Title

Living-Related Liver Donor's Perceptions of Life after Donation

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Publication Date

2007-08-23

Living-Related Liver Donors' Perceptions of Life after Donation

by

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DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

[redacted]

Dedication

To my love, my light, and my strength

Alex Estrada

who has taught me the most important thing in my life:

“Anything can be accomplished with passion and persistence!”

ACKNOWLEDGEMENTS

The journey to a PhD can be compared to a long sailing journey, in that they both require the personal dedication and the cumulative support of many. This dissertation is the product of many crewmembers assisting me in different ways either by trimming the sails, navigating a course, or coaching on technique in order to make it happen. Learning the ropes and taking control of the helm would have never happened with out the strength and knowledge of each of my individual team members.

During the first year of my doctoral studies I was fortunate to have met Dr. Sally Rankin who like the captain of a boat, provided me with the outstanding advice regarding the specific tack I should make in my program of research as she had the incredible insight of introducing me to Dr. Roberta Rehm, who then became my advisor. It was through the guidance, and unfaltering patience of working with my advisor and dissertation chair Dr. Roberta Rehm that I had the fortuitous experience of creating this dissertation. Dr. Rehm's mentoring, methodological expertise, and research competence was instrumental in my development as a researcher and scholar. She had the ability to teach me how to command a research project, identify each of my participants as individuals, and strive to understand the social processes of the donors I interviewed. As my dissertation chair, Roberta always made time to sit with me and discuss the particulars of ethnography and qualitative research. I will always cherish the hours we spent plotting our course and fine tuning the sails in order to make the voyage smooth and efficient.

I will always be grateful to Dr. Susan Kools, like the keel of a boat, provided balance to this adventure. She managed to approach the seas we sailed with optimism,

enthusiasm, and insight. As the chair of my qualifying exam, she helped me in determining a course that created balance to my life. She constantly challenged me to better understand my participants and to go as deep as possible in analyzing the text! It was this balance that allowed me to appreciate the beauty of the sail!

Dr. Sally Higgins generously extended mentoring throughout the sail, and provided me with the necessary coaching to build my future as a nurse scientist. Her expertise in pediatrics and transplantation provided me with the direction and counsel that made even the roughest seas look calm. Like a seasoned tactician, she guided me though all the correct tacts in order to launch my research career!

If it were not for the support of the Pediatric Liver Transplant teams at University of San Francisco, Lucile Packard Children's Hospital, and Stanford Medical Center, this project would have never set sail. I would like to thank Dr. Carlos Esquivel, Dr. Kenneth Cox, Dr. Nancy Ascher, Dr. John Roberts, Debra Strichartz, Marsha Castillo, Carmello Juno, Christine Mudge, and all of the living-related liver donors that participated in my study for their invaluable contributions. Dr. Garrett Chan, my angel in disguise, who provided guidance and mentoring throughout the sail.

I am deeply appreciative of the consistent support and encouragement provided by the Lucile Packard community, namely Dr. Karen Wayman, Dr. Nancy Donaldson, Dr. Amy Nichols, Susan Flannagan, and Lori Armstrong for consistently reassuring me that I was sailing a straight course! A special thank you to my life long friend Gina Arnold PhD(c), as well as my two classmates Dr. Teresa Ward, and Anna Villena PhD(c) for their friendship and academic support.

A heartfelt thank you to my mother Charlotte Nasr (1925-2006), and my father Gabriel Nasr (1924-1982) who taught me to hold fast to my dreams, and strive to be the best I could be! I am additionally thankful to my second mother Martha Estrada, who through rain or shine was always willing to be on deck, trim a sail, and provide love and comfort. To my brothers Dr. Tony Nasr, Phillip Nasr, Raymond Nasr, and my sister Mary-Rose Reade for all their love, phone calls, and support I am grateful.

Most importantly, and above all, a gracious thank you to my dear husband Alex Estrada and my son Miguel Estrada, who together provided the home atmosphere that seemed to settle the seas no matter how high they became. Alex's encouragement was insurmountable; he was the one person, who experienced every high and every low with me. He never allowed me to loose sight of the end point, and constantly reassured me that I would reach the finish line. It is Alex I have to thank for instilling in me the concept of persistence that will be with me forever, and what I hope to pass on to our son Miguel.

This voyage has been a privilege and honor.

Thank you to all!

This dissertation research was supported by:

Graduate Dean's Fellowship Award at the University of California, San Francisco

Innovations in Patient Care Grant at Lucile Packard Children's Hospital

Century Club Award University of California San Francisco

ABSTRACT

LIVING-RELATED LIVER DONOR'S PERCEPTIONS OF LIFE AFTER DONATION

Annette Sue Nasr RN, PhD(c)

Purpose: The purpose of this interpretive research study was to understand the perceptions of life experiences of individuals who participated in living-related liver donation (LRLD). The specific research question of this study was: What is the impact of LRLD on the physical, emotional, and familial lives of the donor post-donation?

Background: Pediatric patients suffering from end stage liver disease (ESLD) must depend on cadaveric liver donation or living liver donation in order to sustain life. According to the United Network of Organ Sharing (UNOS) approximately 85,000 candidates are listed for organ transplantation, 17,000 are listed for liver transplantation. Cadaveric liver donation cannot meet the demand presented by children with ESLD, therefore alternatives to cadaveric donation must be established. One alternative to cadaveric donation is living liver donation. Historically there have been over 2,000 living liver donors in the United States (UNOS, 2004), most often a parent of the child with ESLD.

Methods: This interpretive study used ethnographic methods to gather information from 13 living parental donors regarding their physical, emotional, and familial lives since their donation. Donors were recruited from two transplant centers on the western coast of the United States. Interviews were audio taped and transcribed. Data was analyzed in order to produce themes and revealed specific dimensions of these phenomena. This study was approved by the Internal Review Board at Stanford University as well as the Committee on Human Research at UCSF.

Results: The overarching theme that expressed the impact that LRLD had on the donor was that of transformation. Within this theme of transformation major categories included: a self-awareness process, a re-clarification of familial relationships especially with the child who received the donated organ, and a change in perspectives on community.

Implications: Information developed in this study can be used to prepare the donor during the pre-transplant phase as well as to develop interventions to facilitate the adjustment of donors post-transplant. This study will provide nurses and healthcare professionals working in the field of transplantation insights about the issues that LRLD face.

TABLE OF CONTENTS

TABLE OF CONTENTS (Cont'd.)

TABLE OF CONTENTS (Cont'd.)

TABLE OF CONTENTS (Cont'd.)

TABLE OF CONTENTS (Cont'd.)

TABLE OF CONTENTS (Cont'd.)

TABLE OF CONTENTS (Cont'd.)

LIST OF TABLES

LIST OF FIGURES

CHAPTER I

THE STUDY PROBLEM

Introduction to Problem

Children suffering from end stage liver disease (ESLD) depend on liver transplantation as a means to save their lives. Currently over 18,000 individuals in the United States are waiting for liver transplantation and approximately 700 are pediatric candidates (UNOS, 2004). Children less than two years old have the highest mortality rate of any age group on the waiting list (Langham et al., 2001). Approximately 10 percent of patients on the United Network of Organ Sharing (UNOS) waiting list die while waiting for a liver transplantation and many others die after they are removed from the list because their clinical deterioration eliminates them from transplant candidacy (Trotter, Wachs, Everson, & Kam, 2002). Seventeen percent of infants under the age of 12 months die while waiting for an organ to become available (UNOS, 2004).

As a result of this trend for pediatric patients with ESLD, surgeons have developed methods of using segmental grafts from living donors to decrease mortality rates in children (Broelsch, Whillyton, Thistlethwaite, Baker, & Lichton, 1998). Other surgical methods of decreasing mortality rates in children with ESLD include split grafts, which involves taking one cadaveric liver donation and splitting it between an adult and a child. This surgical option allows for two individuals to benefit from the donation of one liver. One-year survival rate for living donor grafts is 88%, split grafts is 82%, while whole liver grafts is 83% (Langham et al., 2001). Living-related donation as well as split-liver allografts have made significant contributions to reducing waiting times and improving patient survival for pediatric patients (Goss et al., 1998).

Having been a nurse for over 20 years, my interest in LRLD became apparent during the first few years as a new graduate as I worked in a Pediatric Intensive Care Unit (PICU). I was emotionally touched as well as clinically impressed when I observed the mother and living liver parental donor of a 10 month old child that I was taking care of in the PICU come into the unit to see her child who was post-operative day one from a liver transplant. This mother arrived to the PICU in a wheelchair, with several intravenous catheters, and a smile that lit up the whole unit. I had to hold back the tears when she rolled to her daughter's crib, where I was busily changing abdominal dressings, and extended her hand to her daughter and said: "My love, you're not yellow anymore, I am so happy my liver worked!"

My interests in LRLD grew from this experience, as I became a Pediatric Liver Transplant Coordinator at LPCH and where I have worked as a coordinator for over 7 years. As a Liver Transplant Coordinator, it was my responsibility to screen all possible living donors for our pediatric patients and assist potential living donors in getting the clinical as well as psychological evaluations completed for donation. Occasionally, as a Liver Transplant Coordinator, I would receive phone calls from donors a few months following the donation stating that they had lost a great deal of weight, they had not returned to work, or they had not been feeling well since the donation. Prior to the inception of this study, there were not any official national follow-up systems in place, from a pediatric perspective, to deal with the long-term physical and emotional health of the donors at the respective transplant centers. As Liver Transplant Coordinator, I would advise the donors to see their primary care physician for necessary medical, surgical, and emotional follow-up. Over the course of the last three years, the United Network of Organ Sharing (UNOS) has initiated mandatory 6 month and annual follow-up visits at the transplant center for all living donors in the United States. This lack of follow-up that existed three years ago left me in a position of not knowing how the living donors dealt with the donation on a long-term basis and what, if any, were obstacles for them post-donation. This was information I needed to know in order to perform my role as a Pediatric Liver Transplant Coordinator as I need to present all the current data related to live liver donation to my patients and families. It was this issue that led me to study the LRLDs and their lives in the everyday.

As a Liver Transplant Coordinator, I was consistently wondering what happened to the donors after their donation was complete and they returned to their homes. Did they suffer physical ailments? If so, what were their symptoms and for how long did they last? How did the donation impact their relationships with the child they donated to? Were other children in the family possibly affected by the donation? Did spousal relationships change as a consequence of the donation? Professionally, I found it difficult to properly inform parents and families regarding the long-term consequences of donation, as this type of information was not readily available. My desire to know more about these individuals and to better understand the affect a donation could have on them and their families led me to choose to study this phenomenon.

This study has provided extensive knowledge in regards to the everyday life of living parental liver donors, which has the potential of guiding transplant professionals in creating policy that supports not only the donor, but the whole family during a living organ donation. There is a need, in the field of pediatric transplantation, for clinical interventions to be developed that are grounded in research and focused on the family unit. The results of this study offer substantial evidence to guide practice and improve patient outcomes for nurses and transplant professionals.

Statement of the Problem

Cadaveric liver donation cannot meet the demand currently presented by children with ESLD; therefore, alternatives to cadaveric donation must be made. One alternative to cadaveric donation is living liver donation. Historically there have been over 2,000 living liver donors in the United States (UNOS, 2004). By surgically removing the left lower lobe of the living donor's liver, surgeons can replace a child's liver with this donation.

Potential LRLDs need answers to their questions regarding the long-term physical as well as emotional consequences of donation. Information of this nature is not currently available in the literature thereby creating a gap, which needs to be addressed. Offering families all the possible information regarding LRLD is essential in order for donors to make the most educated decision regarding donation and to cope effectively with the aftermath of this important decision.

Purpose of the Study

The broad aim of this ethnographic study was to explore the everyday life experiences of parents who donate the left lower lobe of their liver to their child and to describe how LRLD impacts individual physical and emotional health and family dynamics. The goal of this research study was to provide nurses and healthcare professionals working in the field of transplantation, insights into issues the LRLD may face following donation. By conducting an ethnographic qualitative study, it allowed for in depth analysis into the lives of the LRLD and to identify the long-term impact a donation had on the donor, their family, and their community.

The specific aims of this research study were to: 1. Describe the perceived physical and emotional consequences of LRLD donation for parental donors. 2. Describe the perceived impact of donation on intra-familial relationships and family dynamics. 3. Analyze the ethical context of parental liver donation, including impacts on pre-donation decisions and life after donation. As a result of this qualitative study, a better understanding into the everyday lived experience of LRLDs has been provided for families and transplant centers. The findings will contribute valuable information from which to deliver quality patient care to LRLDs and their families.

Significance of the Study

The primary treatment modality for children with ESLD is transplantation, by either cadaveric or living donation. As the demand for cadaveric donation cannot meet the availability for size-matched liver grafts, the transplant community has developed both living-related liver donation as well as split liver techniques as alternatives to cadaveric donation. Historically, a technique called “reduced-size” liver transplantation was used to achieve a balance between the need and the availability of liver grafts for children by using cadaveric donation (Broelsch et al., 1998). A reduced-size liver transplant occurs when an adult cadaveric liver is donated to a child and the surgeon reduces the size of the liver in order to fit into the abdominal cavity of a child. The one problem with using reduced-sized livers was this technique created competition between adult and pediatric patients waiting on the candidate lists (Strong et al., 1990). Both living-related and split liver donation have greatly decreased the mortality rates for children with ESLD while not causing organs to be taken away from adult patients waiting for transplantation (Busuttil & Goss, 1999).

The most common indication for pediatric liver transplantation reported by Cox, Berquist, and Castillo (1999) are biliary atresia (43%), metabolic disease (13%), acute hepatic necrosis (11%), and acute hepatic failure of unknown etiology (33%). Five year survival for pediatric liver transplant recipients is greater than 80 percent as a result of new surgical techniques and immunosuppressive agents (Cox et al., 1999).

Mortality rates in the 1980's for children waiting for liver transplantation at leading transplant centers in the United States were 20 to 30 percent. By the late 1980's, innovative surgical techniques had been developed that included the use of reduced-size and split liver cadaveric grafts; these techniques reduced the number of deaths among infants and children on waiting lists (Emond, Whitington, Thistlethwaite, Alonso, & Broelsch, 1989). One year survival rates for reduced grafts has been reported as 74%, whole cadaveric livers 83%, living-donor grafts 88%, and split grafts 82% (Langham et al., 2001).

On the donor side of the experience of liver transplant, there is currently very little research on the long-term physical and emotional consequences of LRLD. One research team published a hallmark study in regards to the long-term quality of life issues among adult-to-pediatric living liver donors. This study was conducted by Crowley-Matoka, Siegler, & Cronin (2004) and was one of the first of its kind to investigated a long-term cohort of adult-to-pediatric living liver donors, and also one of a few published studies that discussed issues such as marital tension, financial difficulties, problems with other children in the family, and the donor's own sense of physical and emotional well-being.

Forsberg, Nilsson, Krantz, & Olausson (2004) illustrated the way in which LRLD could impact the physical and emotional state of the donor. In the form of in-depth interviews they demonstrated that parental donors suffer physically, mentally, socially, and spiritually as result of the donation. These researchers were able to show that despite expressions of pain and loneliness that these donors experienced, the hospital staff's attitude towards the donor was they were healthy individuals and should be back on their feet as soon as possible. The donors that were interviewed in this study felt abandoned, isolated, and left to their own destiny as a result of the way they were treated by the healthcare professionals.

Many transplant researchers have addressed the physical consequences of donation; however, no long-term donor outcome data has been published using an instrument that permits an anonymous response from the live donor or evaluates the health of the donor following donation using a widely recognized health survey (Diaz et al., 2002). The overall incidence of donor complications, including hemorrhage, pulmonary embolus, biliary injury, hernia, postoperative bowel obstruction, and sepsis, reported from multiple centers ranged from 10 to 15 percent (Malago, Rogiers, & Burdelski, 1994). Malago et al. (1994) concluded that data on LRLD are deficient and not regularly updated because of the lack of well-established registries with audit mechanisms. The lack of long-term tracking of live donor recipients by a national registry like UNOS is minimal in comparison to the tracking that exists for cadaveric recipients, which makes the extent of long-term complications less certain for the living donor recipients (Trotter et al., 2002). It has been demonstrated that 15-32 percent of recipients of living-donor livers have more biliary complications than recipients of cadaveric organs. (Bak, Wachs, & Trotter, 2001; Broelsch, Malago, Testa, & Gamazo, 2000; Marcos, 2000; Marcos & Ham, 2000; Testa, Malago, Valentin-Gamazo, Lindell, & Broelsch, 2000; Toto, Furukawa, Jin, & Shimamura, 2000).

By using a phenomenological approach in order to identify the emotional impact regarding the decision to donate for the living donor, one research team found seven categories leading to motives to donate—namely, a desire to help, increased self-esteem from doing good deeds, identification with recipient, self-benefit from the relative's improved health, mere logic, external pressure, and feeling of moral duty (Lennerling, Frosberg, & Nyberg, 2003). All seven led to one common theme which was that donation was the only option for them. Though their research was focused on the living kidney donor, they interviewed twelve potential living kidney donors and determined that the decision to donate was based primarily on emotions.

Living liver donation not only impacts the life of the donor, but also affects the lives of other members in the family. Family relationships play a pivotal role in live transplantation, a situation compounded by both the complexity of the concept of the family and by the fact that family structures have changed over time (Franklin & Crombie, 2003). Family becomes key when studying the lives of living donors, because a family that experiences a living-related donation sends two members of their family to the operating room and helps two family members with post-operative follow-up.

Cadaveric donation, in contrast, requires only one individual to be operated on and only one family member to experience post-operative follow-up.

The individual that assumes the responsibility of caretaker plays an enormous role and one that carries with it the potential of a great deal of stress. To date, very little literature on post-donation quality of life for the donor exists and a qualitative understanding to the long-term consequences is critical (Crowley-Matoka et al., 2004) . Research on the long-term effect of LRLD on the family is lacking and more focus in this area is necessary so that families can make a well-educated decision for their child and family.

When a child with liver disease and their family visits a transplant center and are evaluated for liver transplantation, the option of living donor transplantation is usually discussed. If the child’s family decides to participate in LRLD, the selection and evaluation process by the transplant center is rigorous and labor intensive. Donors need to meet both physical and psychological criteria before entering into a living donation. The one bit of information that is not currently available to potential donors is the long-term consequences of the donation (Rudow & Brown, 2003). The emotional as well as the physical impact a donation may have on a donor must be made apparent to the donor and may assist them in the decision making process. Since the inception of this study, UNOS (2006) has implemented national follow up forms to be completed by all transplant centers participating in LRLD. UNOS, as of July 2006, requires all transplant centers to have 6 month and yearly follow-up visits with the LRLD. This is a first step in establishing comprehensive, national follow-up data on living donors in the United States.

The main advantage of living donor liver transplantation is that it provides immediate organ availability to those awaiting transplantation and is one way to help cope with the shortage of organs from cadaver sources (Caplan, 2001). All aspects of donor outcomes must be measured to determine the impact of donation on the living liver transplant donor (Trotter et al., 2001). Outcomes of recipients and donors need further study so that techniques can be improved and all forms of morbidity and other consequences reduced (Rudow & Brown, 2003). A commitment to making information available to patients and families regarding the long-term physical as well as emotional impact a living donation can have on them is essential. A living donor is a healthy individual who is putting their life in jeopardy to save another life. All risks and benefits of the donation must be made available to every living donor and this information should be grounded in research.

CHAPTER II

REVIEW OF THE LITERATURE

Solid organ transplantation from live donors began in 1954, during an era when transplantation biology had not yet provided a means to use cadaveric sources effectively. Faced with increasing numbers of patients who need transplantation, deaths on the United Network of Organ Sharing (UNOS) waiting list, and a fixed number of available organs, transplant programs are working to increase the number of transplants from living donors (Olbrisch, Benedict, Haller, & Levenson, 2001). With respect to liver transplantation, one surgical technique used to bridge the gap between the demand for livers and the supply is living liver donation. Orthotopic liver transplantation (OLT) has become a well established modality for the treatment of previously fatal liver diseases in pediatrics (Ghobrial, Amersi, McDiarmid, & Musutil, 2001). Cox, Berquist, and Castillo (1999) reported that the most common indications for pediatric liver transplantation are biliary atresia (43%), metabolic disease (13%), acute hepatic necrosis (11%), and acute hepatic failure of unknown etiology (33%) (p. 1066). With the advent of new surgical techniques and immunosuppressive agents, pediatric liver transplantation has resulted in greater than 80 percent five-year survival rate (Cox et al., 1999). The literature review that follows focuses on living related liver donation (LRLD) from a parent to a child. The areas discussed include an overview of liver transplantation, ethical implications of LRLD, donor evaluation, complications and benefits of LRLD, pediatric kidney living donor experience as a comparison experience, quality of life (QOL) for the LRLD, family dynamics and the LRLD, implications for transplant centers, and future dimensions for living liver donation for the pediatric patient.

Children suffering from end stage liver disease (ESLD) depend on liver transplantation as a means to save their lives. Beginning in the 1980's, leading transplant centers in the United States were faced with mortality rates of 20 to 30 percent among children on their organ waiting lists (Emond et al., 1989). Finding liver grafts appropriately sized for children was difficult (Cronin, Millis, & Siegler, 2001). By the late 1980's, innovative surgical techniques had been developed that included the use of reduced-size and split liver cadaveric grafts; these techniques reduced the number of deaths among infants and children on waiting lists (Emond et al., 1989).

In 1989, in Australia, Strong et al. (1990) performed the first successful transplantation from a live liver donor. In Japan, the first successful living donor liver transplantation (LRLT) was performed in 1989, with transplantation of the left hepatic lobe, and technical advances in left lobe liver transplantation were achieved in the mid-1990s. Japan has emerged as a world leader in the field of LRLT, primarily as a result of cultural factors that make cadaveric transplantation an uncommon event (Hashikura, Makuuchi, & Kawasaki, 1994; Yamoaka, Washida, & Honda, 1994). In both Japan and the United States, partial left-lobe transplantation utilizing only segments 2 and 3 has been a mainstay of liver transplantation for pediatric patients since 1989 (Singer et al., 1989).

Of all solid organs, the liver has the unique ability to regenerate after injury and/or resection (Shiffman et al., 2002). The liver promptly regenerates in both donors and recipients, and normal liver mass restores within 14 days of surgery (Marcos et al., 2000). Essentially, four standard surgical techniques are employed to perform liver transplantation in children: (a) split liver transplantation, in which an adult cadaver liver is split and the left lobes go to a pediatric recipient and the right lobe to an adult recipient; (b) reduced sized liver transplantation, in which a cadaver liver from either a child or an adult is cut down to fit a pediatric recipient; (c) living related or unrelated liver transplantation, when a designated individual donates a portion of his or her liver to a child or adult in liver failure (most commonly, the left lower lobe of the living donor for an adult-to-child pediatric donation, and the right lobes for the adult-to-adult donation); and (d) full sized cadaver donation, when the size of the organ perfectly matches the size of the recipient and no alterations are necessary.

The Organ Procurement and Transplant Network (OPTN) is the unified transplant network established by the United States Congress under the National Organ Transplant Act (NOTA) of 1984, to be operated by a private, non-profit organization under federal contract. The United Network of Organ Sharing (UNOS), awarded the first OPTN contract on September 30, 1986, has continued to administer the OPTN under contract with the Health Resources and Services Administration of the U.S. Department of Health and Human Services for more that 16 years and four successive contract renewals. The primary functions of UNOS consist of (a) assisting in placing donated organs for transplantation, in gathering donor information, in running the donor/recipient computer matching process, and in transporting organs and tissues for the purpose of transplantation, and (b) acting as a resource to the transplant community regarding organ sharing policies (UNOS, 2004).

All recipients being considered for living donation must be listed with the UNOS prior to transplantation (Marcos, 2000). According to UNOS reports, from January 1, 1988 to December 6, 2004, 72,399 livers were allocated to individuals suffering from ESLD; 69,900 of these liver organs originated from cadaver donation and 2,499 from living liver donations (UNOS, 2004). In 2002, 359 living liver donations occurred in the United States, 54 of which involved parents donating to their children (UNOS, 2004). In the past decade, recipient survival for LRLT has exceeded 90 percent (Goldstein et al., 2003).

Today, with the widening application and excellent results of cadaveric split-liver transplantation (introduced in 1987) and LRLT (introduced in 1990), children less commonly die while on the waiting list (Delmonico, 2000). However, each year approximately 10 percent of patients on the UNOS waiting list die while waiting for liver transplantation, and many others die after they are removed from the list because their clinical deterioration precludes them from transplantation (Trotter et al., 2002). With this growing number of deaths among patients waiting for organs, the transplant community eagerly attempts to develop ways to increase the number of donated livers.

In adult-to-pediatric live donor liver transplant surgery, donor mortality is less than 0.1 percent, and donor morbidity ranges from 10 to 15 percent (Crowley-Matoka et al., 2004). Mortality for donors undergoing left-lateral segmentectomy for pediatric recipients has been reported to be in the range of 0.1-0.2 percent (Shiffman et al., 2002). Cronin, Millis, and Siegler (2001) indicated that 22 transplant centers in the United States perform LRLT, but that only seven centers have conducted more than ten such procedures. Short-term survival rates for the recipient after living donor liver transplantation differ little from those after cadaveric transplantation (Trotter et al., 2002). In the United States and Europe, the reported rate of survival for the donor after LDLT is between 86 percent and 88 percent (Bak et al., 2001, p. 683).

Ethical Implications of Living Related Liver Donation

On June 1-2, 2000, the National Consensus Conference on Living Donor Organ Transplantation took place in Kansas City, Missouri, with its main objective to recommend practice guidelines for transplant physicians, primary care providers, health care planners, and other professionals interested in the well being of the live organ donor. Conference participants concluded that an individual who consents to be a living donor should be: competent, willing to donate, free of coercion, medically and psychosocially suitable, and fully informed of the risks and benefits of being a donor and of the risks, benefits, and alternative treatment available to the recipient. Moreover, the benefits to both the donor and the recipient must outweigh the risks associated with the donation and transplantation procedure (Abecassis et al., 2000).

Olbrisch, Benedict, Haller, and Levenson (2001) discussed such ethical concerns as the right to donate, donor autonomy, freedom from coercion, nonmaleficence and beneficence in donor selection, conflicts of interest, “reasonable” risks to donors, and recipient decision. This team of researchers outlined psychosocial and ethical issues to be considered when evaluating the potential living organ donor. In identifying six types of living organ donors, they emphasized the importance of defining certain psychological and ethical issues that exist for the donor. They stated that medical practitioners have an obligation to learn as much as possible about the positive and negative long- and short-term effects for the good or ill of transplantation from living organ donors and to make this information available to prospective donors (Olbrisch et al., 2001).

The concept of living donation has been the subject of intense ethical debate for transplant teams as well as ethics committees. Fox and Swazey (1974), in their book, *Courage to Fail*, stated that professionals must act as the gatekeepers for this gift-giving ritual through evaluation and selection of donors and recipients. Transplant centers have a moral and ethical responsibility to potential donors to carefully select donors and inform them about all the possible risks associated with the procedure. Donors must be adequately screened for donation, using standardized approaches for evaluation, and should be given consistent information in order to make informed decisions.

The manner in which families are presented information regarding transplant issues can create ethical dilemmas for families. In a study by Higgins, Paul, Hardy, Ternullo-Retta and Affonso (1994), a questionnaire was designed to survey 117 physicians on their beliefs regarding heart transplantation for the infant. They found that some parents of children with severe heart disease and possibly in need of heart transplantation seemed to be discouraged from asking for additional information about transplantation or were not encouraged to gain information regarding transplantation, or were given inadequate information in regards to heart transplantation across the board. It was further concluded that a negative presentation of transplantation could actually place the physicians who are giving the information in a position of gatekeepers to the transplantation procedure. Families faced with a child in need of a liver transplant are also dependent on the information given to them by physicians and nurses regarding LRLD. If physician bias does exist, it may also cause a negative presentation for families faced with a choice of LRLD. This study provides enormous insight for the health care community.

The impact physicians have on the decision to pursue LRLD is well articulated in an article recently published by Martinez-Alarcon et al. (2005) in Transplantation Proceedings. Though it focuses on adults listed for kidney/liver transplantation, it supports the concept that physicians can have an enormous power when it comes to the decisions patients and families make in regard to medical treatment options. Martinez-Alarcon et al. concluded that living donation as a first or second treatment option was only offered to patients by physicians in 51% of cases, versus 42% who did not receive any type of LRLD option. Only 6% of those surveyed stated that physician offered LRLD as a first treatment option. This study illustrates the need for all appropriate treatment options to be proposed to all patients by physicians.

Donor Evaluation

The OPTN/UNOS Ad Hoc Living Donor Committee proposed guidelines for potential living liver transplant recipient and donor evaluations, including provisions for an independent donor team, psychiatric and social screening, and appropriate medical, radiologic, and anesthesia evaluation (UNOS, 2004). Though these were not proposed as OPTN/UNOS policy, the committee believed that the guidelines could evolve into the standard of practice for living donor evaluation. According to UNOS, the following qualifications must exist in order for a donor to qualify. The donor must be physically fit, in good general health, and free from high blood pressure, diabetes, cancer, kidney disease and heart disease. Individuals considered for living donation should be between the ages of 18 and 60. Gender and race do not factor into determining a successful match. The donor must undergo a blood typing, x-rays, arteriogram, and a psychiatric/psychological evaluation. Risks, benefits, and costs of the surgery must be communicated to the potential donor prior to the consent (UNOS). Trotter, Wachs, and Trouillot (2002) reported that 60 percent of the potential donors who undergo formal evaluation are ultimately accepted as donors. In most cases where donors have body-mass indices over 28, they are excluded from evaluation due to hepatic steatosis (Rinella, Alonso, & Rao, 2001).

A study performed at the University of California San Francisco (Renz et al., 1995) had as its goal to estimate the frequency of acceptable living donors for an unselected population of pediatric orthotopic liver transplantation candidates in San Francisco. By using retrospective analysis, the researchers were able to identify 75 potential donors for 38 pediatric candidates. Twenty-three percent of the potential donors declined the evaluation, and only ten (13%) were found to be acceptable for donation. This study emphasized the fact that medical, surgical, and ethical guidelines limit living donation. The authors recognized that ABO incompatibility accounted for a significant number of exclusions and represented a possible area where expansion of donors could take place. One significant issue discussed in this study was whether a correlation exists between socioeconomic status and extent of insurance coverage and selection of LRLDs. This topic is worthy of future research, especially considering the current gap in literature.

Psychosocial Suitability

The current literature does not address the issue of psychosocial sutiablility, however leaders in the field of transplantation have written policy papers regarding the issue. The Consensus Statement on Live Organ Donors (Delmonico, 2000) outlined the goals of a psychosocial evaluation as follows: to evaluate psychological, emotional, and social stability, to rule out unsuitable donors and enhance the donation process by identifying individual or donor-related factors that warrant appropriate intervention; to establish whether the potential donor is competent to give informed consent; and to assess the degree to which the decision to donate is being made freely, without undue pressure or coercion (Abecassis et al., 2000). There needs to be a clear understanding by the transplant team as to the motives of the donor as well as the psychological state of the donor. If any negative consequences arise after the donation, the transplant team could be held responsible.

Informed Consent

The legal, regulatory, philosophical, medical, and psychological literature tends to favor the following elements as the components of informed consent: (1) competence, (2) disclosure, (3) understanding, (4) voluntariness, and (5) consent (Beauchamp & Childress, 2001). Assuming that one is competent, receives thorough disclosure of the intended intervention, understands the disclosure, and acts voluntarily, he or she is considered fit to give an informed consent. Informed consent for the potential LRLD requires three specific elements: adequate provision of information to the patient, adequate capacity for decision-making, and freedom from coercion (Olbrisch et al., 2001). Does the potential donor understand the donor surgery and all of the possible complications? Is he/she properly informed about the recovery time and approximately when to expect to be back to work? Is this potential donor making the decision to donate independent of family pressure, or has there been undue influence on the part of the recipient? Has the information from the health care professional been unbiased? These types of questions must be addressed by the transplant team to the potential donor during the evaluation process in order to gain informed consent.

The transplant community is constantly in the midst of ethical debate regarding the methods by which to practice living liver donation. It is imperative to ensure that transplant centers properly assess the motivation of the donor. A donor is a patient and, as such, is not a client, a consumer, or otherwise considered merely the carrier of an organ. Thus, his or her interests cannot be summarily overcome by a recipient's needs, by a transplant center's goals, by government regulation of a vendor sale, or by the demands of a donor for the surgeon to perform a procedure (Delmonico & Surman, 2003).

It is the responsibility of the donor to give a truthful medical history and a reason to donate; the transplant center's responsibility is to follow the guidelines proposed by National Consensus Conference on Living Donor Organ Transplantation to ensure that donors are competent, willing to donate, free of coercion, and medically and psychosocially suitable. The donor must be fully informed both of the risks and benefits of being a donor and of the risks, benefits, and alternative treatment available to the recipient.

Coercion

During the psychosocial evaluation, the transplant team usually evaluates the possibility of coercion of the potential donor. Renz et al. (1995) demonstrated that 23 percent of their donors interviewed expressed no interested in becoming a LRLD, which provided strong evidence that the availability of living donation was not inherently coercive. The transplant team evaluates the relationship between the potential donor and the recipient, and any possible financial compensation for the donation must be ascertained. Any chances of a subservient relationship between donor and recipients, for example, employer and employee, may place the potential donor in a vulnerable position (Olbrisch et al., 2001). Coercion, however, occurred if and only if one person intentionally used a credible and severe threat of harm or force to control another (Beauchamp & Childress, 2001).

The ethics of using live donors has been a major concern, with questions arising about the potential for donor coercion by transplant teams, the possibility of undue pressure among family members to volunteer as donors, and the morality of taking a healthy organ from an individual (Russell & Jacob, 1993). The donor surgeon (who is different from the surgeon for the child), along with the transplant team, must decide what is in the best interest of the donor when it comes to the decision making process. The donor-patient relationship may contain a negotiated mix of physician decision making and patient autonomy, but it should also be clear to the donor that he or she has no obligation to donate (Spital, 2001). While the element of coercion created by the choice of donation cannot be removed completely in the case of a sick child, an attempt must be made to minimize its effect by introducing the concept of LRLD in the context of a complete description of all transplant options available to a particular recipient (Renz et al., 1995).

For patients with fulminate hepatic failure (FHF), Samstein and Emond (2000) reported that the inherently coercive nature of the emergency transplant made them hesitant to recommend LRLT without a full consideration of its potential impact on the donor. The impact, as described by the authors, relates to the fact that donors who decide to donate to a child with FHF have little time to prepare for the dramatic event and are at risk for significant psychiatric complications following the donation, especially if the transplant fails.

