organ donation.

Some donors managed to deal with these barriers by getting their loved ones' consent and deciding on their own. This field can be understood on the basis of the concept of consent. In a qualitative study, Fujita's et al. (2004) reported that donors gave three types of content. 'Unconditional consent' was a voluntary consent in order to save family members' life, 'pressured consent' was a consent whereby the donor felt pressurized to become a donor. 'Ulterior-motivated consent' was a consent whereby the donor had a hidden motive. In the current study, regardless of the pressure donors felt aimed to give 'unconditional consent' rather than other types of consents. Therefore, clinical consultations should foster this type of consent if the aim is to help donors adjust to liver failure and transplantation surgery.

Donors also reported some factors which facilitated being a donor. These factors included having few responsibilities and having not many people to leave behind. These factors have not been before, so they extend the literature. They may be potentially destructive although these seemingly facilitate organ donation because they may cause a low self-worth, security and emotional well being. Therefore, following clinical consultations and psycho educational interventions, these factors should be targets.

All these barriers to being a donor and factors facilitating to be a donor can be understood on the basis of the constructs of barriers to and benefits of treatment postulated by Health Belief Model. The current findings reflect the specific ways in which these benefits and barriers can take shape.

4.1.3. Beliefs about Transplantation Surgery

Physical effects of transplantation surgery were reported by donors. In the present study, donors experienced excessive pain after surgery and as a result, their physical movements decreased. Only chronic chest pain has been reported before Walter et al. (2006). Other physical effects including opening of stitches, putting on weight and feeling stiff have not been reported previous literature. Clinical consultations and/or psycho-educational should target these if the aim is to increase organ donation and facilitate adjustment after transplantation surgery.

4.1.4. Beliefs about Organ Donation

Most of the donors changed their attitude positively after transplantation. Their awareness, in relation to organ donation, increased. Even so, they reported that in order to encourage organ donation, they could do some organizations such as joining non-governmental organizations, interviewing for magazines, talking with doctors, writing their experiences in a book and planning with media. These have not been reported previous literature. These reflect the general attempts to promote organ donation and demonstrate donors' willingness to help others who shared the same experiences as them. Donors recounted also that organ donation for money should be legalized but this argument carries the risk of abuse of socioeconomically disadvantaged people and it is also contrary to established ethical guidelines of organ donation.

4.2. Living Donors' Evaluation of Life Following Liver Transplantation Surgery

4.2.1. Limitations brought by Liver Failure and The Transplantation Surgery

According to donors, there were many social and physical limitations brought by liver failure and the transplantation surgery. First of all, donors mentioned limitations in their social lives. Donors stated that they avoided social gatherings because they felt that they dedicated their lives to ill person. These social limitations potentially cause quitting one's job and neglecting the other family members including spouse, children, siblings and disruption in plans. Physical limitations were also reported by donors as another limitation brought by liver failure and the transplantation surgery. In the present study, donors experienced excessive pain after surgery and as a result, their physical movements decreased. Mother donors concerned with their health status. They feared of inadequate of doing house work and taking care of their children like before surgery. These physical limitations, social gatherings and disruptions of plans are consistent with the previous qualitative findings so donors' quality of life is low (Walter et al., 2003). However, dedication of one's life to the ill person even to the point of neglecting the other family members reflect the burden of care brought by liver failure to the whole family system and resulting in transformed relationships among family members.

4.2.2. Changing Lifestyle

After LDLT many donors changed their life styles whereas others did not. For example, they quitted smoking and drinking alcohol and they put on weight after surgery. These findings are consistent with the previous qualitative study by Fujita et al. (2006). In addition, increasing their level of exercise and experienced an improvement in their health had been reported by donors like in previous study by Sargent(2007). In the current study, donors perceived these lifestyle changes as externally imposed constraints and they reacted both with obedience and disobedience instead of perceiving them as beneficial lifestyle and internalizing them by tolerating, adapting or circumventing. Perceiving lifestyle changes as constraints may trigger reactance (Brehm 1966) and consequent non-adherence. Therefore, this should be target following clinical consultations and psychological interventions programs in order to promote adjustment.

4.2.3. Emotional Changes and Changes in Character

Donors reported emotional changes on their life. They experienced negative and positive feelings following the transplantation surgery. After transplantation, they reported also some positive changes in their character and worsening aspects of character.

The present study is consistent with those of previous studies that also have shown that donors had several negative feelings in relation to diagnose of liver failure, transplantation surgery and convalescence period. These feelings included; getting confused, feeling down, feeling shocked, being unable to face, depression, feeling unhappiness, helplessness and anger, being uncertain, worry and fear (Chou et al., 2008; McGregor et al., 2008; Papachristou et al., 2010; Walter et al., 2003; Walter et al., 2006). Fear was the generally related with the liver failure and transplantation surgery whereas worry was related with the recipients' health. They worried about the recipients' uncertainty future due to regular use of prescribed medications, their side effects, rejection of the liver and recurrence of liver failure. Furthermore, they worried about the possibility of infertility and the occurrence of liver failure in recipients' offspring and in donors' other offspring. These findings have been also reported by previous quantitative studies have shown that donors and/or primary caregivers experience depressive symptoms (Bolkhir et al., 2007; Fukunishi et al., 2001) and qualitative studies have also reported the experience of similar negative emotions among donors (Walter et al., 2004; Chou et al., 2008; McGregor et al., 2008; Papachristou et al., 2010). These negative emotions should be target following individual consultations and psycho-educational programs if the aim is to promote adjustment. On the other hand, donors managed the negative emotions by focusing on destiny and recovery. This may lead to decrease anxiety and depression. These findings can be understood on the basis of the construct of coping strategy. Praying is also consistent with managing anxiety which have been reported before (Lamprecth and Sack, 2002).Denial of anxieties is an adaptive coping strategy on the part of potential donors following confrontation with a stressful life events or trauma (Lamprecht and Sack, 2002). In the present study, donors recounted that after the treatment period of physician, praying had a positive effect on the recipient's health. This may reflects that donors denied anxiety to cope with traumatic liver transplantation by praying. In trauma with the earlier stages denial tend more to exclude one another, which is not favorable, can lead those concerned to cling to one of the two extreme positions (Horowitz, 1979).This may reflect the specific ways in which emotion-focused coping can occur within the context of liver failure and transplantation surgery. Clinical consultations and psycho-educational programs should also promote these ways of coping negative feelings.

