Roller Coaster Marathon: Being a Live Liver Donor

Charlotte C. Cabello
New York Presbyterian Hospital

Janice Smolowitz
Montclair State University, smolowitzj@mail.montclair.edu

Follow this and additional works at: https://digitalcommons.montclair.edu/nursing-facpubs

Part of the Nursing Commons

MSU Digital Commons Citation
School of Nursing Faculty Scholarship and Creative Works. 33.
https://digitalcommons.montclair.edu/nursing-facpubs/33

This Article is brought to you for free and open access by the School of Nursing at Montclair State University Digital Commons. It has been accepted for inclusion in School of Nursing Faculty Scholarship and Creative Works by an authorized administrator of Montclair State University Digital Commons. For more information, please contact digitalcommons@montclair.edu.
The goal of this study was to describe the meaning of being a live liver donor. Whenever the term donor is used in this article, it refers to a live donor of a liver transplant. Liver transplantation evolved from an experimental procedure first performed in 1963 to become the standard treatment for end-stage liver failure worldwide.1 The number of patients referred for transplantation has been increasing, but a concomitant increase in the supply of livers from the traditional pool of deceased donors has not occurred.2-4 According to data from the Organ Procurement Transplant Network, as of May 16, 2008, a total of 16 334 people with end-stage liver failure were listed on the national liver transplant waiting list in the United States.

Live donor liver transplantation (LDLT) evolved because of the shortage of deceased donor livers for children. The success of adult-to-child transplantation led to the application of LDLT to adults. The first adult-to-adult LDLT in the United States was performed in 1998.5-7 As LDLT evolved, research was focused on recipients’ outcomes, surgical techniques, and site-specific program outcomes.3-15 Donor risks, outcomes, and perception of physical, social, and emotional health after donation have been described in quantitative studies.16-23 Researchers have discussed the need for qualitative studies that examine the donor experience.24 Two qualitative studies25,26 examined specific aspects of the donor experience. In a study26 of 15 adult-to-child donors 3 to 10 years after donation, researchers found that donors never really made a decision to donate; rather, it was an automatic leap. In a study26 of 28 donors’ motivation to donate, researchers concluded that the degree or type of coercion and how donors viewed coercion, rather than the existence of coercion, should be the focus for understanding the motivation of donors. The donor experience has not yet been described by using donors’ own words from their own frame of reference. Therefore, in this phenomenological study, we sought to examine the meaning of the experience of being a live liver donor.

**Methods**

This study was conducted at a northeastern, urban, academic medical center. Approval was obtained from the institutional review board. Phenomenology guides the philosophical framework of the study and the study design. The philosophical aim of phenomenology is to provide an understanding of the experiences of the participant. It answers the question, What is the phenomenon that is experienced and lived?27 Phenomenology seeks to uncover meaning and essences in the participant’s experience so that understanding is facilitated. That is, how the donor feels about, understands, and interprets being a donor must be described before patterns of behavior and interactions can be understood. Phenomenology allows for the variation in individual experience while recognizing the similarities within the shared experience of participants.28

The purpose of this phenomenological study was to examine the meaning of being a live liver donor. Six people between ages 27 and 53 years participated. A qualitative, in-depth, semistructured interview format was used to explore donors’ thoughts and feelings about being an organ donor. Five themes were identified: (1) no turning back—how do I live without you? (2) roller coaster marathon, (3) donor network, (4) the scar, and (5) reflections—time to think. At the center of the experience was the donor’s commitment to the recipient. Once donors began the process, they were determined to see it through. The process was complex, and donors received various levels of support from family, friends, health care professionals, and others. After donation, as donors recovered and were able to resume their usual daily responsibilities, they reflected on the impact of the experience and how it changed their view of life. (Progress in Transplantation. 2008;18:185-191)
Table Munhall’s phenomenological method as used by the principal investigator in this study