Decision to Donate

The donor is expected to make this vital decision to donate within a very limited period and in a state of fear and shock, which can impair or block his or her understanding of information about procedures, risks, and prognosis (Forsberg et al., 2004). According to a study by de Villa, Lo, and Chen (2003), the ethical soundness of the practice of living donor liver transplantation rests in the hands of those who provide the service. This is one reason why transplant centers must be competent in ensuring that a donor is making the decision to donate free from coercion and that he or she is fully informed of the risks and benefits of the donation.

Higgins and Kayser-Jones (1996) conducted a rigorous study of informed decision making in a prospective ethnographic study including 24 parents of 15 children prior to their decision to choose cardiac transplantation as an option for their children. Data were coded into relevant themes and clustered into categories. This research team identified four specific factors that affected parental decision-making, which were: psychological/emotional, familial, social, and physician endorsement of a certain treatment plan. The researchers observed both spontaneous and logical decision-making processes (five families used spontaneous and ten used logical decision-making processes). The researchers concluded that logical decision makers prefer more autonomy in their decision making process, whereas spontaneous decision makers respond better to a paternalistic approach on the part of the physician. In order to study the effect of physician presentation of treatment options and the family's decision, the family's perspective had to be assessed before the decision could be made. This study defined the parent's perspective both before and after the discussion took place with a physician. Only two of the 15 families had a change in perspective pre- to post-discussion with a physician. This research illustrates that physician endorsement does not always play a significant role in decision-making processes for families. A clear explanation of the phenomenon to be studied and the specific steps that were taken in order to answer the research question demonstrated rigor in this study.

Higgins, Kayser-Jones, and Savedra (1996) observed physicians' initial presentation to parents of children needing cardiac transplantation, cardiologists' discussions among themselves regarding their beliefs about transplantation, and the parents' discussions among themselves regarding issues of cardiac transplantation. Findings of this research showed that the medical consequences of cardiac transplantation were actually well addressed by the pediatric cardiac transplant team. However, little information was given regarding the non-medical concerns of the parents. These non-medical concerns included psychological, social, and financial implications for the family faced with a child needing cardiac transplantation. This study successfully outlined the importance of nursing interventions related to information giving and support for parents who where faced with decision-making about cardiac transplantation for their children. It would have been very interesting to include observations of nurses with families at the bedside, as nurses provide important information to families during critical times often explaining or elaboration on what physicians said. That would have offered a different angle to the decision making process for families and may have added a more complete descriptive quality to the study. A long-term follow-up study with these same families would also contribute additional information on the decision-making process.

Forsberg, Nilsson, and Olausson (2004) found that liver donors emphasized their moral responsibility as parents and the impossibility of living with the guilt associated with refusing to donate. Based on this knowledge, the question arises as to whether it is ethical to discuss living parental liver donation as a choice. This concept supports the idea that health care providers must enable parents to discuss alternatives other than donation when it comes to the health of their children. One alternative to LRLD, namely, to wait for a cadaveric donation, may take weeks or months for some families, depending on how sick their children are, as well as on blood type and size. Using a computerized program, the UNOS lists patients according to clinical presentation, with the goal of offering organs to the sickest children first.

The decision to donate is frequently spontaneous in both kidney and liver living donors, and a majority of LRLD embrace the concept of living donation when initially presented with this option (Diaz et al., 2002). There are cases, however, when donors experience regret. For example, a study conducted by Johnson et al. (1999) examined a series of 524 questionnaires that had been mailed to 979 kidney donors who had donated between August 1, 1984 and December 31, 1996. Of these donors 45% were siblings, 31% parents, 8% unrelated, 5% other than first degree relative, >1% twin. An evaluation of responses to the SF-36 quality of life health questionnaire concluded that 4 percent of the donors expressed dissatisfaction and regret about their decision to donate. In addition to the SF-36 they conducted a second questionnaire of 25 questions about how donors received information about donation, stresses related to their donation, specific expenses incurred during the donation, physical changes they experienced, emotional changes, and preexisting factors such as marriage, sex, level of education, and relationship to the donor. Twenty-three percent of these participants admitted to feeling depressed after surgery and 15% admitted to feeling depressed or anxious during the 4 weeks before responding to the questionnaire.

Franklin and Crombie (2003) conducted two substantive qualitative studies that examined similar aspects of live donation: one study from a psychological perspective (study A) and one from a social-cultural perspective (study B). The overall findings suggested that living-related renal donors did not express regret after donation and did report enhanced self-esteem. The decision to donate was immediate and altruistic for most parents, although some fathers expressed a degree of ambivalence. Siblings found the decision to donate more difficult and complex. That decision may also lead to conflict between family of birth and family of marriage (Franklin & Crombie, 2003).

These authors decided to combine these two qualitative research studies into one paper because they believed that psychological, social, and cultural aspects of live donation are closely intertwined. Study A used a phenomenological research approach for discovering the meaning of the life to the donor, and study B used an ethnographic approach to uncover the social processes of those who donate. Utilizing both phenomenological and ethnographic methodologies allowed for in-depth interviews as well as participant observations, which added richness to the study. A weakness of this paper was that the authors did not clearly state all the steps of the study and failed to present its key elements, which presents a threat to the rigor of this study.

In a powerful article published in the *Journal of the American Medical Association*, the authors created an important construct for understanding the dynamics associated with the donor's decision-making process to donate (Merrill, Murray, Harrison, & Guild, 1984). They classified this process into three characteristic models: (1) moral decision-making, which reflects a seemingly spontaneous choice with no real deliberation; (2) deliberation and conscious choice; and (3) postponement, in which a decision is not made until there is no other conscious choice available, i.e., the potential donor is ruled out for medical reasons or becomes the only possible donor choice for a certain recipient. Simmons, Klein, and Simmons (1987) used these classifications to code 52 subjects who became kidney donors. They found that 62 percent of those who chose to donate adopted the "moral" model; 23 percent were coded as using "deliberation"; 4 percent actually postponed the decision; and it was unclear into which classification 17 percent of the subjects fit. They also applied the same codes to those individuals who decided not to donate and found that out of 235 subjects, 21 percent fit the "moral" model, 31 percent utilized the "deliberative" pattern, and 24 percent employed postponement (Simmons, Klein, & Simmons, 1987).

Russell and Jacob (1993) stated that the potential donors in their study faced a no-win situation during the decision-making process. If potential donors said no, they were bound to regret the decision and lose the chance to save a life. If they agreed to donate, they might regret the loss not only of an organ, but also of the opportunity to make up their minds without pressure. These authors determined that even with a fair and thorough transplant team, it is still uncertain whether the question about donation is itself a reasonable one to ask when realistically only one “right” and “moral” answer exists (Russell & Jacob, 1993, p. 95).

Renz and Roberts (2000), in a study performed at University of California San Francisco (UCSF), highlighted the fact that donors endorsed the LRLD procedure. Eighty-eight percent of the donors in the study’s sample believed the role of LRLD should be “increased” and should not be reserved for only “emergency situations.” One of the most significant reasons that LRLD should not be reserved for “emergency situations” is because it has profoundly impacted pediatric waiting list times and decreased waiting list mortality (Emond, Heffron, & Krotz, 1993). None of the donors in the UCSF study felt abandoned or “forced” to donate. All of the donors expressed satisfaction with the pre-donation information given to them (Renz & Roberts, 2000).

Martinez-Alarcon et al. (2005) conducted a study in Spain that analyzed attitudes regarding living donation expressed by adults on the waiting list for transplantation. They found that only 6% of patients waiting for liver or kidney considered living donation as a first choice, and 42% did not even consider the option. Ninety-one of those surveyed were in favor of donating their organs when they died, 6% had doubts, and 3% were opposed to the idea. It is interesting to note that candidates for transplant are opposed to LRLD for themselves, yet they are favorable to participating in living donation if a family member is in need of an organ. This finding is difficult to interpret, but it may be that the individuals on the waiting list are more comfortable in helping others than having others helping them.

Uribe et al. (2005) addressed the question of why living related donation was being rejected as an option in Chile. They have preformed 57 pediatric liver transplants, of which 17 (29.8%) used living related donors. They found that the reasons that living related donations was not an option were: fear of surgical complications expressed by parent (4), drug abuse (2), single mother without family support (1), medical reasons (2), anatomical reasons (1), and, in one case, cadaveric graft was made available during the father's evaluation. Though this is a small transplant center, very few studies such as this address the reasons why parents choose not to participate in LRLD.

The decision to donate is a personal choice made by the donor, and must take into account parental preferences. Parents' preferences during the decision-making process such as a family's view of QOL issues for their child, influence parental choice regarding transplantation (Higgins, 2000). Pediatric liver transplant coordinators can assist families in providing emotional support, clarifying transplant options, as well delivering clinical support during the decision making process.

Viewing the Donor as a Patient

Most of the literature on complications and benefits of living related donation focused on absence of morbidity, days in the hospital, and post-surgical complications, and a very few addressed the time required for the donor to achieve normalcy following transplant. Employing an interpersonal interview format, Crowley-Matoka, Siegler, and Cronin (2004) explored the donor's perception of return to normalcy and time required to achieve it. The authors defined normalcy as the time it took for the donor to return to the physical and emotional state experienced prior to donation. Caring for a post-transplant child seemed to postpone addressing the needs of the individual donor, and many of the common emotional and physical stages associated with "healing" after the donation were delayed, such as post-operative pain management, long-term follow-up and financial strain. Crowley-Matoka and her research team believed that their research results supported the delay in returning to “normal life” in two ways. First, study subjects confirmed that the first year after transplant was too soon to assess long-term quality of life effects; second, donors lacked information on the long-term effects of the donation process (Crowley-Matoka et al., 2004).

A hallmark study conducted by Crowley et al. (2004) is one of the first of its kind that investigated a long-term cohort of adult-to-pediatric living liver donors, and also one of a few published studies that approached issues such as marital tension, financial difficulties, problems with other children in the family, and the donor’s own sense of physical and emotional well-being. Using the University of Chicago Hospital transplant program database, the research team identified a cohort of 130 adult-to-pediatric donors from November 1989. They conducted telephone interviews, audiotaped with subject permission, analyzed the tapes, and pinpointed recurrent themes. The data analysis demonstrated key issues that emerged from the interviews: (1) deciding and preparing to donate, (2) perception of donor as a non-patient, (3) family relationships, (4) financial and insurance issues, and (5) return to “normalcy.”

This exquisite qualitative study is significant because it was the first of its kind and because it provided applicability to clinicians. The possibility of sampling bias must be mentioned in this critique because the results derived from a single center. This fact makes it difficult to generalize these findings to the general population of liver donors. Another noted weakness of this study lies in the fact that it relies on telephone interviews alone, which did not permit any observational memos. This poses a threat to the descriptive vividness of the study. Nonetheless, these authors demonstrated commitment to gaining a qualitative understanding of the process and long-term consequences of living liver donation.

Forsberg, Nilsson, and Olausson (2004) in another qualitative study demonstrated that parental donors suffer in every possible way: physically, mentally, socially, and spiritually. Despite these expressions of pain and loneliness, the staff's attitude was that these donors were healthy and should be back on their feet as soon as possible. Rather than receiving confirmation of their worth and recognition of their heroic sacrifice and subjective feelings, the donors felt abandoned, isolated, and left to their own destiny.

These researchers used an interpretive phenomenology as a method to understand the donor experience. They discovered the essence of living parental liver donation, a struggle for holistic confirmation. They identified three categories leading to this central theme: total lack of choice, facing the fear of death, and transition from health to illness. The results of the study demonstrated heuristic relevance. They clearly described phenomena throughout the article, compared their research to other study findings, and integrated research findings into a body of knowledge applicable to the transplant community.

In order to address the limited information available about the physical and psychological risks of donation and long-term outcomes, creation of a national donor registry could provide consistent, long-term information for potential donors. The literature reveals that treating the donor as a patient is important from the perspective of the donor, and that consistent follow-up is recommended. Post-transplant follow-up has many benefits to the donor, such as continuity of care, but it also provides an opportunity to gather crucial outcome data, especially psychosocial impact useful in addressing changes in the assessment and treatment of living donors (Olbrisch et al., 2001). In order for live donation to thrive and to ensure that transplant clinical success does not occur at the cost of psychological and social harm to the donor, it is important to offer evidence-based psychological and social support (Franklin & Crombie, 2003)

Culture and Language

When evaluating a donor, the transplant team must consider language and culture issues, which can be challenging, and must recognize individual social and cultural differences of parents (Higgins, Kayser-Jones, & Savedra, 1996). Assessment is difficult when a potential donor does not speak the same language as the evaluator, even if an interpreter is available (Delmonico, 2000). Interpreters can at times allow their own values and beliefs to affect the translation. Olbrisch et al. (2001) identified routine inquiries about private matters, such as medical history, changes in sexual desire or performance, and mental health history, as especially difficult for donors to discuss in the presence of a third party. Additionally, some lines of questioning may be culturally inappropriate. They offered the following vignette to illustrate how culture can influence ones perception of the concept of LRLD:

> A woman from another country presenting as a donor for a friend stated that their bond was extremely close, as the intended recipient of her kidney was the godmother of her child. She explained that within her culture, the role of the godparents was far more important and meaningful than in the United States and included the commitment to care for the child in the event of the death if the parents. Some members of the transplant team, who wondered whether financial motivation was somehow involved, regarded this claim with skepticism. However, a physician from the same culture who was not associated with the transplant program was consulted; he verified the cultural significance of the godparent role in the donor and recipient’s culture. (Olbrisch et al., 2001, p. 45)

The actual idea of donation, living or cadaveric, varies greatly from culture to culture. For example, in Japan, where the idea of mutilation after death is abhorrent, the number of cadaveric kidney transplants amounts to less that half of the total number of kidney transplants done in that country, whereas in the United States approximately 75 percent of all kidney transplants performed use cadaveric donations (Russell & Jacob, 1993). According to Haruki (1989), the Japanese feel comfortable in having their organs removed after they die, but they would not approve the removal of organs of a relative who dies.

Fox and Swazey (1974), in their landmark research on kidney transplantation and dialysis, presented a scenario in which organ donation cannot be reciprocated either in spirit or in kind. They stated that as long as organ transplantation is considered a gift or a donation, it will be associated to the same norms as giving, receiving, and repaying (Fox & Swazey, 1974).

Summary

The literature reveals that the mere idea of LRLD can elicit discussions involving a variety of ethical principles. The potential for donor coercion, the possibility of undue pressure among family members to volunteer as donors, and the risks of taking a working organ from a healthy individual are paramount in discussing ethical issues and living donation. Many transplant researchers have addressed the psychological consequences following LRLD, particularly in the case where organ rejection or infection causes death of the recipient. Comprehensive psychological, physical, and emotional assessment of the donor is recommended as part of all LRLD evaluations. Post-transplant follow-up has also been recommended in the literature as benefiting the donor by providing an opportunity to gather crucial physical and psychosocial outcome data, which can be useful in the management and treatment of the living donor post-donation. Most importantly, the donor must be treated as a patient, not as a commodity, and should be given all the information necessary to make the best decision for themselves and their families. The transplant center has an ethical responsibility to define, understand, and communicate all risks that can affect a donor.

Benefits and Complications of Living Related Liver Donation

Benefits

Singer, Siegel, Whitington, Lantos, Emond, Thislethwaite, and Broelsch (1989) reported that the benefit of LRLD to the donor is psychological, and, as a parent of the recipient, the prospective donor has a powerful motivation to participate. If the transplant recipient dies, the donor may take comfort in knowing that he or she did everything possible to save the child. A survey of 150 LRLD donors conducted by Cotler, McNutt, and Patil (2001) found that 60 percent expressed a preference to be live liver donors and die rather than see the recipient die. On the other hand, if the transplant succeeds, the donor has the extreme satisfaction of having actually saved the life of a child (Singer et al., 1989). It is the belief of Singer and his colleagues that, from the perspective of both recipient and donor, the benefits of LRLD outweighed the risks, and that it was ethically appropriate to proceed with a trial of liver transplantation using a parent as a living donor.

Trotter and his research team (2002) at University of Colorado Health Sciences Center discussed advantages and disadvantages of LRLT. They contended that the most important advantage to living liver donation was a reduction in waiting time. Once a potential donor was evaluated and found suitable, LDLT could be scheduled within hours to weeks. For patients with decompensated liver disease, a shorter waiting time might reduce the risk of death. Another advantage to LDLT was that it allowed for more flexible scheduling, unlike urgent cadaveric transplantation. Finally, Trotter et al. (2002) indicated that living-donor liver transplantation greatly reduces cold-ischemia time (the period between removal of the donor liver and its implantation in the recipient). In cadaveric transplantation, the cold-ischemia time usually lasts eight to twelve hours, whereas with LRLT, because the donor and recipient undergo surgery in adjacent operation rooms, the cold-ischemia time is one hour or less. Prolonged cold-ischemia time has been associated with increased complications and graft dysfunction.

Grewal et al. (1998) found many of the same benefits associated with LRLD as did Trotter et al. (2002), but added that LRLD increased the number of organs directly available for the pediatric population. Also, there was a theoretical immunologic advantage of receiving a living-related organ, as suggested by the lower incidence of steroid-resistant rejection compared with cadaveric liver transplants. Russell and Jacob (1993) argued similarly in cases of the recipient organ where a family member might be screened and ready for the procedure. In addition, organs from blood relatives offer the promise of a better immunological match than what might be expected from a cadaver organ from a stranger.

From October 1991 to January 1995, a team of researchers in the Department of Pediatrics, Pediatric Gastroenterology University Hospital Eppendorf, Hamburg, Germany conducted a study examining 43 LRLT, 40 left lateral lobe, and 3 right lobe. These researchers demonstrated that the UNOS waiting list mortality in 1994 was zero percent for LRLT and 5.5 percent for cadaveric pediatric transplantation candidates

(Bassas et al., 1996). These results did not establish the severity of the liver failure of the pediatric patient, a fact that posed a threat to external validity, however their aims were innovative and new for the field of transplantation, which made this an impressive study.Furthermore, the researchers were able to demonstrate another benefit of LRLT—namely, the absence of primary non-function and chronic rejection in recipients.

Complications

Many reports showed that the average donor hospital length of stay consisted of less than seven days and that living donation can be performed without the need of nonautologous blood transfusions (Haberal, Bilgin, & Karakayah, 1998). Donor hospital days normally ran less than ten days, average donor blood losses were approximately 400-800mL, and the need for heterologous blood transfusion of the donors was uncommon (Renz & Roberts, 2000). Nevertheless, living donation is performed with significant risk (Diaz et al., 2002). The overall incidence of donor complications, including hemorrhage, pulmonary embolus, biliary injury, hernia, postoperative bowel obstruction, and sepsis, reported from multiple centers ranged from 10 to 15 percent (Malago et al., 1994). Malago et al. (1994) concluded that data on LRLT complications are deficient and not regularly updated because of the lack of well-established registries with audit mechanisms. That fact means information on donor complication and deaths are incomplete, leaving opportunity for dangerous rumors.

Trotter et al. (2002) admitted that long-term tracking of living-donor grafts is minimal compared to that for recipients of cadaveric liver transplants, making both incidence and extent of long-term complications less certain. Initial results suggested that recipients of living-donor transplants may have more biliary complications than recipients of cadaveric organs as the surgery requires more extensive dissection to the biliary system of the harvested liver that comes from a live donor. This occurs in 15 to 32 percent of patients (Bak et al., 2001; Broelsch et al., 2000; Marcos, 2000; Marcos & Ham, 2000; Testa et al., 2000; Toto et al., 2000).

Disadvantages of LRLD focused primarily on the risk to the donor. In cases reported in the *New England Journal of Medicine* in April 2002, 2 of 706 donors died (0.28 percent) (Trotter et al., 2002). Trotter et al., agreeing with Malago et al. (2001), suggested great difficulty in approximating the exact number of donor deaths due to living liver donation as a consequence of the absence of a national donor registry. Transplantation physicians have expressed concern about mortality among donors and about the underreporting of deaths (Strong, 1999).

According to the American Society of Transplant Surgeons: Ethics Committee, risks to the donor includes the following:

> 1. Risks associated with any surgical procedure, such as like bleeding, infection and anesthetic complications. 2. Possibility that the donor will be left with insufficient hepatic function. 3. Possibility of biliary complications, both in the early and late postoperative periods. 4. Risks associated with blood transfusion; 5. Unknown, long-term risks associated with major hepatic resection (Delmonico, 2000, p. 2920).

Grewal et al. (1998) reviewed 100 living liver donors to evaluate the peri-surgical complications of the procedure, with the goal to quantify risks to the donor. This quantitative study collected donor data by chart review, anesthesia records, and computerized hospital database. Patient variables were compared by Fisher's exact test and the Student's t-test. The study included 57 women and 43 men with a median age of 29; 91 had donated were left lateral segments and 9 donated left lobes. Results showed no recorded deaths. Fourteen major complications occurred in 13 patients; these included seven biliary complications, one hepatic artery thrombosis, one intra-abdominal abscess, one splenectomy, one perforated duodenal ulcer, one gastric outlet obstruction, and two wound dehiscence. Two patients required laparotomy for bile leaks, two patients required fascial reclosures for wound dehiscence, and one patient required an omental patch for a perforated duodenal ulcer. Minor complications occurred in 20 percent of the donors. These included: two wound infections, two adverse reactions to medication, one case of urinary retention, four episodes of prolonged ileus, one pneumothorax, four urinary tract infections, two cases of pneumonia, one case of mild neurapraxia, and three others, all of which were managed conservatively (Grewal et al., 1998).

In a study performed at UCSF Medical Center, Renz and Roberts (2000) concluded that donor outcome after LDLT depended on the type of liver resection the donor experienced, i.e., left lateral segmentectomy used for pediatric cases and right lobectomy used in adult cases. Their analysis showed that biliary complications occurred in 5 to 10 percent of both the adult and pediatric cases; estimated morality was 0.13 percent for pediatric donation and 0.2 percent for adult donation. They reported that all donors returned to pre-donation activities; 25 percent by one month, 75 percent by three months, 88 percent by six months, and 100 percent by one year. This study can be compared to similar results by Toto et al. (2000) at Hokkaido University School of Medicine in Sapporo, Japan. They performed 308 LDLT at 20 centers in Japan and found that 9.3 percent of donors experienced mild to moderate complications. Biliary complications were the most frequent (N=9) (Toto et al., 2000).

Renz and Roberts (2002) detailed donor complications. Their study results showed that donor cholestasis commonly occurred after donation and were caused by different factors, for example, reduced hepatic mass, impaired hepatic function due to regeneration, anesthetic drug reaction, and surgical stress. Renz and Roberts' (2002) study of 41 living liver donors found that the cholestasis typically resolved on its own over several weeks to months. In this sample, hernias occurred in approximately 5 percent of donors, and 11 percent experienced dyspepsia and/or gastritis (Renz & Roberts, 2000).

The Pediatric Kidney Living Donor Experience

As current procedures for live donor segmented liver and lung transplantation gain in familiarity and practice, the questions raised by live donor kidney transplantation (LDKT) serve as a paradigm for our understanding of living donation as a whole (Russell & Jacob, 1993). Currently conducted routinely and worldwide, LDKT is the most commonly performed living donor transplant, has a long-term graft survival rate which exceeds that of the cadaveric transplant (Grewal et al., 1998). Unlike liver transplantation, the kidney transplant, and donor does not necessarily "save the life" of the recipient, because there is always the option of dialysis (Simmons et al., 1987).

Using a phenomenological approach, Lennerling, Frosberg, and Nyberg (2003) interviewed twelve potential living kidney donors and determined that the decision to donate was based primarily on emotions. Most donors, in fact, did not weigh risks and benefits. Lennerling et al. (2003) identified seven categories leading to motives to donate—namely, a desire to help, increased self-esteem from doing good deeds, identification with recipient, self-benefit from the relative's improved health, mere logic, external pressure, and feeling of moral duty. All seven led to one common theme, i.e., that donation was the only option.

Baines, Beattie, Murphy, and Jindal (2001), undertook a descriptive study with the goal to better understand changes that occurred within the primary family unit resulting from living kidney transplantation. They studied seven donor-recipient pairs (five father-to-son, one father-to-daughter, one mother-to-daughter). The researchers subjected recipient-donor pairs to four semi-structured interviews immediately after transplantation and at three-month intervals over a period of one year. They asked patients about their experience of ongoing chronic illness, the decision to donate, characteristics of their relationship and those of other family members, and any relational alliances and allegiances between individuals in the family. They found that family dynamics did not necessarily change as a result of the transplant; rather, existing configurations, alliances, and allegiances tended to be amplified. There did not appear to be any detrimental effect in family dynamics that could be directly attributed to the transplant process. The interview technique used in this study may not have reached the true experience of the donor or the recipients, since subjects were interviewed as pairs. One suggestion would be to interview the donor and the recipient separately, which may produce a richer, more accurate narrative.

A plethora of studies in the literature focused on quality of life (QOL) and living kidney donors. These present a framework from which to better understand the LRLD, since very little research is available on QOL issues and the LRLD. Simmons et al.

(1987), the first to report long-term follow-up results of kidney donors' quality of life, performed a mail survey of 536 kidney living donors, 96 percent of whom reaffirmed their decision to donate regardless of recipient outcome. A majority of donors who participated in the study reported a complete return to pre-donation activities following the surgical procedure.

Another study (Jacobs, Johnson, & Anderson, 1998) at the University of Minnesota concluded from a survey of 529 living kidney donors that donors scored higher than the overall population with regard to QOL issues. The research showed that the overall donor experience was stressful for 12 percent of the sample population, and donors more likely experienced stress if they had post-operative complications. The results did not include severity and frequency of complication. Only 4 percent of those surveyed said that they would not donate again, and 9 percent were unsure (Jacobs et al., 1998).

Studies such as these use very large sample sizes, which add statistical power to their results, and can be generalized to the general population of living kidney donors. However, threats to internal validity arise when questionnaires and surveys are not necessarily valid and reliable, or consistent between studies and the content of the questionnaire or survey is unavailable. A threat to internal validity can also be present when response rates to surveys and questionnaires are low.

Franklin and Crombie's (2003) study on living-related renal transplantation addressed the psychological, social, and cultural issues of donation. Reciprocity and feelings of obligation did not seem to cause relationship difficulties for siblings, but were reported by a few of the adolescent recipients who had received grafts from their parents, leading to psychological distress and social-familial alienation (Franklin & Crombie, 2003). In the psychological perspective branch of their study all of the parent donors stated that they had donated “out of love - it was the natural thing to do” (Franklin & Crombie, 2003, p. 1249). One father did admit that he had always felt some jealousy toward his wife because she had the experience of birthing their son; he thought that donating would give him a special bond with his child. Eight of the ten siblings interviewed also “donated out of love.” However, the other two had different feelings about donation. One of these siblings, a male who did not want to donate, went through with it,

> Because I couldn’t have faced my parents if I had refused. I have never liked my sister very much, but once the request was made it was impossible to refuse - sort of family and moral duty. I really wish the question of live donation had never come up. I felt a bit like a fish on a hook. (Franklin & Crombie, 2003, p. 1251)

The other donor, a female sibling who felt pressure to be accepted within the family, said: “I was always the rebel, and Mary (the recipient) was the goodie goodie. Several times our parents had banished me, but all was forgiven once I offered to be a donor” (p. 1249).

This study provides the transplant community with insights into the potential for coercion and the need to properly evaluate the living donor. Unlike kidney living donor transplant, currently liver donors have not included children.

Heidelberg University Hospital has developed a family-oriented consultation procedure for recipients, donors, and family members before a living kidney transplant. Schweitzer, Seidel-Wissel, Verres, and Wiesel (2003) conducted 67 consultation interviews and explored by rating family interaction, consultee-consultant interaction, decision making process, and intervention strategies. This team’s results demonstrated that donors presented themselves as eager, but that the recipients appeared to be more reluctant. Expectations focused on the spontaneity of the donation and having a “normal life.” The donors usually expressed fears not about themselves, but about the partner involved. The researchers recognized that family experiences of medical trauma might have influenced content and level of anxiety.

The living kidney donor experience has a longer history and provides extensive research on the issue of QOL of the donor. Unfortunately, despite the magnitude of the literature available on QOL and kidney donors, very little research is available on familial relationships and the donor. This gap in the literature exists not only for the kidney transplant arena, but also for the field of liver transplantation. Living kidney donors continue to provide the optimum outcome for kidney transplant recipients, despite limited information on how donation can affect the donors and their families (Johnson et al., 1999).

Quality of Life for the Living Related Liver Donor

In discussing QOL issues it is important to make the distinction between adult-to-adult living donation and adult-to-pediatric living donation. As reported by Marcos (2000), right lobe donation is preferred to left lobe donation in adult-to-adult donation, whereas left lobe donation is preferred for adult-pediatric donation. Mortality rate for right lobectomy for the donor has been less than 0.3% in 275 procedures performed to date and morbidity (major and minor) has been approximately 16%. Overall, morbidity and mortality rates for left-lobe resections are 19% and .2%, respectively. Historically, right lobe donation began in 1998, whereas left lobe was introduced in the mid 1980s.

The World Health Organization (2004) defined QOL as an individual's perception of his or her position in life in the context of the culture and value systems in which he or she lives and in relation to goals, expectations, standards, and concerns. This broad ranging concept is affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships, and relationship to salient features of the environment (World Health Organization, 2004). The LRLD's QOL encompasses an extensive range of emotional, physical, and cultural characteristics. In examining the concept of QOL as it relates to the LRLD, the domains will embrace those outlined by WHO.

While the literature on QOL and the living liver donor is minimal in comparison to the living kidney donor, a few very significant studies require attention. Limited donor outcomes data suggest favorable results, but no outcomes data have been reported using an instrument that elicits anonymous response from the donor or that employs a widely recognized health survey (Diaz et al., 2002). Diaz and her team at the University of California San Francisco (UCSF) investigated long-term follow-up (greater that one year since the transplant) donor health. The research team identified and included 41 living donors between June 1992 and June 1999, regardless of specific donor or recipient outcome. They employed a standard McMaster Health Index Questionnaire (MHIQ), which included a 68-question survey. The MHIQ, a widely recognized measure of quality of life, consists of 24 questions assessing physical health, 24 questions on social health, and 19 questions addressing emotional health. It has been used to assess outcomes in a variety of patient populations.

In response to the MHIQ, donors surveyed reflected that they returned to physical activities by above-mean scores. Scores for social and emotional health did not differ from general population data. There were no reported changes in sexual function or menstruation after the donation. Donor perception of time to “complete” recovery turned out to be longer than expected, with roughly one-quarter of donors requiring greater than three months and 5 percent requiring greater than one year to achieve “complete” recovery (Diaz et al., 2002). The fact that the “expected time of recovery” relayed by the transplant team to their potential donors went unmentioned in this article poses a threat to construct validity. However, this study succeeded in producing research that focuses on long-term outcomes of donors, and it permitted anonymous responses from the donor. This study could have benefited by expanding it to other transplant centers or pediatric transplant registries, as well as by addressing issues such as familial relationships, financial hardships, and emotional stress, all of which are key issues in long-term follow-up of donors. These two major issues comprise threats to both the external and the internal validity of this study.

Follow-up reports on living liver donors have generally focused on medical complications (Trotter et al., 2002), rather than on quality of life (QOL) issues (Crowley-Matoka et al., 2004), for two specific reasons. First, existing studies have relied primarily on standardized questionnaires of a general nature, for example, the Medical Outcomes Study Short-Form Health Survey (SF-36). The SF-36 provides a measure of health status designed for use in clinical practice, research, health policy evaluation, and general population surveys (RAND, 2005). Standardized surveys lack both the specificity and the sensitivity necessary for capturing some of the particular quality of life issues that may emerge for living liver donors. Second, previous studies have contacted liver donors within a relatively short time after the donation (often less than one year). This short duration after donation does not allow for an accurate appraisal of the long-term consequences of living donation (Crowley-Matoka et al., 2004).

Among the donors interviewed, all parents who had donated a portion of their liver to a son or daughter, all but one admitted that they had never really made a decision to donate, that it was simply an “automatic leap” (Crowley-Matoka et al., 2004, p. 745). Ten out of the 15 donors interviewed reported having felt treated as non-patients by the medical team and family members in two primary areas—post-operative treatment of pain and long-term follow-up areas. Family relationships were reported to have been strengthened by the donation process.

The Crowley-Matoka et al. (2004) study made a critical contribution to the investigation of long-term outcomes of LRLD. Interviews, whether administered in person or over the telephone, do allow for a rich understanding of the effects that donation has on one’s life. However, interviewing in person would have provided the researchers with additional observational data to use in their analysis. This study was conducted at a single transplant center and with a very small sample size, therefore limiting its transferability to the general population of LRLD. Overall, Crowley-Matoka and her team conducted qualitative interviews that produced data with the potential to improve care for transplant donors.

There exist a number of instruments available for measuring content domains pertaining to the construct of quality of life. The overall goal in using a selected tool is that it provided data that will benefit the future potential LRLD and advance transplant science. Quality of life data can yield specific information relevant to planning and evaluating nursing interventions (Grant, Padilla, Ferrell, & Rhiner, 1990). The ability to offer potential donors information about QOL and familial relationships experienced by living donors may help guide the decision-making process. The potential donor should have available all possible information regarding life after donation, and should be educated on the possible consequences of the donation on QOL.

Family Dynamics and the Living Liver Donor

Family relationships play a pivotal role in live transplantation, a situation compounded by both the complexity of the concept of the family and by the fact that family structures have changed over time (Franklin & Crombie, 2003). Family, indeed, becomes key when studying the lives of living donors, because a family that has experienced living-related donation will have two of its members, the donor and the recipient, to care for following a transplant, and not just one, as in cadaveric donation. LRLD carries with it the potential of placing a great deal of stress on a family, especially on the member who serves as designated caretaker.

Very little research is available on familial relationship and LRLD. Goldman (1993) conducted a study that examined donor outcomes pre- and post-operatively to evaluate adverse psychiatric outcomes. Out of a total of 22 pre-operative interviewees, 20 donors actually went to surgery. Only nine subjects completed the Minnesota Multiphasic Personality Inventory (MMPI), the Symptom Checklist-90 (SCL-90), and a post-operative assessment to measure processes of decision-making, anticipation of surgery, effect of child's illness, previous stressors and coping, previous mental health contact, support system, and family history. Goldman's article does not clarify the post-operative length of time after which subjects were brought back for the follow-up assessment. Goldman declared that almost all of the families and donors were extremely committed to proceeding with LRLD and seemed almost unswayable in their convictions about the procedure. He also pointed out that almost all of the donors (the mothers and even one grandmother especially strongly) described their willingness to proceed as "simply part of doing whatever you can for your child" (Goldman, 1993, p. 337). Additionally, several mothers expressed guilt about the child's illness and even speculated about what they might have done during the pregnancy to cause it. Unfortunately, Goldman did not quantify "several" or "almost all" in his study, which may compromise the study's validity. Goldman also indicated that during the immediate post-operative period he discovered two marital dissolutions and one donor with adjustment disorder.

