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Family Process Through the Prism of Living Donation: Courage, Coercion, Calculus and Coalescence

Abstract

ABSTRACT

FAMILY PROCESS THROUGH THE PRISM OF LIVING DONATION:

COURAGE, COERCION, CALCULUS AND COALESCENCE

Living donor liver transplantation is a relatively recent worldwide development in the field of transplantation due to a shortage of cadaveric organs. In 1989, the first successful living donor liver transplantation was performed (Gruessner & Benedetti, 2008, p.439) and by 2009 it had become an established way to treat end stage liver disease. The reasons that an individual decides to donate remain poorly understood. There are serious medical and psychological risks to the donor that necessitate careful psychosocial assessment prior to donation. Family processes for selecting a donor must be theoretically as well as clinically explored to refine our understanding of living donation. This study's intent was to give voice to the experiences of a small number of transplant professionals experienced in working with living donors and their families. The work of the object relations theorists Klein, Kohut, and Winnicott provide background for this qualitative research study while the methods of Weiss (1994) were used to analyze the semi-structured intensive interviews. This research sheds light on the health care professionals' perceptions of the experience of living liver donors and their families and offers direction for transplant social workers as they guide potential donors and donor families through the donation process.

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Presented to the Faculty of the University of Pennsylvania

In

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Degree of Doctor of Social Work

Family Process through the Prism of Living Organ Donation:

Courage, Coercion, Calculus and Coalescence

2010

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Laura Kotler-Klein

2010

Dedicated to

My father

Martin Kotler

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ABSTRACT

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Laura Kotler-Klein

Ram Cnaan

Living donor liver transplantation is a relatively recent worldwide development in the field of transplantation due to a shortage of cadaveric organs. In 1989, the first successful living donor liver transplantation was performed (Gruessner & Benedetti, 2008, p.439) and by 2009 it had become an established way to treat end stage liver disease. The reasons that an individual decides to donate remain poorly understood. There are serious medical and psychological risks to the donor that necessitate careful psychosocial assessment prior to donation. Family processes for selecting a donor must be theoretically as well as clinically explored to refine our understanding of living donation. This study's intent was to give voice to the experiences of a small number of transplant professionals experienced in working with living donors and their families. The work of the object relations theorists Klein, Kohut, and Winnicott provide background for this qualitative research study while the methods of Weiss (1994) were used to analyze the semi-structured intensive interviews. This research sheds light on the health care professionals' perceptions of the experience of living liver donors and their families and offers direction for transplant social workers as they guide potential donors and donor families through the donation process.

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Chapter I.

Living Liver Donation

“...to refuse to give, to fail to invite, just as to refuse to accept, is tantamount to declaring war; it is to reject the bonds of alliance and commonality.” (Mauss, 1950. p. 13).

Living liver donation is a serious procedure for the donor, not without risk of death to the donor. A portion of a healthy liver from a living, insured, informed donor, given of his or her own free will, is offered to a significant other or relative who requires a liver transplant. This process is one of two ways to obtain an organ needed for a patient with end stage liver disease. The other option is cadaveric donation from a brain- dead donor however this option carries its own risks and benefits. The option of living liver donation is feasible because a healthy liver can regenerate itself and continue to function normally after partial resection. “The liver is the only solid organ that has the ability to proliferate in response to loss of cell mass and restore cellular architecture and function after resection, substantial toxic injury, or infection” (Gruessner & Benedetti, 2008, p.459).

There are serious risks involved in living liver donation. Only family members or those with significant relationships are considered as donors in the United States. “First reported in the United States in 1998, the use of adult-to-adult living donor transplants (ALDLT) has now been reported in over 1600 patients and has been performed in 94 centers across the United States” (Olthoff et al., 2005, p. 315). The number of living donations is growing.

Due to the shortage of cadaveric organs, living liver donation became common in the late 1980's, primarily in Japan. The shortage of cadaveric organs exists in the Japanese society, according to Gruessner and Benedetti (2008), because some Buddhist sects do not accept the

concept of brain death. Brain death as a definition of declaring end of life remains socially controversial and poorly understood. Pope Benedict himself recently expressed concern about deciding end of life issues based on the criteria of brain death. (Schwarz, & Rosanio, 2009, p.3).

There are advantages to living organ donation as well as risks. Living donation saves a cadaveric organ for another patient. It expands the donor pool so that more patients can avail themselves of needed liver transplants. Surgery can be scheduled at the most favorable time for recipient rather than emergently when an organ becomes available. In addition shorter “minimal transit time reduces ischemia and damage to the organ... Graft survival in kidney transplants from related and unrelated living donors exceeds that for cadaver organs” (Olbrisch, Benedict, Haller, & Levenson 2001, p. 40). The recipient can receive an organ when he is just sick enough, but not so debilitated that he or she does not thrive after surgery. And finally, the donor is able to schedule a convenient time for donation in conjunction with the recipient when he or she can arrange for time off from work, caregivers for family, and support at home.

After reviewing the literature, there appears to be a lack of knowledge and understanding of the family process in living donation. From my experiences as a transplant social worker, one of the main issues of concern in transplant families is coercion. Transplant related coercion comes in many forms and donors must be protected from coercive relatives and situations. Transplant teams are charged with the responsibility to assess a potential donor for their suitability from a medical and psychosocial point of view. The transplant team is the only possible mechanism that can protect a donor and they are charged with the responsibility to do so. This dissertation depicts aspects of living donation through the perception of members on liver and kidney living donor transplant teams. The following research questions attempt to illuminate in some degree how living donation affects donors and families. How do transplant

professionals perceive the process, consequences and rewards of living donation for the patient and family (which includes the donor)? How do they feel about their participation in living donation? Would an emphasis on family dynamics and culture improve our ability to detect coercion when deception is present? Would deep contextual information about donors and their families be beneficial in choosing living donor-recipient pairs?

By 1999, transplant centers in the United States had begun to perform living donor surgeries. In the ensuing decade some interesting themes have emerged, worthy of study. Among them are issues of coercion, informed consent, the “medical excuse” and the effects on the donor and on the recipient.

Patients with end stage liver disease deteriorate while waiting on a transplant list, and many die before they receive an organ transplant. Living donation is a way to save patients’ lives and to increase the donor pool. However, there is potential for physical harm to the donor as well. Ringe et al. (2008) described a case of severe postoperative liver failure after a living donor surgery from a healthy 22-year-old male who suffered from multiple organ failure 11 days after the procedure. He required his own liver transplant. (Donors requiring postoperative transplants go to the top of the UNOS list.) He required intensive care treatment, ventilator, and chemicals to keep his blood pressure high enough to sustain life, dialysis, and repeated procedures and exploratory surgeries. He was discharged from the hospital after 79 days. He recovered fully except for neuromyopathy and bilateral foot drop. His recipient, his good friend, was discharged from the hospital after 19 days and resumed her normal activities. While there are instances of harm to the donor as this example illustrates, in the 42 cases that I observed in my role as transplant social worker at the Hospital of the University of Pennsylvania, no such negative consequences have been recorded.

As a result of the concerns for potential harm to the donor, at our program, the medical work-up is careful and prolonged (at least 6 weeks long) with time built in to allow the donor to change his or her mind. Within the following parameters any healthy adult can potentially be a living liver donor: under the age of 50; have a significant relationship with the recipient (Good Samaritans or internet buddies are not allowed); have their own health insurance; and pass a battery of medical tests to assure that are able to sustain an organ donation procedure.

The above are the inclusion criteria to meet the baseline requirements of a liver living donor. Insight into the person, and from the person who wishes to donate, is needed to give details about the family group to the team. Melanie Klein's (1975) theory may hold a key to understanding some of the underlying motives of both donor and recipient (in addition to saving the life and health of the recipient), which could seriously affect the psychosocial outcomes of living donor families. It will help the team not only to have an understanding of the individual donor's motivation, but also to be able to put the individual in the larger context of the family. There is critical information in what has transpired to bring the person to the medical center, prompting him or her to ask to be a living donor. It would add to the knowledge of the subject of living organ donation to discover how families select a primary candidate to be the donor. If the selected first donor candidate is found to be unsuitable for medical or psychiatric reasons, very often another donor candidate will be introduced to the process from the same family. If the person was approached directly and asked to consider donation, who was approached by the family and why? During this process, family members' thoughts may differ from each other's about the prospect of the donation. What are the consequences to each family member? There is a likelihood that one family member wishes to be donor while another does not wish to be a donor, and very likely that there family members with mixed emotions about the possibility of

becoming a donor. What are the prospects that the transplant team will obtain the truth we hope for and expect as we guide patients and families through the transplantation process?

Coercion

Coercion is commonly understood as the use of force to compel people to do things against their will. While watching a loved one suffer may in and of itself be considered coercive, other more active coercive influences in transplantation include threats of banishment or financial ruin. Overt blackmail or promises of future financial rewards such as mortgages and inheritance are other potential coercive influences utilized by families during the donation process. These coercive threats or enticements can be explicit or implicit and present a challenge to transplant teams. The team must be keenly aware of signs of negative coercion in the family while recognizing that the patient's illness itself may provide enough coercion to propel a donor through the surgery.

Coercion may also manifest in the aftermath of the living donor surgery. Recipients have reported that the donors have requested financial or other help even years after the surgery, a type of reverse blackmail. In fact, a frequent predicament for living donors is that of a "Black Sheep" donor who wants to redeem himself within a family by helping the patient to survive, but then finds to his grave disappointment that his status in the family remains unchanged.

