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Investigation of Adaptation After Liver Transplantation Using Roy's Adaptation Model

Introduction

Liver transplantation (LT) has become a treatment of choice for patients with end-stage liver disease and is the most effective treatment for many patients with acute or chronic liver failure (Bufton *et al.*, 2008). LT in Turkey began in 1988 (TNS, 2012) and currently there are 23 transplantation centers, where a total of 592 LTs were carried out in 2008. Turkey has a high rate of living related donation (66.5% of all LTs) (The Ministry of Health of Turkey, 2008) in contrast with the United States of America, where less than half a percent of all donor livers come from living donors (OPTN, 2010). Liver living donors in Turkey are mostly first degree relatives such as parents, siblings or children, and therefore living-donor liver transplantation (LDLT) is affected by family dynamics for both recipients and donors (Watanabe & Inoue, 2010).

Patients experience an adaptation process after LT (Mize & Cupples, 2004). Numerous studies report that liver transplant recipients (LTRs) undergo problems with their physical, psychological and social well being after transplantation (Ordin *et al.*, 2011, Forsberg *et al.*, 2000; Bean 2005; Nilsson *et al.*, 2008; Watanabe & Inoue, 2010). Together with recovery of physical conditions after LT, patients reportedly experience fatigue, pain, weight loss as well as impairments in memory and thinking processes (Forsberg *et al.*, 2000). LTRs whose liver failure was related to hepatitis B (HBV) and C (HCV) virus infection experience poorer recovery outcomes than LTRs associated with other causes of liver failure (Aytaman *et al.*, 2010). Hypertension, diabetes and obesity associated with immunosuppressant therapy may develop in the long term post-LT period (Lui & Thomas, 2007). There is considerable evidence of other problems that LTRs experience including pain, changes in appetite, nausea, vomiting, infection, loss of concentration, becoming hairy, moon

face (Cushingoid), bruising, loss of sexual desire and depressive feelings (Moons *et al.*, 2003; Estraviz *et al.*, 2007; Drent *et al.*, 2009; Kugler *et al.*, 2009).

Psychologically, although LTRs feel lucky because they have survived (Bean, 2005), they also experience fear of organ rejection, depression, anxiety and fear of impairments related to their future health. Several studies have reported patients with LDLT experience greater negative affects (Fukunishi *et al.*, 2002; McGregor *et al.*, 2009; Watanabe & Inoue, 2010).

Socially, patients may return to work after LT and their familial relations improve (Bean, 2005; Watanabe & Inoue, 2010). However, many patients experience reduced competence in their work, economic problems and social isolation (Forsberg *et al.*, 2000, Bean, 2005). Interaction with other patients and participation in support groups can positively affect the patients' adaptation after transplantation (Robertson, 1999; Sargent & Wainwright, 2007). LTRs need psychological (Fukunishi *et al.*, 2002; McGregor *et al.*, 2009) and social support from both their families and health professionals (Forsberg *et al.*, 2000; Jones, 2005). LTRs need information related to rejection, activities of daily living (Forsberg *et al.*, 2000), drug therapy, long term care and the possible physical and psychological problems (Myers & Pellino, 2009) associated with their LT.

Research exploring the experiences of LTRs predominantly relates to samples of people living in European, North American and East Asian countries. We were unable to locate any research that investigated experiences of LTRs in Turkey, which is located in West Asia. Additionally, no work was identified investigating the post transplantation adaptation processes of LTRs using a nursing model.

Therefore, the purpose of this study was to explore experiences of LTRs using the Roy Adaptation Model (RAM) and a qualitative approach. We aimed to contribute to the further

development of RAM (Perrett, 2007; Roy, 2009). The results of this research will assist in developing nursing practices based on adaptation process of LTRs.

Aim

This study explored adaptation of LTRs using Roy Adaptation Model following transplantation.

Conceptual Framework

Roy Adaptation Model

The study was guided by RAM (Roy, 2009). RAM depicts the individual as an adaptive system who interacts with a constantly changing environment, including focal and contextual stimuli. Focal stimuli are the internal and external factors that immediately confront the person, and in this study was LT. Contextual stimuli are all other factors present in the situation that contribute to the effect of the focal stimulus and in this study were socio-demographic characteristics (age, gender etc.) and liver disease characteristics of LTRs (Roy, 2009). (Figure 1).

