

The Psychological and Mental Experiences of Living Liver Donors in South Korea

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Abstract

The aim of this study is to investigate the aspect of the psychological and mental experiences of living liver donors living in Korean culture. This study is qualitative research design that applied ethnographic research method through in-depth face-to-face interviews and participant observation. Data was collected from 10 living liver donors of the snow ball method. The results were delineated into 6 domains, 30 categories, and 35 subcategories by theme and the 6 domains include: 'positive emotions', 'negative emotions', 'difficulty in expressing feelings', 'mental difficulties', 'body image damaged' and 'thinking about living organ donations'. An appropriate medical care and continuous and systematic psychological and mental consultation before and after donation for the donors are required and the development and support system for them must be arranged.

Keywords: living liver donors, experiences, psychological, mental, qualitative research

1. Introduction

Liver transplantation is currently an established treatment method for terminal liver diseases or liver failure and was first performed by Starzl in the United

States in 1963. With the use of a new type of immunosuppressant ‘Cyclosporine’ since 1979[1], the results of the liver transplant substantially improved and the demand for liver transplants has continuously increased due to the increased survival rate.

In Korea, a living donor liver transplantation was conducted for a 9month old biliary atresia patient successfully in 1994, and the first living donor liver transplantation for an adult patient was conducted successfully in 1997.

Living donor liver transplantation(LDLT) can select healthy donors and reduce the ischemia of the transplanted liver to lower tissue damage, and because it is achieved between family, it has various advantages[2]. Furthermore, the recipient does not have to wait long and transplantation can be performed on schedule before the recipient’s state of health worsens. Meanwhile, there are also a number of disadvantages. First, the healthy donor must receive a surgical operation called major liver resection. Second is that there is a 10-20% chance of various surgical complications for the donor. Third is that though rarely, there have been extreme cases such as death of donor [1]. In the case of liver transplantation, LDLT is most commonly performed in Korea and 1/4 of all LDLT performed worldwide are carried out in Korea [3].

According to the statistics from Korea Network for Organ Sharing(KONOS)[4], 10,836 cases of liver transplants were conducted by March 2014. Among them, 2,366 cases were from brain dead donors while 8,470 cases were from living liver donors. However, for religious, cultural, and other reasons, the brain dead organ donation is restricted in Korea[7].

Living liver donors may experience fear and terror before operation and there is a high possibility of the occurrence of serious complications such as bile leak, bleeding, portal vein thrombosis, wound infection, seroma, atelectasis, pleural effusion, cicatrix, hernia, and even death[5]. Although most of them have to overcome these various experiences, the management of living liver donors is limited to physiological care during their hospitalization and most of them must solve their potential problems for themselves without receiving any appropriate help after being discharged[6]. This indicates that the success rate and surviving rate have been focused on while our interest in the mentalpsychological experiences of living liver donors has been neglected[7].

Currently in Korea, there is a lack of brain-dead donors, but even if there was an increase in brain-dead donors, it is expected that LDLT will continuously increase like the United States or Europe. Therefore, true understanding and investigation on the psychological and mental experiences of LDLT when surviving is necessary.

Accordingly this study is to find out what kind of experiences these living liver donors have gone through in their daily lives living in Korean culture to develop the appropriate care, management, and education programs and provide required basic data to develop the necessary support system and policy for liver donors.

2. Method

This study is qualitative research that applied ethnographic research method to investigate what kind of psychological and mental experiences living liver donors experience in their daily lives living in Korean culture.

10 informants for this study were selected from the members of *café.daum.net/liverdonor* who voluntarily participated in this study. Their average age was 31.6 and donated part was right lobe of liver. Data collection was conducted through participant observation and indepth interviews from July 2010 to March 2011, 2~3 times of interview per person were conducted for individual in-depth interviews and each interview required 1~3 hours. The place of interview was pre-selected to provide comfortable time without any interruption for both informant and researcher and it was recorded by smart phone after receiving written consent. After interviews, memos were made for lacking areas and were supplemented at the second interview or via internet or phone.

Researchers tried to not lead the answers or give hints intentionally during the interviews and data was collected until the data was saturated.

To protect the ethical aspect of the informants, the purpose of study, method of study, confidentiality, and cancellation of interview were explained to them.

3. Data Analysis Methods

Each interview was recorded and memo was done during interviews. After each interview was completed, the researcher immediately wrote in the study note in handwritings. The recorded and handwritten data were transcribed and organized.

Data analysis and data collection were a simultaneous ongoing process and they were analyzed based on the analysis method suggested by Spradley[8], and consulted by 2 professors of nursing who had experience in the qualitative research, 2 professors of education and 2 medical specialists. Finally it was confirmed validation process by 3 major informants.