| I. Immersion                                      | • Completed extensive course work on qualitative inquiry during her doctoral studies
|                                                | • Read literature by the different generations of phenomenologists
|                                                | • Participated in regularly scheduled scholarly discussions to enhance her ability to characterize, understand, and explain the philosophical underpinnings of phenomenology.
|                                                | • Focused on Dr Munhall’s methodology in the context of health care delivery
| II. Coming to the phenomenological aim of inquiry | • Expressed the study aim: To examine the experience of liver organ donors
|                                                | • Described the context of the study
|                                                | • Reflected on her clinical experience in transplant nursing and explicated her assumptions, beliefs, and biases, verbally and in writing with the study team, to decenter self and came to “unknow”
|                                                | • Formulated the study aim as a phenomenological question: What is the meaning of the experience of being a liver organ donor?
| III. Existential inquiry, expressions, and processing | • Increased her awareness of self and others, as applied to the study, by maintaining a personal journal, in which she recorded her reflections, thoughts, and understanding about liver donors
|                                                 | • Contemplated the experiences conveyed by liver donors and recorded these insights
|                                                 | • Attended transplant conferences, participated in nursing grand round on liver donors, and read experiential material written by donors
| IV. Phenomenological Contextual Processing | • Engaged in conversations with others who had experience in this area to hear other perspectives
|                                                 | • Transcribed the audiotaped interviews verbatim and examined the words or phrases the study participants used to describe their experience
|                                                 | • Analyzed the study participants’ experiences in the context of relationships with others, time, the physical experiences, and the locations of these experiences
| V. Analysis of interpretive interaction | • Compared the transcript of each interview to previous participants’ interviews to identify similarities and differences among participants’ narratives
|                                                 | • Reviewed the interview transcription with each participant
|                                                 | • Reviewed the emerging themes with clinicians familiar with the care of liver donors to determine if descriptions were consistent with their experiences
| VI. Writing the phenomenological narrative | • Wrote a narrative that described the experience of study participants
|                                                 | • Incorporated quotes from participants’ interviews to illustrate the themes
|                                                 | • Reviewed the narrative with study team members and confirmed the emerging themes
| VII. Writing a narrative on the meaning of your study | • Presented study findings to add to the knowledge about liver donors via completed dissertation, poster presentation at transplant conference, and presentation at hospital center research day
|                                                 | • Identified study implications for future research, clinical practice, and education of future liver donors and transplant staff

The principal investigator identified her assumptions about living donor liver transplantation so they did not influence data collection and analysis. This was done verbally through regular peer debriefing sessions with a faculty member and another doctoral student. Additionally, she maintained a personal journal of her thoughts and reactions as the study progressed.

Steps III and IV occur concurrently.

The study was guided by Patricia Munhall’s 7-step phenomenological method. These steps consist of immersion; coming to the phenomenological aim of inquiry; existential inquiry, expression, and processing; phenomenological contextual processing; analysis of interpretative interaction; writing the phenomenological narrative; and writing a narrative on the meaning of the study. The steps may not always occur in sequential order and may occur simultaneously. The steps used in this study are presented in the Table.

Sample

Purposive sampling was used to conduct this study. Study participants were English-speaking adults more than 18 years of age who had completed their follow-up visit 1 month after donation. Sample size was determined by data saturation. Data saturation was considered achieved when interviews of participants did not reveal new themes.

Setting

This qualitative study was conducted at a northeastern, urban academic medical center where pediatric and adult deceased donor and live donor liver transplants are performed. More than 120 liver transplants are performed at this center annually; approximately 10 of those transplants are live donor transplants.

Data Collection Procedures

A formal meeting was conducted with the liver donor transplant team at the study site to discuss the purpose of the study, explain the criteria inclusion and exclusion of participants, and request the team’s assistance in recruiting study participants. Team members referred patients who met the inclusion criteria.