Behavior in RAM refers to internal and external actions and reactions of people to stimuli. Behavior is categorized into four modes of adaptations: psychological, self-concept, role function, and interdependence. The physiological mode is the manifestation of interactions as physiologic activities of all the cells, tissue and organs and was represented in this study by physiologic components of adaptation. Self-concept mode has been identified as psychic and spiritual integrity, composite of beliefs and feelings and deals with interpersonal relationships. The self-concept mode was represented in this study by the emotional component of adaptation. The role function mode focuses on the roles that individuals have in the society and was represented by the functional components of adaptation. The interdependence mode deals with social and relational integrity as well as provision and receipt of social support. For the purpose of this study, the interdependence mode was

represented by the social components of adaptation. In RAM, behaviors are considered as either adaptive or nonadaptive/ineffective. Adaptive behaviors promote the integrity of the human system in terms of the goal of adaptation. Therefore, ineffective behaviors are those that neither promote integrity, nor contribute to the goals of adaptation and integration of people with the earth (Roy, 2009).

Method

Design

A descriptive qualitative design was used for this study and data were collected from LTRs in either individual or group interviews.

Participants

In this study, purposive sampling was used (Sandelowski, 2000; Neergaard *et al.*, 2009) to recruit participants who met the following inclusion criteria: aged between 18 and 65 years; willingness to participate in the study; no record of psychiatric disease; being native Turkish speaker; and experiencing their first transplantation. One of the investigators (YO) provided information to LTRs when they attended out-patient clinic. Twenty one patients volunteered to join the study, 16 males and 5 females who were aged between 19 and 61 years (mean: 48.67, SD: 11.35). Participants joined the study between 1 and 52 months post LT with a mean time of 16 months. Demographic data of participants were regarded as contextual stimuli.

Data Collection

Data were collected from May 2009 to February 2010 at a transplant outpatient department of the university hospital in Izmir, a big city in western Turkey. Initially focus groups were planned for data collection, but only one focus group interview was undertaken with seven participants. Due to practical difficulties participants faced in attending group work, individual semi structured interviews were conducted with the remaining 14 participants.

Interviews were conducted with participants in a private room at the outpatient department. The focus group interview lasted 1 hour 15 minutes, and individual interviews were 20 to 60 minutes in duration. The first and second researchers collected data in the focus group interview and the first researcher conducted all individual interviews. The interviews were audio-taped and transcribed verbatim by the first author.

Instruments

Two forms were used to determine adaptation behaviors of LTRs and stimuli affecting the behaviors of LTRs in this study.

A Background Data Form, developed by the investigators for this study, was used to record demographic and liver disease information. The form included questions about demographic data (age, gender, marital status, education level and occupation) and clinical data (liver disease etiology, donor type, living donor relation, LT time and immunosuppressive therapy).

Adaptation after liver transplantation interview form was used to determine the LTRs adaptation responses to LT. The form was developed by the investigators based on the literature (DeSanto-Madeya *et al.*, 2006; DeSanto-Madeya *et al.*, 2009). The form included seven open-ended questions; four open-ended questions were about how LTRs felt physically and emotionally, effects of social roles and social relations after LT. Three open-ended questions were about LTRs' support needs and knowledge needs and people who supported them during and after LT.

Ethical Considerations

Written consent was obtained from all participants prior to data collection. Approval was given by the administration of the hospital where the study was conducted as well as from the Ethics Committees of Dokuz Eylul University and School of Nursing.

Data Analysis

Data were coded using deductive content analysis as recommended by Elo and Kyngas (2008) where the structure of analysis is operationalized on the basis of previous knowledge and theory testing. Deductive content analysis was used to identify and categorize the LTRs responses. The responses were categorized according to the four RAM modes of adaptation (physiological, self-concept, role function, interdependence). The deductive content analysis process required development of structured analysis matrices, using words, phrases, or sentences that express a response within each question unit, coding data according the categories (adaptive and ineffective behaviors based adaptation modes of RAM), model testing and comparisons to determine correspondence with the study questions as well as reporting the analyzing process and the results (Sandelowski, 2000; Elo & Kyngas, 2008).