4. Results

The psychological and mental experiences of living liver donors living in Korean culture were delineated into 6 domains, 30 categories, and 35 subcategories by theme and the 6 domains include: 'positive emotions', 'negative emotions', 'difficulty in expressing feelings', 'mental difficulties', 'body image damaged' and 'thinking about living organ donations'(Table 1).

Table 1. Psychological experiences of living liver donors living in Korean culture

Domain	Category	Subcategory	Verbatim	
Positive emotions	Happiness	Joy greater than pain	“Just as there is pain and joy of giving birth, there was also pain, but I think the joy was bigger (#7)	
	Pride	Pride out of saving a life	“Proud of donating my liver...”(#3) “I felt proud to think that I saved a life.”(#10)	
	Gratitude	Gratitude to medical staff	“I am thankful to the doctor who performed the operation and the medical staff.”(#10)	
Negative emotions	Fear and terror	Fear and terror about surgery	“Honestly, it felt uncomfortable and I was anxious and did not want to even think about it (#1) “I felt scared.” (#9)	
	Emptiness	Emptiness out of donation	“I felt more emptiness than a sense of fulfillment of donating my liver.”(#3)	
	Perplexity	Cholecystectomy known after donation	“My gallbladder was removed without me knowing. I felt perplexed.”(#7)	
	Unfairness	Unfairness about insufficient support	“I think it is unfair not to give any benefits to the donor.”(#5)	
	Regret	Regret about donation	“If only I hadn’t had that surgery then...” (#5) “I didn’t know that I would regret it this much. I didn’t think much of it at the time...”(#4)	
	Sadness	Having no sick leave from work		“It was sad that my discomfort caused by complications due to the surgery was not accepted for sick leave.”(#10)
		Sadness can’t be expressed in words		I have to withstand this pain now until I die. My sadness cannot be expressed in words.” (#4)
	Resentment	Resentment out of insufficient information		“If I had known about the physical side effects, it wouldn’t be so tough mentally. I resent that I wasn’t given information about this.” (#3)
	Sense of loss	Death of recipient		“The loss of family is huge.(#6)
	Frustration	Frustration about the changed life after donation		“I felt frustration and depression”(#8)
				“I was so frustrated when my body would not recover and when I lost my job.”(#10)
Concern	Concern about health		“I get concerned when I feel sick. I think that something has gone terribly wrong...”(#8)	
Sense of alienation	Focused interest on recipient		“The donor also underwent a huge operation but all the guardians go to the recipient...”(#5)	

Hurt	Hurt from receiving notice to quit	“I put my one and only life on the line, but I felt abandoned(advised to resign) and was hurt.”(#10)
Disappointment	Feeling disappointed by recipient	“I feel disappointment to the recipient.”(#7)
Betrayal	Feeling betrayed by recipient	“I felt betrayed when I saw the recipient drink and smoke.”(#4)
Distrust	Distrust of the media	“I don’t believe TV anymore. It tricked us by showing a donor saying that nothing was wrong after the donation.”(#4)
Difficulty in expressing	Difficulty in open mind	“We can’t tell the recipient where we are hurting. Even if we are hurting. We have to be careful.”(#4, 7, 10) “Honestly, I didn’t. I just didn’t”(#8) “I can’t open express how I feel. It’s probably the same for everyone, but especially if the family member is the recipient.” (#9)
Depression	Depression from slowed physical recovery	“I thought my body would recover, but it didn’t. It made me feel depressed so I didn’t leave my home for four months after the operation.”(#10)
Mental trauma	Depression from helplessness Mental shock after liver donation surgery	“I get really depressed. The loss of energy makes me feel really depressed.”(#5) “The pain and hard memories gave me mental trauma and I am afraid that I might have to suffer that pain again”(#1,10) “Going through surgery is not a good memory. Honestly, it was a nightmare...” (#4) “I cried alone thinking about the fear after waking up from the surgery.”(#3)
Personality change	Feeling nervous and anger	“I get really irritated and frustrated.(#4) “I easily get angry after the transplantation.” (#10) “I find myself talking filled with irritation.”(#8)
Sleep disorder	No deep sleep	“Even after two years since donating my organ, I can’t sleep well and even when I do sleep, it feels like I didn’t sleep properly.”(#4)
Reduced personal ability	Reduced desire and confidence Poor concentration and judgment Amnesia and loss of memory	“I get tired easily and I lose desire and have reduced confidence over my health.”(#4, 7) “When I study, my concentration and judgment is not the same. I think that I might have become stupider.”(#5) “I have really severe amnesia.”(#3) “I feel like I have amnesia and my memory worsened for eight months after the transplantation.”(#10)