The study of family dynamics in living donation may yield results that can clarify the way families handle one member needing the vital organ of another. Do family members share the same apprehensions, or are they experiencing the same occurrence very differently? Of particular concern are the people who are peripherally involved in the transplant experience. If, for example, a daughter is donating to her father, the daughter and father receive the full attention of the transplant team. Often overlooked, is the patient's wife (the donor's mother),

possibly the most important figure in the family constellation. In a prospective pilot study of living kidney donors, “Half of the donors indicated that the decision to donate was a shared family decision. Married donors were slightly more likely than non-married donors to involve another family member in this decision” (Walton-Moss et al., 2007, p. 86).

Gruessner and Benedetti (2008) addressed the issue of coercion: “decision making for a live organ donation is significantly influenced by the fear to die before transplantation, or to advance into a critical stage of cirrhosis. Thus, a psychological coercion cannot be completely excluded. It is still under ethical discussion, how much coercion in terms of taking a certain risk to save the life of a loved one is appropriate” (p. 440). Thus, coercion is a factor in the lives of living donors, but in what way should it be measured or address? How does the transplant team decide when a coercive effect is bearable or not? The team has the ethical responsibility of declining to perform the living donor transplant should the situation be untenable. While each patient and donor have the right to be considered for living donor transplant, each team has the right to accept or decline if psychosocial factors are not optimal.

The attitude of the team can also coerce the donor. In some transplant centers, the team that evaluates the patient to be listed for transplant initiates the suggestion to the patient to find a living donor due of the nature of the patient’s illness or the slim likelihood of receiving a cadaveric organ. Some patients will never rate highly enough on the MELD score scale (Model for End Stage Liver Disease, which is comprised of three blood tests: creatinin, bilirubin, and the international normalized ratio test also known as prothrombin time, which is used to evaluate the ability of blood to clot)) to receive a cadaveric organ. In such cases, living donation is suggested. Arguably the coercion starts at the medical center when living donation is first recommended. In addition, if the community is notified about the need for transplant, individuals involved may

stage fundraisers for the family or otherwise make public announcements in venues such as at church, or on social networking websites, adding to the coercion. Further compounding the coercion are physicians who convincingly present to the patient and family that the transplant center has an excellent reputation and that all of their surgical outcomes have been favorable. Even though the medical staff does not attempt to persuade a donor, just the attention alone of a prominent surgeon taking the time to meet with the donor and family can be both ego- enhancing and intimidating.

The transplant team may also assist potential donors in opting out of the transplant process and while avoiding overt conflict with the family. The medical excuse is offered to a potential donor who does not wish to go through with the donation but cannot or will not address the decision directly with the family presumable due to potential or actual coercion. The medical excuse gives the donor an “out,” leaving the family to believe that the donor was medically unsuitable for donation. Due to the lack of research on this population, we do not know the long-term intrapsychic and family dynamic effects on the donor or the family following the medical excuse.

Donor Advantages and Disadvantages

Central to the workings of the hospital is the issue of reimbursement. In *Medical Ethics*, Pence (2008) points out that reimbursement to the medical center is done through the recipient's insurance, not the donor's. This may be a reason that sometimes “the team understandably focuses on the sick recipient of the organ, not the donor... the transplant team and its hospital gets paid for medical services to the recipient...in sum, transplant teams have asymmetrical relationships to donors and to recipients.” (p. 271). Donors are required to have or to obtain their own medical insurance in case medical issues arise for the donors that are not related to the

transplant. Clearly physicians are most attentive to the sickest party, the recipients, out of necessity. The physicians in this study appear to be cognizant of the extraordinary ethical and psychosocial issues and the unique status of donors.

For example, a young woman needed to have thirteen teeth pulled before she could be considered a candidate for living donation and unfortunately, this issue was not discovered until immediately before the transplant was to occur, thus delaying the operation. The patient was angry that the problem with her teeth was not addressed earlier in the evaluation process, supporting an argument for earlier noninvasive workups with hepatology, internal medicine and anesthesiology. Fortunately, the poor dentition was discovered before the surgery, otherwise the patient could have aspirated a loose tooth or suffered a septic infection. This issue points out that the medical work up leading to living donation can bring to light serious health issues for the donor. Cancerous growths may be located during the evaluation as well as other diseases that disqualify the potential donor but indicate a need for further medical care.

Advantages of living donation for the donor include enhanced self-esteem, discovery of other important medical issues during the workup and saving the life of the loved one. One study cited By Trzepacz, P. & Dimartini, A. (2000) found that “about one fifth of donors (liver) continued to have minor physical discomfort several months after donation and that many experienced financial or professional difficulties and family conflicts related to the donation” (pp.61-62). The story of living liver donation is a mixed one with many donors reporting the benefits of living donation post operatively.

Informed Consent

In living donor transplantation, and cadaveric donation, informed consent must be sought. To this end, all potential transplant donors are assigned an Independent Donor Advocate as part

of the evaluation process. The Independent Donor Advocate, who is mandated by Medicare, reviews the possible risks and effects of the surgery with the donor prior to consent. Families also meet with the transplant surgeon who reviews the risks and benefits of the surgery, and demonstrates the location of scars which will result from the transplant. The surgeon makes him or herself available to the donor and family to answer questions while simultaneously evaluating his or her comfort in proceeding with the donor workup and consenting process based on the interactions with the donor and family. Of interest, there is currently no registry in the United States tracking injuries, complications and mortalities resulting from liver transplant thus it is reasonable wonder whether the patient is really giving informed consent since the transplant team is unable to offer rigorously compiled statistics of the risks associated with the transplant. As of 2003, there were five documented deaths of donors from adult living donor surgeries (Pence, 2008.) however other deaths may have occurred but were not documented for review.

The History of Living Donation and Liver Transplantation

The first human liver transplant took place in 1963 in the United States, performed by Thomas Starzl, however it was not until 1967 that the first successful liver transplant was performed. The first recipient lived for just one year. Liver transplantation did not flourish until the 1980's when cyclosporine was discovered. Cyclosporine, an immunosuppression medication, made transplants more feasible by preventing the recipient's body from rejecting the transplanted organ.

Living liver donation became prevalent in Japan, as mentioned before, when "organizational problems and indifference as well as negative press coverage has diminished the number of cadaveric organs" (Gruessner & Benedetti, 2008, p. 24). Due to the shortage of cadaveric organs in the Japanese culture, parents in Japan began to offer parts of their livers to

their children. “The Japanese became the most experienced and skillful exponents of this technique” (Caine, 2008, p. 1777). The first adult-to-adult living donor surgery was performed in Brazil in 1998 (Umeshita, et al., 2003, p. 687). While the mortality rate is relatively low at 1% (Gruessner & Benedetti, 2008, p. 505) living liver donation is not without risk and some donors have been harmed so badly that they required a liver transplant themselves which is especially troubling in the parent-child dynamic.

The Living Donor

Who can be a living liver donor? At the large urban teaching hospital where I am employed, donors must be between the ages of eighteen and fifty years old, although some transplant centers may accept donors up to age fifty-five. They must have a significant connection with the recipient either by relationship or blood. They must know the patient with end stage liver disease who can be helped by a liver transplant. They must have their own health insurance, and successfully complete medical testing. Acceptable donor-recipients include parents donating to an infant or child, a husband and wife, adult progeny for one of their parents, or siblings donating to siblings. Donors can also be best friends, partners, aunts, uncles, a coach, teacher, clergy or member of the same religious organization. They should be free of coercion, financial or otherwise, and be able to describe their reasons for wanting to donate. They must be able to understand the risks they will undergo by giving informed consent. These factors are evaluated by a transplant team of professionals who works together to assure the best possible outcome for the donor and recipient.

Role of Families of Donors and Recipients

There would be significant treatment and selection improvements for living donors and their families if commonalities were discovered in the living liver donation patient, family and

process. If there are shared characteristics in families who undergo the living donor process, the study of these shared traits would allow researchers to build a systematic approach to the assessment, treatment and intervention strategies for clinicians.

Family dynamics occupy a critically important territory, which should be examined further for its role in living donation. Family dynamics clearly influence the motivation and reason to donate. “The motivation and decision to donate emerge within the dynamics of a family, which has its own history.” (Papachristou, et al., 2004, p. 1512). These family issues often emerge during the selection process of a living donor to which the transplant team psychiatrist and social workers must have fluency with family theory and family therapy techniques. Under the stress of chronic illness, donation, and transplant, family dynamics most likely will change or be stressed.

Family Issues

Based on my experience as a liver transplant social worker, the family constellation should be illuminated before proceeding with live liver donation, when there is such a serious risk to a healthy individual. The desired conclusion is for the procedure to result in a fortuitous exchange with good and enduring relationships after the surgery. Melanie Klein’s theory of object relations and “love, guilt and reparation” (Klein, B, 1975, title page) may help us to understand some of the underlying motives of both donor and recipient (another motive in addition to saving the life and health of the recipient), which could seriously affect the psychosocial outcomes of living donor families. While it is important to have an understanding of the individual donor’s motivation, it is equally important to put the individual in the larger context of the family. The events which transpired to bring the person to the medical center, prompting her to ask to be a living donor, to know in what way was she was selected or self-

selected and what occurred within the family that brought them to this point can be used by the transplant team to choose donors with fewer problems. Families frequently hold informal family meetings or discussions, or the donor might be approached directly by the recipient. More often, a “broker” or interested third party such as the wife, sister, or cousin will approach the person they think is likely to be approved by a transplant team. Family calculus is usually involved, such as a childless younger sister or brother being thought to be the best candidate by the other family members.