According to the present study findings, other relatives such as fathers experienced feeling down and upset because of the diagnose of the liver failure and transplantation surgery and findings are consistent with Chou and his colleagues' study (2008). The caregiver also in the current study needed to care of the donor and recipient simultaneously (double caretaking role). They simultaneously encounter tension, anxiety and fears about their child's multiple physical changes together with unexpressed feelings including the ''what its'' of failed surgery and the possibility of losing hope again. Moreover, transplantation affected the other children's psychology in same family. Many donors reported that siblings gave some psychological reactions such as wetting themselves, vomiting, having fever and headache. These findings have not been before. This may also compromise adjustment by fueling the feeling of guilt among donors and they need also to be targets following the clinical consultations and psycho-educational interventions.

Donors recounted worsening aspects of character in the present study. These included becoming a half human, turning into an aggressive person and experiencing the bitterness of life. Relatedly, donors also reported worsening of character in the siblings of the recipients, including becoming aggressive and disobedient. These findings have not been reported in the previous studies. However, worsening of the character including becoming selfish and considerate has been reported in Krespi et al. (2008)'s study in relation to end-stage renal failure. Clinical consultations or psycho-educational programs need also promote these worsening aspects of character.

In addition, the present study demonstrated that donors had also positive feelings in relation to diagnosis of liver failure and transplantation surgery and also they believed that they will go to heaven and will be rewarded by God in afterlife and they felt like being born again, saving the world and paying off the debt of conscientious. Donors reported other positive feelings within the context of transplantation surgery. Donors felt extremely proud of themselves, strong, appreciated, reputable, conscientiously comfortable, excited and joyful, happy relived, comfortable and confident. These findings have not been before and extend the literature. However, feeling motivated for an operation and feeling certain have been reported in previous study by Walter et. al. (2004).All these positive emotions should be targets by psycho-educational interventions and clinical consultations in order to promote adjustment.

Religion was an important aspect of donors' experience.It might be said that for donors, possibility of going heaven is an important motivator factor to be a donor and rebirth may reflect the purification from sin that causes the feeling of relief. Paying off the debt may reflect that the donation was a way to express love and thankfulness towards their loved one. Positive feelings of the donors including feeling like being born again and rewarded in afterlife, saving the world and paying off the debt of conscientious could be interpreted within the construct of finding meaning following a traumatic event like diagnosis of liver failure and transplantation surgery. Similar findings have been reported in other chronic illnesses (Sodergren and Hyland, 2000) including cancer patients (Taylor 1983; O'Connor et al., 1990; Salmon et al., 1996) and end-stage renal failure (Krespi et al., 2008) but these findings of the present study extend the literature by suggesting mechanisms whereby religion provides the basis for finding meaning in liver failure.

Similarly, donors recounted also some positive changes in their character. These are becoming more of a believer, being grateful, feeling free, becoming a stronger person, becoming a humanistic and having a better outlook on life. Only feeling free has been reported before (Tong, 2009), other positive changes have not been before in previous studies. This finding may reflect that the experience of being a donor does not only involve experiencing loss but also finding benefits like in study of cancer patients (Taylor 1983; O'Connor et al., 1990; Solmon et al., 1996) and in other chronic illness (Sodergren and Hyland, 2000) including patients with end-stage renal failure (Krespi et al., 2008). Perhaps these findings are mechanisms by which adjustment in liver failure can be promoted.

4.2.4. Mixed Relationships

Donors recounted a number of continua as well as improvement in social and emotional life during the transplantation process. Firstly, some donors received support emotionally from their families or friends, while some donors received support from other post-transplant donors or financial support from their families. These findings are consistent with previous findings of study by Fujita et al. (2005) and Wainright (1995).It is well understood in quantitative and qualitative research that pre and post duration of LDLT, social support has a positive effect on adjustment following a liver failure and when a family member needs to receive organ transplantation because of organ failure, the family endures their family roles and changes in communication modes together with lifestyle adaptations to achieve family stability and to keep on family functioning (Kimmel et al., 1995; Elal and Krespi 1999).On the other hand, in the present study, other donors stated that they did not get support from potential supporters like mothers, fathers and spouse, they also recounted that they had all responsibilities throughout the disease period and this was difficult to be a caretaker on their own.. This may cause the feeling of anxiety and helplessness. These findings have not been before. In particular, financial support was critical factor for better adjustment as well as social support. Many donors stated that they received financial support from their families and some of them said to receive financial support from government. Financial support is necessary for these donors in order to have an operation because without insurance, transplantation is extremely expensive and could not undergo.LDLT is slightly costlier than cadaveric transplantation (Chen et al, 2011). Unfortunately, donors continued to pay most of the outpatient costs, only inpatient costs are covered by the recipients' insurance system (Dubay et al., 2009). Donors who especially have low income or have without insurance might reduce their expenses (Wigmore et al., 2002). Similar results have been reported. For example,according to Walter and his colleagues (2006), some donors complained about low support from insurance, and this causes that donors felt sadness and anger.

