



Experiences of Living Donors for Small Bowel Transplantation

H.S. Kim^a, Y.S. Yoo^{b,*}, M.-D. Lee^c, and J.I. Kim^d

^aSeoul St Mary's Hospital, The Catholic University of Korea, Seoul, Korea; ^bCollege of Nursing, The Catholic University of Korea, Seoul, Korea; ^cCollege of Medicine, The Catholic University of Korea, Seoul, Korea; and ^dDepartment of Surgery, Seoul St Mary's Hospital, The Catholic University of Korea, Seoul, Korea

ABSTRACT

Introduction. Along with developments in surgical and immunosuppression techniques, the success rate of small bowel transplantation has increased. In Korea, the incidence of small bowel transplantations has increased, and the longest surviving living donor recipient has now survived for over 12 years postsurgery. The purpose of this study was to assess the experiences of living donors for small bowel transplantation before, during, and after the transplantation.

Methods. In one hospital, we conducted interviews, based on open-ended questions, with three small bowel donors. We asked them about experiences during small bowel donation. The living donor's statements were analyzed using interpretive phenomenological analysis.

Results. Donors decided to donate because they felt "sorry for the suffering of a family member" and they had "faith in the medical staff." In the early phase after donation, living donors experienced physical changes in their body, including pain, fatigue, altered bowel habits, and abdominal discomfort. Despite temporary limitations in daily and social activities, support from family members allowed the donors to fully recover and return to normal physical, social, and psychological status. The donors mentioned they experienced love and support from their family, as well as satisfaction and pride from donation, during the entire process.

Conclusion. We hope that the physical, psychological, and social experience of living donors during small bowel transplantation deduced in this study will serve as a foundation for the establishment of an intervention method to provide education before donation and help recovery after donation.

EXTENDED survival of an intestinal transplant recipient was first accomplished in 1987 [1]. Transplantation of the small intestine (ITx) has developed into the standard treatment for patients with intestinal failure with a gradual increase in the number of transplants being performed over the past 2 decades [2]. Due to improved surgical technique and better immunosuppression, intestinal transplantation is now a successful treatment for patients suffering from life-threatening complications of irreversible intestinal failure and total parenteral nutrition [3]. According to the United Network for Organ Sharing, the 1-year survival rate of small bowel transplant recipients has increased to 77.5% [4]. A total of 2782 small bowel transplantations were performed prior to October 31, 2016 [4], and the number of patients in the wait list has increased.

The patient with the longest survival since small bowel transplantation was first performed in Korea has now survived for over 12 years. Because the quality of life of living donor transplant recipients has been shown to be stable after transplantation, there is an increased number of living donors. Until now, most studies on living donors for small bowel transplantation have focused on surgical methods or the role of the donor. Furthermore, information or education provided to the donors was based on transplantation of other organs. Therefore, this study aimed to

*Address correspondence to Yang Sook Yoo, College of Nursing, The Catholic University of Korea, 222 Banpo-daero, Secho-gu, 06591 Seoul, Korea. E-mail: ysyoo@catholic.ac.kr

provide fundamental data for the development of an education program for donors, by assessing the experiences of living donors before, during, and after small bowel donation and subsequent transplantation.

METHODS

Design

This qualitative study aimed to collect and analyze the data, using a Benner interpretive phenomenological analysis [5], and interpret the meaning of the results.

Participants

The participants in this study were 3 out of 4 living donors for small bowel transplantation at S hospital in Seoul between April 9, 2004, and May 4, 2016, who agreed to participate in the study (Table 1).

Data Collection and Ethics

This study had received Institutional Review Board (KC14OIS10289) approval from S hospital of C University. The data collection period was between July 11, 2014, and August 4, 2016. Responses were recorded from individual, in-depth interviews held in a private room during an outpatient visit after being discharged after donation. Responses from the interview were transcribed and analyzed immediately. Each participant was interviewed 2 or 3 times until all required information was obtained, and the average interview duration was 60 to 90 minutes.

Analysis

The results of this study were analyzed using Benner interpretive phenomenology. Texts were interpreted and meanings were explained using 3 analytic strategies including the analysis of paradigm case, the analysis of exemplar, and thematic analysis [5]. The validity of the study was assessed by analyzing the results with an experienced researcher. The analysis was audited by the second author, who read over transcripts and theme tables. Where the authors disagreed, further discussion and analysis of the data were undertaken until agreement was reached.

RESULTS

The interviews of the 3 donors were analyzed and divided into 5 themes (Fig 1).

Prior to Donation of Small Bowel

“I really didn’t take the patient’s condition seriously, and I was complacent. Then our patient’s case really turned out to be the worst case.” The donor regretted vaguely expecting the patient to recover, because the patient’s condition continuously got worse after small bowel resection.

Watching the patient suffer was extremely hard for the donor, and the donor started visiting different hospitals to find out the best possible treatment method. When the donor heard that small bowel transplantation was the best option, he was thankful that he was a suitable donor. Furthermore, the donor was hopeful that the patient may recover at last.

Deciding to Donate Small Bowel

“Professor [doctor] told me that small bowel transplantation is a feasible treatment, and I was actually more relieved after hearing that. At least there is a way to treat.” The donor had faith in the medical staff, decided to donate her small bowel to the patient, and had hopes for the recovery of the patient.

“I was really stubborn. I was thinking, ‘What if transplantation fails?’ and I started crying that my mom might pass away when she could live longer.” The donor decided to donate her small bowel to the patient, but still had fear of transplantation failure. By contrast, the donor was also worried that small bowel transplantation was not covered by insurance and wondered if financial support was available. In addition, there were conflicts and tension while deciding which family member would be the donor. However, the donor mentioned that he felt more comfortable after he decided to donate.

“The hardest procedure for me was inserting the Levin tube in my nose.” The donor had several uncomfortable experiences during the examinations prior to donation. Moreover, the donor had trouble in adjusting her daily lives (for example, taking days off to visit the clinic for examinations) for the donation.

From the End of Donation Surgery to Discharge

“I felt pain throughout my body, a little different from pain from cuts... I needed a lot of painkillers.” The donor experienced physical discomfort such as pain or a temporarily twisted bowel. Moreover, as the donor needed to go to the bathroom frequently, the donor had to be careful about the types of food he was eating. When the donor was relieved of pain, he started to wonder whether the transplantation went well. More specifically, the donor was concerned about the condition of the recipient. The donor had ambivalent feelings about donation, was highly optimistic of recovery, and was concerned for the recipient at the same time.

Table 1. Participant Characteristics

	Sex	Age (y) at Donation		Job at Donation		Educational Level	Spouse Donation		Religion Donation		Time After Transplantation (at the Time of Interview)	Donor-Recipient Relationship
		Before	After	Before	After		Before	After	Before	After		
1	Female	27	37	No	Housewife	≥College	No	Yes	Yes	Yes	10 y	Mother-daughter
2	Male	27	28	Student	Student	≥College	No	No	No	No	9 mo	Father-son
3	Female	49	49	Part time	No	High school	Yes	Yes	No	No	3 mo	Sibling

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