Rigor

Two people analysed the data independently. The first author and another person with expertise in qualitative research independently identified the main themes and then compared their analyses and reached an agreement on the findings. Credibility was established by two authors having considerable clinical experience with people requiring liver transplantation. The first author had 5 years experience and the second author 10 years experience. All authors had been trained in qualitative methods. The third author had expertise in qualitative methodology and provided critical review of the methodology.

Findings

Experiences of physical, emotional, functional, and social adaptation to liver transplantation were categorized according to four themes based on the four modes of Roy Adaptation Model. Each theme included both adaptive and ineffective behaviors of participants identified at different times during their recovery process after LT.

Physiological Mode

Roy described the physiological mode as focusing on maintenance of basic human physiological needs. Physiological adaptation requires knowledge about the human body and the pathophysiology underlying the disease processes, and the adoption of behaviors directed toward resolution of physical and physiological problems (Roy, 2009).

In this study, LTRs noted that they experienced problems concerning the physiological mode more frequently in the early period of liver transplantation (first three months). Most of the LTRs experienced ineffective behaviors with digestive system changes including excessive appetite, nausea, and vomiting. Several LTRs reported oliguria, diarrhea, constipation, and abdominal distention. Also, most of the patients explained that they had sores in their mouth in the first three months. They thought these problems were due to the medications they received, but admitted that they did not know the side-effects of the medications well. Most of the LTRs also noted that they did not know much about the diet they had to follow, the medications they received and other things they had to be careful with after transplantation.

“I know some drugs make me feel sick. But I am not sure that the drugs I used cause the problems.”

The LTRs whose living donors were their family members reported that they followed all the recommendations made by the transplantation team and experienced fewer problems since they felt responsible to their donors.

“I take care of myself and my medications well because of the sacrifice my mother made for me” (A LTR whose living donor was his mother).

Some patients explained they took preventative actions against infections (such as using a face mask) especially during the early period after LT and, therefore, they did not have any infections. Most of the LTRs reported that they had upper respiratory system infections in the winter months and that they did not know why they were at risk of infection

and what precautions they needed to take to prevent these infections. Two LTRs said that they experienced organ rejection although they took their medications regularly.

“What is important for me is not to catch an infection? How can I protect myself from infection best?”

LTRs mostly experienced pain at the incision area, wound drainage area, and in their back and joints after LT in the early stage. They reported that they made less physical effort to decrease their pain. Also, LTRs reported pain reduced as the post LT period passed because edema and ascites disappeared. Several patients, however, said that they considered post-transplantation pain as normal.

“I had an important operation and my liver was changed. It is not unusual to have that much pain. I can ignore it”.

All patients experienced fatigue in the early term after transplantation due to daily activities and frequent medical appointments. They in the long term after transplantation experienced some level of fatigue due to travel to the liver transplant center from the city they lived in. LTRs described physical limitations and sleeplessness because of their pain and anxiety.

“I feel much better compared to my cirrhosis period. My energy is unbelievable. I am surprised at myself, too.”

“...I am getting tired easily. For example I am going to the kitchen and do something but then I tire.”

Several LTRs noted that they had hypertension after transplantation, but that they did not know the cause of their hypertension and the things they had to be careful with. In addition, many patients reported that they became forgetful, which had a negative effect on their life. They also noted that they had difficulty in concentrating on and understanding things.

“The most disturbing is forgetfulness for me. I simply don’t remember whether I have taken my medications or not. I don’t remember anything.”

One patient was diagnosed with diabetes mellitus after LT. This patient said that he did not know why he developed diabetes, nor what he should be careful with.

Self-Concept Mode

The self-concept mode refers to how a person views himself or herself. This mode emphasizes psychological and spiritual aspects of the person. Self-concept mode is viewed as having two subareas, the physical self and the personal self. The physical self includes two components, body image and body sensation. Body image refers to how a person feels about their physical appearance and bodily functions. Body sensation refers to the composite of beliefs and feelings held about oneself (Roy, 2009).