The primary investigator contacted all adults who were referred and explained the study protocol. Adults who chose to participate signed the informed consent form and scheduled their first meeting within 2 weeks.
of this initial contact. Each individual who agreed to participate was interviewed at a site of his or her choosing, for approximately 2 hours, twice, during a 2- to 4-week period. Each interview was audiorecorded and brief notes were taken by the interviewer during the conversation. During the first interview, each participant was asked to describe his or her experience with being a liver donor. At the end of the interview, the participant provided demographic data such as age, living arrangements, and relationship to the recipient.

During the second interview, the transcript from the first interview was reviewed so that the participant could add, amend, or delete information from the first interview, to clarify the investigators’ understanding of the transcribed material or developing themes.

Data Analysis

The primary investigator transcribed each audio-tape verbatim within 72 hours of each interview. Data analysis began immediately after transcription of the second interview. Transcripts of each participant’s interview and the primary investigator’s notes were used to analyze data. Data analysis was guided by Munhall’s method, which required reading the text, reflecting on the text, and writing to obtain the essence of the donor’s experience. Data analysis was concurrent with data collection. Themes and meanings were formulated from each participant’s description of his or her feelings about, thoughts about, and understanding of being a liver donor. The themes identified in each donor’s transcript were compared with the themes from previous donors’ transcripts to detect similarities and variations within the experiences.

Trustworthiness is used to establish rigor in qualitative studies just as reliability and validity are used in quantitative research. Before the start of the study, the primary investigator explicated verbally and in writing any assumptions that could influence data collection or analysis. Throughout the study, the primary investigator maintained a personal journal of thoughts and reactions and participated in regularly scheduled debriefing sessions to ensure that her assumptions did not influence data collection or analysis. All participants reviewed the transcript of their interview to verify that it accurately reflected their experience. Another investigator reviewed and verified the audio-tape transcription and the researcher’s decision-making process during data collection and analysis. Two doctorally prepared nurse clinicians, familiar with qualitative methods, reviewed data analysis to ensure that the primary investigator’s assumptions did not influence data interpretation. A liver donor from a different transplant program and 2 clinicians involved in care of liver donors confirmed that the descriptions created from the participants’ interviews were evocative of their own experiences.

**Results**

**Participants**

Ten individuals were contacted and invited to participate in the study. Two persons did not return phone calls and 8 persons agreed to participate. Data saturation was reached with 6 participants, so 6 adults who had donated 7 to 16 months earlier participated in the study. A total of 14 interviews were conducted. Study participants ranged in age from 27 to 53 years. Three of the participants donated to their spouses, 1 participant donated to a sister, and 2 participants donated to a parent. Four participants were married and 3 had children. Five of the participants were white and 1 participant was Hispanic/Indian.

**Themes**

Five major themes were identified: (1) No Turning Back—How Do I Live Without You?, (2) Roller Coaster Marathon, (3) Donor Network, (4) The Scar, and (5) Reflections—Time to Think.

**No Turning Back—How Do I Live Without You?**

This theme, central to the donor experience, depicted the donors’ commitment to the recipients once the donors learned that the recipients were eligible for LDLT. No turning back was precipitated by the donors’ realization that someone they cared for required a liver transplant because of a medical crisis or from worsening end-stage liver disease. This theme continued to be the motivating force driving donors’ actions as they sought to understand liver donor transplantation, completed a medical evaluation for eligibility, underwent hepatectomy, and resumed usual activities after donation.

Donors experienced a sense of urgency as they tried to learn what could be done about the loved one’s condition. Time was a crucial element. Accepting that a loved one was so ill that he or she could die was unthinkable. “I was a mental case upon the Internet. What are we going to do; Oh my God, fix him, do something and then when LDLT was decided, it was what we were going to do.”

After the donor had assimilated the severity of the recipient’s illness, deciding to be a donor was a very personal internal decision. Donors described a sense of waiting for the other shoe to drop and breathed a sigh of relief when each test result moved them closer to LDLT. Donors perceived that time was running out as they got closer to the scheduled date for surgery. What else do I need to do?

