

Comparing the different viewpoints on overseas transplantation demands between genders and roles

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Abstract

This study examined the different demands for overseas liver transplantation between genders and roles from the perspective of overseas liver transplant recipients and primary caregivers.

An exploratory qualitative method was employed using a purposive sample of individuals who had received overseas liver transplantation. We recruited 28 recipients and 29 family members from a leading hospital in Taiwan. Face-to-face semi-structured interviews were conducted with each participant, and data were analyzed using qualitative content analysis.

Three demands were identified across gender and roles:

- (a) sufficient information related to overseas liver transplantation,
- (b) domestic availability of the liver source, and
- (c) supportive policy for receiving continuous treatment and health insurance cover.

Different patterns and meanings related to gender and roles were discussed. Male recipients were less enthusiastic about receiving the overseas liver transplantation. Rather, they complained about losing the economic and decision-making power due to body deterioration after overseas liver transplantation. Their primary need was to increase their dignity and significant position in the family. Female recipients were apprehensive for overseas liver transplantation and required more psychological support and positive experiences from other transplant recipients. Most male primary caregivers required a nursing aide quickly. Most female primary caregivers would engage in the health care task but needed more medical personnel, assistance, and high emotional support from relatives.

This study revealed the common and urgent demands of overseas liver transplant recipients and primary caregivers. The unique demands of recipients and primary caregivers based on their gender and roles were rooted in the potential influences of traditional cultures and modern medicine in an ethnic-Chinese society.

Abbreviations: NHIA = National Health Insurance Administration, WHO = World Health Organization.

Keywords: caregiver, gender, overseas liver transplantation, recipient, role

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1. Introduction

According to the 2018 estimates of the World Health Organization (WHO), there were 325 million chronic hepatitis patients and 1.3 million deaths globally.^[1] Statistics from the Ministry of Health and Welfare of Taiwan showed that chronic liver disease and cirrhosis were ranked 6th and 10th in Taiwan, respectively, over the past 35 years.^[2] Among the top 10 causes of death due to cancer, liver cancer has always been in the top 2 and the leading cause of cancer death among men. In Taiwan, 13,000 people die of liver disease (such as chronic hepatitis, cirrhosis, and liver cancer) every year. This accounts for 8% of reported deaths and severely affects the health of Taiwanese people.

With improvements in liver transplantation techniques and organ storage methods, research and design, use of immunosuppressants, and comprehensive critical care, the 1-year survival rate after liver transplantation have increased from 25% in 1970 to 86% to 93.8% at present. The 5-year postoperative survival rate ranges from 74% to 76.8%.^[3] Therefore, liver transplantation has become an effective treatment for many patients with terminal liver disease. However, due to the influence of Oriental societies, culture, and religion, most Taiwanese have a traditional concept of keeping the whole body intact after death. Thus, viable organs can be considered as straddled between life and death.

Therefore, given a high incidence of liver failure but a low organ donation rate in Taiwan, many patients with terminal liver disease opt for life-saving liver transplant surgery overseas. Family members are core figures that jointly overcome the transplantation process with the patient. Not only do they have the closest social contact with transplant patients, but they also provide essential support as primary caregivers.^[4,5]

“Men are breadwinners, women are homemakers” is a traditional Chinese concept that fosters the belief that men should work hard outside the home while women are only suited to manage the household and educate children. Many women are actively encouraged or forced to abandon their dreams to care for family or sick family members. However, social transformations have resulted in role changes for women in Chinese culture. Although the role of a career woman has emerged, women still play the role of a relative, mother, and primary caregiver. The National Alliance for Caregiving report highlights that the mean age of caregivers is 49.2 years, with females accounting for 60% and males 40%. In addition, an average of 56% of caregivers hold full-time jobs (Whites: 59%, Asians: 61%, Blacks: 52%, and Hispanics: 48%).^[6]

In the past, studies on organ transplantation were mostly focused on domestic transplantation rather than overseas transplantation. The research group also focused on domestic recipients. No study was conducted to compare the individual needs of recipients and their families through different gender and family relationships. It is hoped that the results of this study will enable clinical medical teams to provide appropriate photos for patients and their families according to their own characteristics in accordance with the laws and regulations of organ transplantation Protect.