At some point family members converge on the most likely, appropriate prospect and the family moves the process forward. There are consequences for each of the involved family members, many of which they are not yet aware. Another family member might want to be “the one” to donate, or a sibling may be ashamed of feeling jealous of the donor candidate.

An important backdrop for living donation concerns the recipient. Very often an older parent will not allow their adult child to donate, particularly if the liver disease was brought about by “life-style” choices. In many cases, patients who require transplant have diseased livers due to alcohol abuse, and or drug abuse or even tattoos. The use of drugs or alcohol may have occurred as long as thirty years prior to the diagnosis and onset of illness. When the illness is known to originate from self-inflicted lifestyle choices, the donor may decline. Other members of the family may feel that a patient with a history of drug or alcohol use ought not to receive an organ from a living donor, citing “they brought this on themselves.” When the patient and family are not blaming the recipient for the illness, in my opinion, it seems more likely that both the patient and members of the family can accept donation, and with less ambivalence.

Donor Motivation

Most candidates for living donation have a simple answer to the question of why they want to donate. One potential donor expressed that he wanted to save the life of his uncle for his aunt, mother and the rest of the family and people who love him. He wanted to keep him in everyone's life as long as possible.

In a study that explored the motivation of living donors, Papachristou et al found that, "All 28 donors wished to keep the recipient alive. This constitutes the main, most natural explanation of their motivation to donate. The donors' 'maintaining life'-related arguments revealed two categories: the donor-related (egoistic) and the recipient-related (altruistic) arguments..."(Papachristou et al., 2004).

Papachristou et al. (2004) goes on to delineate the donors' arguments for each category named above. For example, a donor-related argument could be to avoid loss and loneliness. A recipient-related argument might be to protect younger family members from loss of a loved one, or to relieve the patient's suffering. These are interesting ways to view living donors and should be further examined. There may be overt altruistic motives that are important, but there are also possible social and egoistic motives that are relevant and may have painful lingering effects on the donor and family.

Olbrisch and colleagues (2001) discussed the way a committed donor will engage in "impression management" to optimize their chance of being accepted for living donation. Surman et al. (2002) noted, "Olbrisch et al. have cautioned that the donor may engage in impression management, concealment of important health information, or less commonly, deception about financial incentives...some donors feel they cannot gracefully withdraw" (p. 349-350). Impression management is the denial of problems, augmenting strengths, and magnifying the total commitment to provide an organ for their loved one. Transplant psychiatrists and social workers must have the time and adroit clinical skills to see past canny

“impression management.” Olbrisch demonstrates that in addition to impression management, there can be deliberate deception, concealment of important information, and cultural and language issues which limit the clinical psychosocial evaluation. (p.44).

Gratitude and Rewards

Mauss, (1950) wrote about the custom of exchanging gifts of primitive societies, including Polynesian tribes. The word “potlatch” comes from North American Indian customs in the northwest where the host of a feast gains prestige by giving gifts or even destroying wealth for high status in their community. The concepts of exchanging gifts and potlatch intersect with living organ donation. In them we can see how the nature of gifting, obligation and reciprocity are present in living organ donation in a modern society. No matter what the gift is, it carries with it obligations for some form of reciprocity. Furthermore, the recipient is obligated to gratitude.

The concept of gratitude is a universal concept that is very important for all aspects of motivation of donors. Discussions and expressions of gratitude are a significant charge for the recipient and family. The transplant community frowns upon tangible and monetary rewards and in this country, they are illegal. The demand of the transplant community and federal government is for unadulterated altruism, reflecting the nature of our puritanical society. Is unadulterated altruism a realistic paradigm with which to frame living organ donors? The single person who has anything to lose is the donor. The patient must be affected by the illness enough to require a transplant, which means that they are close to death; therefore, they have their life to gain.

Many times families, recipients or even donors might mask from the team what seems to be the reward behind an organ donation. A potential donor being pressured to donate or a family member pressing another to donate may create a feeling in the donor that he has no choice but to

donate. The team tries to detect this type of coercion, and protect the pressured person from proceeding. This type of protection is called the medical excuse.

Medical Excuse

Is there justification to lie to potential donors that they are medically unsuitable as donors? Or to lie to the family in order to excuse and protect the donor? The medical team tells prospective donors that the team will provide an “out” or a medical excuse so that the donor does not have to admit that they do not want to proceed. “By offering the medical excuse, the team infers that a reasonable person would donate, and transmits subliminal messages to the reticent donor that the perceived unwillingness is unacceptable” (McKoy & McKoy, 2008, p.392).

Why would a donor agree to use a medical excuse? Feelings of fear and shame and guilt may be a part of it. Perhaps they feel another member of the family is a more suitable donor, or that the recipient does not deserve this type of gift. They may fear being scapegoated by the family if it were known that they refused to take part in living donation. If a prospective donor accepts the offer of a medical excuse, it will likely affect him over time. If the recipient dies and only the donor knows he took the excuse, his feelings of guilt, and possibly shame, may increase as the years go by. If the recipient receives a cadaveric organ and recovers, the person who took the medical excuse may bear an onerous eternal burden of guilt and regret. The recipient who eventually received the cadaveric organ may suspect that the donor did not truly wish or intend to go through with the donation. If so, their connection may not recover or there could be arduous suspicions in their relationship for the rest of their lives. However, the medical excuse does provide “cover” for someone who would rather decline the opportunity to donate and prefers to keep his or her reasons private. At this point it is the best tool we have to protect someone who has started on the path to living donation but does not wish to proceed. Not

furnishing the medical excuse could have far-reaching negative effects on families and individuals that would be difficult to calculate. Social work research can do much to elucidate these scenarios, and develop relevant theory and techniques to work with families.

New Medicare Guidelines for Living Donation

The Web site OrganDonor.Gov (<http://www.organdonor.gov/>) which is available to the general public quotes the Medicare guidelines, saying “That each institution that performs living donor transplantation provide an independent donor advocate to ensure that the informed consent standards and ethical principles described above are applied to the practice of all live organ donor transplantation.” The ethical principles it refers to include: purpose of donation, nature of evaluation process, surgical procedure, medical alternatives, risks of psychological effects to donor and recipient, site specific statistics, voluntary nature of living donation, ability to withdraw, “prohibition against donor otherwise receiving any valuable consideration for agreeing to be a donor, and ability to provide informed consent.” The Medicare guidelines were written and implemented a few years ago as an additional safeguard for living donors of all organs. The guidelines are indicative of heightened awareness in the medical community that donors experience coercion and need protection. There is an independent donor advocate in all transplant programs that receive funds from Medicare. There is one independent donor advocate for each organ transplant program at this large urban teaching hospital. The independent donor advocate is hired by the hospital administration for each transplant program that employs living donation. It should be someone who has an understanding of transplant, and can be a transplant social worker, psychiatrist or physician. The independent donor advocate is supposed to be able to function separately and autonomously, as a sovereign agent, from the transplant team. They do not come to team meetings or confer with transplant staff. They evaluate the potential donor and

make a written recommendation to the team, which the team is then to follow. This arrangement is supposed to protect the independent donor advocate from pressure from the team.

Culture and Diversity

There may be a group of individuals that tend to present themselves more often to be a donor but we cannot identify them at this time due to a lack of an international tracking system. African-American patients may not have the same opportunities to participate in living donation as other racial and ethnic groups, or there might be unidentified reasons that we see many more Caucasian families than African American families. Siminoff, Burant, and Ibrahim (2006) saw that African Americans had a lower rate of signing the organ donor card or allowing the organs of a loved one to be donated after death. Siminoff, Brant and Ibrahim (2006) suggests that more African Americans than Caucasians think that they will receive inadequate health care if it is know they are organ donors. In my experience, the role of religious beliefs, faith, and religious doctrine affect attitudes about living donation. For some donors, religion plays a prominent role in the impulse to donate, as does the urge to atone for previous mistakes. Religion, access, ethnicity, culture and beliefs are all important areas for further research involved in living donation but will not be examined in this research.

As a liver transplant social worker for the past ten years, I have had the experience of more than 45 living liver donor surgeries. One family pair was African-American, a mother to her adult son. One family was from Puerto Rico, a daughter to her mother. The other families were Caucasian of various ethnic groups. Most of these families were fairly devout and faith played an important role, and at times, a quite significant part in their decision. One article addresses “Racial disparities in preferences and perceptions regarding organ donation” But it only addresses cadaveric donation and increasing the number of signed organ donation cards

after death (Siminoff, Burant, & Ibrahim, 2006). While liver live donation is a new and evolving medical field it is not clear if it will remain predominantly a service to white families or will people of color start taking advantage of it.

Interestingly, some candidates for living donation at this urban teaching hospital reported that they felt that God had directed them to be living donors. There is a dearth of material about living donors and the aspects of religion, faith and racial and ethnic diversity or the lack of it, and there is much research to be done in this area.