Transplant researchers have documented cases where a family member labeled the "black sheep" felt that organ donation might be a route to reconciliation (Kemph, Bermann, & Coppolillo, 1969; Rapaport & Cortesini, 1985; Woodruff, 1964). Kemph and his colleagues (1969) found that a pattern existed for families both pre- and post-donation, wherein the family's attention moved from being congratulatory to the donor for the generous donation to focusing on the recipient whose life was still in question. Sharma and Enoch (1987) also noted this shift in family focus when a 30-year-old donor stated, "I felt neglected after the operation was over. My brother got all the publicity and I was left on my own. I hated him, I wished he was dead." Donnelly, Clayton, and Simpson (1989) found donation from parent to child less problematic emotionally, but that it seemed to have more immunological problems because siblings make a better match. They determined that the issue of reciprocity diminished between the parent and child, perhaps due to the inherent role of the parent to give to the child without expectation of return.

Implications for Transplant Centers Conducting Living Donor Transplants

Fox and Swazey (1974) believed that health care professionals must act as gatekeepers for evaluating living donors. They argued that this responsibility has the potential of creating a relationship between practitioners, patients, and families quite different than the typical professional relationship.

Health care professionals working in the field of transplantation are required to work simultaneously with both recipients and donors. This situation does create a potential conflict of interest. Russell and Jacob (1993) pointed to the advantage of separating the two roles by assigning one health professional to the role of donor advocate and one to the role of recipient advocate. Information collected via this method would assist in eliciting a more accurate assessment of the donor’s perspective.

A hallmark interpretive study conducted by Forsberg et al. (2004) made substantial recommendations based on several clinical implications for living parental liver donation. A few of the salient implications are: to accept that the parental liver donation could be viewed as coercive because of the parent-infant relationship; recommend that potential donors contact previous living donors prior to donation; accept the donor as suffering human being before as well as after the surgery; provide psychological support to cope with the fear of death; provide mandatory follow-up care for the donor up to one year following the donation by a psychologist or social worker;

provide mandatory follow-up by both a surgeon and nurse on a regular basis for the first year post-donation.

Living donor liver transplantation has the capacity to reduce the current discrepancy between the number of patients on the UNOS waiting list and the number of available organ donors. Nonetheless, transplant centers must continue to offer evidence-based research on the long-term consequences of LRLD. The literature clearly shows that the decision to donate is immediate and altruistic for most parents, and that love for their children outweighs any complication or benefit that may occur. But important questions remain unanswered. For example, what happens to the family and the donor following the donation? What family relationships may develop or suffer as a result of the donation? How does the donation impact the donor's QOL in the long term? Crowley-Matoka et al. (2004) published one of the few articles that addressed these issues, and must be commended. More provocative studies like theirs, which examined both QOL issues and family and personal relationships related to donation, will be essential for enhance our knowledge. As well, long-term studies on LRLD will be essential in furthering our understanding of the donor and the life-long impact donation has on a healthy individual.

Future Dimensions for the Living Donor and Liver Donation

Pediatric liver transplantation has made dramatic advancements over the past three decades. A scarcity of cadaveric livers has caused a search for solutions to deal aggressively with this issue. By increasing the use of split-liver transplants, judicious application of living donor programs, and increasing the donation rate, transplantation options now extend beyond cadaveric donation. The current challenge facing the transplant community is to establish a donor-organ utilization policy that encourages all appropriate donor livers to be split (McDiarmid, 2000). This would allow two recipients to benefit from one cadaveric donation. Living donor programs must be conducted exclusively by transplant centers that have the surgical, medical, and nursing support to deal appropriately with such a procedure. Children who are threatened with ESLD occupy a very vulnerable position and must be cared for equally and fairly.

One key criterion in listing patients for liver transplantation remains the proper matching of ABO blood grouping between donor and recipient. On occasion, surgeons must accept ABO incompatible livers for their patients, especially during emergency situations or when cadaveric donors are unavailable for an extended period of time. As a result of extending the living donor requirement to include ABO mismatched livers, donors who would normally be denied donation would be accepted. This could increase the number of organs available for children. In children below the age of three years, liver transplantations across the ABO barrier have been quite successful, especially with living related donors (Rydberg, 2001). Transplantation of hepatic grafts from ABO incompatible donors has been a subject of controversy because of the risk of hyperacute rejection mediated by preformed anti-ABO antibodies (Egawa et al., 2004). A difference in outcome between adult and pediatric cadaveric liver transplant has been reported, with pediatric transplants being more successful (Bell, Beringer, & Detre, 1995; Demetris, Jaffe, & Tzakis, 1988). With the shortage of pediatric cadaveric donors, the use of ABO incompatible livers may become more common. The choice of LRLD or using an ABO incompatible liver is a decision made on an individual basis and it is based on family preference and surgical recommendation.

Other future alternatives for pediatric liver transplantation include: hepatocyte transplantation, gene therapy, xenotransplantation, and the bioartificial liver (Strong, 2001). Hepatocyte transplantation, or encapsulated cell technology, could theoretically permit the transplantation of human cells and tissues without the need for immunosuppression and allow for the use of cells from animal species. Such a procedure could translate into the capacity for a single donor liver to treat a large number of patients. The most likely application of hepatocyte transplantation in the future would be to treat metabolic liver disease in the pediatric patient (Strong, 2001). Using animal sources, xenotranplantation holds major immunologic barriers, which makes this option feasible in the near future (McDiarmid, 2000). Gene therapy that targets site-specific repair can correct a defective gene, and considerable clinical application of this technology is envisaged for the future, with a possible reduction in the need for liver transplantation for diseases in pediatrics such as alpha-1-antitrypsin deficiency, Wilson's Disease, Crigler-Najjar Syndrome Type 1, and disorders of the urea cycle (Strong, 2001). Bioartificial livers using human tumoral hepatocytes or porcine hepatocytes have been utilized in clinical situations as a bridge to transplantations in order to gain time to find an appropriate liver graph. None of these techniques, however, has proved capable of keeping a patient alive long enough for the native liver to recover (Boudjema, Bachellier, Wolf, Tempe, & Jaeck, 2002).

New trends in pediatric liver transplantation constantly emerge, providing options to the current paucity of cadaveric donor organs. Immediate solutions to the organ crisis include expanding the donor pool of living related donors to ABO mismatched livers, increasing the numbers of split livers, and focusing on efforts to encourage more pediatric liver donors. Long-term solutions, and some still in the experimental phase, include hepatocyte transplantation, gene therapy, xenotransplantation, and the bioartificial liver.

Conclusion

As indicated by this literature review, very little research exists on LRLDs' perspectives on their quality of life and on familial relationships after donation. This provides a gap from which to develop new, innovative nursing research. Research has indicated that parents of children with ESLD are comfortable with the decision to donate, but that transplant centers must have strict ethical as well as clinical guidelines for the LRLD. As the demand for organs continues to surpass the supply, the use of living organ donation will expand. Today kidneys, portions of liver, lung, small intestine, and pancreas from living donors are used for organ transplantation (Crowley-Matoka et al., 2004).

The LRLD is a healthy individual who has put his or her life in jeopardy for a son or daughter. It is an amazing act of kindness and generosity. Because the donor must be clear on how such a decision can impact his or her life and the family's future, more research is needed to shed more light on the lives of the LRLD after donation. This type of research can be useful to the potential LRLD when he or she is deciding whether or not to donate.

CHAPTER III

THE GIFT OF LIFE: RESILIENCY AND THE LIVING-RELATE DONOR

A theory is nothing—it is not a theory—unless it is an explanation.

(Homans, 1964, p. 2)

Stress, Coping, and the Gift of Life

According to the United Network of Organ Sharing (UNOS, 2004), from January 1, 1988 to December 6, 2004, 72,399 livers were allocated to individuals suffering from end stage liver failure (ESLD). In 2002, 554 pediatric liver transplants were performed in the United States, 501 from cadaveric donation and 53 from living liver donations from parents to their children (UNOS, 2004). Families with children diagnosed with ESLD and in need of liver transplantation face a stressful situation, requiring them to make decisions that impact their everyday routines and lifestyles. Stress can result from many factors and can present itself in many different forms. Parents of a child with ESLD must not only deal with unfamiliar concepts regarding liver disease and its life threatening nature, but also struggle with monumental decisions regarding the plan of care for the child and the family as a whole. Depending on how this stressful event is perceived, parents and families will use many different coping strategies in dealing with it.

Very little qualitative or quantitative research is available on family stress and the living related-liver transplant donor. This chapter begins by presenting a general overview of stress theory and then describes specific family stress theories and how they can be applied to a family who decides to have one parent donate a portion of his or her liver to a child. A detailed discussion of the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & Patterson, 1987) and how it can be applied to understand the experience of the family involved in a live liver donation will follow.

A child with liver disease most commonly presents to a local pediatrician or nurse practitioner with fatigue, jaundice, nausea, vomiting, diarrhea, and malaise. Most parents are not familiar with liver function and perceive the experience as quite frightening. Based on the pediatrician or nurse practitioner's assessment, the child is referred to a transplant center for further evaluation. This is merely the beginning of an extensive journey a family must travel when they discover their child is living with ESLD. Managing the stress related to having a child with ESLD and needing liver transplantation demands that the family develop effective problem solving and coping strategies.

The purpose of this chapter is to briefly review and critique individual and family theoretical perspectives that may be used to understand the concept of stress and coping as it relates to this study. The work of the Hans Selye, Richard Lazarus, Ruben Hill, and Hamilton McCubbin will be addressed in reference to their specific theoretical models. Research utilizing one of the stress and coping frameworks, resiliency theory, is reviewed for its pertinence to families who are coping with issues facing living-related liver donation (LRLD). A discussion will follow that addresses the resilience framework and how it applied to this study, specifically how it was used to frame interview questions, how it shaped the analysis and interpretation.

General Overview of Stress Theory

The following definitions are offered in order to provide a better understanding of the conceptual model of family stress and coping as it related to families and the parental LRLD.

Family: “A continuing system of interacting persons bound together by processes of shared rituals and rules even more than by shared biology” (Boss, 2002, p. 18).

Family Stress: “Pressure or tension in the family system—a disturbance in the steady state of the family. Family stress is change in the family’s equilibrium” (Boss, 2002, p. 61).

Family Coping: “The process of managing a stressful event or situation by the family as a unit with no detrimental effects on any individual in that family. Family coping is a cognitive, affective, and behavioral process by which individuals and their family system as a whole manage, rather that eradicate, stressful events or situations” (Boss, 2002, p. 79).

Resiliency: “An ability to recover from or adjust easily to misfortune or change” (Boss, 2003, p. 75).

Agency: “An ability to master a situation or problem and is relevant in assessing resilience” (Boss, 2002, p. 75).

This chapter will present a few of the most important stress theorists, starting with those that looked at the individual’s psychological perspective of stress. This discussion will be followed by examples of theorists that addressed families and how families deal with stress and coping. Resiliency theory will help in illuminating the concept that individual stress can be understood in the context of family and the interaction the individual has with the larger world. Table 1 at the end of this chapter includes a summary of theories discussed as well as their strengths and weaknesses.

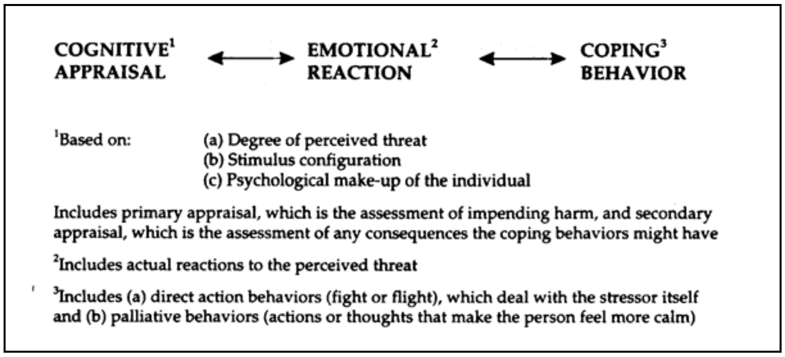
Hans Selye

Theoretical models and frameworks dealing with family stress and coping have a long history in psychological, sociological, and nursing research. Hans Selye, a 1950's endocrinologist, is considered a pioneer in defining stress. Selye originally defined the stress syndrome as consisting of all the nonspecifically induced changes in response to stressors (Antonovsky, 1979). The first to denote and measure stress adaptations in the human body (Boss, 2002), Selye defined stress using the well-known, three stage, general adaptation syndrome (GAS): alarm reaction, resistance, and exhaustion (Antonovsky). In the first stage of the GAS, the alarm reaction, a noxious agent, initiates a neurohumoral process in the body. The second stage of the stress response continues as the body seeks to mobilize and defend itself. The third and final stage of Selye's GAS, exhaustion, exists only if the stressor is severe enough and the struggle so strong that it weakens the body to the point that it can no longer sustain itself and dies (Lazarus, 1999).

Richard Lazarus

Richard Lazarus's research and theories on stress, coping, and emotions have influenced many. Lazarus (1977) viewed coping as a cognitive activity incorporating an assessment of impending harm and of the consequences of any coping action. Lazarus (1999) clarified coping as an essential element of emotional life. "The constructs—motivation, appraisal, coping, stress, and emotion—are conjoined in nature, and should be separated for only the purpose of analysis and discourse" (Lazarus, 1999, p. 101). He approached the combination of stress and coping as a transactional phenomenon and primarily focused on the meaning of the stimulus to the individual who perceives it. He pointed to the difficulty in distinguishing appraisal from coping (Lazarus, 1999) and differentiated between two kinds of appraising—primary and secondary. Since he thought the two always worked independently, he preferred to discuss them separately. Primary appraising deals with whether or not one's values, goals, and beliefs are factors that can influence the action or stress. Secondary appraising refers to a cognitive-evaluative process that recognizes the person-environment relationship and the evaluation of coping options. Basically, primary appraising is an evaluation of whether what is happening is worthy of being acted upon, while secondary appraising focuses on what can be done to cope (Lazarus, 1999). Appraising can be deliberate and conscious, or intuitive, automatic, and unconscious—an important distinction, considering that one family's appraisal can be slow and deliberate while another family's may take place quickly.

Lazarus made a strong case in opposition to Selye, arguing that emotions and the analytical thought process link closely with how individuals process stress, as shown in Figure 1.



[1] Based on: (a) Degree of perceived threat
(b) Stimulus configuration
(c) Psychological make-up of the individual

Includes primary appraisal, which is the assessment of impending harm, and secondary appraisal, which is the assessment of any consequences the coping behaviors might have

[2] Includes actual reactions to the perceived threat

[3] Includes (a) direct action behaviors (fight or flight), which deal with the stressor itself and (b) palliative behaviors (actions or thoughts that make the person feel more calm)

Figure 1. The Coping Process as described by Richard Lazarus.

Source: Lazarus (1977, p. 77).

Both Lazarus and Selye made breakthroughs in our understanding of stress at the individual level and on coping from a psychological perspective. However, to best understand stress and coping as they relate to the family, it is important to broaden the perspective to include literature on the family.

Reuben Hill

In 1958, Reuben Hill created the ABC-X model of family stress, which provides clarity in dealing with complex family stress and coping issues. Hill (1958) and his ABC-X model present a heuristic model for the scientific study of family stress (Boss, 2002). Its elements are illustrated in Figure 2 and include:

> “(A) The provoking event or stressor
>
> (B) The family’s resources or strengths at the time of the event
>
> (C) The meaning attached to the event by the family (individually and collectively)
>
> (X) The family’s inability to restore stability” (Boss, 2002, p. 47).

By definition, “a stressor event (A) has the potential to cause change in the family because it disturbs the status quo” (Boss, 2002, p. 47). Hill (1958) summarized stressors and their impact on the family as: (1) accession, changed family structure by adding a family member; (2) dismemberment, changed family structure by losing a family member; (3) loss of family morale and unity due to alcoholism or substance abuse; (4) changed structure and morale due to a divorce or separation. Boss (2002) elaborated on Hill’s work and stated that the outcome of a particular situation or event depended on the family’s perception of the stressor, and a family cannot progress in managing stress until its members recognized that they had a problem

The (B) factor, the family’s resources for facing the demand presented by the stressor event, Burr (1973), a colleague of Hill, described as the family’s ability to prevent an event from creating a crisis. McCubbin and Patterson (1983) further elaborated these ideas and stated that resources become part of the family’s capabilities for resisting or modulating crisis. A family’s adaptability refers to its ability to meet obstacles and shift its course of action. A family’s level of communication, social support, and flexibility are resources that will determine how well it can resist crisis and promote family adjustment.

The (C) factor in the ABC-X model, defined as “the family’s subjective perception of the stressor; reflects the family’s values as well as previous experience in dealing with stressful events” (McCubbin & Patterson, 1983, p. 10). The way in which a family transitions to meet the demands of the stressor will vary. One family may view a stressor as a challenge, whereas another family may perceive the same or a similar stressor as an irresolvable crisis. “Family distress results from the family’s negative perception of the demands-resources as unpleasant; eustress, a positive state, occurs when the family approaches the demands-resources imbalance as desirable, or as a challenge it may enjoy" (McCubbin & Patterson, 1983, p. 10).

Burr (1973) conceptualized the (X) factor as a continuous variable denoting the amount of disruptiveness, disorganization, or incapacitation present in the family social system. Stress may never reach crisis proportions if a family takes necessary steps to use available resources or to find new ones. Boss (2000) defined a family crisis as a disturbance in the equilibrium that is overwhelming, causing a pressure that is severe enough to immobilize or block a family system. At the point of crisis, many families cannot function effectively and do not perform at optimal levels, physically or psychologically. According to Boss, crisis results when a family hits the lowest point possible, but a family can make the transition to recovery if there is a change in either the stressor event, the availability of resources, or the family's perception of the event or resources.

Hamilton McCubbin

Continuing in Hill's tradition, McCubbin and Patterson (1983) expanded upon the ABC-X model by creating a Double ABC-X model, as shown in Figure 2. They added post-crisis variables, with the overall goal to describe additional life stressors that may influence the family's ability to achieve adaptation. In the Double ABC-X model, a family accomplishes adaptation by reciprocal relationships, wherein demands of one family member are achieved by another, with the outcome to produce harmony at both levels of interaction. A family struggles to achieve balance not only between the individual and the family, but also between the family and community.

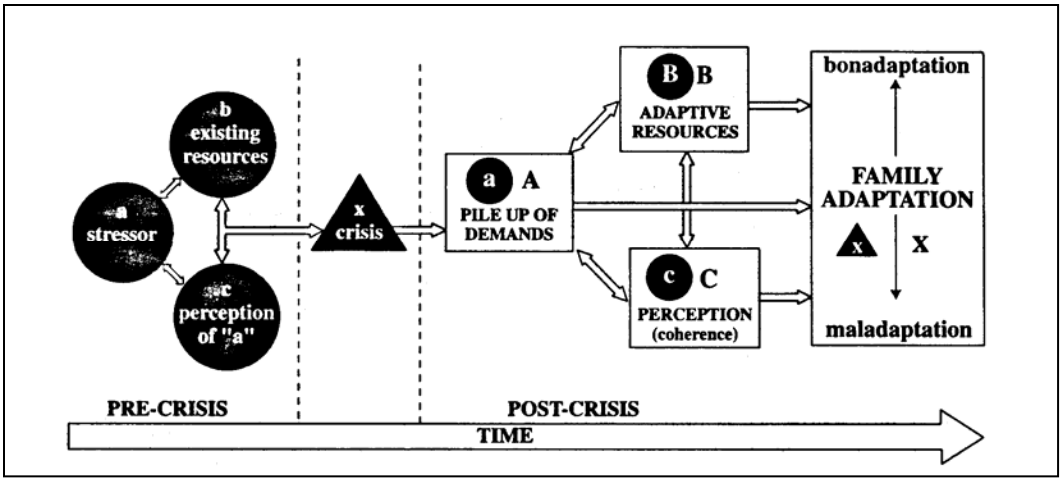


Figure 2. The Double ABCX Model
Source: Adapted from McCubbin and Patterson (1983 p. 21).

In the Double ABC-X model, (aA), the pile-up for the family system, involves five broad types of stressors: the initial stressor and its hardships, normative transitions, prior strains, consequences of family ability to cope, and ambiguity both within and outside the family (McCubbin & Patterson, 1983). The initial stressor carries with it inherent hardships, which increase difficulties a family will face. When these are combined with the normative transitions present with any family, the pile-up demands can be significant. Examples of normative transitions McCubbin and Patterson outlined as normal growth and development of family members, family life cycle changes, and possibly aging parents. Prior strains for families may be the result of stressors or transitions from the past that carries the potential to exhaust the family unit. Consequences of family efforts to cope result from behaviors that may have been used by a family in order to cope with the initial stressful event. Social ambiguity, according to Boss (2002), is common for families in crisis and involves defining boundaries associated with the family system. Defining these boundaries may require its members to state who is inside the family and who is outside, which can be accomplished by asking family members whom they perceive to be in the family.

As described by McCubbin and Patterson (1983), family adaptive resources, the (bB) factor of the Double ABC-X model, address the family's ability to meet the demands presented to them in the context of the crisis and resources they use. Three types of resources affect a family's adaptability to crisis:

> "(1) the family members' personal resources, i.e., any resources available from a family member—financial, educational, physical, or psychological; (2) the family system's internal dynamics, which involves family cohesion and shared power; (3) the family's social support, which could involve emotional support, esteem support, and network support" (McCubbin & Patterson, 1983, p. 16). Social support can act as a safeguard against the negative affects of stressors and can potentially help in leading the family to recovery.

Family definition and meaning, the (cC) factor in the Double ABC-X model, occurs when a family redefines the situation and gives new meaning to the experience (McCubbin & Patterson, 1983). This usually affords an opportunity for a family to redefine the stressful situation as a "challenge" and has the potential to facilitate coping and adaptation. The (cC) factor is a significant component of this model and of family coping because, as family members redefine the situation, they can clarify issues and seek an opportunity for growth. What may have looked like a tragic situation could actually appear manageable and assist in adjustment and adaptation.

The Double ABC-X Model provided basis for analyzing family stress and coping, however did not address adjustment and adaptation as separate entities. Understanding the meanings that families associate with their day-to-day experiences are critical. Issues such as family schema, situational appraisal, and coherence are further addressed in the Family Adjustment and Adaptation Response (FAAR).

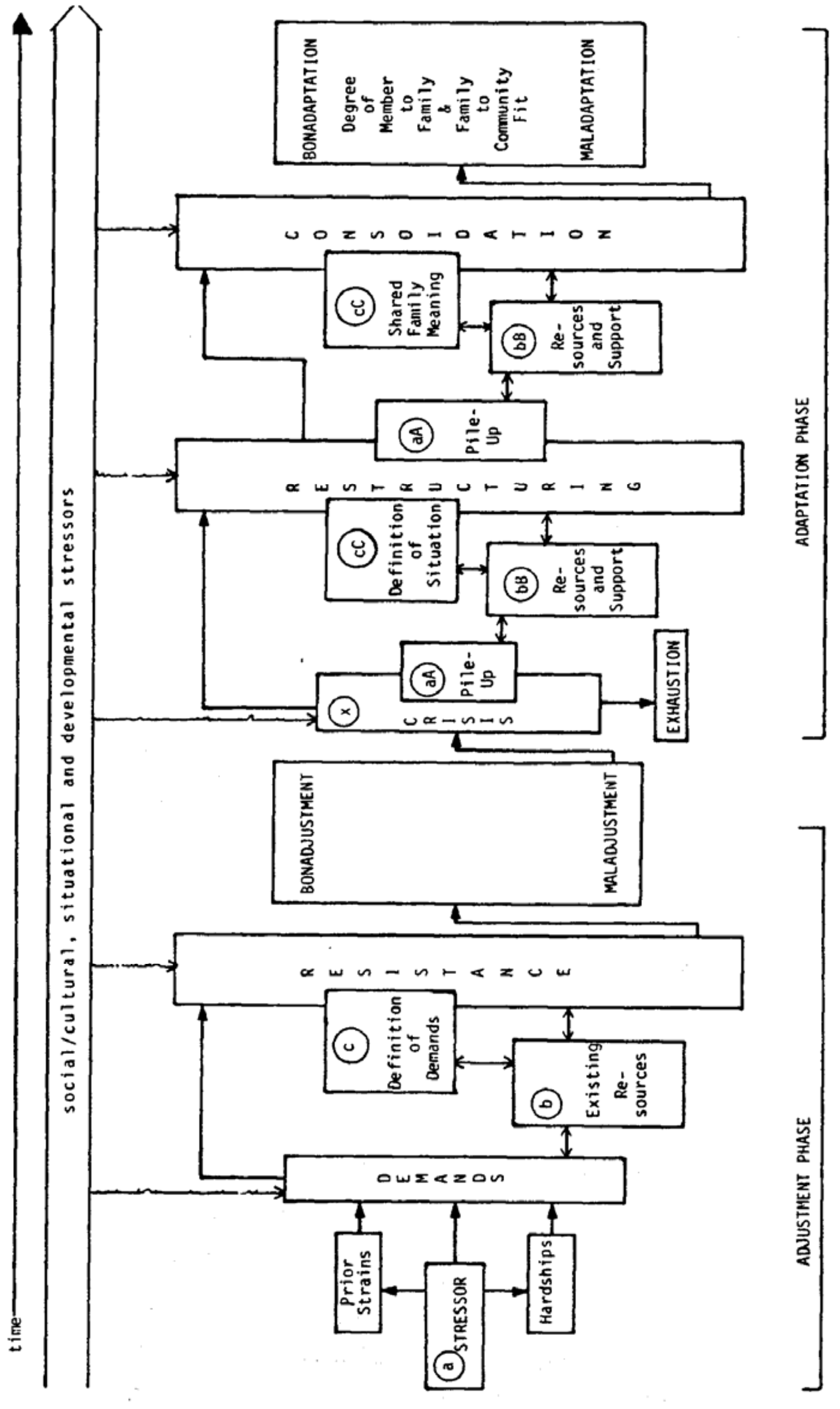
Family Adjustment and Adaptation Response (FAAR)

Viewed as two distinct phases, FAAR was developed by McCubbin and Patterson (1983) and evolved from the Double ABC-X model as shown in Figure 3. A family uses these two phases, termed “adjustment phase” and “adaptation phase,” to achieve stability. The adjustment phase involves the points at which a family confronts a stressor event, the hardships associated with the specific event, combined with the strains that already exist for the family prior to the stressor. A family normally tries to make appropriate adjustments in their lives without much disruption to the current behaviors. “During this phase, a family may use three adjustment coping strategies: avoidance, elimination, and assimilation” (McCubbin & Patterson, 1983, p. 20). Depending on whether a family can reach a demand-capability balance, the family moves towards a crisis phase, this does not mean that a family has failed or is dysfunctional, but that they may need to develop new coping strategies to deal with the stress.

The family adaptation phase occurs when a family, confronted by excessive demands made upon it, comes to realize that changes must be made. This dynamic process involves the family as it restructures and consolidates its resources and coping strategies (McCubbin & Patterson, 1983). Successful consolidation and adaptation require that a family compromise through realistic appraisal of its stressors and willingness to accept a not so perfect resolution. As a family works though consolidation and restructuring, its members must not lose sight of the impacts these changes will have on them.

Figure 3. FAAR: Family Adjustment and Adaptation Response as a Function of Family

(McCubbin and Patterson 1983, p. 20).



Family Schema, Ethnicity, and Coherence

McCubbin et al. (1998) defined family schema as the “shared values, beliefs, convictions, and expectations that are adopted by a family” (p. 43). Family schema may include values and convictions, such as respecting one’s individual ethnicity, honoring elders, caring for one’s property, valuing one’s religion. One of the critical functions of family schema, according to McCubbin et al., is the development of family meanings. Hawley and DeHaan (1996) argued that families with strong schema had the ability to take appraisal to a higher level of abstraction, which allowed the family to have a collective view of the world. Every family has a unique schema that can serve to guide them during stressful events.

Related to worldview and family schema, Antonovsky (1979) believed that a sense of coherence (SOC) provided an understanding of why resources such as wealth, cultural stability, and social support promoted health. Antonovsky defined SOC as:

> . . . a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one’s internal and external environments are predictable and that there is a high probability that things will work as well as can be expected. (Antonovsky, 1979, p. 99)

A family’s culture and ethnicity also play a critical role in developing responses and strategies to stress. Words, language, meanings, the individual, and the culture are influenced by and mutually influence one another (Munhall & Fitzsimons, 2000).

Clinicians as well as researchers are embedded in their own cultures, ethnicities, meanings, and professional orientations. Thus, the family resilience framework offers a neutral context for health care professionals to assess family values, structures, beliefs, and resources relative to each individual family. Walsh (2002) claimed that family resiliency offers us a conceptual map from which to identify significant family processes that reduce the risk of dysfunction, buffer stress, and achieve healing from a crisis situation.

Resiliency Model of Family Stress, Adjustment, and Adaptation

Over time, FAAR evolved into what is referred to as the Resiliency Model of Family Stress, Adjustment, and Adaptation (Resiliency Model) (McCubbin & McCubbin, 1993). The following definition of family resilience, by Hawley and DeHaan (1996), serves to clarify the multiple contributions made in the literature regarding individual and family resilience:

> Family resilience describes the path a family follows as it adapts and prospers in the face of stress, both in the present and over time. Resilient families respond positively to these conditions in unique ways, depending on the context, developmental level, the interactive combination of risk and protective factors, and the family's shared outlook. (p. 293)

The process of adjustment and adaptation is challenging, necessitating that the family undergo an effective process of appraisal. McCubbin et al. (1998) utilized the Resiliency Model of Family Adjustment and Adaptation to assess the meaningful relationship between the family schema, paradigms, and coherence integral to a family's appraisal.

Family Resiliency Model and the LRLD

Parents who care for a child with ESLD are constantly involved in providing care to and making decisions for the child. A family focused on coping and adaptation often faces adversity and is forced to find appropriate resources. The family moves through three distinct clinical phases when dealing with a child with liver failure—the pre-transplant phase, the post-transplant phase, and the long-term maintenance phase. All three confront a family with stressors that evoke physical as well as emotional responses. No one theoretical model can incorporate every aspect of the stress response as it relates to LRLD. However, some of the models are better at expressing some of the concepts that are important to recognize when a family adapts to crisis and stressful events. Solid organ transplantation is an example of chronic illness that entails multiple long-term stresses (LoBiondo-Wood, Williams, & McGhee, 2004). Long-term stressors for these families may involve repetitive admissions to the hospital for infection or rejection.

Current literature does not provide information on the LRLD family and how stress and coping strategies relate to the theoretical underpinnings of the Resiliency Model. However, according to the donors interviewed in this study, during the pre-transplant phase, they were forced to make decisions regarding the future of their children. In agreement with Boss (2002), the appraisal or perception of a stressful event required the family to realize a problem existed. The family and donor had to accept the concept that the child would need a liver transplant or would likely die. The “illness stressor” (A) for the family, as described in the Resiliency Model, was having to deal with the new reality of a child with ESLD. This was in most cases a sudden and frightening realization for a family. The “pile-up” for the family consisted in having to deal not only with a child who may die, but also with other children in the family and work responsibilities. These issues combined to the “pile up” that already existed for the family. The fact that one of the parents needed to undergo major surgery in order to save their child’s life increased the family’s vulnerability. Each donor that was interviewed for this study, perceived stressors through a different lens, yet they all experienced the similar events as a family unit. Walsh (1998) substantiated this idea of individual versus family stress by stating that the hardiness of an individual can be understood and fostered in the context of family and the larger community. She argued that this concept involved a mutual interaction of family, individual, and environment.

The Family Resiliency Model served as a framework for this study on LRLD as it provided direction for me during data collection and analysis. By using the Resiliency Model, it assisted me in understanding and interpreting how donors adjusted and adapted to dealing with a child with ESLD, live liver donation, and the long-term effects of the donation. Within the constructs of the Resiliency Model, I crafted my interview questions as well as shaped my analysis and interpretation.

Interview questions were designed through the context of the Resiliency Model thereby and were focused on how LRLDs move through the process of both the adjustment and adaptation phases. I presented questions that would initiate responses that allowed for me to best understand the degree to which donors achieved healing from a crisis situation and reach a level of stability. I began each interview by asking the donor to tell me about their child, this gave me the opportunity to hear about prior strains, hardships and demands experienced by the donors, which was a primary element of the Resiliency Model. This inspired spontaneous discussion regarding how the donors discovered their child had liver disease and offered candid discussion between myself and the donor about their relationship with their child and their family. My interview guide continued by focusing on aspects of the Resiliency Model which provided insight into the donors existing resources and support systems that were available to them. The social/cultural and situational stressors that were present for the donors were very important issues to address during the interview process and were areas clearly outlined in the Resiliency Model.

During the analysis and interpretation phases of this study, the concept of family schema presented by McCubbin et al. (1998) led me to closely examine family values that were presented by the participants in their interviews. Language and culture were integral aspects presented in the Resiliency Model that guided me during the analysis. It was through analyzing each donor interview I discovered that each donor came from a different culture and through language developed meaning that were unique to both the adjustment and adaptation phases of the donation. The Resiliency Model allowed me to conceptualize my findings and identify family values that were significant to each individual donor as well as to the group of donors as a whole.

Resiliency Model, Research, and the LRLD Family

Geri LoBiondo-Wood, one of the few researchers who have published findings dealing with pediatric liver transplantation incorporating principles of family resiliency theory, conducted a study with a research team at the University of Texas Health Science Center at Houston. LoBiondo-Wood (2004) and her colleagues performed a descriptive longitudinal study of 15 mothers whose children were at least five years out from a liver transplant. Mothers completed several instruments during the pre-transplant phase and again five years out of transplant. Their purpose was to move beyond exploratory research to construct a profile of responses and adaptation processes used both before and after transplantation to maintain adaptation and adjustment in response to a child's chronic illness while using coping strategies and resources and balancing stressors and strains.