2. Methods

This study employed an exploratory qualitative design. A purposive sample of overseas liver transplant recipients and their primary caregivers in the family was obtained from a medical center in northern Taiwan. The Tri-Service General Hospital Institutional Review Board approved this study (1-103-05-022). Written informed consent was obtained from the participants. After the researcher explained the purpose and method of the research, the interviewees agreed to provide their experiences and suggestions for the study. Data were collected through face-to-face in-depth interviews and were analyzed using qualitative content analysis. We considered the rigor stated by Lincoln and Guba (1985) and Sandelowski (1986), including credibility, applicability, consistency, and confirmation.

Based on semi-structured interview guidelines, data were collected through in-depth interviews and analyzed using qualitative content analysis. First, after obtaining the interviewee's consent, each interview was recorded and written as a verbatim draft (including the interview situation and the interviewee's mood, movements, and other reactions), as presented in the text. Second, the data was coded based on the study questionnaire. We initially segregated the collected data into units, carefully examined and compared the similarities and differences, and then asked questions about the phenomenon revealed by the data. We perused the entire verbatim draft to acquire a holistic understanding of the interview content, repeatedly examined its meaning, and pondered over the relationship between the content, the research problem, and the indicated meaning. Simultaneously, we recorded the

interviewee's feelings, attention, focus, and use of keywords, and then gave different classification codes to each word-by-word content and location. Third, the relevant attributes were analyzed using the 5 W (What, Why, When, What, How) thinking perspective to examine the main secondary class of the first category of encoded information between the properties and relationships, different coding links and comparisons, and make appropriate reclassification. Fourth, after coding the data in this study, the above analysis was used to group, name, and define the data for this class group, and was summarized in the coding definition list. The research process, including the formation, naming, and description of class groups, can deepen the researcher's understanding of the interview data, assist their consideration of the content of the group, facilitate the future analysis of the data or determine more detailed attributes and orientation, and then assist in developing a more appropriate classification. After continuous analysis and comparison of the attributes and relationships of the conceptual genus, the results were integrated; a complete and detailed description was composed to give new meaning to form a theme.

3. Results

3.1. General information of overseas liver transplant recipients

In all, 28 overseas liver transplant recipients participated in this study, including 23 males (aged between 28 and 76 years with a mean age of 55.8 years at the time of interview; aged between 23 and 67 years with a mean age of 48 years at the time of transplantation) and 5 females (aged between 42 and 72 years with a mean age of 61.6 years at the time of interview; aged between 25 and 66 years with a mean age of 54 years at the time of transplantation). Of the 28 participants, 26 were married and 2 were unmarried. The destinations for overseas transplantation were cities in China; 24, 2, and 2 participants went to Tianjin, Guangzhou, and Shanghai, respectively. The mean waiting period for liver transplantation after arrival in Guangzhou, Shanghai, and Tianjin was 6, 18, and 39.8 days, respectively. The mean cost of overseas transplantation was 7.98 million NTD.

In this study, 26 interviewees chose to use a medical institution for their overseas transplantation recommended by other patients, 2 employed a middleman to complete the entire process, while 1 sought information on the Internet. Concurrently, 2 participants sold their ancestral property and houses due to the high cost of overseas transplantation, 12 participants used their family's life savings, and 15 participants had sufficient finances to cover the costs.

3.2. General information of primary caregivers

We interviewed 29 primary caregivers who were family members of the recipients, of which 5 were male (aged between 58 and 75 years with a mean age of 67 years at interview; aged between 49 and 69 years with a mean age of 60 years when accompanying transplant patients) and 24 were female (aged between 34 and 71 years with a mean age of 57.1 years at interview; aged between 25 and 63 years with a mean age of 49 years when accompanying transplant patients). All 29 interviewees were married. The care period for overseas liver transplant recipients ranged from 45 days to 12 years. The relationship between the primary caregivers and overseas liver transplant recipients was categorized as spouse

Table 1**Comparison of demographic data between liver transplant patients and their family members.**

Variables	Variable name	Overseas liver transplant patients	Primary caregivers
Gender	male	23	5
	female	5	24
Age at interview (yrs old)	male	28~76	58~75
	female	42~72	34~71
Age at transplantation (yrs old)	male	23~67	–
	female	25~66	–
Age of accompanying transplant (yrs old)	male	–	49~69
	female	–	25~63
Marital status	married	26	29
	unmarried	2	0
Relationship between caregivers and overseas transplant patients	spouse		25
	father and son		2
	mother and daughter		1
	brother		1
Transplant to country / City	Tianjin, China		24
	Shanghai, China		2
	Guangzhou, China		2
Average waiting time for transplantation (d)	Tianjin, China		39.8
	Shanghai, China		18
	Guangzhou, China		6
Average cost (NTD) of the whole overseas transplantation process			7.98 million

for 25 caregivers, father-son for 2 caregivers, mother-daughter for 1 caregiver, and sibling for 1 caregiver.