Altruism, Individualism, and Collectivism

Altruism is understood as a way of behaving with unselfish concern for the benefit of others. Gintis, Bowles, Boyd, and Fehr, (2003) emphasize the trait of strong reciprocity in communities, rather than self-interest or altruism. There is an inherent desire in human beings to cooperate with others. There is also a tendency in society to punish those who do not participate in the community affairs, even when the cooperative action cannot be reciprocated. These types of community forces can cause a potential donor to feel severely pressured. Individualism vs. collectivism (Triandes, 1995) is an interesting and more helpful lens with which to view living donation, as opposed to the polar opposites of coercion versus altruism. The individualist donor may primarily review his options with the focus being on what is best for him. The collectivist donor will consider the wellbeing of the whole system, and make his decision based on the greatest good for all involved. There are no altruistic donors in liver transplantation as only related candidates (emotionally or by birth) are considered at this time. Regarding helping behaviors in individualistic cultures, “it is assumed that whether a person helps or not is a matter of personal choice. But in many collectivist cultures, helping is a moral obligation, thus, obligatory, not voluntary” (Triandes, 1995, p.120).

Issues in Transplantation

A 36-year-old woman died from a drug overdose following a living donor liver resection. The organ recipient, who survived the transplant, was her three-year-old son (Ringe, Petrucci, Soriano, Reynolds, & Meyers, 2007). The above is a dramatic example of a living organ donation that irreparably harmed the donor. It is a rare occurrence but a significant one. The donor in this case used intravenous drugs soon after her living donor surgery, which takes 60% of the organ and leaves the donor with 40%. With her liver function so severely limited by the reduction in its mass, the donor overdosed. While the liver does eventually regenerate, using drugs so soon after the surgery most likely caused her death.

Transplant teams struggle with ethical dilemmas. In this case, there was no cadaver organ available for her son, and even knowing her history of drug addiction, they performed the living donor surgery to save the three year old. Can we determine if, in this case, there was a form of coercion, however subtle? If so, was its source the transplant team? Situations like these led policy makers to write the new Medicare guidelines now in place, mandating independent donor advocates. It is not known if the team members, knowing that the donor was a drug addict, in some way indicated to the mother that donation was the course she should pursue, possibly because of their own bias against addicts. In my experience, a very strong bias does exist in medical centers against drug addicts and those with drug seeking behaviors. Or, most likely, the addicted mother was motivated by her desire to save her child.

Physicians take the Hippocratic oath “first, do no harm”. It is a value and a standard of medical practice, which is pervasive throughout health care, in hospitals, clinics, and private physicians’ practices. “The ethical discussion about the possible harm to a healthy donor still continues. Harm to the donor includes psychosocial consequences of donation as well as the

possibility of medical injury. Possible psychological stresses on the donors that may arise in the family system have been discussed since the beginnings of living donations of kidneys.” (Erim et al., 2007.)

The death of a donor is an outcome naturally to be avoided at all costs. The donor described above underwent the surgical procedure, which did not benefit her health in any way and resulted in her death. That the death occurred several weeks after the donation and not on the operating table or in the hospital does not negate the fact that there is a relationship between the donation and the subsequent death.

Presumably the new Medicare guidelines for transplant teams requiring an independent living donor advocate were set in motion after cases such as this. The guidelines recommend a separate advocate for a prospective living donor, separate from the transplant team, which performs the surgery. There is an assumption that a transplant team cannot help but be affected by the recipients’ need for a new organ. The surgeons like to use their training to operate in order to save lives, and they stand to profit financially from doing more surgeries, as does the hospital. The guidelines were recently released thus data on their effectiveness is not yet available. In reality, Medicare guidelines function as directives. All hospitals and transplant centers want and need a Medicare approved transplant program, therefore all transplant teams interested in government funding will follow the Medicare directives.

Families and Health Systems

By necessity, families and transplant teams have long term relationships, often for decades. A recipient can wait for years, followed by the team, until a cadaveric organ appears. Living donation is recommended for those patients who will benefit from an earlier transplant, maintaining much of their health and vitality for a quicker complete recovery from end stage

liver disease. The length and intensity of the relationship between families and transplant team can create difficult dilemmas when living donors are used. There are confidentiality laws (HIPPA) that preclude open discussion about the reason that a donor could be found unsuitable. Philosophies about family work as a theory of intervention may hold promise for future donor families. These families are also caught in the larger structure of the hospital and the health system. Imber-Black (1998) notes that in a large system such as a hospital, which is oriented towards the individual patient, the families, who are not a target of intervention repertoires, become invisible. Often they are labeled as difficult or needy when they insist on increased involvement. With living donation, this tension is augmented because the donor's ability to act, or not, directly affects the ability of the recipient to enjoy health and life. The act of a living donor can be either destructive or to the family dynamics, or rescue them from disaster.

Emotional aspects of donation

Transplant teams have built-in structures that include social work and psychiatric assessments of potential living donors. These components of the team exist to ensure that the “wrong” patient is not allowed to proceed with a living donation. It is a matter of debate, often a heated and intense one, as to who is a “good” candidate, both for transplant as well as for living donation. However, if no consensus can be reached, the surgeon on the transplant team can (and does) refuse to perform the surgery. There is literature that directly addresses the psychosocial aspects of living organ donation, but less on living liver donation. “Little is known, however, about the factors that impinge on the psychosocial outcome following organ donation.”(Walter et al., 2002.) Of interest, in the same article, was the finding that “anger prior to surgery was the strongest predictor of perceived stress following liver donation.” The authors are referring, here, to anger on the part of a donor as a predictor that requires more attention from the transplant

center. Psychosocial assessment should target their assessments to the level of anger and rage of the donor.

“There is little knowledge of the psychosocial situation of living donors.” (Walter et al. 2005, p. 503). Their findings suggest that patients who are not recommended for surgery showed significantly more negative moods and “narcissistic rage.” Walter and colleagues (2005) recommended assessment of self-image prior to living donation with projective psychological testing. The study in Japan discovered that “two psychological indicators significantly related to the manifestation of PPS (paradoxical psychiatric syndrome), namely, alexithymia, a lack of verbalized emotion, and abnormal projective drawings, such as a truncated tree representation, although they could identify no clear psychological factors” (Shun’ichi Noma et al. 2008. p.121). A living donor candidate who cannot verbalize emotions and projects incomplete objects on psychological tests indicates that he may not be articulate enough to discuss his feelings and the representation may indicate that he feels he is or is going to be mutilated. Fukunishi, (1998), in a letter to the editor of *Nephron*, explains how the consultation-liaison psychiatric services in hospitals in Japan have included a projective psychological test to monitor the emotional state of the recipient nearing a living donor kidney transplant. “Some patients are preoccupied with medical procedures and survival, and may not be aware of, or cannot express, their anxiety and conflicts. Therefore, rather than using a self-report measure of anxiety and conflict, we included a synthetic house-tree-person (HTP) projective drawing test in our evaluation of ESRD patients several days prior to transplantation” (p. 375).

Kohut (1985) understood narcissistic rage from a psychoanalytic viewpoint of “organ inferiority and shame”. By organs he meant sexual genital organs and a sense of “organ inferiority” as the basis for narcissistic rage (Kohut, 1985, p. 134.) Of great interest, in the same

chapter he discusses the motivational role of disturbed narcissism in certain types of self-mutilation and suicide. Kohut repeats, “If thine eye offends thee, pluck it out”. Kohut also cites the fairy tale Snow White’s “Mirror mirror on the wall, who is the fairest of them all?” If someone is fairer, revenge must take place, in Snow White and the evil stepmother. Narcissistic rage demands retaliation and has the characteristic of unforgiving rage, which out of proportion exacts a heavy toll. Kohut believes in narcissistic injury there may be a removal of the cathexis for the organ and therefore can be discarded, “as if it were a foreign body.” (p.139). Kohut also states “Narcissistic rage, especially in its chronic form, when it is blocked from being directed toward the selfobject, (which is experienced as being outside the self or body-self), may shift its focus and aim at the self or at the body-self. The result in the first instance may be self-destructive depression, the consequence in the second instance may be psychosomatic illness” (Kohut p. 159). Does this quotation describe the condition of a donor who is being coerced or is forcing himself to donate? If so, will a self-destructive depression result, or a psychosomatic illness? At all costs, this type of outcome should be avoided.

Comparison Between Living Liver and Kidney Donors

While little is known about living liver donation, somewhat more is known regarding kidney living donation. There is much more literature on living kidney donation, and although the two are not identical, the literature is relevant and offers insight into living liver donation. Living kidney donation was the first transplant procedure done with living donors. Because we have two kidneys, living donation for a kidney transplant is a safer, less invasive surgery. Kidney patients also have dialysis treatments as a life-saving back up whereas liver patients do not have an alternative. “Today, according to the United Network for Organ Sharing (UNOS), almost half of all kidney donors in the US are living. In 2004, living organ donors also provided a lobe of the

liver in approximately 320 cases and a lobe of lung in approximately 15 cases” (Truog, 2005, p. 444). In other words, in kidney half of the transplantations the source is a live donor. Therefore, although kidney living donation is relevant to the analogous liver surgery, they are not identical in terms of mortality and serious complications. Although living donation for kidneys has been a more established surgery, there is still lack of systematic scientific thought and theory about the psychosocial aspects of living donation. “There was a lack of consensus regarding the structure and method of psychosocial assessment in living kidney donors. They found that only a few centers currently carry out a systematic psychosocial follow-up of recipients and their donors.” (Sajjad, Baines, Salifu, & Jindal, 2007, p. 8504).