Instruments tested both the mother's perspective of her family and her self-perspective. The Family Inventory of Life Events (FILE), a 71-item tool used to measure family stress variables, with the added ability of measuring the "pile up" of life events, quantified the mother's perspective of family stress (LoBiondo-Wood, Williams, Kouzekanani, & McGhee, 2000). A reliability coefficient of .81 for a total scale score (N=2470) was reported, indicating internal consistency (McCubbin & Patterson, 1987). The Profile of Mood States (POMS), a 65-item adjective rating scale that measures six identifiable mood states (Mcnair, Loor, & Doppleman, 1971), measured stress severity experienced by the mother. The Coping Health Inventory for Parents (CHIP) was used to measure mothers' coping resources. CHIP, developed to measure parents' coping responses in the management of family life when a child member is seriously and/or acutely ill, consists of 45 items with three scales: Family Integration, Cooperation, and an Optimistic Definition of the Situation. All instruments were assessed for reliability in this sample; all were found to be reliable (alpha=0.70 or greater) (LoBiondo-Wood et al., 2004).

The results of this study focused on changes in mothers' perceptions of variables during the pre- and post-transplant phases. They found no significant changes in family stress as measured by the FILE. Maternal stress, as measured by the POMS, reflected significant changes in confusion, anxiety, vigor, and total mood disturbance from pre-transplant to post-transplant, whereas depression, anger, and fatigue remained unchanged. Mothers' coping scores using CHIP showed significant improvements in understanding medical communication from pre-transplant to post-transplant (t [-5.96], df .14, p<.001) (LoBiondo-Wood et al., 2004). Maintaining social support changed significantly from the higher conflict pre-transplant to below the low conflict norms post-transplant. Family adaptation did not change significantly from the pre-transplant to the post-transplant phase. Scores for the mothers remained stable and within the adaptive norms of the instrument.

This very small study illustrated that, from a mothers' perspective, families were able to adapt to their children's transplant and maintain balance over time toward the health end of the continuum (LoBiondo-Wood et al., 2004). The data analysis suggests that the mothers of the children who received a liver transplant viewed their family as adaptive and adjusted. These findings, according to LoBiondo et al. (2004), supported the fact that having a child with a chronic illness is stressful, but also demonstrated that families viewed themselves as experiencing adaptive manageable stress. They noted that family stress theory views coping as a process in which families use and develop new resources.

One significant weakness of this study was that data were collected only on mothers' perceptions of the family, and did not include other family members' perceptions of the experience, thereby making the results difficult to generalize to the greater population of liver transplant families. This comprises a threat to the external validity of this study. This study succeeded in providing data on long-term needs of families who experience the stress of liver transplantation. It provides valuable insight into the ways in which mothers adapt over time to living with a transplant recipient.

Another earlier study by LoBiondo et al. (2000) reviewed the mother's perspective during the pre-transplant period and explored the relationships between family stress, family coping, social support, perceptions of stress, and family adaptation in the context of the Double ABC-X Model of Family Adaptation. These researchers identified 29 mothers ranging in age from 19-44 years who had been evaluated for liver donation. Six standardized tools were used to measure the concepts in the Double ABC-X model; all reliabilities were found to be .70 or greater (LoBiondo-Wood et al., 2000). Mothers completed the instruments at the time of the evaluation or within one week.

The overall family stress level was measured by the FILE, and family adaptation was positively and significantly related (r=.58, P<.01), coping (r=.41, P<.05), problem solving (r=.40, P<.05), and total family stress were significantly and positively related (LoBiondo-Wood et al., 2000). These data suggest that, as mothers reported family information, there existed a relationship between increased family strains, fewer coping skills, and unhealthy family adaptation. One weakness of this study, again, rests in the fact that it was performed on mothers only, which does not make its findings generalizable to the larger population. Additionally, the timing of the data collection period may have been too close to the evaluation and possibly provided inaccurate results. The evaluation process is an extremely stressful time for parents and families. Being asked to complete questionnaires in light of what is happening to the family may be stressful for the mother and cause questions to be answered quickly and inaccurately.

Weaknesses and Strengths of the Resiliency Model

As noted by Boss (2002), the ABC-X model serves as an important reference point, not a testable model, for sociologists, social workers, or other individuals who work with families in stress. Some scholars criticize it as being a very linear, simplistic approach to dealing with family stress and crisis. Klein (1983), for example, believed that the model received support only if a crisis resulted. He suggested that when the stressor was accompanied by inadequate resources or when family members held a shared negative perception, it was indeed in crisis. According to Klein, because crisis is so difficult to measure, the ABC-X model is better viewed as an analytical definition.

Because resilience is a complex process affected by internal and external contextual factors, more studies are needed, in particular to determine how cultural beliefs and values shape individual and family resilience (Boss, 2002). Hawley and DeHaan (1996) pointed to the fact that literature related to resilience in individuals seems to focus significantly on developmental issues. Moreover, they recognized the impact of developmental transitions on the life cycle of resilience. Resiliency, often viewed in terms of wellness rather than pathology, is seen as surfacing in the face of hardship (Hawley & DeHaan, 1996). Hawley and DeHaan suggested extending the study of family resilience by pulling from the research on individual resilience using models of risk and protection from a developmental standpoint. This is insightful, especially for the family who participates in LRLD, since that is a lifelong commitment requiring the family to deal simultaneously with multiple family life transitions.

Another weakness of the Resiliency Model rests in its applicability. The model seems to function best if paired with quantitative analysis and is seldom used in qualitative research. This creates obstacles, though not necessarily insurmountable, for the qualitative researcher. Research studies mentioned in this paper pair the Resiliency Model with instruments such as FILE, POMS, and CHIP in order to perform statistical analysis. The Resiliency Model theory focuses on a family's effort to adjust and adapt to stressful events while using resources and coping strategies. The concept of resiliency can be instrumental in answering both qualitative and quantitative research questions involving creating and examining applications that foster family functioning.

The question that has yet to be answered, however, and that leaves a gap in the literature regarding the Resiliency Model is how can resiliency truly be measured? One way to address this question would be to look at different resiliency outcome variables. McCubbin and McCubbin (1998) suggested that several variables that have been associated with resilience in families, for example, flexibility and cohesion, can be measured, but that other variables, like schema and coherence, may be more difficult to quantify.

Among the numerous strengths of the Resiliency Model is its capacity to shed light on the nature of adjustment and adaptation strategies that play a critical role in assisting families maintain an ability to recover from crises. Also, it focuses on the central and complex issues of determining the protective factors that are key to family adjustment despite the presence of risk factors, and the recovery factors necessary for a family to adapt to a specific crisis (McCubbin & McCubbin, 1993). Another strength, and the one most significant to the development of the Resiliency Model, rests in its ability to guide clinical practice. One challenge for the clinician dealing with families confronting stressful situations is to assist them to reach a level of functioning that encourages healing and growth from a crisis situation. The Resiliency Model can help the clinician to foster a family's recovery from adversity and to grow from a stressful experience.

Implications of the Resiliency Model for Health Care Professionals

Health care workers must determine the needs of both individual family members and of the family as a whole when planning interventions for families facing stressful events. Not only does the child with FHF need parental involvement, but so do siblings who may be impacted with enormous outside stressors. And the parents must make appropriate decisions regarding cadaveric or LRLD and regarding long-term care issues. In reference to the Resiliency Model, the health care team must evaluate a family's personal resources, internal resources, and social support when dealing with a family's struggle with the demands presented to them. Resources like support from health care professionals can foster resilience for the family in transition. Transplant teams, social workers, and community based health professionals, working in collaboration with families and clinicians, can assist families to navigate through health care chaos and lead them to a level of bonadjusment. Understanding the dynamics of family schema, coherence, and culture, the clinician can help families achieve harmony and balance in their lives.

Family resilience-oriented interventions in clinical practice have the potential to focus on family coping and adaptation in dealing with recovery and adversity. McCubbin and McCubbin (1993) remarked that when health professionals examined illness in the family context, their focus needed to be on the process of adaptation. Their clinical guidelines for pile-up of life changes and adaptation include: assessment of the family knowledge base, making a clinical plan, and using clinical assessment tools. They proposed that without guidelines family adaptation is often a trial-and-error process with negative results. One of the primary functions of the Resiliency Model for clinicians is to identify early behaviors that may potentially lead to future problems for the individual or family.

Conclusion

In working with families who participate in LRLD, health care providers must understand the relationship between the family schema, coherence, and resiliency. Building rapport with the families and being aware of and receptive to their needs associated with being a donor, both short-term and long-term, must be taken into account when delivering care to this population. Families are dynamic; their needs change through time. Short- as well as long-term plans with regard to coping strategies are important for transplant teams to address when working with families involved with LRLD and with parents of children with chronic illness.

Family stress theory has long been and will continue to be an area of study for many scholars. Selye, Lazarus, Hill, and McCubbin and McCubbin have contributed to our knowledge of adverse events and how they affect individuals/families. McCubbin and McCubbin’s (1994) Resiliency Model engages distressed families with its focus on family beliefs, resources, and coping strategies. Its framework has the ability to empower families and bring forth effective coping skills and positive outcomes.

Understanding family behavior in response to stress, health care providers can better prepare families to make difficult transitions with greater ease. Scientific inquiry into the concept of family stress and coping, currently lacking in the field of living related transplantation, is an area with enormous potential for future research. It is critical that transplant teams and the health care community understand the dynamics of adjustment and adaptation for a family during all phases of transplantation. The donation of a portion of a liver to a son or daughter is an altruistic act of enormous proportion, demands further research. The Resiliency Model has the potential of providing theoretical constructs that can assist in further research dedicated to families' needs in both the short and the long term. Family resiliency theory helps us understand how and why families of children with liver disease are able to cope, endure, and survive the experience.

Table 1: Comparison of Stress and Coping Theories

Theory and Authors	**Type of Theory (Family or individual)**	**Purpose of theory**	**Strengths (S) and Weaknesses (W)**	**What makes it Different from Previous theories**	**Comments**
Hans Selye	Individual	To understand the biochemical approach to stress.	S: First attempt by a theorist to define stress. W: Very linear and did not take account for differences in personality and culture.	No previous theory from which to compare.	Very simplistic look did not recognize multiple independent variables.
Richard Lazarus	Individual	To address stress and coping as transactional process. Viewed coping as cognitive activity	S: Linked individual with environment, cognition, and coping. Looked at outcomes. W: Did not address family. Being transaction it incorporates a magnitude of issues associated to stress.	More complex theory, accounted for individual perception.	Made breakthroughs in understanding stress but only on individual basis.
Reuben Hill ABC-X Model	Family	To look at family response to stress.	S: Provided basis for analyzing family stress and coping. W: Did not	Approached stress through a family context, less linear that	This model became the foundation for family stress theory.

			address post crisis variables and coping.	Lazarus.	
Hamilton McCubbin Double ABC-X Model	Family	Expanded upon Hill but added post-crisis variables with goal to describe additional life stressors that may affect adaptability.	S: Described family struggles as a process to achieve balance not only between individual and family but also between community. W: Did not address additional phases that may result for families after the adaptation phase.	Examined at community as being a key element in family adaptation phase.	This model coordinated problem solving strategies for the entire family.
Hamilton McCubbin and James Patterson Family Adjustment and Adaptation Response (FAAR)	Family	To expand upon the Double ABC-X Model by addressing adjustment and adaptation phases of the stress response.	S: Looked at culture as a concept that came under schema. Can be used to guide clinical practice. W: Difficult to test the theory as a whole concept.	Looked at relationships between family, schema, paradigms and coherence.	More studies must be preformed to better understand how cultural beliefs and values shape family resilience.

CHAPTER IV

ETHNOGRAPHY AND THE LIVING-RELATED LIVER DONOR

"Methods are mere instruments designed to identify and analyze the obdurate character of the empirical world, and as such their value exists only in their suitability in enabling this task to be done." (Blumer, 1969, p. 27)

Ethnography in nursing science provides the opportunity to discover answers to questions that center on social situations of everyday life. The organization of social life, the structure of relationships, the attention placed upon everyday life experiences are all central to the ethnographic approach to research (Kaufman, 2005). Researchers interested in participating in ethnographic inquiry must be committed to dedicating large amounts of time in the field, completing the time-consuming process of data collection and analysis, and constructing text that accurately portrays informants' perspectives. Ethnography was an appropriate method to address the research question that focuses on the impact that a living-related liver donation (LRLD) has on the donor and the donor's family because it allowed for the illumination of the context in which they live their lives, make decisions, and create meaning for what happens to them in the course of their lives, especially as related to this shared experience.

This chapter begins with an introduction to ethnographic research, followed by a discussion of culture and ethnography. Key principles found in the ethnographic method, particularly epistemologies and methodologies, will be addressed to explain ethnography and how it was used in understanding the everyday experience of the living-related liver donor (LRLD).

Ethnographic Research

Ethnography is one method of social research that allows the researcher to actively participate in an individual's daily life by watching, listening, and asking questions in order to collect data related to their research interests (Hammersley & Atkinson, 1990). Traditionally, anthropologists utilize ethnographic research with the aim of identifying rules, rituals, daily practices, and beliefs within a given population (Morse, 1992). Nurses, sociologists, and other disciplines, such as education or health related fields, use ethnography in order to understand the experiences and actions of a group of people. Contextual influences, such as culture, ethnicity, socioeconomic level, and health status, can affect the meanings associated with health and wellness (Hammersley & Atkinson, 1990), which, in turn, influence actions and decisions.

A distinction between sociological and anthropological approaches to ethnography is recommended because their aims are somewhat different. In the sociological field, the goal of ethnography is to describe the complexities of everyday experience of the participants. In the anthropological view, the researcher's aim is to provide an in-depth description of the cultural dimensions of an individual or a group of people. It is necessary to understand the cultural influences of an event or phenomenon when looking at an individual or group of individuals because it illuminates the sociological findings. When taking an ethnographic approach to understanding the LRLD, a sociological perspective versus an anthropological view was preferred. Attention to the everyday organization of the LRLD's social life, specifically the structure of relationships within the family and the meaning of the donation to the donor’s and family’s life were the ethnographic foci of this study. Each donor brings with him or her a unique ethnicity, culture, and social status that must be considered when trying to understand his or her everyday life as a donor. Culture in the sociological sense refers to shared practices and contextual elements of everyday life, as well as dimensions of social situations shared by participants (Becker, 1996).

Ethnography strives to understand the life experiences of individuals who are connected by common experiences. Ethnographers from both the anthropological and sociological traditions attempt to learn the deep level of symbolic meanings that comprise a specific phenomenon; however, ethnographers in the sociological tradition usually attempt to triangulate various perspectives of the participants, placing more emphasis on interaction, social context, and the social construction of reality (Lowenberg, 1993).

The common experience for the LRLD is the process of donation. By combining the cultural concepts of the everyday presented by Rosaldo’s (1989) and Geertz’s (1973a) view that culture must be seen as the “webs of meaning,” I created a framework from which I examined the culture of the LRLDs in order to understand their everyday lives as living donors.

Roper and Shapira (2000) identified two perspectives in regard to culture. The first is a behavioral/materialistic perspective that states that culture is the way a group of people behave, or the way it functions, and the second was a cognitive perspective, the beliefs, ideas, values, and knowledge that are used by people as they live their lives. By looking at the two perspectives, the behavioral/materialistic perspective can be compared to what I would like to call the “macro culture.” On the “macro culture” level, the experience of the donation in itself places donors in a culture of their own, or the way a group of people with shared experience behaves. The group of LRLDs shares a common language and possesses viewpoints that distinguish it from other individuals in the community. The “micro culture,” which is similar to the cognitive perspective presented by Roper and Shapiro (2000), involves the ethnicity, values, gender, and religion unique to each donor. Individual donor perception of the hospital as an institution, views on donation, and values about life and family were accounted for in order to study this group as a culture.

Clifford Geertz (2001), though an anthropologically-based ethnographer, provided insight for the sociologically oriented ethnographer. He defined ethnography as rooted in a term borrowed from Gilbert Ryle, “thick description. “ Clifford Geertz (1973b) described the role of the ethnographer to observe, record, and analyze a culture, but also to interpret signs in order to gain meaning within a specific culture. Geertz (1973a) made it clear that ethnography does involve establishing rapport, selecting informants, transcribing texts, taking genealogies, mapping fields, and keeping a diary. However, the interpretation must be based on a “thick description” of an action in order to extract meaning. Geertz used the “wink of an eye” to clarify his point. A “wink of an eye” can be interpreted as a “twitch of an eye,” which is involuntary, or it can be interpreted as a deliberate act to impart a particular message. It is the responsibility of the ethnographer to use “thick description” as a method to understand signs and meanings. Geertz (1973b) took a very humanistic, interpretive angle to ethnographic scholarship. He perceived science through a rhetorical lens dedicated to language and interpretation. This view is in opposition to the purely quantitative method of research that relies on statistical data to draw conclusions.

Hammersley and Atkinson (1990) described ethnography as not being extremely restrictive; rather, they perceived it to be a form of social research that emphasized the importance of studying firsthand what individuals do and say in a particular situation, for instance, LRLD. It is through this process of taking time with people through participant observation and through open-ended interviews specifically designed to understand individual perspectives that this study was conducted. Geertz (2001), like Hammersley and Atkinson, advocated the belief that qualitative research does not match positivist canons and, as a result, can come under criticism as lacking scientific rigor. Qualitative research is not as black and white as quantitative research and requires the researcher to act as a tool during the interpretive process. Hammersley and Atkinson (1990) concluded that research must be carried out in ways that are sensitive to the nature of the setting. Ethnography is a research method founded upon the existence of such variations in social and cultural patterns across and within societies. Trying to understand the meaning of an experience like live liver donation and how it shapes donors' behavior involves many layers of analysis. These meanings were frequently quite apparent during the analysis, while in other cases the meanings were hidden and required a great deal of reflection and thought.

Ethnography and Culture

One central concept of ethnography is that the researcher must enter into the social worlds of their participants in order to understand their social lives and situations. Culture must be discussed when venturing into the depths of ethnography because it is through one’s individual culture and the culture of others that the ethnographer begins to understand the social worlds of oneself and one’s participants. The following discussion will give an overview of culture as well as an individual definition of culture as it pertains to the study of LRLD and the impact it can have on the donor and the donor’s family.

Culture is notorious for being difficult to define because it is so broad in scope. Concepts relating to culture presented by Clifford Geertz and Renaldo Rosaldo were used in combination in order to frame the meaning of culture as it relates to the study of social processes in ethnography. Interpreting the meanings found in symbolic forms (Geertz, 1973a) and comprehending the tempo and practices of everyday life (Rosaldo, 1989) assisted in developing a tangible or nuanced definition of culture that was used in designing a sociologically based ethnographic study on LRLDs. The following discussion will explain how this specific definition regarding culture was developed.

Clifford Geertz, a prominent figure in the world of social sciences, was deeply invested in the concept of culture. Geertz (1973a) argued that culture must be seen as the “webs of meaning” (p. 5) within which people live, and meaning encoded in symbolic forms (language, artifacts, etiquette, rituals, and calendars) that must be understood through acts of interpretation analogous to the work of literary critics. One of the most influential aspects of Geertz's work is his emphasis on the importance of the symbolic and systems of meaning as they relate to culture. These issues are key in designing an ethnographic study and will be used as a platform for the discussion and definition of culture used in this study.

Rosaldo (1997) believed that to think of culture as an objectified thing or a self-enclosed patterned field of meaning is not possible. His postmodern approach focused on doing fieldwork with the goal of understanding other cultures. He contended that fieldwork provided an opportunity to reflect upon one's own culture as well as to analyze other cultures. He believed that his project in studying the Ilongots was conducted in order to describe the differing aesthetics that shape the tempo of everyday life (Rosaldo, 1989). Rosaldo felt that researchers could learn about other people's cultures by reading, listening, or being there. He stated that cultures are learned; they are not part of our genetic fabric.

Geertz's idea that cultures are "webs of meaning" and Rosaldo's concept that cultures are learned and embedded practices of everyday life can be merged together in understanding and studying human behavior specifically those individuals experiencing acute and chronic illness. In the case of the LRLD their systems of meaning as they relate to their culture and how their culture is embedded in their everyday lives needed to be combined in order to better understand the life of the donor since donation. Each individual donor brings with them a unique culture that needs to be understood through ethnographic interpretation.

Key Principles of Ethnography

Key principles in ethnography that are addressed in this paper fall within two broad categories: epistemologies and methodologies. The overview of epistemologies will include a discussion of reflexivity and representation. The methodologies section of this paper will involve a description of symbolic interactionism (SI), data collection, and data analysis. A brief summary of epistemological and methodological concepts, highlighting the relationship that exists between them will be presented at the end of this section.

Denzin and Lincoln (2000) described epistemology as answering the question of "How do I know the world: What is the relationship between the inquirer and the known?" (p. 157). They believed that methodology focuses on the best means for gaining knowledge about the world. Epistemology is a system of knowing that describes how we know the world, the researcher, and the known (Denzin & Lincoln, 2000). Methodology, on the other hand, focuses on the most appropriate way for gaining knowledge (Denzin & Lincoln, 2000; Speziale & Carpenter, 2003). It is impossible to know all there is to know about the world, the inquirer, and the known. However, describing how I positioned myself and the participant through reflexivity and representation helped understand and interpret the informants' actions and behaviors. The process by which researchers select their methods has a great deal to do with the specific research question and purpose. There are many qualitative as well as quantitative methods by which researchers can answer a specific question. However, the method that brings the researcher closest to understanding the phenomenon is the most effective pathway to choose (Creswell, 1998).

Epistemologies

Reflexivity

Reflexivity can be understood in a number of different ways. For the purposes of this chapter reflexivity will be defined as the way in which the researcher acknowledges how he or she is socially situated in a researcher/participant relationship and the impact this position can have on interpersonal dynamics, data collection, and analysis (Denzin & Lincoln, 2000; Hammersley & Atkinson, 1990; Reinharz, 1997). Reflexivity is an epistemology because it causes the researcher to reflect on personal perspectives and engages the researcher in self-reflective processes while generating knowledge (Denzin & Lincoln, 2000).

"Qualitative research is a situated activity that locates the observer in the world." (Denzin & Lincoln, 2000, p. 3). "Locating the observer in the world" however, is not a simple task, and this required me to take a close examination of myself and how I perceive and seek to understand the participant. I needed to first understand (or locate) myself before I could try to understand (or locate) the participants in my study. This was key when exploring the world through ethnography, particularly in nursing science, in which so much of the research is centered on patients, culture, and social systems. Understanding my own world in a socio-historical context influenced both the questions I addressed to the participant as well as the interpretations I made. Acknowledging my own perspectives on the world provided the foundation I needed in order to understand my reflections and interpretations.

Having been a nurse for over 20 years, I have had the opportunity to work eight years in the Pediatric Intensive Care Unit where I cared for liver transplant recipients immediately following surgery and witnessed some of the first living-related liver transplants ever performed. As a Liver Transplant Coordinator for over 10 years, I have worked with members of a highly successful pediatric liver transplant team, which has allowed me to develop clinical as well as personal perspectives with regard to liver transplantation. All these years in transplant combined have given me a perspective on the field of transplantation that I must recognize, yet at the same time remain as objective as possible when listening to the life stories of the participants.

Reflexivity is the process of reflecting critically on the self as researcher, and using the self as an instrument to understand the participant (Guba & Lincoln, 1981). As an ethnographer, I was forced to create a self in addition to the "professional /clinical self" or the "personal self" when conducting my research. In this case, my professional experience of being a Pediatric Liver Transplant Coordinator had to be recognized and understood during the observation period. As stated by Angrosino (2000), by assuming situational identity, or to take part in a social setting, the ethnographer should negotiate and conceptualize the interaction. Being associated with the transplant community has the ability to create bias and possibly affect the natural response of the participant. My professional self had to refrain from giving clinical advice, offering a domineering opinion, or forming conclusions too rapidly based on expectations from past clinical experiences. My personal self avoided making prejudgments and interpretations based on personal values. Though elements of both my professional and personal selves inevitably came through the interviews, my overriding goal in dealing with the LRLDs was to be honest and to try to see the participants through many different perspectives.

Reflexivity is closely tied to my involvement and participation in this study. I had to pay special attention not to become emotionally close to the donors in order to maintain a clear perspective on the phenomenon as interviews, observations, and field notes were conducted. I needed to resist the urge to fall into a clinical role during many of my interactions with the participants. These are just a few of factors that influenced how I understood the data and the findings. The expectation that the researcher act "objectively" is unrealistic or, as stated by Fine (1993), an illusion. I used different worldviews to understand the informant, which required looking outside my own world in order to appreciate the participants' world. To be objective was impossible because my reality has been shaped by my own individual life experiences and cannot be erased from my mind or being. Epistemological reflexivity was accomplished by making explicit and critically reflecting on individual assumptions and influences, and acknowledging the possibility of personal bias.

Literature on reflexivity is abundant and seems to focus on the fact that social research is founded on the human capacity for participant observation, and we act in the social world reflecting upon our actions and ourselves (Hammersley & Atkinson, 1990). Guillemin and Gillam (2004) took a slightly different view of reflexivity than Hammersley and Atkinson. They discussed reflexivity in research as not one single or universal entity, but an active, ongoing process that permeates every stage of the research. They posited that the research interests and the research questions we pose reveal something about who we are. Moreover, how the researcher chooses to present analyses, findings, and interpretations are all key elements of reflexive research. Reflexivity is not only a process of critical reflection about the kind of knowledge we produce from research, but also an insight as to how that knowledge is generated

Reinharz's (1997) concept of reflexivity is similar to Daniels (1999), and Alcoff and Potter (2002), as she believed that the qualitative researcher is not only bringing the existing self into the field, but also creating the self in the field. She suggested that each of us possesses many selves; we have the ability to create selves based on a particular situation. Each of those selves may come into play in the research setting and consequently has a unique voice. Reflexivity as well as post-structural and postmodern ideologies concerning quality in qualitative research, as expressed by Reinharz (1997), demand that we interrogate ourselves regarding the ways in which we shape research efforts, and we must question ourselves regarding how relationships with participants shape who we become to the participants and how we come to “know” and understand them. In the process of doing this, Reinharz believed we become more ourselves. Becoming more ourselves and how we shape relationships with participants can be compared to the epistemological view of how we construct knowledge through reflexivity.

Wasserfall (1997) posited that there were “strong” and “weak” readings of reflexivity in literature. “Weak” readings focused on the researcher’s dedication to self-awareness and the relationship between the researchers and the participant. “Strong” readings suggested that the researchers further deconstruct their own class or power differences and favor a more egalitarian relationship. She believed that both “weak” and “strong” approaches to reflexivity could allow for the researcher to take responsibility for how his or her study could influence a participant’s life. In the process of conducting this research study, I used both “weak” and “strong” approaches to reflexivity in order to best understand myself as well as the LRLD.

Researchers are part of the social world they study, and there is no escape from our beliefs, personal experience, and values. In order to provide “strong” readings I attempted to deconstruct power differences between the donors and myself, thus creating an environment that was more conducive to observation, conversation, and dialogue to take place. This may sound simple. However, realistically it posed a challenge for me. I attempted to deconstruct to the point of removing any power differences between the LRLD and myself, but to remove all power differential was unrealistic. As a researcher, I had to acknowledge their presence and their stories while inviting their participation in my study as informants. Understanding who I am as a researcher and my influence on every aspect of the research process was key while conducting this ethnographic study.

Representation

Representation is the manner in which the researcher portrays the participant and the social world under study. Our knowledge, what we know, represents a world for us. The meanings of our representation must be reviewed by the researcher during the data collection, analysis, and especially during the dissemination phases of this ethnographic study. Trying to articulate the meaning or impact of representation was addressed throughout this study by direct observation of the participant in their home when possible, and field notes.

The art of learning about the participants involved giving full descriptions of their lives as truthfully and accurately as possible. Problems did exist with this idea of representation, because there were incredible differences in the social, political, cultural, and economic make-up of each participant. How the researcher represents the participant and how the participants represented themselves are two very different perspectives and must be recognized in the epistemological discussion of representation.

Gergen and Gergen (2000) explained the use of representation as attempting to give voice to the participant. They believed that, with the influx of postmodern ideology, constructionist, and dialogical formulations, traditional descriptions are limiting. They developed a new vocabulary of research methodology that used relational re-conceptualization of the self. This methodology is increasingly sensitive to the relationship between researcher and subject and, as a result, a reality of relational process is generated. This relational process puts an increased focus on the relationship instead of the individual. In doing so, the researcher is forced to address the cultures in which both the researcher and informant live, thereby creating a representation of the participant through a relationship instead of an outside view by the researcher.

Bourdieu (1996) suggested that for researchers to understand the logic of informants and to properly represent them, they must be able to situate themselves mentally in the place the participant occupies. By placing oneself in the social space occupied by the participant, the researcher is attempting to view the world as the participant. The participant’s world-vision thereby becomes more evident to the researcher, and is not taken for granted. Unlike Gergen and Gergen (2000), who advocated for a relationship to exist between researcher and participant, Bourdieu believed that if a researcher could occupy the participant’s vantage point, or “wore the shoes of the participant, she would doubtless be and think just like her” (p. 34). The ability to take such a proposition literally is arguable. To believe that a researcher can think just as a participant seems a bit unrealistic. However, this conscious exercise increases the awareness and sensitivity of the researcher to the position and perspective of the participant.

This overview of epistemology has highlighted how reflexivity and representation provide a system of knowing that helps to know and better understand the world in which we live. By using different worldviews to better understand the informant, I attempted to create a relationship that constructed new knowledge. The idea that I could deconstruct any power differences and truly be objective was unrealistic because I am a product of my own individual culture and socio-historical background.

Methodology

How we choose our research methodology and the theoretical underpinnings that support our research are influenced by our values, beliefs, culture, and research question. Whom we include and whom we exclude as participants in our research is as revealing (Guillemin & Gillam, 2004) as is our research question. Methodology is a way in which the researcher decides to collect and analyze information in order to answer the research question and fulfill the purpose of the study. This discussion of methodology will include symbolic interactionism (SI), specific data collection techniques, and thematic data analysis.

Symbolic Interactionism

SI is one perspective that many ethnographers use to underpin their work. The creation of meaning through social interaction is a basic tenet of SI (Rehm, 2000). Its emphasis is on understanding how meaning influences actions and behaviors. George Herbert Mead (1934) and Herbert Blumer (1969) are known for developing and envisioning SI as a theory that explains how individuals make sense of their unique situations and the manner in which they live their lives in conjunction with others on a day-to-day basis (Prus, 1996). Prus (1996) stated that, “Humans derive their (social) essences from the communities in which they are located, and human communities are contingent on the development of shared, (or intersubjectively) acknowledged symbols or languages” (p. 10). Prus proposed that humans cannot be understood apart from the community in which they live. There is no self without community and social interaction. Ethnography that is founded on SI, with emphasis on the social and intersubjectivity of findings, was a way for me to understand and move away from viewing participants as “other.”

> The term "symbolic interaction" refers to the distinctive character of interaction as it takes place between human beings. The peculiarity consists in the fact that human beings interpret or "define" each other's actions instead of merely reacting to each other's actions. Their "response" is not made directly to the actions of one another but instead is based on the meanings that they attach to such actions. Thus, human interaction in research situations can be understood as mediated by the use of symbols, researcher interpretation, and understanding meaning from a participant’s actions. This mediation is equivalent to inserting a process of interpretation between stimulus and response in the case of human behavior. (Blumer, 1969, p. 180)

Blumer (1969) stated that ethnographic research, since it attends to intersubjective features of group life, is essential to achieve “intimate familiarity” (p. 141). Intimate familiarity is an ambiguous term that has not been well defined and raises epistemological issues of how the researcher is located in the field. Gaining an “intimate familiarity” for this author involved using in-depth interviews as well as observation of the participant in order to attach meanings to actions while understanding the impact of a specific social challenge, for example, the donation of a piece of a parent’s liver to his or her child. Prus (1996) made a valuable observation about Blumer’s statement about “intimate familiarity.” He posited that the objective of researchers is not to “go native” or to become so immersed in the participant’s life-world that they lose sight of their own views and personalities. A researcher must be able to back away from each inquiry while pursuing “intimate familiarity” and develop some generic appreciation of the focus situation to the wider context within the world, as well as an isolated phenomenon being studied.

In discussing reflexivity and representation, it was important for me to acknowledge the intersubjectivity of SI. The co-creation of the meanings between myself and participant was necessary in order to put to rest the concept of “the other” and look at myself and the participant as sharing a world where relationship could be forged.

Data Collection

As posited by Denzin and Lincoln (2000), ethnographers must perform two critical steps when doing ethnography. First, they must immerse themselves in the lives of their participants and, second, they must produce conceptualized reproduction and interpretation of the stories they gather from their subjects. Immersion can be achieved in many different ways. For example, an anthropologist may decide to live with an exotic island community like Rosaldo, while a sociologist may prefer to have a prolonged contact, using multiple methods (such as multiple interviews, various informants, and observations) and a variety of approaches to examine the phenomenon without actually living in the context. I found that examining the everyday lives of the LRLD by observation, field notes, and in-depth interviews was central to my data collection.

There are four basic methods of data collection found in ethnographic research: observations, interviews, documents, and audio-visual materials (Creswell, 1998). Deciding which methods of data collection will be used is based on the nature of the study, availability of resources, and the specific research question. Employing ethnographic methods, the researcher examines certain experiences shared by people in specific social situations. It was through observation and interviews that I accessed data pertaining to social processes. The following discussion begins with a brief description about how the sample was drawn and then will highlight key elements found in interviews, observation, and field notes.

Sampling. The broad aim of this ethnographic study was to explore the everyday life experiences of parents who donate the left lower lobe of their liver to child and to describe how LRLD impacts family dynamics and physical and emotional health. A purposeful sample of 13 LRLD who were at least one year out of donation, were interviewed in order to collect the necessary data to answer the research question. Participants for this study were recruited by pediatric transplant team members from two prominent transplant centers on the west coast of the United States.

Participants were interviewed one time for approximately 60-90 minutes; and 6 of the donors participated in a second interview of one hour. These second interviews were selected from key informants in order to follow-up preliminary findings, explore topics in greater depth, and discuss preliminary analysis. Interviews took place at the specific location decided upon by both the participant and myself. Fifty-five percent of the interviews took place in the home, 25% in the donor's workplace, 10% in clinic, and 10% took place in a coffee shop. The donor was approached in clinic or by phone call by the hepatologists, surgeons, liver transplant coordinators, social workers, or other members of the liver transplant teams. Flyers were posted in both pediatric liver transplant clinics. The donor had the choice of calling me or to have me call them be in order for them to gain more information about the study. All participants were consented at the time of the interview and they were informed that they could withdraw from the study at anytime.