A number of LTRs expressed feeling powerless and experienced negative changes including excessive weight gain, becoming hairy, edema and spots. They told that they were anxious since they did not know the causes of these problems. However, several LTRs noted that jaundice, skin eruptions, bruises and abdominal ascites decreased compared to the pre-transplantation period. They were satisfied with their physical appearance and felt better.

“My complexion got fair after transplantation. It revived and it is very nice now.”

While many LTRs expressed a considerable improvement in their sexual life in the long term, some LTRs experienced deterioration in their sexual life.

“I have no sexual life after transplantation. My wife tolerates it, but I feel bad. ”

Most of the LTRs felt as if they were reborn and wanted to care for their health more in response to the sacrifice made by the donors. Participants expressed that positive thinking would affect their health positively, and hoped that they would continue to improve as post-LT time passed. Many participants reported an increased interest in religious practices after LT.

“I am very well psychologically. I feel like reborn.”

“... I bought a Koran and I am reading it. I became interested in it after the operation.”

Some LTRs experienced fear of infection and rejection, as well as anxiety due to their drain tubes and medical appointments. They explained that they had fear of rejection although they were careful with their medications and follow-up appointments. They added that they wanted to know the signs of rejection and thus check whether they had it or not.

“I am panicking about everything and I feel very close to death. I feel that something bad may happen any minute and that I develop rejection. Nobody can make sure that rejection will not develop.”

LTRs were also worried about families of deceased donors and the health of living donors (especially when the donors were children) and felt guilty. While some recipients whose living donors were their family members struggled more to survive due to the sacrifice made for them, others felt regretful due the harm likely to be experienced by their donor. Additionally, LTRs emphasized their experiences of anxiety due to their unemployment and the financial effects after LT, and the expense of LT treatment and the distance needed to travel to LT centers.

LTR with Deceased donor: “When I think about the deceased donor’s family, I say I wish it had never happened. I always think about her family.”

LTR with Living donor: “My son gave his liver to me, which affected me psychologically. Now I regret it and I feel as if I die every.”

Role Function Mode

The role function mode encompasses development, performance, and mastery of a person’s roles. These include primary roles (age, gender), secondary roles (husband, teacher), and tertiary roles (association member) on the basis of his or her position within a society (Roy, 2009).

Only two LTRs were able to continue their previous (before LT) employment in their secondary roles and they reported improved work performance. These patients explained that they felt better and that their financial problems decreased after they returned to their work.

“I am working in a government office. I haven’t had any bad experiences at the office.”

Most participants reported that they were no longer being employed after LT. The reasons offered included inability to work due to fatigue, frequent medical appointments and the risk of infection at the workplace. Some participants took disability retirement. These patients expressed their need to be informed about their employment status and what kind of jobs they could be hired for after transplantation.

“I had a job in the past. They fired me after the operation. I am not half person and I am healthy, but I can not find a job now due to liver transplantation, so I have big financial problems”.

Interdependence Mode

The interdependence mode focuses on the close relationships of people, especially two specific relationships. The first relationship is with significant persons who are the most important to a given person. The second relationship is with support systems, that is, others contributing to meeting interdependence needs (Roy, 2009).

LTRs reported improved intra familial relations and also developed communication with other LTRs. A special affection between living donors and the families of the deceased donors was created in most cases. However, all the LTRs whose employment status was affected after transplantation reported that dynamics in their families were distorted due to financial problems.

“I met someone who had undergone an LT when I was staying in hospital and it affected me positively. I like talking to the people who have experienced the same difficulties as me”.

LTRs also noted that they experienced social isolation since they wore a mask to avoid risk of infection. All the patients whose residence was at a distance from the transplantation center, reported that they felt lonely. These patients rented a flat near the center, to be able to attend frequent follow-up appointments in the first six months of transplantation.

“After discharge, my family and I rented a flat near here since I had to have frequent follow-up appointment. We don’t know anyone here and we feel lonely.”

The patients reported that they were supported by their families and health professionals (doctors and nurses), relatives, friends and other LT patients in the LT process. They noted that they needed more support from their doctors and nurses in the early period of transplantation.

“My family provided me with strong support after transplantation. God bless my doctors and nurses for their support.”