For both living kidney and liver donors, if coercion is present, and the exploration of family dynamics and possibility of coercion occurs, the organ recipient may feel exposed and threatened. Family members may identify that the organ recipient is dismissive of or devalues the living donor. The donor may know that the family will not forgive him if he refuses to help the sick individual. Family calculus can arise, with family members reasoning that the youngest person without dependents is arguably the most appropriate to donate. Pressure on that “appropriate” person may result from these reckonings that amount to coercion.

Feminist Theory and Anthropology

The notions of family, sacrifice, and coercion are looked at by some anthropologists and feminist philosophers as political concepts, which are being used in a way that tends to victimize women and other vulnerable family members. A study of family dynamics, coercion and family conflicts could illuminate instances where the donation should not proceed, or should proceed, or if indeed, the “Good Samaritan” donor is a preferable choice in that there is minimal opportunity for coercion” (Mongoven, 2003).

Scheper-Hughes (2007) suggested that families can be predatory towards their more vulnerable members, and that the vulnerable need protection. Almost always, the most vulnerable are women, especially in the countries of Saudi Arabia, Iran, and in Africa and Asia. The number of men and women donor candidates in Saudi Arabia is about equal, but the number of male recipients far exceeds that of female recipients (Al-Khader, 2005, p. 339).

Al-Khadr (2005) in Riyadh, Saudi Arabia, wrote that “a special category of vulnerable subjects...including wives donating to husbands; and females as a whole because it was found, even in Western societies, that there is an unexplained preponderance of female donors and male recipients” (p. 339).

There are groups of individuals that tend to present themselves more often to be a donor. It has been noted that there are larger numbers of women donors than men. “Gender imbalance in living kidney donation is a worldwide phenomenon. The phenomenon of gender disparity is stable and independent from the overall number of living donations.” (Thiel, Nolte, & Tsinalis, 2005, p. 592). Of interest, we see more wife to husband donations, and until now, one husband to his wife (in my experience). According to Mohsin et al. (2007) although there was no gender imbalance in the sample of donors in Oman, there was an imbalance of male over female recipients from these donors. Who are the donors and how are they chosen? Qualitative research can begin to find how these choices are made, individually, within families, within cultures, and how will these choices influence donors and their lives.

Summary and Research Questions

Positive effects of organ donation could include saving the person the donor loves, enhanced self-esteem, and increased regard within the family and community. Negative aspects might include the recipient’s death, and for the donor, loss of health, income and well being.

Hoped for and expected changes in family dynamics may never occur, resulting in severe and massive disillusionment. Psychosocial stress on the donor may increase as the years go by, adding to the psychosocial risks they incur from the outset. There are future effects that remain unknown at this time, since the procedure is a relatively new one.

I have not found a study in my literature review done from the point of view of a social worker. Social workers are the only members of the transplant team that concern themselves with the totality of the family during a most demanding journey towards an end they do not know. This will be a beginning foray from the point of view of social work.

The living liver donor and the family experience the consequences and the rewards of living liver donation. How these donors feel about participating in living donation can be affected by coercion and negative family dynamics, tactics used to select a donor, as well as the activities of the medical team. The potential is real for donors to regret their decision whether or not to donate. While the decision to find a donor is done in a fairly short period of time and under pressure, the consequences are long term and often unknown. What are the reasons that someone volunteers to become a living organ donor and what is his or her motivation?’

The concerns shared by most families will direct attention to the issues that can contribute to the knowledge of living donation and the process of families dealing with living donation. The consideration of family issues in living organ donation will help transplant professionals formulate more knowledgeable and enlightened decisions about the candidacy of living donors and provide impetus for clinical interventions supported by evidence based practice. This study seeks to answer the question: What can transplant team members teach us about the living donor liver donation process?

Chapter II.

Living Donation and Object Relations Theory

Prometheus, a Titan, was punished by Zeus for stealing the secret of fire from the gods of Olympus and giving it to humans. He was condemned to having a portion of his liver devoured daily by an eagle. His liver regenerated each night, thus providing the eagle with eternal food and Prometheus with eternal torture (Gruessman & Benedetti, 2008, p.459)

The mythic qualities of the liver are real. And although living organ donation is a corporeal process, it has the potential to repair psychic and family conflicts as well as to hasten psychic integration, organize families and relationships along new axes and alliances.

Alternatively, if the living liver donor is not in the right psychological frame of mind, or the family is conflicted; organ donation can cause irreparable harm to the individual donating the organ, and to the family system. Organ donation can quicken the resolution of inner conflicts, faster than therapy, but not without pain. When the donor and the family are allowed to go forward with the donation process, and then are prepared for what is to follow, the benefit of organ donation may be a viable and effective force for psychic development. Ramchandani (2006) suggested that organ donation can bind unconscious conflict but may do so ineffectually. "Covert psychological factors may exert a significant role in the motivation to donate and the act of donation might be an attempt to resolve ...conflict more or less successfully." He pointed to the physical symptoms that may persist after living donation as evidence that the donation has not completely integrated all aspects of the donor's conflict, implying a somatoform diagnosis.

There are multiple theorists that can help us to understand what living donation might mean for the donor, and for the recipients. These theorists are Melanie Klein, D.W. Winnicott, Heinz Kohut, and Viktor Frankl. The relationships that are required in order to be a living donor,

that of blood or emotional significance such as marriage, are presumptive that there is significant emotional weight, an emotional burden to be borne by both donor and recipient.

If the stages of personality development and the development of secure object relations continue throughout the lifespan, as many theorists such as Winnicott, and Melanie Klein have hypothesized, then as adults, we can continually evolve in our object relations as we live in the modern world. “The wish to make reparation, so intimately bound up with the concern for the loved one and the anxiety about his death, can now be expressed in creative and constructive ways. In the psychoanalysis of adults, too, these processes and changes can be observed.” (Klein, 1975a, p. 107).

There is a prescient quality to this quote. We know that Melanie Klein did not directly consider the development of living donor surgery in her theories and writings, But factors of reparation, and concern about the loved one’s death to be expressed creatively and constructively describes what it must be like for a donor, of his or her own free will, to embark on the journey of living donation. Melanie Klein and other object relations theorists “have retained an emphasis on bodily experience as a source of ego vitality and creative and constructive thinking. In so doing, they tend to avoid the bifurcation of experience repeated in clinical theory, and do not privilege speaking over being or secondary process over primary process” (Lombardi, 2006, p. 380). The importance of bodily experience in human development theory cannot be over-emphasized. Will the next generation of personality development theorists incorporate current scientific advancements such as living organ donation in their philosophies?

A physical “gift” of an organ, from one to another, may accelerate the same processes of self-realization and integration that psychotherapy attempts to foster.

Organ capture within families involves an intensely private dynamic that often escapes the most careful medical professionals...The tendency is to choose the least valuable,

least productive family member, the unemployed maiden aunt, for example.... The gift the recipient has received from the donor is so extraordinary that it is inherently unreciprocal. It has no physical or symbolic equivalent. As a consequence, the giver, the receiver, and their families may find themselves locked in a creditor-debtor vise that binds them to each other in a mutually fettering way (Scheper –Hughes, 2007, p. 4).

Those who are not medically sophisticated, or superstitious, may view a successfully transplanted patient as an aberration that is an affront to the natural order. However, the scientific progress has saved the life of their loved one and they themselves supplied the key ingredient. Does the introduction of another organism's body parts, or cells, psychologically impact the recipient, especially if that organism is alive and well, in your living room or across the table? For the one who presents the gift, it is their opportunity to bequeath health and life, and to concretely make reparation and love from the emotion of guilt. It does not appear to be as easy an adjustment for the recipient.

The recipient may have uncomfortable feelings of being a debtor, and never able to reciprocate. This may affect the family dynamics. There were several cases in which the recipient said that they knew that they owed the donor their lives, but they worried about when would the obligation of gratitude end. We have also heard from donors that relationships go on as before, with little to no change in terms of affection, attention, or status changes. If the donor is expecting to restore their reputation or place in the family that has been disrupted, there are opportunities for disillusionment and disappointment. We have heard donors express sadness because they expected to be admired, and take a celebrated position within the family. Over time, they may return to the original rank in the hierarchy, with their attempts at repair dismissed and devalued. Donors who receive attention from physicians and surgeons for their heroic deeds may experience them as paternal and maternal ideals. Will the doctors maintain the level of attention and care post transplant? This is highly doubtful, but it is often misunderstood by patients and

experienced as rejection. There are donors who have experienced disappointment at the lack of renewed energy and investment in mutual repair or restoration of the relationship between themselves and the recipient. Careful psychosocial and family assessment along with reminders to have low expectations of gratitude is of the utmost importance for the donor to have a realistic and grounded view of his act.

Conscious and Unconscious Factors

Why does someone volunteer to become a living organ donor and what is his or her motivation? There are multiple theorists that can help us understand the phenomenon of organ donation today. Although organ donation is a concrete process, it does hold the promise to resolve psychic and family conflicts, result in psychic integration, and mobilize families. Alternatively, if the donor is not in the right psychological frame of mind, or the family is conflicted; organ donation can cause irreparable harm to the individual organ donor, and to the family system. Ramchandani (2006, p. 291) stated that there is a “range of overt and covert motives which may operate in the decision to donate an organ. Any individual who volunteers to be a donor likely has mixed motives that derive not only from conscious but also unconscious factors. The decision to volunteer therefore may be psychodynamically understood as a compromise between opposing psychological forces in an attempt to resolve the underlying psychological conflict.” The unconscious psychological forces, which propel donors, need to be recognized by the transplant psychiatrist and social worker prior to any invasive procedure in order to circumvent an undesirable psychological outcome for the donor and for the family. This may require several meetings with the donor, and the family as well, prior to the surgery. Or, the psychological forces may never be revealed.