In addition, relying on doctor and hospital team also played significant role of feeling support in the current study. Like similar results to previous study, donors indicated that getting support from doctors and trusting the hospital had a positive effect on their mood. Otherwise they would never put their health at risk. Tong et al. (2009) study demonstrated similar result like the present study; donors expressed dependence on their doctors and had desire for frequent follow-up contact with them in order to maintain their healthy life. Moreover, Papachristou et al. (2010) found that trusting doctors considered a guarantee for a safe and promising procedure. Donors trust doctors and hospital team as medical system morally. They also perceived surgeons as the ones who preserve the hospital's reputation. Moreover, major factors that influence the decision and risk-perception are social and medical support.

Friend, family and transplantation team are needed as potential source of intensive social support, providing relief and pre operation adjustment to life situation. Trusting and feeling supported by the surgeons and significant others and lack of support from others could be a mechanism whereby adjustment of donors following transplantation can be promoted.

Second, some donors felt the burden of care whereas others did not feel the burden of care. For some donors, the view of not feeling supported from others reduced the burden of care but for mother donors the view of being the sole caregiver throughout the whole process was too difficult and burdening. Parents are the most central and enduring influence in children's and adults' care (Schor 2003).Therefore, this issue increased the burden of care for some donors. However patients or donors' worry over the burden of care giving has not been reported before in liver transplantation although in patients with haemodialysis (Gregory et al., 1990). Therefore, this result extends the literature that provided specific mechanisms whereby burden of care is felt by donors.

Third, the present study demonstrated that there was a special bond, which was formed between recipients and donors. Many donors said that they established a strong connection with each other after surgery. It may reflect that the transplantation may influence normal identification mechanisms that foster adjustment. This also may be understood on the basis of the constructs of psychoanalytic theory of integration process. According to psychoanalytic theory, ''only consanguineous relatives are donors, elements of the family drama may be compounded by the new factors in the transplantation situation. It would appear that the transplant situation might interfere with normal introjections, identification and other intrapsychic mechanisms that foster adaptation. Intrapsychic integration of the new organ and the adoption of traits of the donor are influenced by the relationship between the donor and the recipient'' (Basch, 1973).These findings are consistent with previous qualitative studies that living liver donor transplantation has an effect on the relationship between the recipient and the donors or between the donors and their families (Chen, et al., 2011), in that very close ties have been formed between sons and their mothers and between daughters(Walter et al. 2004), the relationship between the donor and recipient had strengthened since transplantation (Tong et al., 2009; Trotter et al., 2001; Diaz et al., 2002) and that donors were likely to idealize their relationship with the recipients (Walter et al., 2004).

On the other hand, donors recounted worsening aspects of close relationships. Findings are consistent with previous studies finding in relation to haemodialysis patients but not in donors. Krespi et al. (2008) indicated that haemodialysis patients perceived their caregivers as lacking support and understanding and as sources of difficulty and in that patients felt distress, resentment, anger, disappointment and guilt in their relationships with them. This may reflect the patients' aim to sustain some autonomy and to be able to care for themselves. The current study findings extend the previous finding by indicating that donors are subject to similar positive and negative experiences. Previous quantitative research in relation to patients with end-stage liver failure has demonstrated that social support can also have several affects on adjustment (Boyer et al., 1990; Palmer et al., 1983). These findings may provide specific mechanism by which social support can compromise adjustment. Therefore, these negative aspects of donors' social context need to be promoted by the clinicians following clinical consultations and/or psycho-educational intervention programs.

4.3. Living Donors' Views of Recipients' Evaluation of Life Following Liver Transplantation Surgery

4.3.1. Limitations

Donors reported that recipients experienced some limitations in their social life. Many recipients did not want to go out in public because they hesitated from people's looking. Patients were socially isolated and socially stigmatized because of the liver failure and these findings are consistent with previous qualitative study of Sargent (2007). Relatedly, previous quantitative findings including poor quality of life in patients with chronic illness (Lang et al., 1997) in particular decrease in social activities and social network (Wainright, 1997; Robertson 1999) are also consistent with the present study findings. The current study indicates that the experience of limitations in relation to diagnosis of liver failure and transplantation surgery is universal and not culturally bond, so the ways patients evaluate themselves converge with those of donors' evaluation of patients' life.

4.3.2. Mixed Relationships

Similar to previous findings, donors reported that recipients had some negative experiences with others following transplantation surgery. These included feared of being infected by disease and others being insensitive. These findings are consistent with previous qualitative study that has shown fear of being infected by disease and exposure to social stigma by peers (Sargent 2007), being bullied and teased by peers (Tong et al (2009), non-synchronized family interaction (Weng et al., 2011 parental overprotection, peer rejection and dependence on formal and family caregivers (Tong et al., 2009). In addition, the present study extends the literature by showing that patients experienced with disappointment when the potential donor gave up to becoming a donor. In fact, their relationship was disrupted because they destroyed recipient's hope for recovery. Similar results have been reported by both qualitative studies among patients with liver failure (McGregor 2010) and among patients with end stage renal failure (Gordon 2001).

On the other hand, donors recounted that patients were supported by significant others. Similar mixed relationships have been reported among patients with end-stage renal failure. For example in Krespi et al.'s (2008) study caregivers were frequently described as supportive, but patients perceived them as source of distress and difficulty. It is well known that social support can have several effects on adjustment among patients with end-stage renal failure (Boyer et al., 1990; Palmer et al., 1984). The current study extents the literature by showing that patients with liver failure have similar positive and negative experiences. The present study findings suggest mechanisms by which social support can compromise adjustment in liver failure. Clinicians perhaps need to be particularly sensitive to these negative aspects of patients' social context. These findings indicate the experience of mixed relationships is also universal and that donors' evaluations of patients' lives converge with those of patients' evaluations of their own life.