The transplant team protocol included a “cooling off” period, so donors had time to think about their decision, in case the donors wanted to change their mind. Having decided to donate, participants could not or would not change their minds. “I want to help you get through this. I don’t want anything to happen to you. We’re so intertwined . . . if something happens to you,
I’m not me anymore.” Donors could not contemplate life without the recipient.

The donors’ commitment to the recipients’ well-being continued through to the surgery. Donors consistently reported that once they awoke in the recovery room, they asked about the recipients. “You’re so doped up; I didn’t even know if it had happened. I asked where’s my dad. How is he doing? They said my dad was okay.” Some donors insisted on actually seeing the recipient. “Finally they got me in a wheelchair and took me over to him. He was there, the liver was in and I was there. Then I felt better.”

**Roller Coaster Marathon.** The roller coaster marathon theme demonstrated the stamina, endurance, persistence, and determination required. “It’s such an indescribable process: mentally, emotionally, and physically. I felt like I had prepared enough, like training, like going into a marathon.” The roller coaster occurred preoperatively and/or postoperatively and required emotional and/or physical preparation.

Participants changed their eating habits, abstained from alcohol, or exercised in preparation for surgery. “Have a glass of wine. I said, No, I want to be clean. I want my liver to be perfect.” “I just watched what I was eating and ate soup and vegetables, and drank water.” “I was trying to do sit-ups because they said the stronger your abdomen was, it would help so you wouldn’t get a hernia.” Even when recipients were hospitalized due to a deteriorating medical condition, donors continued their preparations despite being unsure the recipient would be healthy enough for LDLT.

Donors were instructed to rest after discharge, but if the recipient was still hospitalized or having a rocky course, the donors’ prime concern was for the recipient. “I didn’t feel strong. One time, I took a shower, put on my make-up, did my hair and called a car service and saw him in the hospital. I thought I’d go there and be the cheerleader.”

**Donor Network.** This theme symbolized the donor’s relationships with family members, friends, and health care providers. People in the network entered and exited at different times. The network provided physical and/or emotional support in different physical spaces at different steps and times in the process.

Family, friends, and community members provided emotional support by talking about the donation process, offering verbal words of encouragement and praise, praying or crying with the donor, and celebrating the donor’s actions. Donors felt support as a palpable force of energy. “All my friends were there. I got stuffed animals to take with me. One of the guys gave me the saint his mother had with her when she was sick. He said to hold it with me.”

Donors also coped with the anxiety their decision produced for people in their lives. These worries surfaced as the date of the surgery approached. “I had some friends who couldn’t handle it, and they just walked away. They didn’t know how to react to me any more.” Donors reported that at least 1 family member was ambivalent about the surgery. “My family was not happy . . . for the longest time my father, to whom I was donating, tried to talk me out of it. He really didn’t want me doing it. My mom was in the middle because ‘I’m her boy,’ but she also didn’t want anything to happen to him.”

During the hospital stay, donors relied predominately on health care providers for their recovery. Donors recalled the attentiveness of the hospital staff, interactions with specific people, and the doctors making rounds twice a day after surgery. The hospital stay was an activity to get through as fast as possible. “Remember the doctors telling me the more I walked, the quicker I could go home. So I was up every morning at 6 am walking the floor, walking, walking, walking, and just trying to get the heck out of there.”

Donors acknowledged that they could not have accomplished the donation without the support of the network. Some donors readily assigned tasks to specific individuals, whereas other donors were reluctant to impinge on family and friends. “You want to be independent; you don’t want to rely on people. Not so much out of esteem, but you don’t want them to stop what they are doing or take days off from work just to do stuff for you. You don’t want that, but it definitely helped that we had people there.” Determining how long the support of family and friends would be needed was a critical step in the donor’s planning strategy.