The apparatus of the collective psyche for donors is differentiated from the non-donor by Cleveland (1975). But he discussed people who will their bodies for donation at the time of death. Is it easier to decide to donate when the body has integrity and there is a sense of identity that will remain intact? This is an interesting area for further study. Are there collective attributes for living donors? Living donors for each organ (kidney, liver) may be even more distinct.

Thirty adults willing their body at death to medical science were compared on a number of personality variables with 30 nondonors, both groups equated for age, education and socioeconomic status. Donors are internally directed, masters of their fate; nondonors rely on chance or luck to explain outcome. A more definite body image characterizes donors while nondonors are more concerned about body integrity. At the fantasy level donors display more hostility, depression and guilt, and the prospective act of donation may represent an attempt at atonement. Donation represents a convenient and socially acceptable outlet for expression of humanitarian needs by donors (Cleveland, 1975, p. 313).

The act of donation transforms and accelerates the “harsh, punitive and retaliatory superego in the paranoid schizoid position to a more forgiving and helpful one in the depressive position” (Grotstein, 2004, p. 257). If all stages of personality development and object relations are with us all of the time, as Winnicott, and others have hypothesized, then as adults, we can continually develop and advance in our object relations as we coexist with new technology. Donors with a psychiatric diagnosis as well as those with no previously diagnosed psychiatric disturbance can psychologically benefit from the act of organ donation. “Based on previous reports of the positive psychological benefits of live organ donation and the fact that donors with a psychiatric diagnosis were no more hesitant to go through the process again, it is also possible that donation led to mental health gains in this subset of donors” (DuBay et al., 2009, p. 1176.)

Melanie Klein

Melanie Klein –one of the founders of the British School of Object Relations- concentrated on the emotional life of the infant and hoped to “draw conclusions about adulthood

and mental health.”(Klein, 1975, p. 177). She believed that infants were born with internalized physical images of body parts, especially the breast, but also the penis, anus, milk, urine and faeces, and other babies and that they phantasized about putting “Badness, primarily bad excrements and bad parts of the self into the mother, and first of all into the breast, in order to spoil and destroy her.”(Klein, 1975, p.181). Melanie Klein’s self was not empty, as Winnicott’s, but came equipped with imagoes, emotions, visualizations and impulses.

Klein imagined that the infant had destructive phantasies when the breast did not gratify her and that her phantasies are of attacking the breast and destroying it. Then, “ the baby finds support against these ... in omnipotent phantasies of a restoring kind: ...he may soon build up phantasies that he is putting the bits together again and repairing her. This, however, does not quite do away with his fears of having destroyed the object, which, as we know, is the one whom he loves and needs most, and on whom he is entirely dependent. In my view, these basic conflicts profoundly influence the course and the force of the emotional lives of grown-up individuals” (Klein, 1975B, p. 308-309).

We can only speculate as to what conclusions she may have arrived regarding adulthood and psychic health today had she known about living organ donation. The adult may achieve reparation and restoration by putting a portion of his own body into, perhaps, his mother or another significant other, which heals rather than destroys. The recipient may feel shame and culpability about accepting an organ. The mothers or father feel that they cannibalize and incorporate their young in accepting the organ donation, or they do not deserve the organ. This may account for many patients who refuse to allow their children or younger relatives to donate.

The concept of gratitude is an important aspect of the discussion with the potential donor and all those who are involved in the live organ donation. Discussions and expressions of

gratitude are a significant task for the recipient and family (Mauss, 1950). The only involved party who has anything to lose is the donor.”...the transplant industry is failing to take into account the key element of gift-giving, the notion of reciprocity” (Ravitsky, Fiester & Caplan, 2009, p.695). The patient must be affected by the illness enough to require a transplant, which means that they are close to death; therefore, they have their life to gain. The physicians and the hospital gain the prestige of being on “the cutting edge” as well as the financial rewards for this surgery. The donor risks her life with no compensation, or is it that simple? “It is enjoyment that forms the basis for gratitude...in my view, these experiences constitute...the basis of...all later happiness...in a good relation to the internal and external object, the wish to preserve and spare it predominates“ (Klein, 1975a, p.188).

“Gratitude is closely bound up with generosity. Inner wealth derives from having assimilated the good object so that the individual becomes able to share its gifts with others” (Klein, 1975a, p.189). Klein was not literally speaking of body parts when she wrote, “Share its gifts with others” but it is a paradox that this corresponds to reality in the 21st century. There is never an end to the debt of gratitude owed by the recipient.

Gifts are never ‘free’: they inevitably come with strings, making the recipient beholden in crucial ways. Every gift is both altruistic and indebted, spontaneous and calculated. Gifts may demand counter-gifts, even though time may elapse and the return gift may or may not be in kind. Pure altruism does not exist, except perhaps towards one’s children...(Scheper-Hughes, 2007, p. 510).

Grotstein (2004) explains Klein’s theory of the superego’s movement from paranoid schizoid position to the depressive position, which results in progress towards reconciliation and restoration: ...”One sees a dramatic change in the nature of the superego as the infant evolves from the paranoid-schizoid position (P-S) to the depressive position (D). Whereas the earlier, archaic superego (or really, superegos) that characterizes P-S is comprised of ‘rogue’ or alienated

aspects of the infant now chimerically altering the image of the object.... There is also a propensity on the part of the infant in D to pine for the loss of the object, which has now become a whole object or really a subject in its own right. Klein associated the onset of D with weaning and other aspects of the experience of separation from mother... mother's disappearance was caused by the infant's sense of badness. The infant then becomes repentant, surrenders its omnipotence and excessive narcissism to the object, becomes more realistic and seeks to undertake reparations and restorations of the object that it felt it had erstwhile damaged."(Grotstein, 2004, p. 26). Living organ donation is illustrative of the infant's impulse to restore damaged parts of the object, but, for living organ donors, the impulse is from the infant within the adult.

Currently the only people allowed to donate in our program are those with significant relationships to a person in end stage liver failure. Consequently, we force relatives to accept gifts that compel them to be indebted to a close family connection. Do relationships between donor and recipient suffer, or are they enhanced over time? How does it affect the rest of the involved family and extended family? Intervention research that explores techniques to assist all involved parties would be a contribution to the field. This paper proposes to enlist the help of Winnicott, Kohut and Klein to understand the dynamics of the gift of living organ donation.

Klein explained how guilty feelings transmute into the impulse to help:

...feelings of guilt and the anxiety about the death of the loved person, with which the child's mind had been unable to cope because they were overwhelming, gradually diminish, become less intense and are then manageable. This has the effect of increasing the child's concern for other people, of stimulating pity and identification with them, and thus love altogether is increased. The wish to make reparation, so intimately bound up with the concern for the loved one and the anxiety about his death, can now be expressed in creative and constructive ways. In the psychoanalysis of adults, too, these processes and changes can be observed (Klein, 1975a, p. 107).

Klein spoke of the “paranoid schizoid position,” that is, during the first three to four months of life, splitting process, involving the splitting of the first object... are at their height. Hatred and persecutory anxiety become attached to the frustrating “bad” breast, and love and reassurance to the gratifying “good” breast. “This precedes the depressive position, which “during the period from three to six months considerable progress in the integration of the ego comes about... The infant perceives and introjects the mother increasingly as a complete person. This implies a fuller identification and a more stable relation with her” (Klein, 1975a, p. 34 & 35).

It is from the depressive position that the individual can integrate the part-objects, the breast, mother and father who were injured by the aggressive infant, who now feels guilt, and “feels an over-riding urge to preserve, repair or revive the loved objects: the tendency to make reparation.” This seems to be a universal attribute that all adults have buried in their psyche. It coincides with feelings of guilt that “the harm done to the loved object is caused by the subject’s aggressive impulses.” (Klein, a, 1975, p.35-36).

As far back as 1975, Cleveland apprehended that donors may have intrapsychic unresolved conflicts, which play out in their decision to donate. More than once this writer has heard prospective donors talk about atoning for mistakes in their past.

Donors (60%) more frequently than nondonors (27%) include in their stories intropunitive themes, people who are suffering or in pain. Hostility in the stories given by donors is treated in an intropunitive fashion so that feelings of guilt and depression are more frequently stressed than is the case in stories given by nondonors. Present findings suggest that donors do have special trouble in handling some problems of living.... donors tend to express hostility intropunitively with attendant feelings of guilt and depression. Perhaps the prospective act of tissue donation represents atonement for such sentiments (Cleveland, 1975, p. 318).

In this study by Cleveland about prospective cadaveric donors before living donation was even possible, the description of the donor seems to bear out the theories of Melanie Klein’s

love, reparation, gratitude and movement from the paranoid-schizoid position by going from aggression to guilt in the depressive position, or to Winnicott's capacity for concern.

Melanie Klein introduced the formation of the superego earlier than did Freud, and located the "origin of the archaic superego in terms of the process of projective identification from the infant to the image of the object which, now modified by the projected identity, becomes internalized, reidentified with, and transformed into a superego....". The phenomenon of projective identification may have some bearing on living donation. The coercive elements within the family would involve projective identification.