Body image damaged	Damaged body	Difficulty in accepting damaged body	“It took a long time to accept the physical changes after the transplantation. I thought I would recover fully. But, it’s been three and a half years, but I still can’t accept the damaged parts.”(#10)
	Defensive posture	Difficulty when using public bath Defensive posture from scar	“People stare when I go to a public bath so I just don’t go.”(#1, 3, 8) “I have a defensive posture because of my scar even when I have relationships with the opposite sex.”(#10)
Thinking about living organ donation	laboriousness	Hard than military life	“Liver donation is not something small that you should do instead of going to the military. Going to the military would have been better.” (#4) “The body is priceless so it would be better to go to the military again.”(#8)
	once in a lifetime	can't do never again once more in a lifetime	“I would never again donate a liver.”(#6)
	Living organ donation is Difficult	Organ donation is not easy between others	“I’m able to go through with it since it was my parents. I would not be able to donate my organ to others.”(#2)
	Careful choice	Careful choice when the determination of liver donation	“Donating livers is not something you should do without thinking through it thoroughly...” (#3)

5. Discussion

This study completed a close investigation of the experiences of living liver donors through in depth interviews and participant observation what and how they experienced in their daily lives.

The results of psychological and mental experiences of living liver donors felt positive emotions that Happiness, Pride, Gratitude. But the results of this study confirmed that they had more negative experiences than positive ones in the psychological and mental aspect. Haruki[9] argues that the mental burden of the donor is great because the surgery is intended to remove the part of an organ from a healthy person adding that they mostly have various psychological and mental problems. And this study has proved his argument. When the recipient died after transplantation, most donors felt frustrated And Shibata and others, Shibata and others[10] report that donors feel anxious about their bodies after surgery and sometimes feel anger and depression.

In a study on the mental state of liver donors who survived, Hayashi[11] of Kyoto University reported that there were symptoms of anxiety and depression before the operation. And it is similar to our study results. In addition, Hukunisi and others(citation by[11]) report that 10% of donors are diagnosed as depression one month after the surgery. Shibata and others[10] reported that the anxiety and conflicts of donors was considerable after conducting mental interview and psychological examinations at a clinic for liver donors. Due to such reasons, the importance of communication between the psychological clinic and the liver department and ward staff was pointed out. Yoo and others[6] report that donors experience psychological difficulties due to the wound after surgery regardless of sex, age, and marital status, which is the same as the results of our study. The above contents are similar to the negative emotions, physical damage and psychological difficulties of this study.

These uncertainties arise when the control and predictions are impossible and are followed by physical and psychological pathological phenomenon when they become serious. And they must be arbitrated in early stage because it will affect recovery after donation negatively. This study has also found out that donors felt sorry about the attitude of recipients. This finding may be attributed to the individual character of each recipient but it is also considered that donors feel left out when most attention and interest are focused on the recipient. In particular, LDLT is an operation that extracts an organ of a healthy person, and thus has a huge psychological load on the donor. Due to such reasons, Shibata et al.[10] reported that by the doctor working with the ward nurse to provide sufficient explanation before the operation, the anxiety of the donor could be reduced considerably.

Like this, it is considered continuous psychological and mental follow up management for donors not limited to the care of the recipient is required because they experience a lot of psychological and mental difficulties. And more communication efforts especially between doctors and donors including between donors and recipients and their families are needed to alleviate their psychological and mental problems[7].

6. Conclusions

This study was conducted to identify the mental and psychological experiences experienced by donors in their everyday life in Korea's culture and applied daily life technical methods as a qualitative study for the appropriate management of liver donors and to provide basic data needed for the development of educational programs, support plans, and policies.

As the results, such as 6 domains include 'positive emotions', 'negative emotions', 'difficulty in expressing feelings', 'mental difficulties', 'body image damaged' and 'thinking about living organ donations', and the 10 living liver

donors are still experiencing psychological and mental difficulties even years after their donation.

This study was conducted on 10 living liver donors so there are limitations on expanding and applying these research results. However, it is judged to be significant for identifying and revealing the psychological and mental experiences of liver donors. Furthermore, in order to provide appropriate management of people who are or may be liver donors, development of educational programs, and providing basic data needed for support plans and policy development needed urgently for liver donors, this study has high significance.

It is considered that their psychological and mental difficulties may continue in the future and appropriate medical management and continuous and systematic psychological and mental consultation before and after donation is required. And it is recommended to develop various education programs and prepare the support system and policy to protect and help living liver donors. In addition, it is proposed to conduct a full investigation to identify the various experiences and difficulties of liver donors from various aspects.

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