4.3.3. Emotional Change

Donors recounted both negative and positive feeling of patients' experiences. Negative feelings included fear of death, feeling down, hopelessness, being embarrassment, and feeling of uncertain, worn out, exhausted, feeling like a loser, feeling of being a burden to others, the feeling that one is going to leave others bereaved and feeling of being driven to the edge. Similar findings have been reported by previous qualitative findings (Bjork 2008; Jonsen et al., 2000; Mishel

1997;Tonget al., 2009; Watanebe 2009; Watanebe et al., 2010; Weng et al., 2011). For example, Bjork (2008) found that feeling of uncertainty was seen among most patients in the waiting period and this feeling was related to life and death issues. These findings may reflect that end-stage liver failure has worsened patients' emotional state. On the other hand, donors recounted that patients have experienced with also positive feelings included feeling happy, general improvement in mood, getting relaxed and being refreshed. These findings have not been in previous findings. All positive and negative feelings of patients' experience is also universal and that donors' evaluation of patients' lives converge with those of patients' evaluations of their own experiences. Therefore, clinicians should reduce the experience of negative feelings and encourage the positive feelings in order to promote adjustment.

4.3.4. Improvement in Life

Donors recounted improvement in patients' life. These included becoming physically improved, socialized again and changing perspective on life. Physical improvement after transplantation included the skin growing white, growing up, putting on weight, getting rejuvenated, the body getting balanced, becoming fit and active and stopping itching. All these findings have not been before in a detail, they extend the literature. Similar findings have been reported that successful liver transplantation not only improves quality of life of the patient and the family but also helps the child with growing and developing normally (Chen et al., 2006; Mazariegos and Machaidze 2007; Asonuma 1998; Zamberlan 1992). Itching was the most frequently seen among recipients following transplantation surgery (Bjork and Naden 2008). The current finding on physical improvement include stopping itching stresses the healing effect of transplantation surgery as evidenced by the disappearance of a symptom that is the characteristic of end-stage liver failure. Clinicians need to help patients managing the whole process of transplantation. In addition to improvement in life, patients started going out in public and getting socialized. These findings are consistent with also previous findings of study by (Chen et al., 2006; Mazariegos and Machaidze 2007). Finally, improvement in life includes changes in perspective on patients' life. Following transplantation surgery, donors recounted that patients appreciated the seriousness of the illness; they held onto life and allocated time for oneself. These findings are consistent with the other chronic illnesses (Sodergren and Hyland 2000) such as cancer patients (Taylor 1983; O'Connor et al., 1990; Salmon et al., 1996) and end stage renal failure (Krespi et al., 2008). Overall these findings may indicate that the experience of improvement in life is also universal and that donors' evaluations of patients' lives converge with those of patients' evaluations of their own experiences. Clinicians need to foster these ways of finding meaning within the context of liver failure.

4.4. Further and Clinical Implications of the Study

The current study implicated the life of donors' and patients' experience, psychosocial and psychological difficulties, motivations of donors' decision making process and the relationship between donors and recipient. However, as there is no study that has been carried in the Turkish culture on this topic, the present findings are pioneering. The present study helps not only to explore donors' needs and concerns in a deeply way, but also to create opportunity identify targets for psycho-educational interventions in order to improve patient's adjustment because qualitative methodology helps to understand the ways in which patients think about their illness and treatment and also to understand their adjustment. The present study has also several implications for clinical practice in LDLT. Health care professionals can provide donors with effective support by using psychological interventions programs in order to improve poor outcomes.

The most important issue is a comprehensive analysis of the complications of living liver transplant donors and recipients. A comprehensive comparison of the expense of LDLT versus cadaveric transplantation should be conducted. Such an analysis should compare the outcome of pre-transplantation, transplantation, and post-transplantation care. LDLT might reduce the expense of pre-transplantation care by shortening the waiting time before transplantation. LDLT has rapidly emerged as a good treatment option for selected patients listed for cadaveric transplantation. The continued careful operation of LDLT in adults could help partially minimize the current organ shortage and reduce the number of patients dying while awaiting cadaveric liver transplantation. The increasing prevalence and long-term survival rate of living transplantation recipients bring the need for better understanding of the psychosocial effect of transplantation. This also provides an opportunity of design interventions to improve post-transplantation follow-up care from the health care.

This qualitative current study was undertaken by studying donors' experience within the constraints of psychological ideas. Psychological ideas that constraints the current study were beliefs and adjustment. However, these theories define components of adjustment and beliefs in general terms, cannot predict the form that they will take in any patient group. Some ways of beliefs and adjusting were not previous study within the context of liver failure and they extend the literature. An application of this approach to qualitative study among living liver donors helped to identify possible targets of interventions for clinical consultations and also helped to design questionnaires to measure donors' experience. The current study also demonstrated that donor's belief about their illness and treatment and also of their understanding of adjustment could help to design patient or donor-based interventions.

4.5. Limitations and Further Recommendation

This study did not investigate non-donors who initially were candidate. They also could be investigated because the psychological processes of them are unclear. An examination of non-donors could further identify the familial conflict inherent to donor selection (Simmons, et. al., 1971). Development of a psychological and social support system for transplantation could improve for treatment quality in transplantation medicine.

In our study, all the transplants were successful, patients were alive and it did not have any complications related to transplant. Therefore, transplant, which was unsuccessful and the recipient died or required re-transplant, should be researched. Donors might feel different emotions after the transplantation when the loss of their loved one.