Almost every living donor that I have worked with has affirmed that donation was the best thing they had ever done, they would do it again, and they felt wonderful about the outcome. The old adage must be true that it is better to give than receive, better to be the one who has the "milk" than the one who wants it. In a summary of a conference at the National Institutes of Health, Shiffman and colleagues (2002) wrote:

After this procedure, donors have uniformly expressed satisfaction with their decision regardless of the outcome in the recipient. None of the donors regretted their decision, and nearly all stated they would donate again despite having lost time from work and incurring significant out-of-pocket expenses. This also was true for donors who experienced minor and even major complications after surgery. Donor quality of life mirrors that observed in the healthy adult population, and in many cases, donors perceive their quality of life to be improved after this experience. (p. 182).

But for some, over the long term, especially for those with low family status, when the gift is not truly recognized for what it is, the recipient can seem to be dismissive and narcissistic. This has also been true of the larger extended families' attitudes about the donation. They say, "It's no big deal. "or "The donor is not the sick one, the patient is! She'll be fine. It's him I'm worried about." Many times, with several families, when asked about the arrangements to provide care for the donor, families are truly caught off guard. They have not anticipated that the

donor will have needs. In 1971, Muslin wrote of the “Psychiatric aspects of renal failure.” He wrote of the reaction of recipients of living and cadaveric donors. “A reaction that we have seen involves an attempt on the part of the patient-recipient to deny, avoid, or repress the ‘gift’ that has been presented to him. One patient said ‘my brother, oh, he’s fine, he’s healthy, he’s a football player. He doesn’t need two kidneys.’ Another patient quickly pointed out that his younger brother was saved from going to Vietnam by being his donor.”(p. 1186).

Melanie Klein’s theories speak directly to the phenomenon of living organ donation in a startling imagistic and concrete voice. Her theory is limiting, having much to do with infantile aggression and its psychic repercussions. Winnicott (1971) has a gentler approach and is more aligned with social work than Klein. Klein preferred to give deep and penetrating interpretations, even to children as she analyzed them. Winnicott was an ideological descendent of Klein’s, and although he never formally repudiated her, his theories evolved well beyond hers. His approach utilized concepts like “Being alone in the company of someone” and the holding environment, which builds outward from concentric circles around the mother and baby. I will now concentrate on the contributions of Kohut and Winnicott that may enhance our understanding of living donation.

Kohut and the “Selfobject”

Kohut’s emphasis on empathy is also more in line with social work theories and more useful to social workers in practice. A case can be made that the transplanted organ, for all transplant patients, is valued as a transitional object or selfobject. Transplant patients with cadaveric organs know its value. Most have waited many years in a serious state of ill health before they are transplanted, whereas living donor recipients have much more latitude and choice about when the transplant is performed. The optimum time for them to arrange the surgery is

when they are not “too” sick. Many cadaveric recipients feel strongly about the donor that they know nothing about. (United Network for Organ Sharing and federal government mandated a policy of anonymity between cadaveric donors, and their recipients.) They imagine what the donor was like, and what they liked to eat. They notice, for example, that they never liked coffee before, but now it is essential every morning. They wonder about the personality of the donor, how they died, and write thank you letters anonymously to the donor family. They keep the family and the donor in their prayers, and ritualize gratitude at celebratory and religious occasions for their donor. They possess this organ; it belongs to them but it remains a “container” of the individuality of the donor.

Perhaps, when seen through Winnicott’s work, the new organ also fulfills a function for the recipient as a transitional object in some way. Winnicott, ’s (1971) transitional object, capacity for concern and the holding environment are much more useful for social workers in practice with any population than the theories of Melanie Klein. Kohut developed the idea of “selfobject” to describe the object in the environment who “performs the actions of the self; these functions evoke the experience of selfhood. (Fonagy, 2003, p.165). The selfobject is created by the parent’s empathy, mirroring, and then allowing the child to idealize and identify with them. The “selfobject” illustrates the unseparated, psychologically merged nature of the infant –parent relationship:” (Cushman, 1995, p. 264). Kohut located the self at “the center of psychological life, and in fact, at the center of the cultural stage.” (Cushman, p. 262). The selfobject not only exists in the infant, but also continues on through adulthood and all stages of life. “...in his last years, ...arguing that to varying degrees healthy individuals use others in this way throughout their lives.” (Cushman, p. 272). The selfobject in adults often looks to merge with charismatic leaders and celebrities in order to help the person feel important, strong and

powerful. This can be used to explain the popularity of political movements and leaders in the past century. To a great extent, Kohut's theories were predicated on the development of modern industrial society, contrasted with feudal and peasant life in the distant past. He felt that in the past, the parents and children were out of necessity, too enmeshed, while in the present, intimacy is lacking because parents work in places separated from the home.

Cushman argues persuasively that Kohut's concept of the psychological self permeated throughout the society of the post-war United States and affected not only patients and their therapy but also the culture and the "new" American self. Even advertising can be explained by the self theory of Kohut, advertising which affect the entirety of American life. A consumer culture was developed in post war America and we can follow a line between the consumer as the new representative symbol of the American and the advent of living donation surgery. What is a transplant patient if not a consumer of health care and new healthy tissue? There are transplant tourists who travel to countries where an organ can be cheaply procured, when the waiting list is too long.

If a new organ from a living donor is a commodity, which is defined as an item bought or sold, or something that people value, it would represent the relationship and life between recipient and donor, both living and cadaveric, just as goods represent the labor in industrial society. The relationship between the giver and the taker, in which the taker cannot reciprocate, is a lopsided and unstable one. Organs have become commodified today, and in the United States they are commodities to be received and given, not bought and sold.

Other cultures have a more contextual grasp of human life. Western thought reifies the individual self and its imperatives often at the expense of the benefit of others surrounding that self. Kohut sees the self as using objects, and selfobjects until their value dissipates, afterwards

the self can move on towards the new selfobject. It is a western, and male, romantic and Victorian view of the self and its importance. (Cushman, 1995). The self, with its imperatives to grow and advance, must ingest and incorporate others as selfobjects in order to achieve integrity and independence. As described by Cushman, (1995) this self suggests a voracious metabolizing machine. It is an empty self, needing to be filled by merging with selfobjects. Unlike Melanie Klein, whose infant comes into the world with internally produced images of body parts including the breast, phallus and the rest; the self that Kohut speaks of is an empty vessel. Cushman states, “Where would the economy be today if Americans did not consider themselves entitled to every consumer item they can purchase or find credit for? In other words, where would these industries be [celebrity, culinary, exercise, diet, cosmetic] if adults were not exhibitionistic and grandiose, hungry for mirroring and merging with celebrities and politicians?”(p. 273). Does entitlement extend to taking organs from our families and friends?

Kohut’s self-object becomes internalized and the self imports new self-objects throughout life to maintain cohesion. Through the act of internalizing these selfobjects, the personality maintains its organization and structure. Will the organ from the living donor become a new selfobject to the recipient? Maybe the following quote can be an explanation of the recipient’s attitude towards the living donor. Fonagy (2003) states, “Selfobjects are experienced as part of oneself whereas objects are the targets of desires, emanating from a more demarcated self-concept.”(p.167). The organ is no longer an object of desire, but a part of oneself. Can this theory be used to explain why recipients of organs from living donors can behave in dismissive narcissistic way?

Kohut has thoughts about courage and the idealization of selfobjects that are relevant to the discussion of living organ donation. A living donor is a person who utilizes his courage, full

strength, in order to help someone he loves. In his discussion about courage, he defines the nuclear self as the one most resistant to change. It is composed of the grandiose self, and has unconscious, preconscious and conscious attributes in the id, ego and superego. However the nuclear self is “transmutable” and changes over time and during important stages of life such as adolescence and responds to changes in the environment. The courageous individual “is compelled to proceed on his lonely road, even if it means his individual destruction, because he must shape the pattern of his life – his thoughts, deeds and attitudes - in accordance with the design of his nuclear self” (Kohut, 1985, p.9).

His discussion of courage includes several heroes of WWII such as Hans and Sophie Scholl, and other people who stood up to the Nazis knowing that the consequences could be their own death. Does this not apply to the living donor, in that the individual, knowing the possible consequences, which include his own death, does deliberately throw himself in harm’s way to protect and help the those who are in need? “Courage can be defined as the ability to brave death and to tolerate destruction rather than to betray the nucleus of one’s psychological being, that is, one’s ideals.” (Kohut, 1985, p.6). In his discourse about courage, Kohut infers that many people who are thought of as courageous are “those who rely on a merger of reality with inspiring prototypical figures...that of the idealized, omnipotent selfobject” (Kohut, 1985, p.8). Here we can see that the selfobject plays a role in living donation for the donor as well as the recipient. Kohut sees the courageous man as going beyond Freud’s pleasure principle. He talks of two archetypes of man, guilty man and tragic man. (Kohut, p.36). “Every individual has two courses open to him and every individual, in one way or another, follows both of them. No man is excluded from participating in the tragic dimensions of life.... the compelling urge to realize the deep-rooted design of his nuclear self” (Kohut, p. 38). The possibility of organ donation places

people in these profound spaces where choices of the average individual will have the import of life or death for another.

Foray's (2003) following quote is a possible explanation for the living donor. "Self objects are experienced as part of oneself whereas objects are the targets of desires, emanating from a more demarcated self-concept"(p. 167). The donor is no longer an object of desire, but a part of oneself. As for the recipient, the organ and/or the donor can be a selfobject to integrate, or expel, as the self uses selfobjects for a time until it moves onto another.