The demographic data of the present study indicated that 29 primary caregivers initially held full-time jobs. However, due to the conditions and effects of the recipient's disease (including providing emotional and tangible support to patients, accompanying them for follow-up visits, and paying attention to dietary requirements), 9 female caregivers left their original jobs (1 was a mother and 8 were wives), 3 female caregivers (wives) switched from full-time to part-time jobs, and 12 female caregivers (wives) insisted on retaining full-time jobs and personally caring for recipients. In contrast, all the male caregivers remained in full-time employment (1 was a father, 1 was an older brother, and 3 were husbands). However, they opted for salary deductions and took leaves to obtain more time to care for their relatives. Alternatively, they hired a foreign maid to assist in caring for their relatives at home.

Comparison of demographic data are presented in Table 1.

3.3. Comparison of gender and role demands

Both genders of overseas liver transplant recipients and primary caregivers had common demands during the entire transplantation process and hoped to attain:

a) Sufficient information that is relevant to overseas liver transplantation (including how to select hospitals and physicians, the amount of money required, transportation management, and post-transplant care).

“I hope that the government can provide transparent and open overseas transplantation resources so that more people have a choice. I hope that the government is not so closed as to think that since everybody does it this way anyway, it is okay. For example, if I see liver transplant hospitals in Mainland China or the telephone numbers of agents on the Internet, I would call to inquire.”

“I feel that there can be more transparency regarding the finances, so that we do not have to spend money needlessly. Examples would include transparent information, such as accommodation prices near hospitals and preparations to be made for liver transplant in Mainland China.”

b) Immediate and healthy sources of livers: Domestic availability of the liver source

“I considered liver transplantation from relatives, but the physiques and blood types did not match!”

“Why did so many of us have to travel as far as Mainland China? It is an unfamiliar environment, yet we were compelled to go there. If there were livers available for transplantation in Taiwan, why would we go there?”

“There is an organ shortage in Taiwan; there are none. If there were organs available in Taiwan and the circumstances were the same, and you asked me to choose, I would definitely choose Taiwan. But choosing Taiwan when organs are unavailable here and then waiting for liver transplantation is like waiting to die.”

“The laws are too strict. It is not like I can undergo transplantation as and when I like; the blood types and tissues must match.”

c) Supportive policy for obtaining continuous treatment and health insurance cover (including care considerations after returning to Taiwan: where to go for follow-up, how to obtain anti-rejection drugs for a long period, and whether it is possible to enroll in Taiwan's health insurance).

“If I want anti-rejection drugs that are covered by Taiwan's health insurance after returning to Taiwan, I would require liver transplant documents as proof, but the information obtained from the hospital may be incomplete as many of the fields are often left blank, for example, the type of organ transplant, country, the name of the hospital, and the name of the physician, etc. This causes us to worry about subsequent treatment.”

“The physician field on my transplantation document stated “overseas physician” and after I returned to Taiwan, the Taiwanese hospital could not make an application to the Ministry of Health and Welfare as according to them my document was incomplete. Does this mean that I will have to pay for medicine myself all my life? Liver transplant is considered a major illness, yet I cannot utilize my health insurance!”

Recipients’ physical and mental changes or unexpected recovery status were usually dealt with differently by men and women. Female recipients tended to receive preoperative experience-sharing by successful recipients, companionship, and psychological support from medical staff and family members.

“I am afraid because I have to go to an unfamiliar place for liver transplantation. I really hope that people who have had successful liver transplantation overseas can share their experiences with me personally so that I can have the courage to undergo liver transplantation in Mainland China.”

“If your medical staff could share liver transplantation cases from Mainland China and tell us about the success rate and the probability of complications, it would help us greatly.”

Male recipients were expected to act like men and were responsible for family finances. They tended to act strong and were unwilling to show any weakness. Concurrently, they also hope that the Taiwanese government or charitable organizations can provide a financial subsidy for an overseas transplant.

“Earlier, I was solely responsible for the finances of my family. Now, I am not only unable to go to work, but also require my family members to raise money for me to undergo liver transplantation.”

“I was once the decision-maker in my family; I made all the decisions. Now, I am no longer in that position.”