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APPENDIX A
INFORMED CONSENT

Bilgilendirme ve Onay Formu

Bahçeşehir Üniversitesi Klinik Psikoloji yüksek lisans programı altında canlı karaciğer nakli donörleriyle birlikte tez çalışması yürütmekteyim. Memorial Hastanesi karaciğer biriminden seçilecek olan bu donörlere her hafta görüşmelerde yer alması için yardım istenecektir. Görüşme süresince, donörlere deneyimleriyle ilgili bir takım sorular soracağım.Sorular, nakil öncesi ve sonrası yaşanan zorluklar, nakil sonrası iyileşme süreci ve nakil sonrası hayatın nasıl değiştiği ile ilgili sorular olacaktır.
Bu görüşmelere katılmaya istekli olursanız çok memnun olacağım.Katılım zorunlu değildir.Katılıp katılmamanız tedavinizi etkilemeyecektir.Ancak katılmaya karar verirseniz, bu durum hastanenin gelecekte canlı donörlerin olanaklarının geliştirilmesine yardımcı olacaktır.
Sizden alacağımız bilgiler görüşmeler boyunca ses kaydı cihazı ile kaydedilecektir. Ses kayıtları bütünüyle gizli tutulacaktır. Tedavinizle ilgili olan hiç bir hastane kadrosuyla paylaşılmayacaktır ve ses kayıtları dinlenildikten hemen sonra yok edilecektir. Eğer bu araştırma projesine katılmayı kabul ediyorsanız, lütfen bu formu imzalayınız.

Teşekkürler
Aslı Tankurt
Bahçeşehir Üniversitesi
Klinik psikoloji bölümü

Ben, (katılımcının adı) ...., yukarıdaki metni okudum ve katılmam istenen çalışmanın amacını, gönüllü olarak üzerime düşen sorumlulukları tamamen anladım.Çalışma hakkında soru sorma imkanı buldum.Bu çalışmayı istediğim zaman ve herhangi bir neden belirtmek zorunda kalmadan bırakabileceğimi ve bıraktığım takdirde herhangi bir ters tutum ile karşılaşmayacağımı anladım.

Bu koşullarda söz konusu araştırmaya kendi isteğimle, hiçbir baskı ve zorlama olmaksızın katılmayı kabul ediyorum.

Katılımcının Adı-Soyadı
İmzası:

APPENDIX B
EXTRACTS FROM INTERVIEWS FOR THE QUALITATIVE STUDY IN RESULTS

3.1. BELIEFS OF DONORS ABOUT LIVER FAILURE AND ITS TREATMENT

3.1.1.1 Causes of Liver Failure

[11]Cliptonic, in other words, unknown cause... **Unknown Cause**

[7]this shows itself with jaundice, bile duct being blocked, AST values, blood values go up. That which comes along with jaundice, even that was difficult for transplantation. Our illness...since it was atresia, since jaundice was added; they said ours was 60%. **Biliary Atresia**

[1]In the meantime, cirrhosis and Hepatitis B were diagnosed according to test results. This was the diagnosis but hepatitis was not found to be present. She only had cirrhosis. [5]I mean, my mother is already a chronic cirrhosis patient; she had been receiving treatment for hepatitis for about 7-8 years.,

[9]The result was that he had cirrhosis. [10]We heard that he had chronic Hepatitis B... They (the doctors) said Cirrhosis. He caught hepatitis B-dependent cirrhosis. He might have had jaundice, maybe when he was a baby, maybe when he was in the army, maybe he may have got it **Cirrhosis**

when working in the hair dresser… so they (the doctors) said. [16]My brother is cirrhosis because of his job. Alcohol is the cause in general, but my brother is not a drinker. You see, he caught cirrhosis over his already existing hepatitis B which he caught because of germs as they went down to the underground too many times while he worked for Telecom Company. They took his entire liver [9]It started to turn into cirrhosis in his liver.

[11]My mother also had diabetes which also had an impact on this illness in wearing out the liver because she always took pills, her blood pressure was getting elevated. She took pills for high blood pressure, pills for diabetes for about 15 years, just think that you use medicine for 15 years, then you are not able to cope with your liver., [9]Yet my uncle previously had vein problems, he has been taking medicine for years, maybe this was because antibiotic drugs, I am guessing so, but still I have no clear information.

Senseless drug use

3.1.1.2. Physical Symptoms

[4] her color was yellow before then turned black from yellow. [2]Someday her eyes started to turn slightly yellow, you see, we know our daughter is getting jaundice.

Yellowing

[11]the beginning of the process started with an abdominal swelling,[10]There was fluid accumulation in his abdomen for 2 years; he had belly hernia which was the most disturbing. [3]fluid came off from his abdomen, every week he went to hospital to have the fluid taken off.[6]His abdomen swelled, and what's more, his abdomen got too much water. One day he came home with his feet swelled too much and his legs also. His legs swelled. [1t] swelled, his abdomen swelled … His hands, feet and face swelled.[1]swelling.

Swelling

[5]weakness and tiredness are the most important symptoms. It gives symptoms such as muscle pain, sleeplessness, but tiredness in general.

Tiredness

[5]weakness. [6]He was very weak. [9]He couldn't walk and he had difficulty in talking. [15]I know, my brother had difficulty in walking 300 meters.

Weakness

[1] itching.

Itching

3.1.2. Beliefs about Being a Donor

[2]First, you know, his uncle said ' I will donate' but then he got engaged and give up donating.

Potential donors had given up after they had decided to be a donor

[3]I already said directly when we came to this hospital, I said 'I will donate'. We talked with our doctors … we talked with the professor, we talked with doctors we wanted to talk… then I gave voluntarily. [12]I was very happy as I had donated very happily, very voluntarily,… Voluntarily, I said 'hey', ' I have a daughter too, of 5 years. It can happen to me too.' I thought, and I said ' I volunteer, no matter how.' [1]They said who will donate in case of transplantation' and I said directly 'I will donate. … I wanted to donate my liver voluntarily, willingly.'