LTRs identified a need for physical care because they had difficulty in personal care activities due to pain and fatigue; particularly during the early post transplantation period. All the patients reported that they needed psychological support a lot after transplantation.

“I think a psychologist should be available for the transplantation patients because we are different from other patients.”

Additional support was identified as needed in the area of financial advice related to the length of sick leave after LT and its effects on salaries, the treatment expenses, transportation expenses, working conditions of the living donors.

“Since I couldn’t work and had to have a work leave in the first six months of transplantation, I was paid less, which I hadn’t known about it. We need to be informed about this issue”

Discussion of Findings

The results of the study will be discussed in the light of the adaptation modes of RAM.

The Physiological Mode

In this study, increased appetite, diarrhea or constipation, nausea, and vomiting were expected symptoms due to immunosuppressive treatment (Bufton *et al.*, 2008; Moons *et al.*, 2003; Estraviz *et al.*, 2007). Education and counseling play an important role in management of these symptoms and enabling patients to gain their autonomy and to adapt to their new life (Sargent & Wainwright, 2007).

Consistent with the results of this study, it has been reported in the literature that LTRs mostly experienced tiredness, decreased physical activity and sleeplessness (Forsberg *et al.*, 2000; Bean, 2005; Dudley *et al.*, 2007; Kugler *et al.*, 2009). This study revealed that the patients expected nurses to fulfill their self care needs due to their tiredness and physical limitations. Failure to satisfy needs of physical care, knowledge and support can be explained by the insufficient number of nurses (about 15-20 patients per 1 nurse) and lack of specialist transplant nurses in Turkey. Specialist organ transplant nurses provide special care, knowledge and support needs of transplant recipients and their families during the transplantation process. It is recommended that a certified program for specialist transplant nurses be developed and define the roles and responsibilities of specialist transplant nurses in Turkey.

Repeated infections, rejections and hepatitis are life-threatening in LTRs (Forsberg *et al.*, 2000; Sargent & Wainwright, 2007; Nilsson *et al.*, 2008). The protection dimension of the physiological mode is an important mode where LTRs specific problems are found.

Transplantation nurses should evaluate patients' behavior in this mode carefully and offer education and counseling directed towards promotion of appropriate adaptation behavior among the patients (Myers & Pellino, 2009).

Pain is an important problem which affects physical activities as well as the psychological and employment status of patients. Although pain management is one of the basic nursing practices, the patients in this study reported that they experienced pain frequently. There are a wide variety of factors affecting pain in transplantation patients, and it has previously been reported that LTRs experience pain more frequently than the other transplant patients (Fukunishi *et al.*, 2002). Frequent experiences of pain among the participants of this study can be explained by the anxiety they felt from the thought they may have harmed their living donors, most of whom were their first degree relatives such as their sons and mothers.

Compatible with the literature, we found that few patients had edema, abdominal ascites and bruises (Drent *et al.*, 2009; Kugler *et al.*, 2009). In this study, the patients reported that they had increases in their blood pressures in the long term after liver transplantation. Increased blood pressure is a common cardiovascular problem due to long term immunosuppressive treatment in the (Lui & Thomas, 2007). Additionally, in the neurological dimension the patients experienced forgetfulness, decreased concentration and difficulty in understanding things (Moons *et al.*, 2003). These patients needed appropriate knowledge and support so that they could adapt to their life.

Self-Concept Mode

It is important for nurses to have knowledge about a persons' self-concept because they play a key role in the enhancement of a LTR's self-concept (Roy, 2009). Nurses need to understand and be comfortable with a personal physical-self and related body image, body sensation, and sexuality to support patients in this mode (Roy 2009).

Consistent with the results of this study, previous reports document patients becoming hirsute, and experiencing changes in their body image, especially in their face, with thinning of the skin and loss of facial hair (Drent et al. 2009). These problems are mostly due to immunosuppressive treatment (Bufton *et al.*, 2008). Therefore, it is important that nurses inform patients about the use of medications and management of side-effects of those medications (Myers & Pellino, 2009).