Concerning caregivers, female caregivers tended to accept caring for the transplant recipient as their responsibility. When the relationship was that of spouse or mother-daughter, female caregivers tended to take more care work than their male counterparts. They also spent more time accompanying and assisting transplant recipients in releasing negative emotions. Therefore, female caregivers required more emotional support and affirmation from medical staff and assistance in seeking care resources to help reduce their care burden.

“Perhaps my husband does not trust other people, and his siblings are unable to share the burden. This is really troubling, unless we hire a nurse. However, we have spent so much money on liver transplantation, and it is difficult for us to fork out more money to hire a nurse who costs 2000 NTD a day. I wish to escape this period so that I do not have to see his suffering every day. But I have no choice as I am his wife.”

“I do not know why, but she just does not feel well. I have to wake up and follow her when she is not feeling well. This makes me feel like I have worked a night shift. Sometimes, I find it difficult to cope with and wish I had someone to complain to, but she is my daughter and I have to take care of her!”

The findings for male caregivers suggest that if the relationship is a father-son relationship, they hope for assistance from medical staff to enable them to readjust their pace of life.

“I hired a special nurse because I am not a professional nurse myself and wanted my son to receive the best care. I was afraid that I was unable to take proper care of him, which added to his suffering. I feel that this was the best option.”

With a sibling relationship, they hope that the hospital can help to apply for a nurse or periodic visits by a volunteer to lessen their care burden.

“I do not have professional knowledge. These nurses know how to take care of patients who have undergone liver transplantation, so I hired them.”

4. Discussion and conclusion

The inception of Taiwanese National Health Insurance in 1995 has helped many patients with major diseases cover medical costs. According to statistics from the National Health Insurance Administration (NHIA), the health insurance cost of medical treatment after organ transplantation is 2.3 billion NTD per year, including the average monthly cost of anti-rejection drugs for each transplant patient (19,000 NTD). To prevent the NHIA from being an accessory to organ trafficking, the Taiwanese government has stipulated that patients will not be eligible for anti-rejection drugs under the health insurance if their overseas organ transplantation was not declared. Both male and female recipients in this study worried whether the organs they received were illegal and were unable to obtain official and legal overseas transplantation documents (including the type of organ transplanted overseas, country, hospital, and physician). In this study, 3 recipients mentioned that the documents submitted by them to the NHIA were incomplete or contained omissions. They are currently paying for anti-rejection drugs themselves, which results in financial strain. In addition, 25 recipients mentioned that they could obtain the necessary documents by paying additional charges.

The Confucian culture has deeply influenced traditional male and female roles and tasks in Chinese societies. One such traditional stereotype is that of men being the breadwinner and head of the family. However, the male recipients in this study were physically weak after transplant surgery and required family members to care for them. In addition, their accumulated savings were used for the surgery and made them feel lost. Although male recipients were unwilling to share their problems with family members, they would seek private financial support or subsidies from government or non-governmental organizations on the Internet. In contrast, female recipients were willing to engage in caring activities but sought emotional support and psychological support through their interpersonal relationships.

The health status of both caregivers affects or even improves the physiological, psychological, and mental status of patients.^[5] If primary caregivers have positive thoughts and possess a good and strong support system, they will be able to help recipients through their recovery and long-term care. However, primary caregivers often have a shortage of information on transplantation-related care and therefore lack sufficient care techniques and knowledge to provide basic care. This results in low confidence and inadequate preparation. In this study, all 29 primary caregivers had insufficient knowledge and skills in post-transplantation care. They experienced caregiver stress due to the volume of, and cumbersome, transplantation care matters.

Terminal liver disease patients can survive because of liver transplantation, but the waiting period for a transplant is very long. Therefore, this study not only reflects the demands of different genders and role relationships of transplant recipients and primary caregivers in Chinese societies but also reflects the urgent demand faced by the Taiwanese people.

At present, countries all over the world emphasize that “the acquisition, transplantation and distribution of organs should conform to the principles of altruism, independence, fairness and justice, openness and transparency, and prohibition of trading.” Although Taiwan’s current laws and regulations are implemented in accordance with the above principles, due to the traditional concept of whole corpses reserved by Chinese people, there are still insufficient organs in Taiwan. How to promote people’s willingness to donate organ through various publicity and education is still a continuous effort in Taiwan. It is suggested that future studies should be conducted to compare gender and family relationships between patients undergoing transplantation in Taiwan and their primary caregivers.

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