Free will

3.1.2.1. Underlying Reasons for Being a Donor

[5]Someone else, I mean a stranger reacts against, I mean he/she may say, ' I wish I didn't donate.,' [2]Those other than mother and father, I don't know, will do it for money, or I mean it should be I'd say for a very close person, mother and father, I mean uncle is also close, but no, no one can do it, I mean mother and father are different, and so. A child will donate to mother and father. This is what I think, because first degree relatives may donate. [13]For example, I guess I would donate, if it was a relative of mine, my brother or sister, my mother, my father, my partner,… I would donate.

Donors did not want to donate their organ to strangers

[1]I believe I saved a life, [8]someone's life depended on me, I just did my part. [15]For example my husband and I think even now that, I mean, if

Saving life

an accident or anything happens, you know, everything can happen, so we think to donate our organs before we die because you save the life of a person. [8]At least the life of a person will be saved.

[2]Then I thought that had she donated would it have been like we owe to her (her daughter) for life? Then 'fortunately it was not her but me who donated. **Indebted**

[11] this has been widely researched religiously, I am too a person who have investigated a lot. I can say that there is nothing wrong with it, This is why we didn't hesitate a bit. **Being not sin**

3.1.2.2. Barriers to Be a Donor

[15]We made this decision together with my husband anyway. I didn't decide on my own. If my husband didn't agree on something like this, then I couldn't accept it either. Because in the end we are a family and there are decisions that we should make together. **Not getting consent of significant others**

[3] she did not want it. She said 'I can't lose my child. **Donors' relatives wishing to protect the donors**

[4]for example my elders pushed me too hard. They said ‘Do not give your liver.’ you know, ‘if the child dies, another one replaces her….’ But I didn’t listen to anybody, because, I said, 'you don’t know, you don’t see how (the name of the patient) suffers. Yes she didn’t die, she lives, but you don’t know how she lives, what she has been through.’

Donors took every risk

[14] Naturally, my father is also concerned about me. He says, 'why did you donate? I wish your husband did it.’ He was afraid that something would happen to me.

Being criticized by others

3.1.3.1 Physical Effects of Transplantation Surgery

[4]I had pain. [5] in intensive care... you lie down for a long time, you have too much back pain, lower back pain, you have too much pain on your surgery spot. … you want to sleep, later on of course you drift away a little. You can’t make yourself comfortable because of pain, you can’t sleep because of the utensils. [11] I had slight pain but then no aches and pains other than that. [1] I had pain, my stitches hurt. [13] In fact as I have too much pain at first, I say ‘Oh God, will I possibly recover?, will I get on my foot again?’ [4] I had pain.

Pain

3.1.4 Beliefs about Organ Donation

[1]‘I can encourage people to the best of my capacity.[4]Certainly there are those who are afraid of transplantation, especially in rural areas

there are many who are afraid of. At least, they see us and are encouraged. They have their spirits lifted. I mean they don't get scared. …When I see such a person, which I sometimes come across hereabouts, I say 'Don't give up, don't you ever get scared, go as far as it goes.' [9] If someone is indecisive, I can persuade him/her I mean, … If there are those I can convince, I will direct everybody around me to organ donation. They should definitely spread this, through either press or talking with people one to one.

Organ donation should be encouraged

3.2. LIVING DONORS' EVALUATION OFLIFE FOLLOWING LIVER TRANSPLANTATION SURGERY

3.2.1. Limitations brought by Liver Failure and the Transplantation Surgery

[2]I try to limit my movements physically, after all 65 stitches were put, I wondered if they would, swell or if I would get to any harm? [10] I am not able to do anything of course, I cannot wash my hair. I mean, you know, I change my underwear with difficulty.

physical limitations

[14]I had a job. My father said 'Don't work for some 6 months. But I will work if I feel good when my sick leave is over.

Social limitations led to quitting one's job

[16]How it changed, we have a little social life, work, work, work,… how far? …. No visits to relatives or friends. It was only from home to work and work to home.

Social limitations

[7] how could I go out and have fun while my baby was in that condition, we were doing nothing, my whole life was him, there was nothing in our life but hospital.

They avoided social gatherings

[11]I had to separate work from home, because, at home your child is expecting care from you continuously, your husband strived all day to serve you, I couldn't make them happy... For example, on a weekend there was nothing like … pack up, let's go there or let's do that, do this. It didn't work, I didn't want; I also started to notice that something had changed between me and my husband…. We started to feel unhappy, then we never argued, there was always silence. There was nothing like cuddling the kids, hugging, kissing, smelling them, you know joking, having fun with them. [2]We also had a boy who was preparing for university exams. We came to hospital always leaving him at his grandmother's. We left him and came. His grades went bad thinking 'my father and mother is not here, they are sorry for my sister anyway, they won't be interested in me'. Despite he was a very clever and successful kid, his grades worsened at that time. And now he says this, he is going to have the exam now, and he says, 'when I was in

At the expense of neglecting others

high school you always took care of my sister, and I didn't go to school when staying at grandpa's. You see, we also harmed him. …. Now, he works very hard, but I am not sure if he could compensate what he lost in between.

[4]But my greatest fear is that if I can raise or be neglectful of him (the patient) when I have the second child? There is this fear. … Will there be jealousy attacks?

Disruption in plans

3.2.2.Awareness of the Need for Lifestyle Changes

[3]I weighed 74 kg when I went into the surgery, then I lost weight, I weighed 72- 73kg, weight was my problem, even 1 kg was a great deal for me. Then you know we were coming here for control, 5-6 months, you know others said 'I put on 6, 7 kg and all. I didn't put on weight, I was very happy, I didn't put on weight during that period, I lost weight, 3-4kg though. Then I suddenly put on 5-6 kg or so again. Now I am trying to lose weight.

put on weight after surgery

3.2.3.1. Negative Emotions

[9]My uncle is like a father to me, I could not face to see him like this.