The inclusion/exclusion specified that all participants had to be English speaking; parental living related liver donors, over the age of 21 years, and at least one year out of donation. Of all donors recruited by the transplant team none of the participants that were recruited refused to participate in the study and no participants withdrew from the study. Data collection was complete when a level of saturation was reached, this was apparent when I found that no new information was being discovered during analysis of the interviews.

Interviews. During an interview the researcher listens to what the participant tells about their world, learns about their beliefs about their work, family, dreams and hopes (Kvale, 1996). An interview for this study was defined as a conversation with a person in which specific information was elicited through a systematic process. The following discussion begins with a focus on individual perspectives regarding interviews and interview style from a selected group of scholars. My personal philosophy with regard to interview technique is a synthesis these authors' messages have in regard to interviews and will be presented as a conclusion to this section.

Steinar Kvale (1996) viewed the qualitative interview as a construction site of knowledge. He proposed that there were five features of a postmodern construction of knowledge: knowledge as a conversation, knowledge as narrative, knowledge as language, knowledge as context, and knowledge as interrelational. He described these five features as serving as a starting point in the discussion of qualitative interviews. Kvale's features of postmodern construction of knowledge are summarized as follows: Knowledge as narrative occurs in the open interviews as people tell their stories. Knowledge is derived from language, in which there is a focus on the interview as a language and the linguistic and textual analysis constitutes reality. Language is not only the tool of interviewing, but is also the object of textual interpretation. Knowledge as context takes into consideration the fact that the meaning of the interview depends on the context. One form of knowledge obtained within one context is not always commensurable with the knowledge found in a different context. Knowledge as inter-relational approaches the interview as an interchange of views between two people about a common topic. Kvale stated that this form of knowledge exists in the relationship found between the researcher, the individual, and the world.

To address this concerns regarding the participant/researcher relationship when conducting ethnographic interviewing, Heyl (2001) recommended that the researcher listen well and respectfully, acquire a self-awareness, be cognizant of ways in which the relationship affects the participant, and realize that only partial knowledge will be accomplished. Heyl reiterated that building a strong participant/researcher relationship is essential in conducting an interview.

Researchers are realizing the complexities of the human experience and using ethnographic interviewing with the hope of hearing stories from their participants' perspectives (Heyl, 2001). This up-close and personal approach to research was found to be very appealing both to myself and the participants in this study because it allowed me to hear the stories about LRLD and the transplant experience that have meaning to the participant and provided participants with a venue to share their life experiences. Heyl outlined the theory and practice of ethnography and how the changing conceptions of ethnographic interviewing have sparked debate amongst academics for years. Heyl recognized the debates since the 1980s that centered on the epistemology found in the social sciences and humanities and post-positivist concerns about ethnography in particular. Questions that seemed to arise concern the relationship between the researchers and their subjects, as well as considerations about what can be known in the interview process. These questions concerning relationships between the researcher and subject involved issues such as power, culture, and motives. I found that each participant came to the interview with different aims, objectives, and beliefs regarding the donation. Building a relationship during the interview and providing an environment that was non-threatening were important for me during the interview process. The stories that were shared between the participant and me required communication that was open and honest. It was through this relationship that an understanding of the participants' worldview was realized.

It was Arthur Frank (1995) who so eloquently wrote about the storyteller and how the personal issue of telling a story gave voice to the body in order to construct maps and new perceptions of the world. A story is not just about the body, according to Frank, but how the story is told, or the embodiment of the story, and when the story is told, the social context is of importance. A story, as described by Frank, gives voice to the body so that the body that has been changed by illness can become familiar again. "As the language of the story seeks to make the body familiar, the body eludes language" (Frank, 1995, p. 2). Frank (2004) claimed that in today's world, personal interest becomes a critical theme for academic writing and that good methodology does not guarantee good product. He claimed also that there has to be a story, and that this story must interest the public. Relating this to the principles of ethnography requires an understanding of subjects' day-to-day experiences. Producing a story from the interviews about which others will be interested and want to learn about is a guiding principle for Frank, and it is a principle I adopted as part of my interview strategy for this study.

One of the greatest challenges I found in using ethnographic interviewing was to develop and maintain a productive relationship with my participants and one that would provide a vivid description of the donor's life experiences. As the previous discussion illustrated, works by Kvale (1996), Heyl (2001), and Frank (1995) advocated the importance of a meaningful participant/researcher relationship. Kvale (1996) posited that the interview is a construction site for knowledge and exists in the relationship. Heyl (2001) suggested that the complexities of human experience could only partially promote knowledge. However, he offered ways of developing engagement with the participants such as though interviews. Frank (1995) stressed the importance of using the relationship in order to produce a story that will interest others. It was my responsibility as an ethnographer to understand the events that donors experienced and to communicate them as truthfully as possible to the public. Interviewing was one method I used to accomplish this goal and to appreciate the experiences participants had to share.

I followed a semi-structured interview guide that encouraged participants to expand on particular questions of interest (Appendix E). Questions were presented to the LRLD in a systematic manner in an interview that usually lasted between 60-90 minutes. Participants were instructed to answer only those questions they felt comfortable addressing, and those questions they felt hesitant to answer could be bypassed. There was no instance where the interview was terminated or the donor felt uncomfortable with the interview process. At the conclusion of my first interviews with the donors, I selected key informants to participate in a second interview. This selection was based on the impression that I felt these participants had stories to share that demanded further exploration. Second interviews followed the same format as the first interview, but the interview guide was altered slightly for each participant based on individual stories told by the participant areas I felt needed elaboration in order to better understand their experience as a donor. Each participant was given a reimbursement of $50.00 for each interview.

Observation

"Participant observation—establishing a place in some natural setting on a relatively long-term basis in order to investigate, experience and represent the social life and social processes that occur in that setting—comprises one core activity in ethnographic fieldwork" (Emerson, Fretz, & Shaw, 2001, p. 352). Observation provided me with the ability to take part in the daily lives of the LRLDs. Learning how to participate in observation is deeply rooted in the researcher's ability to adapt to new situations as well as the social skills he or she brings to the field (Heyl, 2001). Observation can be formal/goal directed, or it can be informal, for example, when the researcher and informant are participating in an interview in which the goal is not specifically observation. Informal observations, the primary method of data collection used in this study, provided valuable insights into the lives of the participants. It was very common to have a spouse, recipient, or sibling in the home during the interview, which provided the opportunity to observe family dynamics that were recorded as field notes. These observations allowed me to better understand the social and cultural processes of the family.

Angrosino, Mays de Perez and Mays de Perez (2000), in their discussion of observational methods in ethnography, recommended that, in an effort to reorganize observational data or to give meaning to the data, the possibility of observer bias looms large in the thinking of both sociologists and anthropologists in the ethnographic tradition. For this reason, emphasis was placed on certain observational methods to report concrete events and things in fieldwork with as little level of abstraction as possible.

Angrosino et al. (2000) introduced concepts to consider when discussing observation as a context of interaction. They stressed the premise that social interaction required taking part in a social setting rather than reacting passively. By assuming situational identity, or taking part in a social setting, Angrosino et al. believed the ethnographer should negotiate and conceptualize the interaction. This interaction is tentative and involves continuous testing by all participants.

Concepts presented by Angrosino et al. (2000) are supported by the fundamental underpinnings of SI, as both are concerned with the social processes found in observation as a context of interaction. Our social behaviors, culture, and how we frame the self and the participant are the building blocks for understanding the methodology behind ethnography. The impact human behavior has on the lives and experiences of individuals as well as the impact experiences have on human behavior are significant. This informal observation of the LRLD's life in his or her home or in a venue decided upon me and the donor created an understanding for me regarding the ways in which meaning affects behavior. At the same time, it allowed for new knowledge to develop.

During the interview process, I paid close attention to behaviors, actions, and interactions of the informants.. I specifically focused on the non-verbal communication exhibited by the donor during the interview such as body language, facial expressions, eye contact, and tone of voice. These non-verbal actions served as cues to me about how the donor was feeling through the interview and signaled areas of the interview I may want to further explore with the donor. My observations also included the opportunity to watch the donor interact with their spouse and other children. Though having only a limited time with the donor, it did allow me time to see family interaction that added another dimension to the observation period.

Field notes. Field notes from observations offered an opportunity to describe specific accounts of the donor's life. For instance, reactions and expressions, to both questions asked and the donor's surroundings were recorded in field notes and used in the analysis of this study. Field notes are a form of representation, that is, a way of reducing just-observed events, persons, and places to written down accounts (Emerson et al., 2001). Field notes have the ability to capture subtleties of the interaction between the researcher, the participant, and the environment, which in many cases ended up being written into the final data analysis of this study. Ethnographers must give attention to the character of field notes as written texts, to variations in style and approach to writing field notes (Emerson et al., 2001).

van Manen (1983) took a slightly different approach to field notes than did Emerson (2001); he underlined an orientation towards stance, or one's positionality, in his discussion of observing participants in the field and the use of field notes. He felt that stance not only has the ability to shape how the ethnographer observes and participates in the field, but also prefigures how the ethnographer orients writing. He believed that field notes are a reflection of how the ethnographer identifies those studied. In this same vein, Daniels (1999) described the experience of fieldwork as leading to self-revelation and to a deeper understanding of one's own strengths and weaknesses. Both of these concepts were acknowledged in my field notes because they allowed for reflexivity to take place as well as for the identification of potential bias.

Field notes reveal an opportunity for the researcher to reduce certain events (Emerson et al., 2001) that underlie the researcher's positionality (van Manen, 1983), and they offer the researcher the ability to gain a deeper understanding of him- or herself (Daniels, 1999). Field notes are a matter of individual choice and can be quite personal in content. I found that field notes provided a canvas to record sensory accounts, nonverbal behavior, interpretation, and personal perspectives that were not possible with audiotape alone. They were interpretive, and dynamic, and influenced the analysis. It is difficult to provide a set of rules to use for field notes, but they offered me a chance for self-reflection and richer analysis.

Data Analysis

Ethnographic studies are unique and demand systematic strategies for analysis. These methods of analysis must be clearly stated and properly followed by the researcher. A variety of analytic methods are available to the ethnographer, and the choice of analytic strategies is dependent on the research question and method of data collection. One method I chose for this ethnographic study was thematic analysis. It was one way I could analyze the set of interviews and field notes I had collected in an organized, systemic manner. Using the software tool ATLAS.ti I was able to categorize words and phrases contained within the text of my interviews and field notes with codes reflecting specific concepts. By clustering and combining I developed three broad categories that best described the everyday lives of the LRLD I interviewed. My analysis was completed by the identification of one over-arching theme that synthesized all three major categories. Throughout this process of analysis, I consistently constructed theoretical memos as a way of explaining my theoretical perspectives as interviews were analyzed.

During the course of my analysis, I met on a regular basis with peers, members of my dissertation committee, and other scholars to share my preliminary findings. This provided me with additional feedback on the accuracy of my interpretations. I shared interview texts, field notes, codes, and themes with these individuals.

“A theme is an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole” (De Santis & Ugarriza, 2000, p. 362). Themes can traverse a number of social system institutions and connote the idea of a unified and holistic meaning. DeSantis and Ugarriza powerfully stated that researchers could confuse the term theme for other terms, such as attributes, descriptors, elements, or concepts. This can lead to confusion and possibly result in misinterpreting or missing major issues. These authors made the point that a mistake such as this may result in intervention strategies that are poorly derived and irrelevant. They stressed the importance of precise use of the term theme, as it has a profound effect on implications for the prioritization of health issues and for nursing practice.

“Theme gives control and order to our research and writing” (van Manen, 1983, p. 78). In his article “From Meaning to Method” van Mannen investigated the relationship between language, meaning, and method in human science research. He approached the questions of “How does the text speak?’ instead of merely asking the thematic analysis questions such as “What does the text speak about?” Though van Manen used dimensions of phenomenology in his discussions, these ideas can be applied to the ethnographer as well. How the text speaks and how it affects our understandings were critical to address when it came to my analysis. Each donor spoke about their experience from a different reference point and each donor created unique meanings from the donation. I conscientiously analyzed each interview taking into account the differences expressed by each donor. I constantly had to ask myself how the text spoke in order to shape an analysis that best met the meanings expressed by the donors. I developed a clearer understanding of the social process of the everyday lives of the LRLD as the interpretation of the text and field notes developed.

One goal of thematic analysis is to transform raw data into a new and coherent description of what is being studied, which is similar to what Geertz called "thick description." Developing this overarching unity that is proposed with thematic analysis was accomplished when I accounted for inconsistencies amongst the participants, and I could make conclusions that helped in explaining my initial research question.

Thematic analysis was well illustrated by Rehm and Bradley (2005) in their ethnographic study focused on the social consequences of raising children who were medically fragile and developmentally delayed (MF/DD). These researchers identified the overarching theme for the families of MF/DD children as the search for safety and comfort in social situations. They isolated major categories found within this theme which were the need to anticipate and plan for the child's care; overcoming environmental, child-related, and attitudinal barriers; and finding social activities that were comfortable for all members of the family (Rehm & Bradley). This study was based on an SI framework and successfully focused on the everyday lives of the family and the MF/DD child. The authors of this study demonstrated rigor by including multiple sources of data and methods of data collection, and by using cross case analysis, which led the researchers to compare similarities and differences amongst families.

For the purposes of this study, I conducted a method of analysis that allowed for me to develop three major categories and one over arching theme as a product of the analysis. The process I followed was as follows: 1. I summarized all 20 interviews in order to capture the overview and outstanding elements of each encounter. 2. I then detailed an open coding system in order to review each line of the transcript for meaningful words, concepts, events, and narratives. 3. I built categories from smaller chunks of data to describe major elements that were common between participants and their families. 4. I sought one unifying theme that tied all three categories together and described the outcomes of the donation process.

Rigor. The concept of rigor has been discussed and debated for many years, and to date there is not one definition that is used consistently by interpretive researchers. In qualitative research the necessity to incorporate rigor, subjectivity, and creativity requires developing validity standards, which is challenging (Whittemore, 2001). Several qualitative researchers have developed validity criteria that help in establishing rigor in qualitative research. The discussion of rigor that follows highlights salient concepts on the issue, followed by my personal interpretation of the meaning of rigor and how I maintained rigor in my study.

A well known qualitative researcher grappled with the concept of rigor and commented that establishing validity, reliability, objectivity, generalizability, and repeatability ensures rigor for the quantitative researcher (Sandelowski, 1993). However, qualitative research addresses rigor differently. Sandelowski compared both qualitative and quantitative research methodologies and reported that in order to evaluate rigor both qualitative and quantitative research must be considered separately because their inquiry is based on completely different assumptions. “Qualitative research is needed to identify the characteristics of phenomena; quantitative research is needed to control phenomena and to predict outcomes of nursing interventions” (Beck, 1993, p. 263).

The two most controversial criteria for evaluating qualitative research for rigor, reliability and validity, were proposed by Beck (1993). She suggested renaming internal validity, external validity, and reliability to credibility, fittingness, and auditability, respectively. Beck claimed that by establishing these three criteria to evaluate qualitative research, the scientific merit of interpretive research could truly be appreciated. Guba and Lincoln (1982) stated that factors of truth value, applicability, consistency, and neutrality were the criteria by which scientific rigor should be addressed. Credibility, as defined by Guba and Lincoln, is the criterion against which truth value of a qualitative study should be evaluated. Fittingness was suggested to be the criterion that applicability of a qualitative study should be judged, and auditability was the criterion from which the consistency of a qualitative research study should be evaluated. Confirmability, defined by Guba and Lincoln, was the criterion by which the neutrality in qualitative research should be evaluated.

Beck (1993) claimed that the three criteria: credibility, fittingness, and auditablity, are necessary in order to appreciate the scientific merits of qualitative methodologies. She stated that credibility of a research study measures how vivid and faithful the description of the phenomenon is in the study. Fittingness measures how well the research question fits into a context other that the one from which it is generated (Guba & Lincoln, 1982). Auditability, as described by Beck, referred to the ability another researcher would have to follow or to audit the analytic decision trail.

Whittemore, Chase, and Mandel (2001) posited that there needed to be a distinction between primary and secondary validity criteria in qualitative research. Credibility, authenticity, criticality defined primary validity and integrity. Secondary validity criteria were identified by explicitness, vividness, creativity, thoroughness, congruence, and sensitivity. In contrast to Whittemore et al., Davies and Dodd (2002) suggested that rigor needed to address the notion of ethics and refer to the reliability and validity of research. These authors stated that the concept of rigor is not the problem for qualitative researchers, but it is the applicability of quantitative notions of rigor to qualitative research that provides a weak instrument for evaluating qualitative research. I agree with their argument that ethics is an essential element of rigorous research, whether the research is qualitative or quantitative, and that ethics is integral to how we approach rigor in conducting qualitative research.

Angen (2000) reviewed various approaches to meeting the aims of trustworthiness in qualitative research, and she reformulated validity by establishing two broad headings: Ethical Validation and Substantive Validation. Ethical validation is a term Angen used to describe how a researcher should conduct research in an ethical manner with an aim of fully understanding the meanings involved in our everyday existence. Substantive validation addresses the coherence and comprehensibility of the research from the reader’s perspective.

A philosophical commitment to ensuring rigor was necessary in order to explain the everyday lives of the LRLD. I demonstrated credibility in this study in the following ways: (a) participated in prolonged engagement with the donor during both the interview and observation periods, (b) used peer-debriefing sessions in which I met with other qualitative research students and discussed data and findings, (c) shared data/findings with colleagues and members of my dissertation committee for confirmation of analytic integrity and rigor, (d) reviewed preliminary findings with outside scholars for verification that the steps of analysis were credible, (e) participated in second interviews with donors that gave me the opportunity to confirm findings with donors and to better understand their experiences, (f) used “thick description” in order to account for similarities as well as differences found among the donors interviewed, and (g) kept a journal of theoretical memos in order to identify any individual biases that may have been apparent during data collection. Theoretical memos also allowed for a self-reflective process to transpire. Memos were also used for the iterative development of conceptualizations during the analysis phases of this study.

In an effort to attain fittingness in this study participants were selected from two transplant centers, on the West Coast. The LRLD was defined clearly so that findings from this study can be applied to other transplant centers that conduct living-related liver transplantation. This study demonstrates auditability, as I have explained specifically how the study was performed. Where, how, and how long interviews were conducted are clearly stated, as is the data analysis process. Another researcher should be able to follow the paper trail and understand decisions made.

The phenomenon of living-related liver donation for this study is defined as donation of the left-lower lobe of the liver by a parent over the age of 18 to a son or daughter. This multi-centered study required the approval of the Committee on Human Research and the Internal Review Board at both transplant centers. The interview guide, consent forms, flyers, and demographic data sheet are available in the Appendix A-E of this paper to ensure auditablity for other researchers.

In concluding this discussion of data analysis it seems worthwhile to cite DeSantis and Ugarriza (2000), who clearly articulated that the concept of thematic analysis is critical to accurate interpretive data collection: “If rigor is maintained, and research terms such as theme, have consistent meaning across methods, the advancement of nursing science will be well served” (p. 369).

Summary of Epistemologies and Methodologies

As a result of the preceding discussion of epistemologies and methodologies, it becomes apparent that these two key principles of ethnography possess a unique relationship that allows for compatibilities to be recognized. Differences, as stated earlier in this chapter, were that epistemologies are aimed at describing how we know the world, the researcher, and the known. Methodology, on the other hand, focuses on the most appropriate way for gaining knowledge. These two key principles, in fact, intersect and share concepts.

SI, described in this paper, served as a theoretical underpinning for the researcher to understand the world and interpret the experience of the participants. SI provided the researcher with the framework to guide many aspects of research, from how to phrase an interview question to data analysis. Geertz’s (1973a) work, which emphasized the importance of symbolic systems of meaning as they relate to culture and cultural situations such as living related liver donation, is compatible with principles of SI because both are concerned with understanding meanings and human behavior. SI not only helped in understanding culture, it also was the conduit that connected epistemology to methodology.

In using reflexivity and representation I imported key concepts of SI, such as the notion that humans derive their social essence from community or intersubjectivity. It must be recognized that people distinguish and develop meaning by interacting with others (Prus, 1996). These donors developed new meanings with regard to their personal life, their family life, and their relationship with their communities as a result of the interactions they established in becoming LRLDs. Using reflexivity and representation, I found myself co-creating the relationship between the participants and myself. Through interaction with others the researcher can develop meanings about his/her own life and see him- or herself from the standpoint of the participant (Prus, 1996). This process brings the researcher one step closer to “de-othering” the participant. As a liver transplant coordinator, I had to pay close attention to my clinical perspective and try to understand the lives of these donors through their eyes. I do not believe at any point during this study that I saw my life from the standpoint of the participant, as Prus stated, yet I did become closer to understanding their lives, not as a clinician, but as a researcher.

As I collected and analyzed the data, elements of SI were used for better understanding phenomena. In using data collection techniques such as observation, field notes, and interviews, SI enabled me to study the ways in which LRLDs define their individual situations. SI provided the opportunity to discover meanings that participants hold for objects in their life-worlds, as well as the way they live the everyday (Prus, 1996). In addition to gaining a clearer understanding of culture, as well as participating in reflexivity, representation, data collection, and data analysis, SI created the necessary framework for understanding the systems of meaning LRLDs used to relate their individual cultures to their everyday life experiences.

Through the interview process I gained a new perspective on what donation meant to donors and how it impacts their families. How donors dealt with the stress of having a child with ESLD, how they communicate with their families, and how they transform meanings in light of the situation in which they are placed produced data from which to better understand the LRLD experience. Interpreting the meanings that the donation have for the donor and the donor's family will hopefully give birth to a better understanding of donors and their daily lives. This, in turn, will lead to interventions that will foster better care for the LRLD in the health care arena.

Conclusion and Reflection

Ethnography is multifaceted and flexible, and has the ability to affect people in positive ways. Research questions that address the issues of culture and meanings are well suited for this type of inquiry. As demonstrated in this chapter, epistemological and methodological principles are key to conducting an ethnographic study. Though there are concepts of epistemology and methodology that overlap and intersect, the one highlighted in this paper was SI. SI has provided the theoretical underpinnings for researching the LRLD. I agree with Robert Prus's (1996) statement that "people together construct and reconstruct meaning, as they act and interact." (p. xiii). By working within the constructs of culture, reflexivity, representation, interviews, observation, field notes, thematic analysis, understanding actions, interactions and meaning provided the necessary foundation to study the LRLD through a sociologically based ethnographic study.

In conclusion, a profound quotation from Kathy Charmaz's (2004) is presented, as it provided inspiration to me as I ventured into the qualitative mode of inquiry. She believed that entering the phenomenon means being fully present during the interview and deep inside the content afterward.

> Do something that makes a difference in the world. Then enter the phenomenon and open yourself to the research experience. Face the inevitable ambiguities. Flow with the existential dislocation of bewilderment. Bring passion, curiosity, and care to your work. In the end you will transform our images of studied life, and your research journey will transform you. (p. 16)

CHAPTER V

FINDINGS

Although the donors were unique individuals with varied life circumstances, all experienced donation as a life-changing event. When expressing the impact of LRLD, the overarching theme that emerged was transformation, which consisted of several major categories, including: a self-awareness process, a clarification of familial relationships, and a change in perspectives on community. As it related to donors in this study, transformation is defined as a path traveled by donors during which they experienced a series of dynamic interactions involving self, family, and community that affected the way they perceived each of those entities and, as a result, changed the way they lived the everyday.

This transformational process began when the donors and their families realized a liver transplant would be the only cure for their children. It continued as an ongoing journey with no distinct endpoint. Though each donor experienced different processes, data from this study demonstrated that the one outcome common to all was that following donation they created new meanings to their lives through interactions between the self and others.

Random House Dictionary (Random, 2002) defines transformation as the act of being transformed, which is to change in composition or structure. Those interviewed as part of this study changed in how they viewed themselves, relationships with their families, and interactions with their communities. They transformed themselves as they became more aware of the importance for them of the decision to donate and how it allowed them to have more control over the clinical situation. The donation also permitted them to better understand themselves and their identities as living donors. Their new identity as living donors affected the way they perceived themselves as individuals, as parents, as spouses, and members of community. They were able to clarify the family unit as a result of the donation because for them the act of giving a piece of themselves to one of their children created bonds that were unique, in some cases stronger than the bonds they had established with their other children. Relationships with their spouses and their other children were also clarified. For some, the family unit was strengthened; for others bonds were weakened. Their perspectives on community changed in structure and function as well, leaving donors feeling a need to give back to their communities. This chapter, then, begins with a discussion of the characteristics of the participant sample, followed by definitions of the major categories that emerged and led to the development of the theme of transformation of self in relation to others.

Characteristics of the Participant Sample

Table 2

Characteristics of Participating Donors (n=13)

Age of the Donor at the Time of the Transplant
20-30 years: 4 (30.8%)
30-40 years: 7 (53.8%)
40-50 years: 2 (15.4%)
Mean: 33.5 years
Range: 27-49 years

Table 2(Cont'd.)

Sex of Donor

Female: 8 (61.5%)
Male: 5 (38.5%)

Race/Ethnicity of Donor Given by Donor Description

Caucasian: 8 (61.5%)
African American: 1 (7.7%)
Pacific Islander: 1 (7.7%)
Hispanic: 1 (7.7%)
Asian: 2 (15.4%)

Annual Family Income

<$10,000: 0
$10,000-$40,000: 0
$40,000-$60,000: 2
$60,000-$100,000: 4
$100,000-$150,000: 3
>$150,000: 2
Participants that did not answer: 2

Marital Status Since Donation

Married to same spouse: 9 (69.2%)
Single never married: 1 (7.7%)
Divorced: 3 (23.1%)
Re-married: 1 (7.7%)

Table 2(Cont'd.)

Medical Complications for Donor Post-donation

None: 8 (61.5%)
Weight Loss: 1 (7.7%)
Decreased Energy: 2 (15.4%)
Gastrointestinal Problems: 1 (7.7%)
Other Medical Problems Requiring Hospitalization: 1 (7.7%)

Age of Recipient at the Time of Transplantation

6-12 months: 9 (69.2%)
12-24 months: 2 (15.4%)
24-36 months: 1 (7.7%)
>36 months: 1 (7.7%)

Recipient Diagnosis at the Time of Transplant

Biliary Atresia: 10 (76.9%)
Citrulemia: 1 (7.7%)
Hemangioma: 1 (7.7%)
Fulminate Hepatic Failure: 1 (7.7%)

Transformation

A symbolic interactionist (SI) perspective, developed by George Herbert Mead (1934) and Herbert Blumer (1969) as a theory to explain how individuals make sense of their unique situations and the manner in which they live their lives in conjunction with others on a day-to-day basis (Prus, 1996), was used in examining the ways donation transformed donors' lives relative to themselves, their families, and their attitudes toward their communities. Particularly because of its emphasis on understanding how meaning influences actions and behaviors, SI served as an excellent theoretical framework for the analysis of this study. Interpretations generated from this study, which helped explain the experiences and lives of the LRLD, required me to understand the meaning the interviewees attached to the donation process pre- and post-transplant. The LRLD's system of meanings, as presented in this chapter, is clearly embedded in the culture of their everyday lives. One participant said the experience of being a living donor had a way of "opening my eyes to a whole different life. It just broadened what life's all about." It was not just about the donor, or the spouse, or the recipient, or friends and family. The donation was a life-changing event that transformed the way they viewed their everyday lives. The transformational processes the donors experienced in the areas of self, family, and community arose from dynamic interactions and resulted in their ability to make sense of their everyday lives as individuals, parents, donors, spouses, and members of community.

Self-Awareness

Self-awareness became an important factor for the donor, as illustrated in this study, in two specific ways. First, the decision to participate in LRLD versus waiting for a cadaveric donation empowered donors because it provided them the capability to better control the circumstances involved in saving their children's lives. Empowerment in this study is defined as the process by which donors realized that they, themselves, could change a life-threatening situation affecting their children. By taking action, that is, donating a piece of their own liver, they gained control over their own lives, and gave their children a potentially healthier future. Empowerment is a social process that required the donor to interact with individuals within his/her family and community. The control that was gained as a result of becoming empowered was manifested by the way in which the donor could decide when the donation would take place and, obviously, who the donor would be. As a consequence of this control, he or she developed greater feelings of comfort and security.

Second, becoming living-related donors influenced the construction of their identity. Following the donation, they were no longer just parents; they were individuals who had saved their children's lives by giving a part of their bodies. This act shaped a new identity.

Decision to Donate Empowered the Donor and Provided Control

When faced with a situation in which a child is encountering end-stage liver disease (ESLD), parents had to make a decision either to be placed on the United Network of Organ Sharing (UNOS) waiting list or to participate in LRLD. This required parents to self-reflect, and ask themselves what was in the best interest of their family and themselves. If they chose to be on the UNOS list, they had to also be prepared to wait until a liver became available, in some cases days, weeks, or months, depending on the child's clinical status, blood type, size, and age. Depending on how critically ill the child was, waiting for a cadaveric donation could have put an undue burden on parents, especially when the child could decompensate quickly. Unlike cadaveric donation, which must be done within eight hours of the organ harvest and is completely out of the control of the family with regard to donor and location, LRLD can be scheduled, as soon or as late as the surgeon and family feel it is necessary.

Having a child with ESLD, in most cases, is out of a parent's control. Liver disease in pediatric patients may require immediate transplantation, as in the case of fulminate hepatic failure. In other cases, such as biliary atresia, transplantation may not be necessary at all, or it may be required in days, weeks, months, or years. In LRLD, once the surgical staff determines that transplantation is required, control over the exact date of the transplant is placed in the donor's hands. This control is left to chance in cadaveric donation. The family who elected to participate in LRLD was provided an advantage because the timing of the transplant could coincide with the clinical prognosis of their child. This brought both comfort and security.

The self-awareness that occurred for many of these donors empowered them by providing them with control over the situation. Becoming an LRLD allowed them, together with the surgeon, to decide the date and time of the transplant, which removed many of the unknowns that accompany cadaveric donation. The medical history of the cadaveric donor, for example, social, sexual, drug, and alcohol history, all factors unknown to the recipient, can potentially affect the quality of the liver. Donors knew their own medical history, and it was reassuring to them that it was their organs and not those of strangers going into their children. This control empowered donors by providing them the comfort of knowing where the liver came from and the security of knowing the organ was genetically linked to their children.

The Right Decision

In retrospect, all donors interviewed felt their decisions were right for them and their families. The steps they took towards understanding their decision to donate brought them to a better understanding of themselves and closer to a self-awareness that (a) did not exist before the transplant and (b) was empowering for them. Suddenly they held the key to their children's recovery. Excerpts of interviews below demonstrate their comfort with deciding to donate rather than waiting for a cadaveric donation. One said, "When you sit back and look at it from a pure analytical standpoint, it just worked. With everything coming into play, it was the right decision." For another, 13 years of life post-transplant for his child was more than he or his wife had expected, and it brought comfort to him to know that to donate was the "right decision." Whether his daughter would have gotten 13 years with a cadaveric donation is unknown, but the process of LRLD left him with a feeling of contentment, that he had participated in extending her life.

> We'd been through a lotta surgeries and, you know, had a lotta tubes and, poking and probing, but, yeah, that was - that kinda - it solidified the fact that we had done the right thing and made the right decision. Regardless, we didn't know at that time that we'd get, you know, 13 more years out of the, out of the process, but you know, we, made the right decision.

He described donation as a unique opportunity, one that he would do again, and an experience he will never forget, despite its ups and downs. It is a memory that added to his self-awareness and led him to a better understanding of his life.

> I would do it again. You still - even with all the pain and the ups and downs and roller coaster ride, it's still a memory. It's still a moment; it was a chance to do something that I'll never forget.

Another donor felt that he had made the "right decision" for him and his family and would encourage other families to participate in LRLD if they were faced with a child with ESLD:

> For me, the decision to be a living liver donor was a no brainer. I think it is the best decision I ever made in my life. I wanted to give my baby a chance. Looking back upon it, eight years later I think it's the best decision I ever made!

Perfect Genetic Match

Several other donors expressed the “right decision” in regards to LRLD, but in the context of their livers being the best genetic match for their children. This group took logical steps to understand the immunological implications of LRLD and, by doing so, became more self-aware. They were aware that their children had ESLD and that they themselves could save their children’s’ lives. Further, each learned that immunologically the best genetic match for their child was to use their own liver rather than that of an anonymous donor. This knowledge about the very specific advantages of their bodily (genetic) link to their child’s well-being was empowering to parents and enhanced their sense that they had made the right decision.

By realizing all of this, they became more self-aware. Like the donors who mentioned LRLD was the “right decision,” the interviewees whose stories are quoted below understood the genetic impact of LRLD on the clinical outcome for their children. As a result of this self-awareness, and thus empowered, they took control of the situation and actually made the decision to donate. Following the donation, they described feelings of comfort and security in knowing that they had chosen the best option for saving their children’s lives, primarily because of the genetic link to themselves.

> I think it’s the best decision I ever made in my life. It was a privilege. It was, probably the greatest thing that I can think of having done in my life. I feel like that it is the best match you can absolutely find is the mother or father giving, you know, it’s your tissue, giving to your child. (Donor father to daughter)

> It is the best match you can absolutely find is the mother or father giving, it’s your tissue, giving to your child. Donating made me realize that life is so precious, and you need to keep it going. It’s such a miracle. It is truly a miracle. (Donor father to son)

> With living related donation, we knew where the liver was coming from, and we could schedule it. It was a better match and the survival rate was better. (Donor mother to daughter)
>
> In my opinion it's so much better to come from the family, you know what I mean? That coming from somebody you know instead of someone you don't know or will never know you know what I mean? I just didn't want her to have a liver from a stranger. (Donor father to daughter)
>
> I'm lucky to be able to live in this day and age that we can do a surgery like this, and to be able to have a healthy liver, of somebody that's related so that you know you think it must be a good match. It's gotta be a good match. (Donor father to daughter)

The Decision was Approached Matter-of-Factly

Matter-of-fact donors framed the experience as just another reality-based life event. One said, "You just play what you are dealt." Another who stated that the donation was a "no-brainer" believed that as a parent, it was his obligation to donate, that it allowed him to feel in control of the situation and to consider the options available to him: "I just looked at it like as a parent this was my obligation, this was my responsibility. And it, like I say, was really a no-brainer on my part."