**The Scar.** This theme illustrated the donors’ reactions and responses to the surgical scar as well as the reaction of others to the scar. The scar was a visible reminder that something momentous had taken place. Donors reported being told what the surgical incision would look like, before donation. Despite the information, donors stated that they were not concerned about the scar before surgery. “They told me the scar was going to look like this. They gave me information and I pretended to look at it until I got home, then I threw it out.” “I remember being told the one thing I could count on was a big ugly scar. I remember thinking at that time, why does everybody keep talking about that?”

In the immediate postoperative period, donors looked at the surgical incision to make sure it was healing properly. As donors became stronger and started resuming other life roles, they began to appreciate the size and significance of their newly formed scar. Donors’ reactions to the scar was colored by the reaction of loved ones and affected how they saw themselves.
after donation. “That’s someone who has to see you in a romantic and sexual way. So if my friends think its ugly, it doesn’t really matter as much, but it was important that she wasn’t bothered by it.”

Participant’s description of the scar varied. Two of the study participants used the words “butchered” and “mutilated” to describe other people’s reaction to the scar. Both felt compelled to justify the appearance of the scar. “It’s not a freaky kind of thing or something horrible. It’s just a mark left over from something I’ve experienced. People need to understand why the scar exists.” Some participants used the word “fascination” to describe the reaction of other people to the scar.

The donor’s personal reaction to requests to see the scar was just as varied. Reactions to the scar ranged from “Two of my very good friends said ‘can I see it? Can I see it?’ Since I was never ‘a let it all hang out babe’ I said ‘No.’” to “I find myself looking for a two-piece bathing suit. I never used to wear one and now all of a sudden I want to. I feel like I want to show off my scar.”

Other donors did not deliberately cover the scar or wear clothes that flaunted its existence. One of the donors felt the need to change what she normally wore. That donor felt she could no longer wear a bikini, stating, “You would think I was a bikini model at Victoria’s secret and I lost my contract.”

Regardless of the reactions of others, donors gave meaning to the scar. Some donors were proud of that scar. It was a visible reminder that LDLT had taken place and what they had achieved by being a liver donor. Some donors compared the scar to “a battle wound” and called it “a badge of courage.”

Reflections—Time to Think. Once the donor and recipient were home, the donors began to reflect on their own life. Donors viewed the experience as positive and rewarding. They came to appreciate what giving a piece of their liver to another person produced—“the chance to live.” There was an incredible sense of joy in seeing the recipient healthy once again. “It’s like night and day. You see the recipient full of energy, running around with really nice skin color and just healthy and vibrant.”

For donors whose recipients were having a difficult recovery, their enjoyment of the donation was marred by the recipient’s continued poor health. They had physically done all they could for the recipient. A second donation by the same donor was not a physical possibility. “Because of the road we are traveling, part of me feels like a failure. . . . Part of me feels what the heck was this? We’re right back where we started from, if not worse.”

As the postoperative aches and pains subsided, there was a desire for a return to normalcy and to one’s regular life. “It took a chunk out of my life, but it was just something I had to do.” Donors reflected on the meaning of the experience and expressed a greater appreciation of life. “Live life now” was a new consciousness that resulted from witnessing the fragility of the recipient’s health. Donors spoke of making time for friends and travel and examining the meaning of their own lives. “It made me realize who I am and what I want to be, the value of life. That you take things for granted or you can just let life pass you by and not do anything.”

Three subthemes were identified: No regrets, I’m no hero, and Spread the word. All the donors said they did not regret donating even when the recipient had a rocky postoperative course. In fact, all the donors remarked they “would do it again, definitely, no hesitation.” “The only thing I would have regretted is not doing it. . . . How could I ever regret donating was how I thought about it. . . . If I don’t do this, how would I live with myself if we don’t at least try?”

Donors acknowledged the risks that the surgery entailed, but they felt that the results far outweighed the risks. They were proud of this experience. When others called them heroes, they were uncomfortable. They did not feel that the term applied to them. To them, the hero was the recipient who had been coping with a life-ending disease.

Watching the deterioration of a loved one motivated donors to make information about living donation mainstream. They found different ways to personally spread the word, including answering questions at work, being interviewed by the media, attending Liver Foundation meetings, sharing their story on Internet Web sites, and participating in this research study.