In this study, all the patients noted experiencing financial problems, which can be attributed to Turkey being a developing country where the income per person is low. Since transplantation centers are located in big cities in Turkey, the patients coming from other cities have to pay for accommodation and travel. The patients are offered financial support for travel and provided with a salary given to the handicapped, but they were insufficient. Besides, getting fired after LT has a negative effect on the financial status of the patients. Due to lack of a financial advisor in LT centers in Turkey, LT are not informed about financial problems they are likely to experience. We recommend that specialist transplant nurses should provide counseling for financial problems in the absence of a financial advisor.

The participants of this study felt anxious and disappointed, although they found themselves lucky that they survived. Since there was a dramatic and fast change in the patients' lives, the self-concept mode was affected greatly. The first factor affecting the psychology of the patients is fear of organ rejection or complications and worries about the future (Jones, 2005; Sargent & Wainwright, 2007; Nilsson *et al.*, 2008). Therefore, the patients should be informed about the problems they are likely to encounter and about long term care (Myers & Pellino, 2009). The second factor is feeling guilty or indebted to their living donors or the families of non-living donors (Fukunishi et al., 2002; Watanabe & Inoue, 2010). The patients had strong feelings of guilt when they received their liver from a living donor. This factor is of great importance in Turkey since the rate of living donors is quite

high. In countries like Turkey where the number of living donors is high, patients, donors and their families should be informed about the phenomenon of living donors and the transplantation process (Watanabe & Inoue, 2010) and provided with psychological support (Forsberg *et al.*, 2000; Jones, 2005). The third factor is using many medications in the early post-transplantation period, using medications life-long and living with the side-effects of medications.

Role Function Mode

Concerning the role function mode, most of the patients in this study had to leave their job, find another job or retire earlier than expected. Likewise as in previous research it was often difficult for recipients to continue to work (Bean, 2005; Sargent & Wainwright, 2007; Watanabe & Inoue, 2010). Due to physical and psychological problems and risk of infection, employment status of LTRs is affected negatively. Another problem is that LTRs require leave from work because LT centers are far away from where they live and they have frequent follow-up care in these centers. Financial losses due to work leaves have a negative effect on family budgets and the roles LTRs play in their families. Nurses should offer information to patients and their families about employment status and possible problems after LT.

Interdependence Mode

Comparable with the previous research, this study showed that LTRs' relationships with members of their families were affected and that LTRs experienced social isolation (Forsberg *et al.*, 2000; Bean, 2005; Sargent & Wainwright, 2007). Since the number of patients whose living donors were their family members was high, the degree that the patients' relationships with their family members are affected is important in this study. The relationships with members of their families were most affected during the early post-transplantation period. Therefore, longitudinal studies including the patients, the donors and their families are needed to examine to what extent they are affected. In Turkish culture, it is of importance to visit

patients and their families. After discharge, patients' homes are usually very crowded. However, LTRs do not allow visits due to risk of infection, which has a negative influence on social relationships of the patients.

Communication between LTRs can have a positive influence on their adaptation (Sargent & Wainwright, 2007). Hence, support groups can be offered to LTRs and their families to provide an avenue for social integration.

Study limitations

The study has two major limitations. First, the study was retrospective and cross-sectional. Therefore, further longitudinal studies are needed to expand understanding of the long term adaptation process of the LTRs. Second, we only considered recipients' perspectives. The rate of LT from living donors is quite high in Turkey. For this reason, further studies including recipients, their living donors and families are needed.

Conclusion

The results of this study provide nurses with fundamental data about adaptation behaviors of liver transplant recipients. According to the RAM, nursing process involves evaluation of stimuli and behaviors which have a negative effect on adaptation of individuals, planning nursing activities accordingly and evaluation of the effectiveness of these activities. It was found that patients needed information and support regarding their ineffective behaviors in all modes of RAM. It is recommended that the information and support needs of the patients be met and provided within their social environment by health professionals using a well structured approach. Also, this research clearly demonstrated the interactions among the adaptation modes of the RAM.

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Conflict of interest

The authors have no conflicts of interest to declare

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Contributions of Author's

YO and ÖK were responsible for the study conception, design, data analysis and development of manuscript. YO recruited participants, and collected data. SW significantly contributed to the critical review of the methodology and the development of the manuscript.

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