Looking Internally at the Decision to Donate

Being comfortable with the decision to donate was a priority for one father who expressed a level of self-awareness that was related to a feeling in his "heart." Beyond comprehending that his donation was the best option for his child, he realized that as a donor he had to look internally and feel "settled" with the concept of living donation. He also came to understand that the donation did not come without emotional pain, in this case as a consequence of a divorce from his wife and, hence, a separation from his daughter: "You have to be settled with it in your heart, I mean you really do," he said. "It's not - it's not a procedure that comes without pain."

Creating Meaning from the Decision to Donate

The reality of having a child with ESLD was very apparent for the following participant, who stated that he realized his decision to donate could have either a positive or a negative result. Either way, however, he believed he or someone else would learn from the experience. As part of his self-awareness process he was able to create meaning from the donation that was empowering to him. The fact that his act of generosity had the ability to help someone in some way brought meaning to his donation. He appreciated that, whether for him or for someone else, a learning process could take place and the donation would provide benefit.

> With my first daughter, you know, you take things for granted. With having done a living transplant, I think once you decide to do something, you complete it to the end, whether the outcome is a positive or a negative, because, if it's a negative, you'll learn from it and you'll just move on, and hopefully that information will be valuable to somebody else.

Two donors, one female and one male, compared the act of donation to "giving birth," which gave it a new meaning. Both demonstrated feelings of empowerment in this act of self-awareness that created comfort for them. The woman felt empowered by having the chance to give life a second time: "I actually gave her [her daughter] a second chance at life. I birthed her and then gave her another chance at life, that's what feels good." The father, while he did not perceive donation as exactly like "giving birth," characterized it as a giving process, a valuable and extraordinary act:

> As a man, a man will never understand what it is like to give birth. Men don't have a clue. I realize that. I've been present at the birth of all three of my kids. I was not in the waiting room. I was right there every time. Still with no concept of birth. To be able to have an opportunity to give life to your child, is the closest thing that I'll ever get to understanding birth. [Laughs] I didn't say I understand birth. I said the closest thing, I will ever get. (Donor father to daughter)

For another, the decision to donate was perceived as an active, empowering process, but the actual donation was seen as passive. This ability to distinguish between the two represents an element of self-awareness on the part of the donor:

> On one hand, it was a really cool thing to be able to do. But on the other hand it was a passive thing. I mean it was active, going in there, making a decision, and stuff. But the surgery was kind of a passive thing.

Control over the Timing of the Transplant

Donors described the option to participate in LRLD as having given them a sense of control over decisions that were normally left to the medical team or to chance. Specifically, they could control the date and timing of the transplant and who would be the donor. If a child was sick, they could postpone the transplant until the child's condition improved. If a child was in desperate need of transplant, they could do the transplant immediately rather than having to wait until a donor organ became available. These situations not only offered donors control over the transplant, but provided comfort to them and their families as well. What follows are examples of how donors expressed their sense of control, comfort, and security associated with donation. The first expressed his feeling of relief when he was finally in control and decisions were in his hands:

> We were in control of the situation suddenly. And the biggest problem with this all along is that we weren't in control. That's probably the biggest thing we had to cope with all along, is not being in control. We're in control of the rest of our lives. We can decide where we go, what we do, how we do it, when we do it.

Control over timing of the transplant was important for the following LRLD because her daughter suffered from a type of liver disease that causes the child to become ill quite often and unexpectedly. The illness could be so severe that, if there would have been a cadaveric liver available during one of the child’s flares, the transplant could have been very risky. Therefore, ability to control the timing of the transplant based on her daughter’s clinical status was comforting for this donor.

> . . . we thought that with the living donor we had slightly a better chance. And actually she was sick so often, it made more sense for us to do living donor because we could schedule it. We could do it when she was well. She seemed to keep getting sick, and when she was sick we couldn’t do the transplant.

When asked whether timing was one of the main deciding factors for the living donation, the following donors replied:

> Without a doubt. I mean we know that without living related that there was a good possibility that our son would continue to go through the disease. As he got sicker, the chance for recovery through surgery was going to be minimized. So we wanted to do it - he wasn’t healthy, but we wanted to do it while he wasn’t in the ICU. (Donor father to son)

> Timing, yes basically, cause we’ve heard how people wait so long, and some people end up dying waiting, so we said-there was no question. We just said, “Let’s do it.” (Donor mother to son)

Flexibility over the timing of the transplant offered comfort to LRLD families because they knew all they needed to do was go to the operating room; they were not required to wait for a cadaveric donor to become available. They did not live with the pressure of wondering if their children would live to see a donor become available.

Exerting or seizing control: A path to self-awareness

The following donor, reflecting on the donation, shared a perception of the hospital stay as a series of steps, much like a multi-step game, the goal being to figure out his next step logistically so that he could progress to the finish line. He realized that knowing when to take control or “exert” control was critical to his recovery. He believed that in order for things to work he must not upset anyone on the medical team. Understanding the way in which the health care professionals operated led him to a better understanding of himself. It wasn't just him and his family, but he had to work with the health care providers in order to make the necessary steps to getting both himself and his son discharged from the hospital. He determined when and how to "fight" in order to win the game. This "exerted" control led him to a level of comfort and security that worked for him in the hospital environment. He controlled the steps in the game by anticipating his next steps, and he was secure in his moves because he knew what the nurses needed him to do for proper recovery. This was meaningful to him:

> Know when to fight. Know when to say, "This needs to happen, this is wrong, this is whatever"- know when to stand up, but don't stand up for piddly things, don't piss people off. That does not help. When you figure out what the nurses want you to do in order to get to the next step, you know what the deal is. You know you need to pass gas, and you know you have to have a bowel movement before they'll let you do anything. So that's like the first thing, the first card you have to collect in this game. So that's the first thing we wanted to have happen. We wanted to get to the next step. And you know what it is that we need to do. What on this scavenger hunt do we need to do to get to the next step? And that was it.

Leaving the Hospital Against Medical Advice (AMA)

Post-surgery, one donor required prolonged hospitalization for gastrointestinal complications. Nevertheless, he felt empowered to take control of his illness, treating it as less severe than what the medical team believed. His perception that his problem could be treated like a bad flu allowed him to "seize" control of the situation, unlike the donor above, who "exerted" control given to him by the transplant team. The result, however, was the same. Both felt empowered. In this case, the donor decided to discharge himself from the hospital despite the doctor's recommendations because he felt he would do better out of the hospital than in. Thus, he seized control from the medical team and did what he thought was best for himself. Fortunately, his clinical outcome was excellent.

> I was being fed intravenously and I had suction down into my stomach, you know, the whole time, and it was just nasty, 19 days of torture. I thought to myself: 'I need to get out of here. I want to go home. I want to, I want to have my wife's chicken noodle soup and I just want to treat this like I would treat a sick stomach at home, like it's a bad flu.' I knew when I checked out of the hospital that I shouldn't. I had seen the x-rays, and my fluids were right up to my neck. I mean I was just full. I was ready to explode. But, I just wanted out! I just wanted out!

Although the decision to donate empowered the donors and provided control in several different ways, it was clear from their stories that there was one similar outcome, which was that it inspired a new self-awareness for all of them. Whether it was seizing/exerting control, feeling like the donation was a parental responsibility, or experiencing a sense of control over the timing and genetic match of the organ, this new self-awareness brought unique meanings to their lives and transformed them as individuals. They all realized that giving a piece of their bodies to their children was a simple task if it could save a life. Contrary to what I thought would be the case, not one donor feared death or confided that they experienced that fear. The goal of saving their children's lives was all that mattered. These donors were able to make sense of a situation that was entirely new to them and control their children's destiny. This required them to become actively involved in the transplant, rather than being passive observers and wait for a cadaver to become available. As this study illustrated, the donors sought control by deciding to donate and, as a result, became empowered. This yielded comfort and security. The one other conceptual aspect that led these donors to a new self-awareness was the construction of a new identity, which played a key role in the transformation they experienced as a result of being donors.

Influence of the Donation on Construction of Identity

All of the study participants constructed a new identity after donation that provided them a way to look at themselves differently. As a result of a reflective process that occurred for them. Identity construction is extremely complex, but for these donors it involved evaluating both their personal and moral values. The donors, through the process of saving their child's life, realized a bit more about what it was to be a parent, a family member, and a human being. The self-reflective process that occurred for the donors demonstrated to me that donors engaged in developing self-awareness that was rich in meaning and significance. This was made apparent through their discussion regarding personal and moral values, which will be further discussed in this chapter.

The experience of being a LRLD changed the way these parents viewed themselves. They engaged in a self-reflection that created a new self-awareness for them. The manner in which they viewed themselves as people, parents, and family members changed as a result of being a donor. One mother commented that becoming a donor may have been her purpose in life: "I wasn't afraid of anything for myself. I thought if this was what my purpose in life is meant to be, this is it!" The following two mothers reflected on their life with a sense of pride, because it was their donation that saved their child's life, one said, " I sometimes feel very proud of myself, because I could save someone." The other said, "The donation makes me feel proud, blessed." The mother that follows looked at her life as it compared to others and thereby created an awareness for herself that brought comfort to her: "Sometimes I feel really bad for my son, but then

I think about a whole lot of other kids who struggle more. Some children don't even have a good father." This last donor also illustrated a mother that experienced a change in the conception of who she was as a parent and a person. The self-reflection that took place for the next woman, as a result of becoming a donor, caused her to assess her value structure, and make sense of herself as a person: "Sometimes I wish I wasn't so strong, but I guess with my upbringing as well as the morals and values I have I want a bit more out of life that is why I don't give up so easily."

Identity is constantly being redefined and reconstructed as we develop as human beings. These donors were no longer just parents, but living donors who had saved their children's lives. As a result of participating as a donor for their child, it created a new lens through which the donor viewed his or her life as a parent. In the process of donating the left lower lobe of their livers to their sons or daughters, they questioned what their personal and moral values were. Although this evaluation process occurred in many ways, they described a common theme—that through their fears they determined what they valued in their lives. In our interviews they openly discussed their fears, and it was clear that each dealt with them in ways that were suitable for them. Their ability to face their fears and deal with a donation shaped their identity in a new way. All the donors commonly shared personal values like compassion, prioritization, commitment, and perseverance. Moral values they reconstructed during the process, pre- to post-donation, were related to such factors as spirituality or growing inner strength. Donors evaluated both personal values and moral values in an internal process that involved deep conversations with themselves about who they were and what they represented. This demanded that they attach new meanings to their lives and their families.

What follows are examples of how donors' values were reconstructed and how that contributed to the development of their new identity.

Personal Values

Compassion. The person quoted below described how becoming a donor opened his eyes to a different life, one that made him more compassionate towards others. It allowed him to realize his priorities and, in doing so, he came to appreciate others' life struggles. Thus, through the donation he reshaped his identity as a more compassionate person:

> The benefit is that I think that it opened my eyes to a whole different life. It just broadened about what life's all about. I think if something like this didn't happen, that I would never know what people go through. And it might have some people frightened of things like this. To me it makes me a little bit more compassionate towards other people who are going through things. I remember work, that people didn't understand the doctor's appointments and all. Until you actually go through it and live it, I think it really does make you realize your priorities in life. It does. It makes me a little bit more compassionate towards other people who are going through things.

Prioritization. It was through being a donor that the next participant learned that being present for his children should be a higher priority than jobs, toys, and games. This revelation caused him to recreate an identity focused on being present for his children. This was very different than the way he behaved prior to the donation. Prioritizing things in his life gave his life a new meaning:

> You learn some things about yourself that you may not necessarily want to know, but that's part of it. As a father, what you learn or what I've learned regarding the issue of being present in their lives. Being present is something I think men have a difficult time understanding because you get very busy with your jobs, your toys, and your games or things that, quite frankly, don't really matter much.

Commitment. The donation for one participant occurred over ten years before the interview, yet he made it clear that what he did for his daughter was nothing out of the ordinary, just part of parenting. He did not want people looking at what he did as heroic or to be credited with anything. In his opinion he simply put "his money where his mouth is." He felt that it was his role as a parent to participate in LRLD. His identity as a donor/parent was to do whatever was necessary for his child. He demonstrated a commitment to his child.

> They think that you are somehow doing something that's, out of the ordinary, and I have long maintained that it isn't anything out of the ordinary, of a parent. If you love your child and if you value the child the idea that old adage about doing anything for your children, that's kind of one example of putting your money where your mouth is. And so I don't look at it as anything heroic. I don't want to be credited with anything. I just want to move on.

Perseverance. Experiencing changes in his relationships led the following donor to transform his identity following the donation. He referred to the emotional aspects of the donation, stating that he felt mentally numb afterwards. Subsequent to the donation he experienced a divorce, lost his relationship with his father, and suffered a separation from one of his best friends. As a result, he built a new life for himself. He remarried, had two more children, and essentially recreated his family and his inner self. His identity experienced a significant transformation, one that required breaking bonds with significant family members and creating new bonds. He described feeling "numb for a while" which could have been related to the fact that his daughter presented overnight with liver failure, which was shocking for him. This donor, unlike any of the other donors in this study, had a child with fulminate hepatic failure, which required him to decide to be a donor within a 24-hour period. His daughter would have died within 24 hours had he not volunteered to be the donor. Seeing his daughter intubated and in hepatic coma may have contributed to this numbness he experienced.

> Mentally, the emotional scars are pretty strong. But a lot of those things you don't feel until a little while afterward, because you're numb for a while. Mentally you're numb. Mentally it takes away everything. By the end of the day I would come to my daughter and you know it was a great impact on my life at that point. It cleansed the mental state. Built a new life by recreating family and inner self.

The identity of the next donor was definitively stated in his narrative. Similar to the donor discussed above, this one demonstrated a relationship change that led to identity construction. He stated that he was more "mentally disciplined" than his wife. Whether that was true before the donation or after is unknown, but his mental stamina seemed to be a very important part of his identity.

> I think I am probably the more mentally disciplined, probably the more stubborn than she is. And I kind of look back at the situation, and although we agreed that . . . with everyone outwardly, that we made a joint decision, and we somewhat did, I kind of took the lead on it and just said: "You know you are here for the kids." Mentally I was prepared to do whatever I needed to do.

Moral Values

Spirituality. For some donors, spirituality was a significant component in the reconstruction of their identity. A religious affiliation brought confidence, strength, and security to their lives and allowed for meanings to develop from their experience. Those who had strong faith and religion in their lives had a security different from the other donors. They sought security in placing their trust in a higher power, which allowed them to feel proud and thankful to have God in their lives. These donors experienced another level of empowerment, one that developed from the control found in their faith. It was not a newly acquired faith; it was part of their individuality prior to their children having received a diagnosis of liver failure. Placing control of their children's future in the hands of God relieved them of fears about the future. God, for them, was powerful and could work in ways that were best for everyone. These donors, like the donors who did not express religious beliefs, became empowered. But for the non-religious donors their empowerment was newly acquired, either from within or from their interactions with family or community. Religious donors had religion as a source of support to use in desperate times such as these. The fact that these recipients did very well post-transplant may, in fact, have reinforced their religious beliefs. The following examples attest to these findings:

> I put things in God's hands, you know? That made me feel better and it gave me a lot of confidence. (Donor mother to son)
>
> I don't take credit for saving her life at all. I think it's all God. He saved her life, and you guys. It's all God. He saved her life and you guys. (Donor mother to daughter)
>
> It makes me feel proud, blessed. I don't feel like it is something I did, God has given me the strength; He has allowed me to do that. I feel proud and thankful, thankful she is fine and she will have productive life. (Donor mother to daughter)
>
> There was nothing that would change my mind. What happens if I don't wake up? She may survive and I may not, who will take care of my child? I had to take the chance. I took a chance, I am spiritual I knew God would not make it so I could not take care of my child. So, I had to have faith at this point. I didn't have a choice at this point. (Donor mother to daughter)

Inner strength by facing fears. When fears were discussed with donors, they seemed to come closer to understanding themselves and their identity. These fears as illustrated in the donor that follows, indicated that though his donation saved his child's life, he still feared that she may not live to do all she wants to do in life. However he gained a personal strength by the donation, as indicated by his second fear, which was reducing the long UNOS national candidate waiting list for organs. It was clear by this interview that his donation allowed him to experience an inner strength knowing that he did not take an organ away from someone who was waiting on the list, as well as it saved his daughter's life. Both of these fears as described by the donor that follows illustrated a newly defined identity.

> My biggest fear is that I'll outlive Tammy. I don't - I want her to continue on and have a happy and healthy adult life and marry, kids, whatever, college. Whatever she decides to do. But, my biggest fear is that she won't have enough time on this earth to do the things that she wants to do. That's my fear. My, my second fear is that we need to get more organs donated by the people that have the ability to do so, to get these kids and these adults off this list, because if those who would donate, do, this list would go away.

Fear for these donors was not associated with losing their own lives, but finding out that their livers could not save the lives of their children, that somehow their own livers would fail them and not save their children. Saving their child's life was of utmost importance. One articulated a fear that,

> . . . they would open me up, or open up Amy and then they would say, "I'm sorry. It's not gonna work." You know? And then they'd have to you know, wait for a cadaver anyway. That was my worst fear. It was it - they were gonna cut me open and then they were gonna say, "We can't do it." That was probably my biggest fear at that time.

Another said, "My biggest fear was her not surviving it and her rejecting, especially right away."

The data demonstrated that by living the experience of LRLD the donor developed a unique identity and moved along on the self-awareness continuum**.** This dynamic process required the individual to become involved in events that stimulated personal growth. These donors did not remove themselves from others, such as friends and families, while constructing identity. Neither the decision to donate nor identity construction occurred in a vacuum. It was an internal process fostered by outside influences and interactions with health care professionals, family, friends, God, and community. A heightened awareness associated with the decision to donate had a way of empowering donors. Through their empowerment they exerted/seized control of the situation, felt comfort, and gained security. As the evidence illustrated, donors' identities were transformed in several ways. Some became more compassionate, or reprioritized their lives, recreated families, strengthened religious beliefs, and better understood their fears. Combining self-awareness with the construction of identity shaped the transformational process for each of these individuals.

Family Clarification

Donors consistently clarified family dynamics, especially their relationships with their spouses, recipients, and other children. Family, for these donors involved pre-existing relationships that were brought into better focus and clarified as a result of the donation. Elements of the relationships that they already shared were re-examined through a new lens that the donation provided. This clarity created new meanings to develop for the donors in relation to their families. LRLD impacted not only their relationships with the recipient, but the family as a unit. Data used to support these findings begins with those pertaining to spousal relationships, followed by those with other siblings and, finally, those with the recipients.

Spousal Relational Clarification

Spousal relationships evolved in many different ways as a result of the LRLD. Parents arrived at the transplant center with spousal relationships already defined, yet the donation had the effect of adding stress to these relationships. Both the donor and the spouse were strongly involved in the process of living donation. While one undergoes major surgery, following the transplant, the other is left to care for both the spouse and the recipient. Findings of this study demonstrated that for some donors, spousal relationships thrived, while for others their relationships were challenged.

Of the 14 participants, three experienced divorce: one remained close to her family and ex-spouse, while the other two had very distant relationships with their spouses but claimed to be close to their children. The two who experienced fractured spousal relationships reported the spouse as not feeling a part of the donation process, and, as a result, harboring some resentment. All other donors described a spousal relationship that grew from the experience, and they felt their spouse played a role even more important than their own.

Clarifying intrafamililal relationships was important in order to better understand the impact the donation had on the donors' everyday lives and the meanings they associated with the donation. Ways in which spousal relationships evolved, as well as how meanings surrounding the concept of marriage developed as a result of the transplant, are presented in the following section.

Spousal Relationships that Were Challenged

The "Good Wife." One donor felt her relationship with her spouse was "OK", but shared a concern about how she should behave in order to maintain her role as spouse and continue be a “good wife.” She stated that, at the time of the decision to donate, her husband did not talk to her about their relationship, yet they both had a clear understanding about what was going to happen to them. Although the specifics of what “was going to happen to them” were not made clear, she felt that her husband did what was right during the post-operative period in the hospital, which was constructive. She perceived her role as behaving in a manner that allowed her to be a “good wife,” i.e., to be calm and to face things independently. This seemed to be the way she had always conducted herself in this relationship. She was doing her best to figure out how to maintain the “good wife” model she had lived by up until the donation. She knew that she could face all the responsibilities and stressors associated with the donation and was confident that by so doing she would meet the criteria of being a “good wife.”

> Like we are OK. Like in the sense our relationship, you know, he does not talk to me about. Otherwise we are OK. We know like what we are going to face and we basically know like what is going to happen. So he’s very nice actually. He took care of our son very well. He stayed in the hospital for a month actually. I should be calm and I should be able to face all those things. So that’s a good wife, you know.

The relationship needed to go. For one donor in particular, understanding his role as a spouse required that he take stock of his relationship and recognize that there were weaknesses and issues that had existed prior to the surgery. His child’s illness and the operation brought him to a place where he needed to clarify his spousal relationship. Through the process of donation it became clear to him that his marriage must end. This he perceived as a benefit of the donation. The transplant had a way of escalating the deterioration of the relationship he had with his ex-wife:

> My relationship needed to go. If anything, the transplant in some ways, the after-effects - they didn’t compound - they, they compounded a

> problem. But they also made it crystal clear that it was a problem, that I had problems in my marriage and problems in, in my relationship. The transplant pushed forward some things that needed to happen in terms of my own relationship or lack thereof with my ex-wife, and that was a benefit.

Resentment. One participant claimed that his spouse felt some resentment at the fact that he made the donation and then received credit for so doing. Her resentment, according to the donor, led her to become angry. He had neither intended nor expected credit for having donated, but her anger prompted arguments over "credit" and his ultimate discovery that their relationship prior to the donation was not as strong as he had wished.

> I think she felt as if she didn't get any credit for it. We argued a lot about the issue of credit, because I told her, I said, "I didn't ask for credit. I don't want to be credited with anything. I just want to move on." And she was upset because she felt as if people would just automatically give me credit for something, and she wouldn't receive any. And - I, you know, I told her that was something that was completely unintended or unexpected, given what we had gone through. But it - I knew it was something that bothered her a lot, and she was angry at me about it. [Laughs] It was resentment that moved toward anger later on. It expressed itself, you know, in ways that I had never imagined.

Later in the interview, this same donor described his own feelings of resentment and feelings of being left alone in the relationship following the donation. This example, juxtaposed with the narrative above, illustrates how both the spouse and the donor faced struggles and feelings of resentment in the relationship following the transplant:

> My ex-wife never took care of me. She essentially was taking care of my daughter. I was left to my own devices in terms of my recuperation. I did - I had a friend that was trying to, you know, come over and did this, but essentially it was up to me to do it. Does not do a lot in terms of making you feel like, like you're part of a family because in some ways it's almost as if - um - it - you know, I think I felt a little bit discarded really. Not, not so much that I was expecting her to, to fawn all over me. It's just that you - the rest of that process is, is basically alone.

The spousal relationships discussed above were challenged. They experienced difficulty engaging in open communication with their spouses. Their interactions required them to exchange fears and feelings pertaining to the transplant as freely as possible, but this posed a challenge. The spouse, in most cases, was left to care for both the recipient and the donor, which carried with it a great deal of responsibility. In some cases, like those discussed above, donors found new insights into their lives, for example, what being a “good wife” required, ending a relationship that was meant to go, or dealing with the resentment experienced by the spouse. All of these situations, and others described by other participants caused clarification to occur in the spousal relationship. Only two of the entire sample of participants described these shifts as causing a break in their marriage. For the rest the need to face challenges at the time of the donation and afterwards transformed the spousal relationship into something stronger and more meaningful after the donation. These individuals described mutual understanding and consistently open and respectful interactions with one another. Thus, the outcome of LRLD for the majority of donors interviewed was that their spousal relationships were strengthened, became more meaningful, and they became even closer than they were before donation. Connections that existed between donor and spouse before the surgery were helpful in fostering a strong relationship. Of the three couples whose marriages ended in divorce, two experienced a relationship that was distant and unproductive, and one described an ongoing, close relationship with her ex-spouse.

Spousal Relationships that Were Strengthened

The 11 donors who reported that their marriages thrived following the donation described having experienced more meaningful spousal relationships, based on the following: recognizing spousal needs, creating a friendship with their spouse, respecting their spouse, or developing a new meaning to their relationship.

Recognizing Spousal Needs. One donor demonstrated a special connection to his wife during the LRLD experience. He explained how his spouse could have benefited from some support pre- or post-transplant in order to help her adjust to having a child with ESLD who required transplantation. His narrative depicts someone not so much concerned with his own well being as he was focused on his spouse's. He recognized that nurturing was an integral part of his wife's makeup. This segment represents his commitment to his wife and his great concern about the emotional impact of transplant on her life:

> I think emotionally if I had the chance to look back at it again, the support unit that we should have set up for my wife should have been put in place, because she really did have fallout afterwards, probably more so that I anticipated. I know she still worries about it daily. I think it's something that is constantly with her. She's mentioned that many, many times. It doesn't go away for her. Subconsciously she thinks about, you know, when our daughter catches a cold, you know, oh gosh, here we go again, you know? And those type of things. And I think it's just the nurturing aspect of her that seems to be part of her makeup. But it stays with her.

Friendship with Ex-Spouse. Despite facing a divorce since the donation, another donor described having a very close relationship with her ex-spouse. She described being "good friends" with her ex-husband and their close relationship despite the divorce. She stated that the LRLD "had nothing to do with the divorce," that she still sees her ex-husband and enjoys quality time with him and their children: "We're still really good friends today. Yeah, so we're pretty tight. He comes with me to take her to the doctor, you know, he's at our house twice a week to spend time with the kids."

Respect. One donor described his relationship with his spouse as one of respect, admitting that her role in the transplant was just as difficult as his. The experiences of being a donor led him to gain deeper respect for his wife. He perceived that her role was even more important than the doctors'. In fact, at one point he commented to her that he felt he should get her a "white coat," but instead gave her an expensive gift to show his thanks and respect:

> I have probably more respect for my wife's ability to do what she did because it's absolutely true that her role in this was just as difficult as mine. I remember waking up about every hour that night as my stomach started to work, and I said to my wife, I said, "You know, you're better than a doctor. I'm gonna have to get you a white coat." And she didn't miss a beat. She rolled over and said, "No, I'd like a white [car] or a white diamond." [Laughs] So when we got back home - when we got back home, she actually got a [white] Porche.

New meaning. The following donor shared an example of how the donation strengthened her relationship with her spouse. She shared that prior to the donation her marriage was not very strong, but afterwards it was transformed for the better.

> Prior to the transplant, we weren't planning on staying married. So our life was kinda like I would sleep in the living room so that the other one could have the bedroom. And I know our daughter felt it, 'cause she remembers. Even to this day she talks about that. But now, when we got home, that first year home was really, really rough, and I didn't know that I was depressed, but we finally went for marriage counseling, and I don't know it if was a social worker, or whoever it was that saw us, referred me to a psychiatrist for evaluation and said that I was depressed and so put me on Prozac, so I was on that for a year, and that really helped to kind of improve our marriage a little bit. And we've come a long way since. We love each other like a lot, and our marriage is so much better, and I think we're going to maybe do a renewal ceremony, maybe next year, 'cause it'll be our ten-year anniversary.

The informant above admitted to suffering from depression for the first year following donation, but made clear that this was short-term. A year out of the transplant they shared a fulfilling marriage, due in part to the over-involvement of her father in decisions regarding the transplant. When her father overstepped in trying to take control of family decisions, she supported her husband. The transplant process allowed her to clarify relationships with both men and, as a consequence, allowed her to see that she could simplify her life and eliminate additional, unneeded burdens.

> My husband did not get along with my dad. I agree with my husband. I don't think it was my dad's place to be trying to tell us what to do. But my dad was trying to be the man of the house, and so it was - it was hard for me to be in the middle and I didn't feel like I needed that extra, I guess, burden, it felt like to me.

Donors interviewed articulated ways in which their spousal relationships evolved during the course of the transplant. Through the act of role clarification, three donors ended their relationships, while the others built on and further developed them. Whether feelings of resentment or feelings of respect resulted from the donation, spousal relationships transformed and donors were led to understand them with newly acquired meaning. Essentially they came to a place that may not have been reached were it not for the donation.

Relational Clarification for Other Children in Family

As reported from the perspective of the donor, other children in the family besides the recipient played a key role in the dynamics of the family system during transplantation. Nonetheless, for most families the focal points during a LRLD were the donor and the recipient. Finding time for them can be challenging. Donors were aware of the fact that the siblings were put in a difficult position. However, the majority felt that the donation brought their families closer together. Of the three couples who divorced, all described having close relationships with the recipient and/or their other children. They created new meanings associated with the concept of family during the decision making process. Deciding to become a donor required that they assess their family as a unit, and to realize that potentially it could lose two members as a result of LRLD. Through their interactions with family members, they clarified relationships, which was a transformative process for them. The narratives that follow illustrate how familial relationships strengthened as a result of the donation.

Family Bonds Strengthened

For the following donor the LRLD experience was not a question of whether there were differences in relationships between himself and his other children or between himself and the recipient. Instead, it was the family unit that became stronger as a result of the transplant. He perceived donation as an event that solidified his love for his family: "I think it [the transplant] really did solidify my love for our family, and what extent I would go through to make sure that our family came first."

Another donor felt that the transplant might have given his children more character and more strength. He described his children as having to stay with friends and neighbors during the time that he, his wife, and son traveled to the transplant center. Adapting to life without parents around allowed them to become more independent, one way this donor thought his children gained strength. It was important for him to know that his entire family, and not only himself and the recipient, benefited from the experience.

> Life isn’t smooth every day, so we just got through it each day, and I think, if anything, that will hopefully give our kids more character, more strength, and maybe just maybe, understanding that they have an incredible strength.

Family-Centered Care

For some donors, family branches out beyond the nuclear unit to the extended family, as was the case for the following donor. For many of the interviewees extended family played a key role during the pre- and post-transplant phases. Not only the donor and recipient, but the entire extended family, underwent the experience, and for them the transplant became a family-centered event:

> It probably brought us all closer, you know, because it’s like, I don’t know how to explain it. I would say it brought us all closer, being that we all know what needed to be done for her, you know, what we all went through. It’s not only our family. It’s like my mom, my grandparents, people who take care of her. It, it definitely, more than likely, brought us all closer after the transplant.

Strengthening bonds with other children in the family besides the recipient was an experience commonly shared by the LRLDs. Whether a family that had endured a divorce or a tightly knit family that included extended members, the donors mentioned that the process strengthened bonds they had already established with their other children. What brought family close was the shared experience of having a child in need of a liver transplant and a parent who could save a life. It was not an easy task to watch a parent and child go into the operating room for an eight- to ten-hour surgery, not knowing what the final result would be. Donors reflected that all members of a family felt the mercurial nature of this event, yet it was this that linked them together for a lifetime.

Recipient Relational Clarification

Several donors talked about experiencing relationships with the recipient that were stronger than typical child-to-parent bonds. Donors often described these bonds as "special relationships", and stronger than those they experienced with their other children. Donors claimed they shared something unique with the recipient that was explained by the fact that a piece of their bodies now lived inside their children. The relational clarification that led to a transformation in the donor's life involved dynamic interactions with the recipient that donors described as "overprotective," "more exaggerated," "a stronger bond than normal child to parent bond," or "a different type of relationship," illustrations of which follow.

Overprotective

Some donors described the issue of becoming overprotective during the interview process. All the donors whose responses appear below expressed feeling a bit more concerned about the welfare of the recipient and taking additional steps to protect this child. In most instances it was clear that the donor worried about the risk of infection for the recipient since he or she was immunosuppressed, unlike their other children. This fear translated into a relationship that was more watchful and protective of the recipient:

> I'm a little more paranoid when it comes to Leigh [the recipient], especially going to school, I guess with the hand washing, making sure she eats well, you know? I am a little more paranoid with her that I am with my son. But that's all I think. Just because I know she has the transplant and we have to keep her healthy. (Donor mother to daughter)

Another donor said:

> I'm just worrying about what's going to happen to him. Even if they get a small fever or even if they get a small cough or cold, even if they get

> injured, we worry so much, because you don't know like, if it's going to affect them. (Donor father to son)

A third donor remarked:

> We are very close. I was very protective of her. When she got sick, I started becoming very protective - we have a really great bond. She tells me, "Oh, don't tell Daddy, but I love you more. I mean I know she loves him too, but it's really a special bond that we have. (Donor mother to daughter)

Another donor claimed that she was more protective of the recipient than of her other children. She felt that having a piece of her liver inside her daughter brought a connection between them that was not present with the other children. It was this shared tissue, what she called a "piece of mine," that created the special connection and caused the donor to pay closer attention to her daughter. She experiences a constant feeling that she must keep an eye out for the recipient:

> I'm close with all three of them. I know I'm more protective of Celine [the recipient] that everything she does is always in the background. What do I need to keep an eye out for? So I am probably a little closer because I know that's mine in there. That it's my liver. I don't think I'd be any less distant from her, but it's nice, it's a nice connection to have. But I can say, "That's mine in there." Well, not mine, but a piece of mine.

More Exaggerated

Comparing the sibling with the recipient, this father claimed that the fear factor he attached to each is much different. He described the relationship with the recipient as "more exaggerated," perhaps because he, unlike the sibling, is a transplant recipient and at risk for a number of life-threatening complications. This fear changes this father's relationship between himself and the recipient and himself and his other son: "I don't have that [crying] same fear with the sibling. It's different. I mean I have the usual fears for him, but not - it's, I guess, more exaggerated with the recipient [still crying]."

A Different Type of Relationship

The following donor felt that he and his wife had "circumvented the system" by using a living-related donation for their daughter. As a result, the way in which they interacted with her became a bit different than it was with their other children. According to the donor, the recipient was living a life different than her siblings because she had a "39 year-old piece of liver" inside her, which created a different type of relationship:

> Now, the boys, if something happens, you know, God's will. For Sally [the recipient[we know that we have circumvented the system, so to speak, a little bit, because we've taken a 39 year-old piece of liver and plopped it into her, so yeah, it's [the relationship] a little bit different than with the boys. It's a bit different. It's a bit different.

Another donor characterized his relationship with the recipient as more like "brothers" than father/son. He was very candid in discussing his relationship with his son, who was 18 at the time of the interview. He said they were "liver brothers" who competed their way to recovery, mentioning specifically their having fought for the first bowel movement. His remarks represented a close relationship fostered by competition. He and his son had shared the transplant together and celebrate the day every year:

> We have a very close relationship, different than our other children, because we're, you know, we're liver brothers. And so, you know, we celebrate December 20th each year as our liver anniversary. But I think it made us feel a little bit different than father and son. It was a little bit more like brothers, because we're kind of on the same plane in some ways. I mean we've gone through the same thing together at the same time. We've both had the same kinds of risks. There was a certain amount of competition as we were recovering, because I remember we both were, you know, looking for that first bowel movement.