Limitations of the Study
Study participants were all recruited from 1 transplant center, so caution should be used before assuming that these findings are meaningful in all contexts. The findings reflect the perspective of adults donating to adults. Only 1 man participated in this study, so the influence of the donor’s sex cannot be determined. The influence of time on the donors’ experience is unknown. The findings are limited to the moment of recall. Donors might have felt differently if they had been interviewed more than 2 years after donation. The recipients of the donated livers, who informed this study, were alive at the time of interview. It is not known if the experience of the donors would have been different if a recipient had not survived.

Discussion
Participants in this study understood and accepted the risks of donation. Donors may have had moments of fear and doubt, but none regretted the decision to
donate. All said that they would donate again even when the outcome was not positive in the recipient or themselves. Donors reported that the potential benefit to the recipient warranted the personal risk to them. This finding supports data reported in previous studies. \(^{5,16,18,20,22,23,25}\) Donors were satisfied with their decision to donate, and none felt “forced” to donate.

The decision to donate was an emotional one. Awareness of the recipients’ medical condition added a sense of urgency to the donors’ decision. Results of 2 studies\(^ {23,25}\) of adults donating to pediatric recipients indicated that parental donors minimized their own preoperative needs as they focused on the ill child. These researchers noted the parents’ willingness to proceed, describing it as “simply part of doing whatever you can for your child.” In the current study, donors weighed the pros and cons of donation. Donors availed themselves of the type and amount of information they deemed necessary to make the decision to donate. Research is needed to understand and appreciate the emotional aspects of donation and determine what differences, if any, exist between adults donating to adults and adults donating to children.

Although designed to protect donors, the “cooling off” period before surgery produced anxiety and stress for donors in this study. Donors in this study were concerned that the surgery would not take place. This concern has not been mentioned in previous studies.

The influence of the donor network on the donors’ experience must be explored. In this study, network members were initially supportive of the donor’s decision but wavered as the day of surgery approached. Several donors said the recipient tried to discourage them from being the donor. The impact of support or nonsupport by the informal network for LDLT donors has not been addressed in detail in the literature.

The impact of the scar merits further examination. The donor’s reaction to the scar varied among the study participants. Complaints of pain at the surgical site and a larger than expected surgical scar have been reported in studies that used quality-of-life instruments.\(^ {3,18,19,21}\) Authors in 3 of these studies\(^ {8,18,19}\) noted that 28% to 37% of donors found the scar less aesthetically pleasing and larger than expected. In the other 2 studies,\(^ {21,22}\) researchers reported scar numbness in 2 donors and scar pain in 7 donors. The reaction of the donor’s significant other to the scar after donation has not been described in other studies.

Spousal donors in this study reported feeling stressed caring for a spousal recipient who was having a rocky course. A study of 8 interspousal LDLT couples found marital maladjustment occurred for 5 donors. Two other studies\(^ {23,25}\) of adults donating to children cited substantial marital strain. Preoperative and postoperative counseling have been recommended for spousal donors and recipients. How the recipient’s recuperation affects the donor’s psychosocial recovery in the long term merits study.

Research is needed to understand the impact of donation on the donor at different points in the process. Enabling donors to communicate their experience from their frame of reference provides a better understanding of liver donors’ concerns. Findings from this study have been shared with staff at the transplant center and are being used in the delivery of patient care. We have used these study findings in the development of written discharge instructions for liver donors that are given to all our donors on discharge from the hospital. We have added a tour of the inpatient unit and a meeting with the nurse manager as part of the donor evaluation process. Last, we have designated certain nurses within the transplant unit as “donor nurses.” These nurses have received additional education on donor management and are assigned to the donors when their donor surgery is scheduled.

**Financial Disclosures**

This research study was funded by the Sigma Theta Tau Alpha Zeta Chapter of Columbia University School of Nursing.

**References**

104-111.