Confused

[4] I wasn't aware if I was alive or dead, in so much that I wasn't even conscious of myself. It was tearing me apart, my child being like that.

Feeling shocked

[4] I was mentally down. I couldn't think of anything, I couldn't do anything. … I was financially and spiritually down.

Feeling down

[7] I didn't have any hope for this.

Being hopelessness

[13]It makes you scared. I mean, I don't know,… if her illness goes on, you know. [7]I think of my baby. What will I do if I lose my baby? I guess, I wouldn't think of having a baby again. These are very bad things, I don't know, I wouldn't be able to do it, thinking of her every moment, hugging her. I want to see her, I mean I miss him even within minutes, you know, I want to see him … May God never test anyone with illness of children, It would be very hard. I mean I have never thought of losing him but sometimes it went through my mind. [1] Talking about transplantation, we don't know at all how to do it and where to find it. Because this is not something that is experienced a lot in our neighborhood.

Fear of losing the recipient

[9]Definitely it is nothing to be afraid of, people generally scared of the word itself when organ transplantation is mentioned but it is nothing like that.

Other donors did not experience fear

[4]All in all, it is an operation, I mean, it has risks. If you die, what happens? … I had this anxiety of leaving them alone, [13] How much did I think of him (my other child), ' I thought 'What if I can't survive the surgery, (she is crying).

Fear of losing oneself

[6] I couldn't stand seeing my brother in such situation. [12]For instance when I got married, as I wasn't happy with my husband, as I experienced many problems, many things, then you can't help feeling down.[3] I remember it was the only time that I cried, I turned to my right, you see, when I was hurt after the surgery, not that I was hurt, you know, as you can't lie down, I was full with emotions anyway.'

Being stressed

[1]I can say that as if an irritability formed in me as I deprived myself of these things (alcohol, smoking).

Feeling angry

[4]'I am afraid that he will let himself go and his treatment will fail and all, but I have never skipped his medications of course but I don't know, I still have this fear.

Worries about necessity of using prescribed medications

[7]I mean, I have a question mark in my mind will anything happen? Will the liver get rejected?

Fear of rejection of the liver

[13]Besides, when we last came…, I asked if we had the 3rd kid would he/she have a thing like that. I don't want to have another child and make him/her to experience the same things and I also don't get myself experienced the same things again and again.

infertility

3.2.3.2. Positive Emotions

, [4]it gives power, pride. [14]'Some people say 'not everyone can do it, well done'… Everybody said that they were proud of me.

Being proud of oneself

[5] You look at your surroundings with very different eyes. I feel that, they point at you, they say 'well done! How dutiful children there are!, also some parents maybe, I mean you can feel it. People approach you with appreciation.

Feeling appreciated

[9]But saving human life is really, I mean, when people come after that and say 'well done, you are something,' you know,' you are this, you are that,' really you feel incredibly happy. [5]Transplantation, as I donated to my mother, I think, this is a pleasure, I mean, I think it is a happiness that will last for lifelong.… To save a person's life, even if not your mother's, to save an individual's life is a great pleasure and when this person is your mother you really feel great happiness.,

Feeling happy

[11]I was very happy even when I had pain. My husband accompanied me when I stayed at the hospital, I mean , even he realized, I was very happy, you know there wasn't anything wrong, any problem, I mean, I was back to what I was before, I mean, whether or not I had the surgery I didn't care at all, all I cared about was that my mother was good. … It gives happiness, I mean, her being able to breathe, every moment she lives, thanks to first God, then to the doctors and to something which I provided , this is awesome. May God grant this to everyone! I can say it is like being heralded that you will go to heaven. It is that great.

[2]Now I lie down, we bought a new bed, the latest model, now we lie down and relax.

Feeling relieved

[12]You feel yourself like an innocent new born baby. [11]Let me put it this way, I am like a newborn that I can say. Many donors describe the post-transplantation period as to be born again. [5]You know, God forbid everyone, but may God grant every child, not maybe this kind of happiness but such a pleasure', I mean, I am happy in this regard, plus I have strong bonds with my mother, it was quite, um, as I saw my mother that well, happy, saw that her pain reduced and knowing that she would live for the rest of her life, of course thanks first to her doctor and then to me.

Being like born again

3.2.4.2. Positive Changes

[4] Thank God thousand times! Dear God made me see these days, now I see it. [7]I mean, I learned to be more grateful. [15] When you open your eyes, you thank God that you are alive.

Being grateful

3.2.5. Mixed Relationships

[3]People coming from Arabia, or I don't know, coming from everywhere of the country, Everyone has the same problem, when you come near them and talk as you are a relative then you feel relief, when somebody says 'I went through this, this and that happened,' I said to myself, from the very first day, "Okay, thank God, we will be saved.' [7]My husband has an aunt in law, an uncle, they helped them a lot, they were interested in us. …. Yes I would be uncomfortable if I felt like a stranger, feeling like an outsider in a house. I didn't feel like a stranger at all, I mean as if it was my own home. My husband provided a lot of support anyway. It was very difficult for him to wait during that surgery. He looked after me and my mother in law stayed with my baby. My mother in law, my father in law and sister in law all were here. After all there was this support; you were supported by your family.[7]I mean the grandmother, grandfather did a lot to me. While I stayed in hospital they went back and forth to the Ministry of Health. I mean they went to the Ministry of Health, you know, to say that 'the kid is getting worse, what shall we do?' so that they call the