During the immediate post-operative period this same father experienced some clinical complications that required him to stay in the hospital longer than the recipient. His son expressed some guilty feelings regarding this situation and felt somehow responsible. The relationship evolved during this post-operative period, as the following narrative illustrates, as the donor took control of the situation and made it clear to the recipient that his extended hospital stay had nothing to do with him. This type of conversation was enriching for this father/son relationship and took it to a new and deeper level. It was not that only that "liver brother relationship," but more a father reassuring his son that he was not responsible for his clinical set backs. This relational clarification created space for this donor to define his relationship with his son on a different level.

> Men are probably not the best communicators in the world, but that's what I was trying to do. I want to just get him to know that this wasn't his fault, that it wasn't his responsibility that this was something that I had decided to do, and that we were going to get through it, no matter what. Even though at that - if at that moment it wasn't working, it would work. It just was a matter of time.

A Stronger Bond than Normal Child-to-parent Bond

By listening to the recipient, one donor concluded that she and the recipient share a unique bond. She described sibling relationships among those who do not experience living-related organ donation as the "norm" and her relationship with her recipient daughter as "more than the norm." This indicated that something happened to the donor and her relationship with the recipient following donation that redefined it.

> Things that she does, things that she says and things that she tells me indicate that, we have this enormous bond that's a little bit more than the norm. She knows that her mommy has done something extra special for her. I think that's why she is so clingy. I think she would have been close to me without the liver donation, but not as much probably.

In confidentiality, another donor stated that she considered the recipient her "favorite" child. Although she tries not to give that child more attention than her other children, she insisted that she had a special relationship with the recipient:

> I try not to spoil her [the recipient] too much and give her too much of the attention 'cause, you know, we have two other boys still in the household, but since this is confidential, I'll tell you she's my favorite.

Summary of Family Clarification

Donors clarified the family unit as a result of the donation, as they did their spousal relationships, their relationships with other members of their families, and their relationship with the recipient. All of these shifted as a result of their being donors. The one outcome of the donation experienced by all donors was that the concept of family gained a new meaning than what it had possessed prior to the transplant. In terms of the spousal relationship, for only two donors this evolved into a more distant relationship, but the other 12 described their relationships becoming stronger. All donors, even those whose marriages ended in divorce, felt the donation strengthened bonds with other children in the family. The relationships donors experienced with recipients were very dynamic. All expressed sharing stronger bonds with the recipients than with their other children. Whether that was a result of their becoming more protective of the recipient due to the transplant and the immunological risks that are associated to the transplant, or whether it was the fact that anything that happened to the recipient became more exaggerated since the transplant, or because by giving a piece of themselves to one of their children they created unique and, in some cases, stronger bonds with them than their other children—all of these situations caused shifts to occur in the recipient relationship.

These familial relationships involved powerful interactions that required effective communication among all members.

Changed Perspectives on the Meaning of Community

While community carries different meanings for different people, during analysis of donor interview transcripts, the definition of community that developed was a group of individuals in the donor’s neighborhood, workplace, hospital, or friendship circle who were connected by living through something extraordinary together. These groups of people assisted the donor and family during all phases of the transplant process and, as a result, changed these interviewees’ perspectives on what community meant and how it impacted their lives. Those interviewed revealed a more acute awareness of community, specifically how it provided support and comfort to them and their families’ pre- and post- transplant and how it also left them with a strong desire to give back to their communities. This final section of this chapter focuses on how the donors’ views of community changed during and following their donation.

Defining Community

In the interpretive process that transpired when analyzing the transcripts, it was found that community took on a whole new meaning for the donors from the pre-donation phase to post-donation. Not only did they create new perspectives on community, but their role in community was made clearer and more definitive following the donation. Community had the ability to shape their lives based on the way in which they interacted with others and associated themselves with others *vis a vis* their individual belief systems.

Community played a very important role for them, as it provided support and comfort to them and their families in ways that had not been demonstrated in the past. Though each traveled a long and different road in discovering new meanings for community, they all reached the same outcome, which was that community provided comfort and security, and left them with a desire to give back.

The narratives that follow are divided into three broad areas: definitions of community for the donor, the ways that community worked for the donor and new perspectives on community that left donors with a strong desire to give back.

Definitions of community. Donors defined community in a variety of ways, yet they reported that community included individuals from different circles of their lives who had experienced an aspect of the donation with them. One donor mentioned below exemplifies how broad the definition of community can be and how many different groups of people may be encompassed within it. Families often defined community as including personal ties through relatives or friends and professional ties through their own work place or the transplant center staff and providers. She became more aware of the power community had on her life when she became a donor. She described how people worked together when others needed help, which surprised her, and that even people who did not know her well would rally for a cause. The hospital community became her second home:

> We had a community of family, people coming to help us out. We had the community of the neighborhood, the parents at the preschool, and the community of [transplant center]. The parents at the preschool formed a dinner brigade and said, “We’re making you dinners. When do you want them?” It was a nice surprise from the community because we didn’t feel like we know some of those people that well, but it didn’t matter to them. Just somebody needs help, they all rallied. And we helped them back.

> The [hospital[community we're still giving back to. It's been a great community in all the ways you know, I just walk in there, and it's like it still feels like home. Good and bad.

Community for several donors was defined by a group of friends and neighbors. This donor became very tearful when reflecting back on the time immediately following the donation and the significant role his neighbors, school, and 4H group played in his life. He sensed a genuine desire to help that brought him to a better understanding of his community:

> Different people in the community that knew we were just remodeling our kitchen when he was sick, and they came in and, you know, finished it [cries]. For us. These people within our community fed us all for like six months. Every night they would bring food to us. That was good. [Crying] So we have a good community that, you know, some have known our son ever since he was a baby. I think people want to help. We have you know, we're very active in our 4H and school, and it really helped us. It really did.

Community for the following donor seemed to be everyone from friends to family, anyone who came forward and asked what they could do to help.

> We had friends, family, everybody pitching in to assist. Everybody. There were a few people that instantly distanced themselves from us very quickly when this happened. But by and large most of the people came forward and said, "What can we do?"

In the following example, community was defined as a group of individuals whom the donor barely knew, but who pitched in and rallied for her and her family. Community involved individuals who simply wanted to help. She greatly appreciated their acts of kindness.

> Many members of our community were strangers to us, yet they all rallied together and, you know, it made us feel very humbled, but grateful because we really needed that support for our daughter. So I never did see that before, the way they came together for us.

Friends, family, people from school, social clubs, neighbors, healthcare providers, and anyone who shared in the life saving experience of LRLD defined community for the donors in this study. Extraordinary people looking outside their own busy lives to offer support and security defined community for these donors.

Ways community worked for the donor. Not only did donors change their perspectives on how community was defined, but also they constructed new perspectives about how community worked for them as a result of the donation. The donor whose narrative follows experienced a community of family, neighbors, and work associates, all teamed together in caring for him and his family. They all gave their time and energy to make the transplant experience more positive. Through his experience as a LRLD he became more aware of how community worked for him and taught his family the way community is "supposed to work." This pleased him because his children were able to witness it. "I think it was a good experience for our other children to see how a community is supposed to work, how friends and neighbors are supposed to work, how parents and children are supposed to work."

Another donor described community as his co-workers. Particularly one individual, the president of his company, took an hour and a half out of his day to be with him in the hospital. Though this may not be the way in which all companies' presidents work, it demonstrated a model members of a professional community can emulate in supporting their employees. This type of concern from a colleague and professional superior meant a great deal to this donor and left a lasting impression. Though he was only one person, he represented a larger community, which was his work, and symbolized how community should work in times when people need assistance:

> People who were down in the [transplant location] on business came by. My manager from my, actually the president of the company I worked for at the time, located in [this area] , came out and spent probably about an hour and a half talking to me in the hospital, which you know, an hour and a half for a visitor at a hospital is an eternity.

This donor described community on a business level, demonstrating how companies like Alaska Airlines can work together with customers in times of need. He realized that large companies could work to help you even if you did not work for them:

> There was community on the business level. For example, Alaska Airlines was extraordinarily great in helping us set up airfare to and from [this area]. They gave us employee discounts, they gave to us as if we were flying as an employee of Alaska Airlines, so we just had to pay the taxes. They moved the flight; they moved the seating around so we could get on flights that we couldn't get on. They were incredible. So, as a corporate part of the community, they were very, very, very good.

Giving back to community. As a result of these newly acquired perspectives on what community is and what is supposed to do, donors emerged from the process with a strong desire to give something back to the community from which they had received so much. One donor's eyes were opened to the power community can have on one's life. Giving time to help, to lend a hand to a neighbor, is how community should perform. This is what leaves a donor with a desire to give back. Community is a circle in which all its members can benefit, an excellent example of the saying that "what goes around, comes around":

> The donation did open our eyes to do something to reach out and to pick your neighbor up, that kind of attitude and we knew right after the donation that we were now responsible for putting something back into the kitty.

For this donor the "kitty" represented the community.

Some donors became very involved with transplant support groups following the donation. They felt a need to share their stories, with the goal of helping others undergoing a similar process. The need to give back to the community is apparent in the following statements by two of the donors interviewed:

> We talk about the transplant, we've done a video for the Liver Foundation and . . . it's a pretty good video. I was very impressed with what the editor did with what we gave him. They did a really good job.
>
> We volunteered often to be someone that a potential candidate could call and just get some information. There were a few people that we called before it and we want to be able to let people know how it went for us, because we were one of the positive outcomes, and we felt very happy and excited that it worked well and that, you know, it was a successful proposition. And so we've done that for the American Liver Foundation.

The following are comments made by one of the first living-related donors on the West Coast, who described how his donation contributed to transplant science and, hence, society and the community. He hoped that through his experience as a donor he could inform potential donors that living donation is a viable option for treating children with ESLD. He was giving something special back to his community:

> They had only done 60 total [transplants], so this was '93, so this was all in its infancy. So I feel kind of nice knowing that we were involved in something special back then too, not just for ourselves, but for all those other living related that were gonna come after us, and to know that it works, and that these families have options, and they just don't have to say, you know "It's a 50-50 crap shoot." You know? It's a 90 percent success rate now!

Community for the following two donors was found with other families undergoing the same process. By talking to other families they discovered a sense of community and comfort, avenues to network and to create relationships:

> Well, at first I met another couple that also did living related up at (the transplant center), and we became pretty good friends with them, and we

> stayed in touch for years many years. And so that was really good ‘cause we could bounce stuff off of each other.
>
> I have - you know, I have a pretty good group of friends in our community. We talk to them and you know we’ve had calls from people. Our name’s still out there. So once in a while I’ll get a call from somebody, you know, going through it. And want to talk, which is really cool.

Health care providers as community. There were a few respondents in this study who found a sense of community within the hospital setting. The examples that follow illustrate how donors found comfort and support within the community of doctors and the transplant team members. They found comfort and support in the faith, trust, and information the transplant team was able to provide to them pre- and post-donation. They thought this was how the community of health care professionals should and did work for them and their families:

> If I didn’t understand something, we were going to discuss it and make sure that I did understand what was going on. Dr. C was very thorough, he’d get a piece of paper or a napkin, and he would draw me a picture and show me exactly what’s connecting and where it’s going, and he really did put the information out there so that you could ask the questions. He didn’t leave too many things out for you to ponder about. (Donor father to son)
>
> We got some information from our gastroenterologist, but most of the information, love, and support came from the transplant team. (Donor mother to daughter)

Two donors mentioned that their relationships with the social worker played a significant role during the transplant experience. Transplant centers have a moral and ethical responsibility to evaluate potential donors for suitability as well as to understand their reasons for donation. The particular social worker described was responsible for screening donors prior to the donation in order to clarify their motives for donating. The two interviewees were impressed with the social workers' job efficiency. Like the other members of the transplant team, these professionals functioned as part of the donors' community, shared their experiences of the process, and even had the power to prevent a parent from donating. These narratives illustrate how the community of social workers did what they were supposed to do:

> I can't remember her name, but she was particularly good. And only during the interview did I realize that, oooo, this is the gatekeeper. This is the one we have to get past. We had our ducks in a row and we were ready to go. So I think that's probably the biggest thing that I remember about this whole thing, is that it was a spectacular event. It was wonderful. And still is.
>
> The social worker really grills you. She asked about my parents, his parents, my husband, the family, the doctors, and who asked you to donate? Who's pressuring you and who's - you know. She was really good at finding out like if anyone is making you do this.

The following donor discovered community within the walls of the hospital in a family care program, offered at one of the transplant centers, which focused on the needs and welfare of the whole family and not merely the individual patient. The program provided this donor and his family support and comfort during an extraordinary experience, and also a vehicle for establishing ways to help other families deal with children diagnosed with ESLD. Through this program, he met with families and spoke to them about donation in hopes of increasing awareness in the hospital community. He also wished to continue community outreach subsequent to his experience as a donor:

> Speaking to people about donation, helping with the [family program] really did open our eyes to the fact that it's just not us in this little old world, that there are other people out there that need help. And the experience that we went through, hopefully it helped some other people get through it a little bit nicer and a little bit easier, so that was our goal.

Community, what it means, how it works, and the impact it can have on their lives were all well articulated by the donors in this study. Their perspectives on what defines community varied, but all believed that their community consisted of individuals who actually experienced the donation process with them and their families. How community worked for them differed among the donors, yet in all cases they were left with a desire to give back, not just specifically related to the LRLD community, but to their general communities when someone is in need. The overall outcome for these donors was that they developed a more acute awareness of community and the impact it can have on their lives. They concluded that community provided them with support and comfort during both the pre- and post- transplant phases. Frequently they learned a great deal more about their communities than they realized before the donation, and the dynamic interaction amongst members of their community allowed them to develop new perspectives and a stronger appreciation of what community stands for in their lives.

Summary of Findings

Findings from this ethnographic study suggested that LRLD has a multi-faceted impact on the donor. Transformation is the overarching theme that emerged from the data, analysis of the interviews, and the field notes. The donors changed structure in reference to themselves, their relationships with their families, and views of their community. As uniquely different as these are, all share common transformational experiences. The donation allowed them to gain control over a very uncontrollable situation and to develop a better understanding of a new identity as living donors. Their familial relationships were remodeled as a result of their becoming living liver donors.

They attached new meaning to the concept of community that drove them to give back to their communities. All of this combined creates a substantial body of knowledge from which potential donors, transplant professionals, and the general public can gain insights into the everyday life of the LRLD.

CHAPTER VI

DISCUSSION

The overall aim of this study was to better understand the impact LRLD had on the physical, emotional, and familial lives of the donor. This chapter will discuss and summarize the study findings, relate them to the research question and current literature. A comparison between these findings and the current literature on living organ donation will be presented. The theoretical significance of the study will be discussed as well as limitations found in the study. Finally, clinical implications and future dimensions will be shared as a conclusion to this chapter.

Study Conclusions

Findings of this ethnographic study illustrated that living related donors experienced a life-changing event, which was perceived as being transformational. Transformation is a concept of interest to various types of researchers, clinicians, and scholars. All 13 participants in this study perceived their life following the donation as being transformed, this included changes that transpired at the individual, family, and community levels. Donors became more self-aware which had the affect of empowering them as it provided them with a sense of control over the donation. This self-awareness also caused donors to construct an identity that was different than the identity they possessed pre-transplant. This new identity required donors to evaluate their personal and moral values, which created different meaning to their life. Following the donation, donors were not only parents, but also individuals that had saved their child’s life. It was by risking their lives, that parents were given the opportunity to save their child. Family dynamics were clarified as a result of the donation as well, specifically relationships the donors shared with their spouses, the recipient, and their other children. One of the most poignant findings of this study was that donors gained a new perspective on community and developed a desire to give back to their community as a result of this transformational experience.

Self-awareness

Empowerment, control, comfort, and security were common feelings expressed by donors in this study in relation to the category of self-awareness. The participants found that the control they acquired from the decision to donate assisted them in managing the overall process of the donation. It was the control found in the decision to become a donor that comforted them and allowed them to feel that their decision to donate was the right one. They held the key to the cure for their child, and by participating in donation they did not have to wait for a cadaveric liver to become available. Together with the surgeon, the donors decided when the donation would take place. Becoming a donor rid them of the unpredictability of cadaveric donation and led them to feeling secure about the donation, as they knew where the organ was coming from. Donors did not have to concern themselves with the uncertainty and inherent risks of transplanting a liver into their child from someone they didn't know. Data from this study indicated that donors experienced an identity construction which involved evaluating both their personal and moral values. The donors, through the process of saving their child's life, realized a bit more about what it was to be a parent, a family member, and a human being.

Family Clarification

The parental donors in this study revealed that the donation impacted their family relationships and caused them to clarify existing relationships, specifically between spouses, and with the recipient, and their other children. The most profound change in relationships described by donors occurred between themselves and the recipient. There was a special bond described by all of the participants that was stronger than the bonds that they normally shared with their other children, however much they loved their other children. The bonds that developed as a result of the donation were dramatic, and as a result, left the donors feeling more protective of the recipient than of their other children. This closeness was in most cases a result of knowing that they had saved their child’s life and knowing that the recipient was more vulnerable than their other children, and because it was a piece of themselves that lived inside their child. Also, the recipient, unlike their other children, could reject the transplanted graft at anytime which may have played a role in the overprotective nature of the relationship between the donor and the recipient.

Spousal relationships for 11 of the donors, strengthened as a result of the donation. Three couples divorced since the donation; one stated she was as close to her ex-husband after the divorce as she was before; The other 2 donors reported the relationships with their spouse dissolved following the divorce, and of the 2 donors that experienced fractured relationships. One felt that having a child with a chronic illness might have contributed to the separation. The other stated that the donation helped to move things along in the relationship, and that they would have most likely separated, regardless of the transplant.

Community

Perceptions of community for donors following the donation became richer, and touched their lives in a unique way. Each donor expressed a view of community that was different than prior to the donation. Whether community consisted of neighbors, friends, church groups, health care professionals, or colleagues from work, and sometimes strangers, these individuals comprised a community for donors that had the unexpected ability to smooth the road they traveled as a parental donor. Dealing with a child in need of a liver transplant, as well as deciding to become a donor was challenging for families. Having community to share in the responsibilities of taking care of other children in the family, cooking meals, finishing a kitchen re-model, or just listening, all supported the donor in tangible ways. As a result of this community involvement, the donors felt a desire to give back and make contributions to their communities in return for what communities had done for them.

Findings and How They Related to Aims of the Study

The findings presented in this study only partially answered the initial research question, which was focused on the physical, emotional, and familial lives of donors post-donation. The data addressed the emotional and familial impact the donation had on the donors, however, the physical issues were not a main focus of the donor during the interviews. The donors were much more interested in sharing information regarding their relationships with self, family, and community than discussing physical concerns. Though 5 of the 13 donors interviewed described having physical complications following the donation, surprisingly it was not something they felt inclined to talk at length about.

All 5 donors who suffered from clinical complications following the donation are currently recovered and have returned to their former level of physical health. These donors at the time of the interview had healed completely and their focus was no longer on their physical problems. The lasting effects of the donation seemed to be rooted in the areas of self -awareness, family bonds, and their desire to give back to their community. It was these areas that donors wanted to discuss and share, not the physical issues that seemed to be a part of the past and not a current health issue.

Findings and the Current Literature

In comparing the findings from my study with the current literature, a gap that was present in the research is now partially addressed. This study was one of the first ethnographic research studies that focused on the long-term psychosocial effects of living related liver donation. Semi-structured interviews were used to better understand the everyday life of the LRLD. In addition to reviewing the literature that actually addressed the impact a living donation can have on a donor's life, since this research is limited, the literature review that follows branches out into related areas including pediatric transplantation, caregiving for children with other types of acute and chronic illnesses, as well as general nursing research. A comparison was drawn between what is currently known regarding the impact a child's chronic illness can have upon parents and findings from my study.

For the donors interviewed in my study, the impact the donation had on them was that it transformed their lives. This transformation occurred on three different levels: personal, familial, and community. It was through engaging the literature that I sought validation and better understanding of where my findings fit with, extend and challenge the current knowledge. The following discussion will begin with a presentation of the literature as it applied to the concept of “transformation”, followed by a review of the current literature pertaining to the three major categories developed from my data which were “self-awareness”, “family clarification”, and “new perspectives on community”. Each of these areas will be briefly discussed followed by a comprehensive summary of the caregiving literature for children with chronic conditions and how it pertained to or challenged my findings. Databases used for this literature search were Medline, Ovid, PsychInfo, CINAHL, and Cohrane.

Transformation

The over arching theme of “transformation” has not been used in current literature as a way of describing the everyday life of the LRLD, yet other transplant researchers have found that families and patients faced with the option of transplantation did experience changes in the self and family (Baines, Beattie, Murphy, & Jindal, 2001; Crowley-Matoka et al., 2004; De Villa V., Lo, & Chen, 2003; Forsberg et al., 2004; Higgins & Kayser-Jones, 1996; Higgins et al., 1996).

Transformation in its simplest form can be viewed through the metaphor of a caterpillar developing into a delicate, beautiful butterfly. The changes that exist for a butterfly require a transformational process to occur from the basic larva stage to pupa, and finally to a butterfly. Another example of how transformation exists in our world on a daily basis is the transformation of sunlight into electrical energy. This transformational process of converting the sun’s rays into useable energy involves extensive physical transformation.

Spiritual transformation has been described as the acquisition of a unique relationship with spirits or Gods (Koss-Chioino, 2006). Koss-Chioino, a psychologist, studied spiritual transformation and how it affected individuals. She developed a model to better understand the process of ritual healing that focused on key components of spiritual transformation, relatedness, and empathy. She posited that spiritual transformation involved a kind of learning that created an inter-subjective space in which individuals can enter into an intimate relationship with each other. She reported that with spiritual transformation there was a general pattern that existed, which led to less suffering to and resolution of crisis. The individual experiencing this transformational process in her study reported a change in their identity, social position or worldviews. In my study, the donors may or may not have experienced a complete “spiritual transformation” as described by Koss-Chioino, however they did describe that the donation resulted in marked changes in their life and they claimed they entered into a new closer relationship with the recipient. The donor traveled from a point of suffering (having a child with ESLD) to a point of resolve, which according to Koss-Chioino was one phase of spiritual transformation and may have created the spaces she found facilitating the clarification in family relationships and identity growth we both described. For the donors and the individuals that experienced spiritual transformation, both had profound self- awareness processes occur.

A rigorous study by Crowley et al. (2004) demonstrated that the long-term consequences of parental liver donation left donors feeling undervalued after the donation, and many of the donors felt they did not have a free choice in making the decision to donate. These donors expressed a continued stress associated to the financial responsibility and health care demands of being a donor. Crowley et al. illustrated that for many of the donors, the demands associated to the recovery of the recipient may have postponed their psychological recovery from the donation. Though this was not labeled as “transformational”, the donor did in fact experience uncertainty about the decision to donate, faced financial hardship following the donation, felt undervalued, and had difficulty returning to normalcy after the donation. All of these factors combined could be viewed as transforming their lives and changing the way in which they lived the everyday.

Similar to the findings reported by Crowley et al. (2004), Forsberg et al. (2004) demonstrated that parental liver donors suffered in all possible ways, physically, mentally, socially, and spiritually. She identified three categories leading to the central theme that was a struggle for holistic confirmation, these categories were: The total lack of choice, facing the fear of death, and the transition from health to illness. Again these factors combined could be viewed as transformational, as they portray the donor experience as being a struggle. However, it is important to note that the donors in my study did not describe these same negative outcomes. In contrast they were overwhelming certain that they had made the right decision, described few financial difficulties and had resumed a satisfying life following the donation. Providing explanation for these differences is difficult, however it was clear in my study that the donors in my study came from high socioeconomic status; this information was not available in either Crowley et al. or Forsberg et al. studies. Age and education may also have contributed to the differences in study results, but unfortunately this information was not available in the other papers.

The concept of transformation has been incorporated into current nursing research. Shu, Lo, Hsieh, Li, and Wu (2006) found that mothers who were primary caregivers of autistic adolescents experienced a process of self-identity transformation. Shu et al. identified four themes that emerged through stories told by mothers living with autistic adolescents. These were: relationships revisited; self-awareness inspired; reconnection constructed; and self-identity formed. This process of self-development occurred through social interaction that was constituted and reconstituted through several different mechanisms. It was described as being dynamic and interchangeable. Shu et al. found that by transforming their identity, these middle-aged women revisited their relationships with their autistic children. The four themes outlined above, were quite similar to my categories of self-awareness, and clarification of familial relationships. These women experienced life transformations similar to the parental liver donors, as they both experienced a richer understanding of their self-identity in relation to themselves and their families. These women, like the donors, discovered the importance of connections with others, specifically their spouses. Though this study was focused on women and did not identify any connection between the mother and the community, as did the donors in my study, it did describe a similar transformational journey that may be traveled by not only LRLDs, but also individuals struggling with families and chronic health conditions.

Informed by Margaret Newman’s theory of Health as Expanding Consciousness, Jane Neill (2002) conducted an interpretive study focused on life patterns of women living with rheumatoid arthritis. She found that personal transformation revealed a transcendence of self-boundaries that offered these women new ways of living. These transformations could be appreciated as specific processes that individuals used in order to see situations differently and to make decisions accordingly. Neill recognized that by understanding health as the expansion of consciousness she was able to understand unique life patterns that existed for these women suffering from chronic illness and it allowed them to seek meaning in the context of wholeness. The LRLDs as illustrated in my study, transformed in a slightly different dimension than the women described in Neill's study, yet like her participants, the donor experienced change in their lives that brought new meaning and represented a change from one identity to another.

Carpenter, Brockopp, and Andrykowski (1999) conducted a study on breast cancer survivors and developed three categories of transformation as a result of their analysis. They identified positive transformation, minimal transformation, and feeling stuck. The positive transformation group presented with higher self-esteem and well being in comparison to those survivors in the minimal transformation group or the feeling stuck group. Carpenter et al. described the process of self-transformation as involving a redefining of the self within the context of having cancer. This was similar to the aspects of transformation found with the LRLD. Though the LRLDs were not battling a life-threatening illness, they were voluntarily subjecting themselves to a life-threatening surgery and did define the self with a new identity within the context of being a donor. As described by Carpenter et al., these cancer survivors went through a process of increased awareness and introspection, a process similar to the LRLDs. Findings from this study support the idea that self-transformation may play a role in the self-esteem and well-being of the individual, which overlap with the findings of transformation found in living donors' everyday life experience.

These researchers used the concept of transformation as a way of describing life patterns that resembled the LRLD. Whether it was living with an autistic adolescent, dealing with rheumatoid arthritis or surviving breast cancer, these studies described a process of transformation that had some similarities with that experienced by living liver donors. These individuals like the LRLD were all forced to reassess their own lives as parents, spouses, patients, and community members in the course of making important decisions and taking actions to manage the life changing chronic condition..

Self-Awareness

Self-awareness was made apparent in my study in two specific ways. First, the decision to participate in living donation versus waiting for a cadaveric donation empowered donors because it provided them the capability to better control the circumstances involved in saving their children's lives. Second, becoming a living-related donor influenced the construction of their identity by looking carefully at their personal and moral values.

Decision-making, Control, and Empowerment:

The decision-making process for the donor provided them with a sense of control and empowerment. The donor no longer had to think about waiting for a cadaveric donation, and together with the surgeon could decide the date and time of the transplant. The decision to choose live liver donation required the parents to digest information given to them by the transplant team and weigh it against what they felt was the right decision for their family. As a result of this reflective process, these donors constructed new identities that involved both personal and moral deliberation.

Current literature does support the idea that the method in which medical information is disseminated to families of children having to make decisions regarding transplantation can seriously impact the life and therefore the identity of the decision maker. By observing physicians' initial presentation to parents of children in need of cardiac transplantation, Higgins, Kayser-Jones, and Savedra (1996) demonstrated that the medical consequences of cardiac transplantation were adequately addressed by the pediatric cardiac transplant team yet very little information was given to parents regarding the non-medical issues. These non-medical concerns included issues such as the psychological, social, and financial implications that affected a family faced with a child that needed cardiac transplantation. The psychological and social concerns were a primary focus to the donors interviewed in my study, and were aspects not currently part of the evaluation process for living donation for transplant centers (Abecassis et al., 2000). Gathering the necessary information and making the right decision in regards to pediatric transplantation forced families to come face to face with their identity as parents and in some cases as donors. In comparing Higgins et al. findings to my study, I concur with their conclusions that the non-medical issues must be presented to families and patients in order for the most educated decision to be made by families.

Guilt, associated with refusing to donate, feelings of abandonment and isolation, experiencing a total lack of choice, facing the fear of death, and dealing with the transition from health to illness were not among the findings in my study as they were for Forsberg (2004). Struggles for the donors in my study included issues related to the act of taking control in the decision making process, specifically making sure the timing of the transplant was clinically appropriate for their child. There was one donor that expressed feelings that the decision to donate was a “no brainer” and it was his obligation as a father to donate, however there was no mention from him of feeling guilty if he did not decide to donate. This same donor expressed feelings that he was “left to my own devices in terms of my recuperation”, and he experienced a sense abandonment from his wife, father, and best friend, however this was not the same level of abandonment from the medical team as described by Fossberg (2004). This same donor did mention in his interview that his divorce with his wife would have occurred whether or not the donation took place. Despite the data from this one donor, the 12 other donors in my study produced findings that paralleled those findings of Renz and Roberts (2000) who found that none of the donors they studied felt abandoned during the donation process, and all of the donors expressed satisfaction with the pre-donation information given to them.

The concept of control was a finding in my study that developed from the category of self-awareness. Control was not mentioned in any of these other studies as playing a part in the donor’s participation in LRLD. The concept of comfort was also a finding in my study yet similar findings were apparent in Singer et al. (1989) who discovered donors took comfort in knowing that they did everything possible to save their child. Grenwal et al. (1998) and Russell et al. (2002) presented research findings that showed that there were theoretical immunologic advantages of receiving a living related organ. This was not addressed in my study, however, many of the participants suggested that by donating their organ, it eliminated the mystery associated with cadaveric donation and they believed that immunologically, it provided their child with the best option available. The benefits of donation were discussed in research by Cotler et al. (2001), Singer et al. (1989), and Trotter et al. (2002), all of whom reported that one of the most important advantages to living liver donation was a reduction in waiting time for the patient. This finding was also identified in my study, but it not only provided the donor with reduction in waiting time, but it allowed the donors to decide with the surgery team the best time to transplant based on the child's clinical status. This decision gave the donor increased control over a very uncontrollable situation.

Empowerment was not described in the literature as developing as a result of a decision-making process as was the case in my study, however Gibson (1999) demonstrated that the process of empowerment for mothers of chronically ill children was largely a personal process. This process involved a dynamic interaction with overlapping phases including the discovery of reality, critical reflection, taking charge, and holding on. Empowerment for the LRLD came as a result of the control the donor gained through the decision to donate and led to the donor's new concept of their identity. Gibson provided validation to my study finding in relation to empowerment and parents dealing with chronically ill children because she found that through the process of empowerment mothers became more aware of their abilities, strengths, and resources. Though these mothers' sought empowerment in a different way than the donors in my study, however, empowerment still emerged as a process that allowed parents a way of taking charge of a difficult event in their lives.

Parental decision-making for families was also addressed in a study by Rehm (1999). She investigated religious faith in Mexican-American families who had to deal with a chronically ill child. Amongst her many significant findings, one pertained to decision-making and how six specific dimensions of religious faith were in fact related to caretaking and decision making for the family. These beliefs and actions interacted in a manner that provided guidance for families in developing emotional and practical decisions related to their child’s life. For the donors in my study, a religious affiliation bred confidence, strength, and security to the donor’s life and this assisted them in their decision-making processes. Those who had strong faith and religion in their lives had a security different from the other donors. They sought security in placing their trust in a higher power, which allowed them to feel proud and thankful to have God in their lives. These donors experienced another level of empowerment, one that developed from the control found in their faith. Rehm’s findings related to religious faith served to validate my findings because she was able to show that faith was one way families could process living with a chronically ill child and make decisions that impacted the life of their child.

The current literature on LRLD does not indicate similar findings in regards to control and change in identity, as did my study, however several articles discuss the ethical implications of living related donation, which do share similar findings. (Forsberg, Nilsson, & Olausson, 2004; de Villa, Lo, & Chen, 2003; Diaz et al. 2002; Franklin & Crombie, 2003). Control and identity construction have not been precisely mentioned in the current literature, however studies do report that benefits of LRLD can be psychological and that the donor may feel an extreme level of satisfaction for having saved the life of their child (Cotler, McNutt, & Patil, 2001; Singer et al., 1989; Trotter et al., 2002; Grewal et al., 1998). These authors did not specifically discuss the concept of identity or control; however, their studies contribute to the current knowledge regarding the impact living donation can have on the donor psychologically.

Change in Identity:

Current pediatric research has not articulated the personal experience and long-term impact a living donation had on the donor, however by looking at pediatric nursing research on chronic illness there are findings in the areas of parental identity, and relationship changes that can extend and strengthen current knowledge. Young, Woods, Findlay, and Heney (2002), suggested that mothers' experienced many consequences related to the chronic illness of their child, which altered their sense of self and social identity. Though this study focused on motherhood and did not consider the father parental role, it demonstrated how maternal obligations of having a child with a chronic illness heightened the demands made on parents, specifically the need to keep a careful watch on their chronically ill child in order to secure the emotional and physical well being of their child. Parents, including several fathers in my study, described a relationship with the recipient that was more “protective” and “closer” than other members of their family. It seemed that children having experienced a liver transplant may have created a situation where donors and spouses assume a role that has the potential of compromising other aspects of their roles as parents. Young et al. reported that having a child who was medically vulnerable could alter personal obligations in order to protect their child. These findings could be extended to parents in my study as they reported having concerns and obligations in living with a child with a transplanted organ, particularly the risk of their child rejecting the transplanted liver.

Parental identity was also addressed by Sandelowski & Barroso (2003) in their research on motherhood in the context of maternal HIV infection. By conducting a metasummary and metasynthesis of 56 qualitative studies dealing with HIV-positive women, they found that motherhood decreased the negative physical and social effects of HIV. They described a “virtual motherhood” which was adopted by HIV positive mothers that allowed them to tackle the forces that had the ability to disrupt their relationships with their children as well as their identity as mothers. This article, like Young et al. (2002), focused on mothers. Their identity as mothers and their motherhood role made coping with the physical and stigma ramifications associated with HIV easier. Motherhood for the participants in the Sandelowski et al. study provided them with social support, self-esteem, and a reason to live and to battle the HIV infection. Parental identity for the maternal and paternal donors in my study, like the mothers in Sandeloski et al. study, created meaning through increased self-awareness. Though the donors were initially healthy, without a chronic condition like the mothers with HIV, they were involved in a struggle to save their child’s life and at the same time putting their own life in jeopardy.

Contrary to the findings of my study, yet pertaining to the issue of parental identity, Hodgkinson and Lester (2002) reported that mothers living with a child with cystic fibrosis expressed they had lost their identity as individuals as a result of having a child diagnosed with cystic fibrosis. This loss of identity was a direct result of their child’s diagnosis of cystic fibrosis. Some of the mothers were unable to return to work, missed work, and described feeling socially isolated. Living liver donors expressed that they needed time to recover following the donation; however, a loss of identity was not a common finding amongst the donors in my study. Identity changed, but it was not lost. Personal priorities were mentioned in this article as changing as a result of the news that their child had cystic fibrosis, which was similar to finding of Young et al. (2002) and also similar to findings in my study. The priorities for the donors in my study were clearly their family and the health of the recipient. Similar to the findings reported by Hodgkinson et al., the LRLD seemed to care less about material possessions or work and more about the health of their child.

Family Clarification

Baines et al. (2001) confirmed my findings as they reported that family dynamics did not necessarily change as a result of the transplant; however existing configurations, alliances and allegiances tended to be amplified. Baines et al. concluded that if the donor had a relationship with their spouse or a child that was weak or strong prior to the donation, it tended to become more intensified following the donation. All donors in my study reported having stronger bonds with the recipient that their other children, and all but two donors described spousal relationships that were strengthened after donation.

One current research article addressed some of the long-term issues that impacted the everyday life of the liver donor; this study was conducted by Crowley-Matoka et al. (2004). Similar to my study, they audio taped each individual interview and identified recurrent themes that seemed to emerge across the interviews. Though it was medically focused, it provided knowledge in regards to the long-term quality of life issues that existed as a consequence of the donation. Ten out of the 15 donors interviewed reported feeling as though family members and the medical team treated them as a non-patient from the medical team as well as by family members; however family relationships were reported to have been strengthened by the donation process. None of the donors in my study expressed feelings that they were treated as a non-patient and 11 of the participants felt familial relationships were strengthened by the donation. Among the 15 donors interviewed by Crowley-Matoka et al. two cases (13%) ended in divorce after the donation, but in both cases the donors stated that the marital strain they experienced was primarily due to problems such as infidelity, alcoholism, and financial problems, not the donation. My study indicated that 3 of 13 (23%) participants experienced divorce and only one claimed the divorce was related to having a chronically ill child.

A systematic literature review conducted by (Shudy et al., 2006) clearly and succinctly described what was currently known and what remains unknown in the field of research related to childhood illness and injury on families. They reviewed 115 reports related to the impact of pediatric critical illness on families, stressors, needs, coping, and interventions. They found that the effects of critical illness on families were variable and the permanent impact on siblings and marital relationships was considered detrimental (Shudy et al.). It was apparent by their literature review that the majority of the studies reviewed did not investigate cultural diversity, socioeconomic status, gender differences, and financial stressors. A recommendation made by these researcher was that additional studies on family and childhood illness needs to continue in order to enhance our knowledge about this population and better understand the dynamics within families.

Fathers that participated in the Brody & Simmons study (2007) were affected in many ways by the diagnosis of cancer in their children, however one way in particular that was similar to my finding was that these fathers found that familial relationships were strengthened by the experience. A majority of these participants indicated that their spousal relationship was also strengthened. Unlike the findings in my study, the physical, mental, and financial stressors for these fathers made adjusting difficult in their family life. The travel to and from the hospital, having to explain the diagnosis to their child, and finding ways to pay for the cancer-related costs where all demands that made adjusting difficult for them and their families. The physical, mental, and financial issues did not seem to be a significant burden for the LRLD in my study. This may be attributed to the fact that the possibilities and the outcomes of cancer and liver transplantation are different. Offering a liver section to a child can save a child's life and restore health in the short term; for the child with cancer, this is not a possibility.

Changed Perspectives on the Meaning of Community

The role that community can ultimately play in a parent's life who faced a life threatening illness with their child was well described in the current literature, however research highlighting the sense of wanting to give back to community as a result of parenting a chronically ill child was not found in the current literature, and therefore was one of the salient findings of my study.

Unlike the findings of my study, Brody et al. found that fathers of children with cancer had difficulty obtaining support outside the hospital. Their community did not provide the support they needed in dealing with their child's diagnosis. These researchers reported that parents who had less supportive workplaces may have experienced more stressors and this may have affected their ability to cope. Community for the LRLD in the current study provided enormous support to the donor and their family's pre and post-transplant. Brody et al. was one of the few qualitative studies that used interviews to gain insights into community, personal awareness, and family issues, which was very similar to my study. Changes and adjustments that occurred in the family created an ongoing, dynamic process for fathers' whose children were diagnosed with cancer. This article used a rigorous research analysis that projected findings related to parents and pediatric illness similar to my findings and made a valuable contribution to the literature on parental perspectives regarding chronic illness.

Grey, Knafl, and McCorkle (2006) presented a framework for the study of self and family in the management of chronic conditions that contributed to the literature pertaining to coping, illness and community. LRLDs articulated that they possessed a new perspective on community as a result of being a donor. Though Grey et al. did not address how parents perceived community, it offered the researcher a method of understanding how individual and family management are interactive and how environmental resources, within the community, may influence them. This study highlighted the point that self and family management of illness involved dynamic interactions and can create a variety of health care outcomes. This management framework can be used to delineate the roles that the LRLD played in the donation process and how these factors impacted their association with their environment. The donor's new perceptions of community and their desire to give back to community can be better understood and guided toward the implementation of interventions to improved outcomes for the donor and their families through this framework. My study illustrated the fact that donors experienced a desire to give back to community, and when these findings are conceptualized through the framework developed by Grey et al. interventions can be implemented that directly enhance the donor's ability to achieve the highest self-management behaviors and strive for improved outcomes. Donors themselves did not have to deal with their own chronic illness but they had to manage the chronic illness of their child who after the donation was left with a life requiring long-term immunosuppressive therapy and medical follow-up. This framework outlined outcomes that may be associated with effective self and family management which included an environmental context, namely access, utilization, and provider relationships in the community. By using this framework, it may be possible to test interventions that promote positive outcomes, specifically the donor's relationships with their families and their communities.

Parminder et al. (2007) discovered through the use of interviews and questionnaires that parents caring for a child with cerebral palsy (CP) found that the assistance of friends, neighbors, and extended family was secondary to the care provided by immediate family. The support provided by family, and not community, played a central part in the physical and psychological health of the parents. Community was a critical aspect of support for the LRLD, not a secondary form of support. This difference in findings between my study and Parminder demonstrated that nursing interventions for both parent populations might vary slightly from the parents dealing with a child with CP. It may be that the fact that CP is a long-term chronic condition that makes slow progress, whereas LRLD occurs in a crisis context, community members are more comfortable in helping in the short-term. Maybe community needs to be educated about the needs of families with more chronic conditions like CP and families need to learn to ask for what they need.

Stress, emotional support, and coping behaviors in mothers with disabled pre-school children was addressed by Oka and Ueda (1998). The results of a Home Care Resources Inventory (HCRI) indicated that the major source of support for these mothers was social support from their own mothers and grandmothers as well as emotional support from mothers who experienced similar stressors in dealing with a disabled child.

The support available to these mothers by other mothers seemed to assist them in coping and dealing with the loneliness they experienced. The mothers that could share in the same experiences were more likely to overcome their emotional stress and cope more affectively. The donors in my study reported that speaking to other LRLD helped them in adjusting to the stress of having a child with ESLD yet they did not address the issue of support from grandmothers.

In addressing the concept of community as it related to cadaveric donation versus LRLD, the research demonstrated that donor families do communicate with recipient families in the community (Clayville, 1999). From 1992-1995, a total of 542 donor families and recipients were noted to have communicated with one another in Cleveland, Ohio, with recipients writing more that 80% of the letters to donors (Vajentic, 1997). Research illustrated that the general public knowledge regarding donation is low and current efforts should be focused on promoting a philosophy of sharing the gift of life at the time of death for every individual (Cantarovich, 2004). It should be a moral obligation or moral duty for the deceased individual to donate their organs to someone in need (Howard, 2006).

The California Transplant Donor Network (CTDN) is the organ procurement organization (OPO) for Northern California and Northern Nevada. CTDN provides individuals dealing with transplant issues a family service department that promotes community awareness for donor and recipient families who participate in cadaveric donation. CTDN (2007) sends letters of appreciation to cadaveric donor families and gives them updates on the recipients on a regular basis. They also offer donor families on-going support and resources such as community support groups, grief counselors, and information about supporting families though grief (CTDN, 2007). Community outreach by donor procurement agencies is a main goal of OPOs as they believe that education the community on the benefits of donation at the time of death is extremely important.

For the family that chooses to wait for a cadaveric versus pursuing LRLD, they are completely dependent on the community for the donation. Community is an essential part of saving their child’s life. For families that choose to donate a piece of their liver to their child, they do not depend on community for the donation, yet as this study demonstrated, community served the LRLD in other outstanding ways, which left donors with the desire to give back to community. Community for the family faced with a child with ESLD worked in ways that had the potential of having enormous impact on the family, whether the donation was cadaveric or living-related.

Theoretical Significance

The resiliency model of family stress, adjustment, and adaptation proposed by McCubbin & McCubbin, (1993) served as a template to describe the stages that the donor traveled while they experienced the transformational process. The parental donors in this study adapted and adjusted to the new identity of “donor”. In relating the findings of this study to the resiliency model of family stress, adjustment, and adaptation (McCubbin & McCubbin, 1993) the “pile-up” of stressors required the donor to assess the situation of having a child diagnosed with ESLD, and make the choice to become a LRLD. They worked within the scope of their financial constrictions, and dealt with their individual family issues as well as work responsibilities. The 13 donors interviewed in this study shared different perceptions of what stressors were in their lives. For some it was dealing with other children, for others it was feeling alone, yet as a group they shared similar life experiences, specifically how the donation transformed their everyday lives.

During the pre-transplant phase, the transplant center gave families the option to donate or to wait for cadaveric donation. The donors in this study looked internally and decided together with their family what the best decision was for them. Making sense of the stressful event and deciding a course of action that would blend with the characteristics of their family impacted whether the family benefited or “bonadjusted.” If the donors and family could not problem solve and successfully cope with the severity of the illness, they will be maladjusted. None of the participants in this study fell into this category. The results of this study pointed out the fact that the donors were able to make sense of the situation and create meaning from the donation experience, which lead to bonadjustment. Resources such as family and community helped participants in this study to cope and problem solve. The donors evaluated their personal and moral values for this strength, which led them to a new level of self-awareness.

Coping for donors and their family at this preliminary phase can depend largely on the family’s prior experiences with their values, and the meanings they attach to the situation. The adjustment phase, as described by McCubbin & McCubbin, (1993) was relevant in the discussion of the donor and their perception of stressors within and outside the family. Additional resources, such as extended family, transplant team, social workers, transplant coordinators, nurses, neighbors, and work colleagues all assisted the donors in adjusting to the transplant experience. Fitting with the design of McCubbin & McCubbin, (1993), during the immediate post-transplant phase, the family encountered an additional “pile up” of stressors and strains. For the donors in this study, some reported the recovery being quite stressful while others found recovery to go quite smoothly. Family schema played a key role in the family appraisal during the adaptation phase, which was apparent in this study. The donors described goals, shared values, and expectations that helped in how they adapted. For example for a few donors religious affiliation brought confidence, strength, and security to their lives and allowed them to develop a security different from the other donors. This security in a higher power permitted them to feel proud and thankful to have God in their lives.

Dealing with transplant issues such as rejection and infection demanded a lifetime of commitment on the part of the transplant recipients and their families. The long-term lifestyle of the donors and their family required strict clinical follow-up. Some of the donors in this study expressed that the stress of having a child with a liver transplant continued to be on their minds everyday. In the Resiliency Model, according to McCubbin and McCubbin (1993), family adaptation became paramount in understanding a family's struggle to manage illness and to achieve a balance. This balance demanded a fit at both the individual-to-family and family-to-community levels. The family must achieve collaborative arrangements between themselves and the health care community in order to reach a level of bonadaptation, which was illustrated in the findings of my study. For two donors it was the social worker that provided security and confidence to the donor's experience. For another donor it was the transplant team that provided this collaborative arrangement for the family: "Most of the information, love, and support came from the transplant team."

The resiliency model had the capacity of highlighting a family and donor's ability to cope and problem solve which made it well suited for the discussion of how a donation impacted the donor. The ability to help in defining the nature of adjustment and adaptation strategies can play a critical role in assisting families and maintaining an ability to recover from crises. For the clinician, the resiliency model can foster understanding between donors, families, and communities, in hopes of moving towards recovery for the donor.

Limitations

Sampling Bias

Limitations of this study must be discussed and reviewed in order for the reader to be clear about any potential bias found in the study. The sample of donors used for this study were recruited from two prominent transplant centers on the Western Coast of the United States, and included donors from 3 western states. This sample was not representational of all donors throughout the United States as it was small and included participants from three states.

In addition, all donors came from high socio-economic status. Two donors combined family income was $40,000.00-$50,000.00 per year, four donors combined income was $60,000.00-$100,000.00, there donors combined family income was $100,000.00-$150, 000.00, two donors combined family income was greater that $150,000.00, and two donors did not answer the question. The median household income in the United States in 2005 was $46,326.00 (United States Census Bureau, 2006) (United States Census Bureau, 2006). It could be that lower income families may experience a slightly different impact from a LRLD than these higher income families, which presents a limitation at this point, yet an opportunity for future research.

Clinical Involvement with Participants

I was actively involved as a Pediatric Liver Transplant Coordinator with the care of five (38%) children of participants during the transplant prior to starting this research. This participation may have impacted the donors' ability or willingness to report their feelings openly, due to a possible fear that what they say could jeopardize the care they receive in the future. As the researcher, I paid close attention to this issue, and tried to remain as reflective as possible in order to view the donor's story objectively and openly. My preconceptions and biases were constantly acknowledged throughout the study, by engaging in field notes and memos.

Donors at one point in the interview described their child's clinical experience. It was natural for me to hear their stories regarding the clinical status of their child. By engaging in a reflexive approach to the interview I found myself refraining from commenting on clinical issues and reminding myself that I was a researcher and not a clinician for the purposes of this study.

Recruitment Strategy

Participants in this study where recruited by transplant team members at both centers. This recruitment strategy may have carried with it potential bias as those donors recruited may have been donors that had good relations with transplant team members and may have had positive experiences to share. Transplant team members may not have selected the donors with negative experiences because the team members may not have wanted their center to be represented in a negative light. Those donors that participated in this study may have been more open to discussing their experiences than those donors that did not participate: in other words those with negative perceptions of the donation may not have wanted to participate in a study of this sort. This may have resulted in a participation group not representational of the whole group of donors, just those with positive stories to share.

In addition, none of the LRLD in this study had children who later died following the transplant. While they may have also reported similar findings regarding self, family, and community, this remains a subgroup of the population whose experiences need investigation.

Exclusion Criteria

All participants as defined by the exclusion criteria were English speaking; this is yet another limitation to this study, as those donors that were non-English speakers where not represented in the group of participants. This may have eliminated cultural and ethnic factors that could impact the effect the donation may have on donors, families, and communities. Though this study represented five ethnic groups, it did not demonstrate enough of one particular group to attribute findings to any particular culture.

Clinical Implications

This study in combination with the current literature on LRLD, indicated the need for more extensive pre-transplant education as well as comprehensive follow up for the donors post donation. Not only medical and surgical information is required, but also the non-medical issues need to be addressed. These non-medical issues should include areas such as the impact a donation could have on oneself, family relationships, and views of community. This study illustrated the significant impact an organ donation can have donors, thereby indicating the need for transplant programs to make available to potential donors the non-medical concerns and strategies for their positive resolution. .

During the pre-transplant evaluation, when families come to the transplant center and meet the transplant team, they discuss the surgical options of both cadaveric and LRLD. It is here that attention must be given to guide families in making the right decision for themselves and their family. As a result of my findings, serious evaluation into the current personal, familial, and environmental stressors experienced by the potential donor and their family must be assessed by the transplant team. Current literature does address the in depth evaluation process necessary in assessing the psychological and physical integrity of the potential donor; however, very little current literature suggests attention should be given to offering the potential donor anticipatory guidance regarding the effects of a donation on a family and community level.

Meeting with spouse, family, and siblings together as a family unit may assist in making the evaluation process complete. As my study indicated, it is not just the donor by himself or herself that experienced the impact of the donation, it is the whole family unit and his or her community. Based on the findings of my study, it is clear that interventions for these families experiencing a child with ESLD, must incorporate family conferences with the transplant team with the overall goal being that the donor, spouse, and siblings understand how this donation could affect them as a family. During this time, guidance can be given regarding how one’s view on community may change and how community can provide support and strength to families experiencing this stressful event. Having parents that are LRLD available at the evaluation to talk with families would also be an implementation strategy that could be used by transplant centers to assist families in coping and support.

Since community played such a large role in the adaptation and transformation of the LRLD, it would be very effective if transplant teams could mobilize community for families dealing with LRLD. This may need to occur in collaboration on a state level with the Organ Procurement Agency or possible on a national level with UNOS. As this study illustrated community support is essential to the donor pre and post-donation and must be made available to donors and their families.

Seeking Additional Information

Data collected from this study illustrated that only 2/13 (15%) of the donors interviewed did not seek additional information outside the information given to them by the transplant team prior to their decision to donate. These two donors trusted the recommendation of the transplant team without seeking addition information. Unlike these two donors, 11/13 (85%) admitted to seeking additional resources before making the decision to donate. Many donors reported using the internet in order to gain more information regarding liver transplantation and transplant options. This indicated that families who donate desired more information on the procedure and looked outside the medical center in order to gain knowledge. As discussed earlier in this paper, very little information is currently published in reference to the non-medical, long-term impact a donation may have on the living donor. Transplant centers must make information available for potential donors, including research-based articles, regarding LRLD so that they can make the most educated decision for themselves and their family.

Donor Follow-Up

Results of this study demonstrated that 6/13 (46%) of donors received no follow-up medical care, and 7/13 (54%) were assessed by a physician at 12-14 days post-donation, with no additional follow-up. Since the inception of this study, UNOS (2006) has implemented national follow up forms to be completed by all transplant centers participating in LRLD. UNOS, as of July 2006, requires all transplant centers to have 6 month and yearly follow-up visits with the LRLD and to complete the necessary follow up forms supplied by UNOS. The follow-up forms are to be completed by the transplant coordinator or physician caring for the patient, which are focused on medical data. This is a significant advancement for the transplant community and provides a method of tracking and organizing data regarding the physical health of a donor post donation, despite the fact they neglect to address non-medical issues which should be addressed in the future.

National Donor Registry

The creation of a national donor registry has yet to be developed, however it could also be an effective way for potential donors to gain additional information on long and short-term outcomes for the living related donor. This registry could be administered through UNOS and use the data compiled from the follow-up forms that are currently in place.

Future Dimensions

In order to fully understand the everyday lives of living related liver donors and the impact the donation can have on them, future studies such as this qualitative study as well as other quantitative studies are critical. Understanding the long-term consequences of donation on the donor and their family will serve to assist not only the families faced with the choice of LRLD, but also transplant center staff and the general community. Findings from this study illustrated that live liver donation transformed the life of the donor. Based on this creation of new knowledge, future research questions have been developed:

1. How do other members of the family perceive this transformation experience namely spouse, recipient, and other children in the family? This study only interviewed the donor, thereby receiving only one side of the story that in reality involved the donor, recipient, spouse, other children in the family, and the community. Future research involving all participants may lead to richer life stories from which to make clinical recommendations and improve patient care.
2. Should families faced with a child with acute liver failure be offered the option to participate in LRLD since the decision must be made in 24 hours? Only one of the 13 participants interviewed in this study had a child with acute liver failure, which required him to decide to be a LRLD within 24 hours. This puts undue pressure on families, and may cause decisions regarding donation to be made too quickly. The experiences of families with children with acute liver failure does require further study.
3. How do parents who chose to wait for a cadavaric donation feel about donation options, and what factors did they use in making their decision? This study only interviewed those individuals that decided to become donors, but questions come to mind as to why the majority of parents decide against LRLD. Conducting a study that would focus on

this population may bring light to this question, and lead to a better understanding of the negative perceptions of LRLD.

4. How does the adolescent living related recipient feel about having had a parent donate a piece of their liver to them? Interviewing the recipient who reaches adolescence would allow for clearer understanding of donation from a recipients' viewpoint. This study focused on the donor's perception, but hearing the story from the recipient could be very enlightening.
5. For donors who lose their child following the donation, how do they adjust and adapt? This study only addressed donors whose child survived the transplant, but what about the families and donors that are not so fortunate?

These are just some follow up research questions that have been stimulated by this study. Studies such as these could be investigated through both qualitative and quantitative methods and could also involve multidisciplinary research teams in order to maximize findings and foster dissemination.

Summary

As indicated in this chapter, the findings of this study reflected that of the 13 LRLD interviewed, all experienced a transformation process that affected them as it created a new level of self- awareness, clarified existing family relationships, and changed their perceptions of community. Donating the left lower lobe of their liver was a decision that they made based on what they felt was the best for them and their family. None of the donors expressed resentment or regretted their decision to donate. The fears expressed by the donors were not focused on their physical well-being, but the life of their child. All donors believed their decision was the right decision and they were thankful for having the opportunity to save the life of their child.

Transformation has been a term used frequently in nursing literature, however it has not been used to describe the process that living liver donors experience as a live donor. One poignant finding that was not found in the current transplant literature was the concept that donors experienced changes in how they perceived their communities following the donation and demonstrated a desire to give back to their communities.

Limitations of this study were mentioned in areas of sampling bias, clinical involvement with participants, recruitment strategies, and exclusion criteria. It is my hope that from this study clinical interventions can be made at transplants centers to foster quality patient care for living liver donors. Additional studies such as this study are necessary so that the everyday lives of parental liver donors can be better understood and the best care possible can be delivered to this population of patients.

Conclusion

As indicated by the literature review, little research exists on parental liver donors and their perspectives of life after donation. It is my aspiration that together with other researchers we can bridge this gap in the literature and produce research studies that are innovative and lead to the development of better methods to care for the living donors. As the demand for organs continues to surpass the supply, the use of living organ donation will expand and more attention will need to focus on this issue.

Ethnography was an appropriate method to address the research question that focused on the impact that a living-related liver donation had on the donor and the donor's family because it allowed for the illumination of the context in which they live their lives, make decisions, and create meaning for what happens to them in the course of their lives, especially as related to this shared experience. Donors in this study developed new meanings for themselves in regards to their identity, family relationships and community. These new meanings will be with them for the rest of their lives and have changed the way in which they perceive illness and health care.

Understanding family behavior in response to stress, health care providers can better prepare families to make difficult transitions with greater ease. Scientific inquiry into the concept of family stress and coping is currently lacking in the field of living related transplantation, and is an area with enormous potential for future research. It is critical that transplant teams and the health care community understand the dynamics of adjustment and adaptation for a family during all phases of transplantation. Donating a portion of a liver to a son or daughter is an altruistic act of enormous proportion, and demands further research. The Resiliency Model provided the theoretical constructs that assisted in understanding how and why these families of children with liver disease are able to cope, endure, and survive the experience.

The United States is faced with a huge dilemma over meeting the demand for organs with a limited supply. Over the past decade, the waiting list for transplantation has increased 150% (Jasper, 2004). One answer to this shortage of organs is LRLD. The living donor is a unusual type of patient in that they are healthy individuals who put their life in jeopardy for their son or daughter. It is an amazing act of kindness and generosity. As the donors in this study demonstrated, the donation was transformational, and left the majority of them with a stronger sense of self, closer bonds with their families and a new appreciation for community. All donors must clearly understand the impact a donation can have on their lives before making the decision to donate. It must be the commitments of all transplant centers to better understand this impact and translate research findings to their patients.

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Appendix A

Informed Consent

[redacted]

[redacted]

CONSENT TO BE A RESEARCH SUBJECT

Living-related Liver Donor’s Perceptions of Life After Donation

A. PURPOSE AND BACKGROUND:

Annette Sue Nasr, RN, MPA, PhD(c) is a doctoral student, and Assistant Professor Roberta S. Rehm PhD, RN in the School of Nursing at the University of California, San Francisco, are conducting a research study to investigate the everyday life experiences of living related liver donors post-donation. They are interested in discussing the physical, emotional, and familial dimensions of your life since donation. As a liver donor we ask for your participation in this study.

B. PROCEDURES:

If you agree to participate in this study, the following will take place:

1.Annette Sue Nasr will interview you once for approximately 60-90 minutes. There may be a possible second interview requested by the research team.

2. The location time and date of the interview will be agreed upon by you and the researcher. The interview may take place at your home, or another mutually agreeable location. You will be asked about your physical, emotional, and familial experiences you have had since your donation.

3. The interview will be audio taped and transcribed for the researchers.

4. You will be asked to complete a “Demographics Questionnaire” that will ask you basic demographic data on you and your family.

C. RISKS/DISCOMFORTS:

1. Participation in this study will remain completely anonymous. In order to maintain confidentiality, only a code number will identify tapes and transcriptions of the interview. The tapes and transcripts will be destroyed after the study has been completed.
2. As a participant in this study you have the right to refuse to answer any questions, or withdraw from the study at any time.

D. BENFITS:

There will be no direct benefit to you for participating in this study, however the information that you provide may help health care professionals as well as future living-related liver donors in understanding the life of a donor.

E. COSTS:

There will be no costs to you for participating in this research study.

F. PAYMENTS:

You will be given $50.00 for your participation in this research study.

G. QUESTIONS:

You have spoken to Annette Sue Nasr regarding this research study. If you have any additional questions you may call Annette Sue Nasr at (650) 498-5602 or Roberta Rehm PhD at (415) 502-6762**.** If you wish to have questions answered otherwise you may contact the Committee for Human Research, which is concerned with the protection of volunteers in research studies. You may contact them between 8:00a.m. and 5:00 p.m., Monday through Friday by calling (415) 1814 or by writing: Committee on Human Research, Box 0962 [redacted]

H. CONSENT:

You will be given a copy of this consent form and the Experimental Subject’s Bill of Rights to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to participate or to withdraw at any point in this study without question and with out jeopardy to your present or future relationship with [redacted]

IF you agree to participate in this research project please sign below.

____________________________ ____________________________

Date Signature of Study Participant

____________________________ ____________________________

Date Signature of Person Obtaining Consent

Appendix B

Experimental Subject's Bill of Rights

[redacted]

[redacted]

The rights below are the rights of every person who is asked to be in a research study. As an experimental subject I have the following rights:

1. To be told what the study is trying to find out.

2. To be told what will happen to me and whether any of the procedures, drugs, or devices is different from what would be used in standard practice.

3. To be told about the frequent and /or important risks, side effects, or discomforts of the things that will happen to me for research purposes.

4. To be told if I can expect any benefit from participating, and, if so, what the benefit might be.

5. To be told of the other choices I have and how they may be better or worse that being in the study.

6. To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study.

7. To be told what sort of medical treatment is available if any complications arise.

8. To refuse to participate at all or to change my mind about participation after the study is started. This decision will not affect my right to receive the care I would receive if I were not in the study.

9. To receive a copy of the signed and dated consent form.

10. To be free of pressure when considering whether I wish to agree to be in the study.

If I have other questions I should ask the researchers. In addition, I may contact the Committee on Human Research, which is concerned with protection of volunteers in research projects. I may reach the committee office by calling: (415) 476-1814 from 8:00 AM to 5:00 PM, Monday to Friday, or by writing to the Committee on [redacted]

Call (415) 476-1814 for information on translations.

Appendix C

Recruitment Flyer

!!!!LIVING-RELATED LIVER DONORS!!!!

RESEARCHERS AT [redacted], ARE LOOKING FOR LIVING RELATED LIVER DONORS TO PARTICIPATE IN AN INTERVIEW FOCUSED ON "YOUR LIFE AS A LIVING-RELATED LIVER DONOR"

- ❖ All you need to do in order to participate is to engage in one interview approximately 60-90 in length. A second interview of approximately **60-90** may be requested of some participants

- ❖ During this interview you will be asked questions related to your physical, emotional, and familial experiences since donation.

- ❖ The goal of this research is to learn as much as possible about the life of a living-related liver donor in hopes creating a better understanding for health care professionals as well as future living-related liver donors.

- ❖ **Participants will be paid $50.00 per interview.**

If you are interested and want to find our more about this opportunity please call Annette Sue Nasr at (650) 498-5602. All calls are confidential.

Appendix D

Letter of Support

August 15, 2005

Dear Annette Nasr,

[redacted], I am pleased to write the following letter of support for the research study you and Dr. Roberta Rehm are proposing which is to study the lives of living-related liver transplant donors. The transplant community as well as potential living-related donors can benefit from more research concerning the lives of these donors. Very little data is available regarding the physical, emotional, and familial experiences of living-related liver donors, which is the topic of your research study. Together with my colleagues at [redacted] we will be happy to discuss your study and refer patients to you, once you have obtained CHR approval. We will also be happy to post a flyer in our transplant clinic as a source of recruitment for your research study.

Once you attain CHR approval please forward a copy of the approval, a copy of the study, and your flyer so that we can offer this opportunity to our clients.

Sincerely,

[redacted]

August 15, 2005

Dear Annette Nasr,

[redacted] I am pleased to write the following letter of support for the research study you and Dr. Roberta Rehm are proposing which is to study the lives of living-related liver transplant donors. The transplant community as well as potential living-related donors can benefit from more research concerning the lives of these donors. Very little data is available regarding the physical, emotional, and familial experiences of living-related liver donors, which is the topic of your research study. Together with my colleagues at [redacted] we will be happy to discuss your study and refer patients to you, once you have obtained CHR approval. We will also be happy to post a flyer in our transplant clinic as a source of recruitment for your research study.

Once you attain CHR approval please forward a copy of the approval, a copy of the study, and your flyer so that we can offer this opportunity to our clients.

Sincerely,

____

[redacted]

Appendix E

Interview Guide

Interview Guide

This research study will involve interviewing live liver donors as a means of obtaining perceptions and accounts of the lived experience of a liver organ donor. The interview guide that follows contains questions as well as general probing questions that will be used in order to gain information about the donor's life since the donation.

Introduction:

Thank you for taking the time today to meet with me and discuss with me your life since your donation. As you may know, this research study is focused on gaining a better understanding of what it is like to be a live liver donor. We would like to discover how liver donation affects a donor's life and their relationship within their family.

Please feel free to stop at any time for clarification or to take a break. If you would rather not answer a question, because you feel uncomfortable, that is fine. I value everything you have to say, or feel.

Initial Interview Questions:

I. Perceived physical and emotional consequences of LRLD:

1. ***Tell me about your child?***

   Probes:

   a. **When did you first find out your child had liver disease?**
   b. **What type of liver disease did your child have?**
   c. **How soon after this time did you consent to be a LRLD?**

2. ***How does it feel to you to have been a liver donor for you son/daughter?***

   Probes:

   a. **Who do you talk to about your donation?**
   b. **Can you share this experience with others?**
   c. **What worries you most about the donation? Did you have any worries about the donation? What worries you most since the donation?**

3. ***Describe to me the impact your donation has had on your life?***

Probes:

a. **Following the donation how long was your recovery?**
b. **When did you return to work?**
c. **How did you feel physically after the surgery?**
d. **Did you have any physical problems or issues following the surgery?**
e. **How soon after the surgery did you see your child?**
f. **Did you see a doctor once you left the hospital?**
g. **How did the donation affect you emotionally? What kind of emotions did you experience? What was hardest think about the donation? Did you have any positive emotions at that time? And since the donation?**
h. **Describe your relationship with your spouse since the donation?**
i. **Describe your relationship with your other children since the donation?**
j. **Describe the financial impact this donation has had on you and your family?**

II. Perceived impact of donation on intra-familial relationships and family dynamics:

1. ***Describe your relationships with your children and spouse:***

   Probes:

   a. **Is your relationship with the child that you donated to different in anyway to the relationships you share with your other children?**
   b. **How has the relationship with your spouse changed or not changed since the donation?**
   c. **Do you and the recipient talk about the donation? Do you celebrate the date of donation in anyway?**

2. ***Can you identify specific ways in which the donation has benefited as well as challenged you and your family?***

   Probes:

   a. **Do you experience stress today related to the donation? If so, how do you handle the stress that the donation produced?**
   b. **Did you have any particular fears in donating your liver?**

c. How do you take care of yourself physically/emotionally?

d. What is the hardest thing for you to deal with today in regards to your donation?

e. Has the donation strengthened your family relationships with your son, daughter, or spouse?

<u>III. Ethical context of parental liver donation:</u>

1. ***Looking back at the time you decided to donate do you feel you made the right decision?***

a. At the time that you decided to donate, was the information presented to you by the liver transplant team complete?

b. Did you seek out other ways to get information regarding LRLD?

c. Do you feel you were well prepared by the transplant team about the impact the donation would have on your life?

d. What do you wish you would have known today that you didn't know then?

e. What advice would you give potential donors today regarding donation?

f. Describe you state of mind when you made the decision to donate?

g. Was the medical language used during the time you made your decision to donate clear to you?

2. Has your son or daughter ever been admitted to the hospital for infection or rejection?

a. Describe the feelings you have when your son or daughter is admitted to the hospital with rejection or infection.

b. Do these times remind you of the time of transplant?

c. How do you take care of yourself when your son or daughter is admitted the hospital?

Appendix F

Living-Related Liver Donor

Demographics Questionnaire

Demographics Questionaire

1. **Name:**
2. **Age:**
3. **Sex:**
4. **Marital status:**
5. **Age at donation:**
6. **Number of children and ages:**
7. **Recipient:**
8. **Age of recipient at the time of transplant:**
9. **Child's diagnosis:**
10. **Are you Hispanic:**
11. **What is your race:**
12. **What is your child's race:**
13. **What is your combined annual family income:**
    - **Under $10,000**
    - **$10,000-$40,000**
    - **$40,000- $60,000**
    - **$60,000-$100,000**
    - **$100,000-150,000**
    - **Over $150,000**

Library Release Form

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I hereby grant permission to the Graduate Division of the University of California San Francisco to release copies of my thesis or dissertation to the Campus Library to provide access and preservation, in whole or in part, in perpetuity.

Annette NASR
Author Signature

8|20|07
Date