Donors were supported by people around them

kid as soon as possible. [10] I always talk with whoever I see for 2 years, I mean, with people who are discharged. I always talked with them and get their opinions. I mean I always followed them in hospitals. I talked with both donors and recipients. Everyone was so happy; they told positive, nice things. And of course I took courage from them. …. My brother's son always comes with me for the checks. [12]My mother, father, my big brother, my sister, my aunt's daughters were with me to support me. …. their support is very good, improves your morale nicely…. my aunt and my mother helped me very much, God bless them. They all helped me. This is very important, getting support from family is very important. … May God bless them? All relatives were with me let alone the family. You see, the moment I come out of the surgery the phones were blocked, having everybody by my side is a very nice thing for me. [13]Her aunt looked after my daughter. My brother and sister were here and they were coming regularly. God bless them for their presence. When I stayed here it was my husband who stayed here and took care of me. ….. I mean the support of your life partner is more important than anything. …. he does more than his best. [15] Of course my mother was with me and my husband was on sick leave. My mother also with me, my mother has been with me since the day I went home, she takes care of the child, cooks and all so that I don’t get tired, they do and prepare everything together with my husband.

[8]I mean he did things maybe he didn't do for his brother or child. We were so good, I mean. You know how a father treats his child both financially and emotionally, you also know more or less. [9]My uncle and his family also provide financial support anyway, I don't have any financial problem.

They received financial support from family

[7] This hospital, I am not sure, would it be that good, successful if we went to another place, I don't know, because the doctors were very good, all of them I mean, their interest during the period after the surgery, they were all really great. 'God, then doctors saved us. I was pleased with from the cleaning person to the nurses they all have my consent; they provided a very good care to both of us, to my child and me. I mean, I am very contented with the hospital. Thank God I came here. … . We trusted here very much. [10]Our doctors are super anyway. We left ourselves into their hands blindfolded. ... I mean their smiling faces are really something super. I mean they give positive energy to people. Morale is very important, incredibly important. … Doctors with their eyes smiling, shining… this is a very beautiful thing…. It gives you great happiness, gives you confidence. I trusted more, and was never scared as we really were in safe hands. [14]I was very contented with this place too, all doctors and nurses in the hospital are very caring. Smiley face was very important for us, as our morale was already low. When they take care of us then it is easier for us. [15]but God bless him, we talked with Mr. (the doctor's name), talked with other

They got support from doctors

professors and all. They all motivated us nicely. You know they knew for sure that nothing bad would happen. [16]Really, when you are staying in the hospital, you want to get ill and come to this hospital because of doctors' and nurses' behaviors. I mean even that psychology made us happy. It is surprising, for example, you know, chats you maybe would not have even with your family, doctors, nurses, their behaviors are nice, and their interests are nice.

Other donors did not get support from potential supporters

[3]After the surgery his attitude changed suddenly.

Some donors felt this reduced the burden felt

[3] I am separated now, Thank God I am, had I got married, then had my mother needed it, he would cause a problem. Maybe I wouldn't listen to him but in the end I would have been married and divorced.

Mother donors felt that they were the sole caregiver

[7]I only had trouble when I stayed in the hospital in Trabzon. Because my husband had to work and my mother in law had to look after them.... I stayed 17 days all alone, I felt myself a little lonely at that time. I called them, I cried…. all the time, because my child was getting worse. It was only me who was with him, always me when they open vein access, There is always me I mean during hard times.

[7]Now the bond between her and me is more important, it is a more different thing, It became stronger. [4]Neither he can not break off with me nor can I with him. He cried and run after me even from room to room. He says ' Don't leave me mom,' He thinks I would go, leaving him behind.

special bond was formed between donors and recipients

[15]they grew away from each other; especially they broke their relationships with my brother in law's sister. …. my aunt and her family broke their relationships rightfully, because there was this thing, there was hope, they destroyed that hope, they knocked it down.

Close relationships got worse

3.3.LIVING DONORS' VIEWS OF RECIPIENTS' EVALUATION OF LIFE

3.3.1. Limitations

[3]My mother does not want to go out in public, as her belly swells and all. The same thing happened in the wedding ceremony of my big sister, she couldn't see my sister's wedding which affected my mother very much.', [4]Firstly, she could not mingle with children as she always cried, she was a baby anyway, but she was growing, her peers were laughing, playing, going to parks, visiting neighbors, but we couldn't go anywhere. We were always at home, we were always at home. Neither she become a normal kid nor I could make her live a normal life.'

Limitations to patients' social life

3.3.2. Mixed Relationship

[4] When I took him to hospital in my arms and everybody asked ‘ Why is the color of this kid like this, what is wrong with him?’	**Fear of being infected by the illness**

3.3.3. Emotional Changes

[3]‘I mean there was this thought that ‘I am going to die.’	**Fear of death**
[5]Then organ transplantation was spoken, she came back home, it was then she first cried, I mean if organ transplantation is not done then she will have a limited lifetime. She will have difficulty during the rest of her life.’	**Feeling down**
’blessing before they went into surgery, [1]You know there was this word my mother told me ‘if I die God forbid, don’t you ever leave your treatment unfinished, you recover and get better my child. Thank you for everything you did, but you never leave your treatment unfinished!’	**Patients need theirloved ones**

3.3.3.2 Positive Feelings

[11]We keep coming here once a week for1.5 months now, he has this smile on his face. [16]’At least he is got this smile on his face now. This is good enough for me.	**Feeling happy**

3.3.4. Improvement in Life

[12] She is doing what all 6 month old babies should do. But now touch wood she is all upright before us.	**Growing up**
[16]He recovered from hepatitis right now. [12]He didn't have any trouble... He sleeps, wakes up without any problem … He eats very good sometime, he doesn't in others.	**Active**
[11] she can cuddle her children, grandchildren.	**going out in public and getting socialized**