Winnicott

Winnicott is a member of the British Object Relations School, loyal to both Freud and Klein. He moved far beyond them with his own theories. Among his outstanding contributions to object relations, are the transitional object and the false self. Winnicott's (1971) transitional object, capacity for concern and the holding environment are much more useful for social workers in practice with any population than the theories of Melanie Klein. Perhaps the new organ also functions as a transitional object in some way. A case could be made that the transplanted organ for all transplant patients, is valued as a transitional object. Winnicott (1971) describes the transitional object as different from oral excitement and satisfaction:

The nature of the object, The infant's capacity to recognize the object as not-me, The place of the object-outside, inside, at the border, the infant's capacity to create, think up, devise, originate, produce an object, the initiation of an affectionate type of object relationship. I introduce the terms ...to describe primary unawareness of indebtedness and the acknowledgement of indebtedness. Use made of objects that are not part of the infant's body yet are not fully recognized as belonging to external reality (p.2).

Greenberg and Mitchell (1983) explained the spirit of the transitional object in a way that seems to also describe aspects of organ donation for the recipient. Unspoken rules, gratitude unexpressed or ignored and tacit agreement between the parties sound like the way the infant and parent handle transitional objects.

How is it possible for an object to be neither under illusory, omnipotent control nor part of objective reality? Winnicott suggests that what is necessary for the establishment of a transitional object (such as a blanket or teddy bear) is a tacit agreement between the adults and the baby not to question the origin and nature of that object. The parent proceeds as if the baby had created the object and maintains control over it, yet also acknowledges its objective existence in the world of other people (Greenberg & Mitchell, 1983, p. 195).

Is the newly donated organ a transitional object in the relationship between the donor and the recipient? “The transitional object is used to facilitate separation” (Berzoff, Melano-Flanagan, & Hertz, 2002, p. 139) between the infant and the mother. If the organ functions as a transitional object, it might be because the transplant is an uncomfortable subject; if things go well, then life goes on, yet something has changed in the relationship between donor and recipient. Perhaps the organ from living donation, because it is a transitional object, then helps to assist a healthy separation between the donor and recipient.

Recipients

Transplant patients with cadaveric organs know the value of the organ. Most have waited many years in a serious state of ill health before they are transplanted, whereas living donor recipients have much more latitude and choice about when the transplant is performed. The optimum time for them to arrange the surgery is when they are not “too” sick. Many cadaveric recipients feel strongly about the donor that they know nothing about (United Network for Organ Sharing mandated a policy of anonymity between cadaveric donors and their recipients unless both sides are willing to be in contact.) They imagine what the donor was like, and what they liked to eat. They write thank you letters anonymously to the donor family. They keep the family and the donor in their prayers and ritualize gratitude at important and religious occasions for their donor. They possess this organ; it belongs to them, but it remains a “container” of the individuality of the donor.

The anonymous nature of the cadaveric organ donor allows for more idealization and positive cathexis than for the living related donor. More often than not, I had noticed a dismissive devaluing response from recipients of living donors. The donated organ links two individuals. The donated organ can take on the features of a selfobject as discussed by Kohut, or a transitional object as described by Winnicott. If it is a transitional object, the organ is a means of separating from the donor, just as the transitional object is a tool for the infant to separate from the mother. We know that some recipients of cadaveric organs tend to idealize the donor and patients organize ceremonies to honor the dead donor and the donor family. We do not know how, or if, the recipients of organs from living donors honor their donors.

Viktor Frankl

Viktor Frankl's theory may hold a key to understanding some of the underlying motives of both donor and recipient, which could seriously affect the psychosocial outcomes of living donor families. In *Man's Search for Meaning* (1959) Frankl said "...it did not really matter what we expected from life but rather what life expected from us...our answer must consist, not in talk and meditation, but in right action and in right conduct. Life ultimately means taking the responsibility to find the right answer to its problems and to fulfill the tasks which it constantly sets for each individual" (p. 77).

Many of the donors that we meet have indicated that their decision to risk their lives in donation was 'the right thing to do.' The recipients also have indicated similar feelings when they reject the offer of donation, usually from one of their children. Often they feel it is ethically wrong to take a vital organ from one's child. They feel they had their chance at life and do not wish to interfere with their child's ability to do the same. By their refusal they are risking death, or long, chronic and severe illness, sometimes with cognitive side effects that mimic senile

dementia. Their expressed feelings often consist of moral judgments of right and wrong.

Viewing living donation through the prism of Viktor Frankl's existential philosophy has offered a different understanding of the motivation of the donors.

Viktor Frankl was unaware that in 2008 it would be possible to donate a significant portion of your liver to a loved one and then regenerate your own liver back to its normal size. It seems though, that he would have recognized that living donation has its potential, not only to save lives, but also to improve and enhance the meaning of the lives of the donors. One important group I have not mentioned are the parents of infants and young children who need liver transplant. In every case in which this social worker has been involved, the parent donor is without doubts, full of conviction, and is frantic to proceed with donation as fast as possible in order to save their children's lives. Frankl's logotherapy is referenced by Papachristou, Walter, Frommer and Klapp, (2009) as a tool for helping donors and enhancing the assessment of living donors. The authors (2009) stress that an important benchmark for the donor is the ability to "embed the donation into a context meaningful for them" (p. 1683). The emphasis on context and meaning supports the idea that individual donors must be able to discover, in their own individual stories, a significant reason, intention, or principle, for themselves. Opposing that view, Scheper-Hughes (2007) says... " Anthropologists entertain different assumptions than physicians about the nature of families, altruism, gifting and human sacrifice. Families are often violent and predatory, as inclined to abuse and exploit as to protect and nurture their members... Pure altruism does not exist, except perhaps towards one's children, and bio-evolutionists would point out that parental sacrifice hides another sort of (genetic) self interest"(p.3).

Surely this applies to many families, but when I meet the parents of a sick child, this point of view appears overwrought. Even in families with older children and adults, most cases

seem more to reflect Frankl's viewpoint rather than Scheper-Hughes' viewpoint. Gintis and colleagues (2007) have interpreted their findings in a way that support Frankl's more optimistic view of the person. They noted that: "Forms of human behavior involving interaction among unrelated individuals that cannot be explained...strong reciprocity is a predisposition to cooperate with others...at personal cost even when it is implausible to expect that these costs will be repaid either by others or at a later date" (p.605). The donor knows that the gift cannot be repaid, either by the recipient, the family or by society. Yet there continue to be new volunteers – Good Samaritans as well as involved family members.

Living organ donation is a psychologically complex development in modern life. I have attempted to use the theories of Melanie Klein, Heinz Kohut, D. W. Winnicott and Victor Frankl to theorize about the psychological basis of organ donation and the experience of the recipient. Melanie Klein's infant with preformed imagoes of body parts develops to attempt repair for the mother with whom it was angry. A living donor could attempt to repair a parent or parent substitute by donation, or act to atone for previously imagined or actual wrongs. Kohut's infant requires merging with another more powerful individual, called the selfobject, in order to flourish and develop into adulthood. The living donor may wish to merge with a more powerful individual, or use another person as a selfobject to enhance his development. Additionally, a recipient could apprehend a new selfobject in the newly donated organ. Winnicott's infant uses something that is "not me" as a transitional object to bridge infancy and later development. A recipient may cathect to his new cadaveric or living organ as a transitional or a selfobject. The transitional object is "not me" and also contains source of the donor's individual vitality. Frankl's adult organizes his life around moral obligations and right action in responding to a situation in which one's help is required.

With the recent developments in stem cell research, organ transplants may become obsolete when stem cells regenerate a new organ from a patient's own cells. In November of 2008, surgeons were able to take a windpipe from a cadaver and from the frame, add recipient's cells to grow a windpipe that was compatible. This type of intervention would do away with the need for immunosuppression medications. Until the day that organs can be grown from one's own stem cells, it behooves us to take extreme care with living donation, and "do no harm."

The theorists Klein, Kohut, Winnicott and Frankl have shown that their theories are relevant to situations that result from the most current and cutting edge of science available today.

Chapter III:

Methods

Rationale for Research

There is a lack of knowledge about family processes in living donation, and the negative effects of living donation can include death. Yet living donation is a life saving and life affirming medical procedure. We are inexperienced in our understanding of the full progression of a family towards living donation. Coercion, a primary concern in living donation, comes in many forms and the living donor must be protected from acting against his or her will. Finally, there are cultural, ethnic and religious factors which effect living donors that are still underestimated and cause barriers for some to avail themselves of living donation for their loved ones.

The finding that recipients with an unstable family or support system tended to be depressed after living liver donation might indicate that conflicted feelings related to organ donation from living family members could exist. If we could obtain more specific information about the relationship between the recipient and donor or other family members, the factors of the family situation significantly associated with post-transplant depression would be revealed (Noma et al., 2008, p. 124).

Research Questions

This study focuses on learning from the transplant team members about their professional experiences of living donation. How do transplant staff perceive the process, consequences, and rewards of living donation for the patient and family? How do they feel about their participation in living donation? Would deep contextual information about donors and their families be beneficial in choosing live donor-recipient pairs? Would an emphasis on family dynamics and family culture improve a team member's ability to detect coercion when deception is present?

Methodology

This dissertation presents a qualitative study of transplant team members' perceptions of living liver donation, based on their experiences working with such donors. Qualitative description is especially suited to answering questions about "concerns of people about an event, ... what reasons do people have for using or not using a service or procedure?" (Sandelowski, 2000, p. 337). Qualitative studies are also ideal for discovering "themes and patterns that underlie developments in every sector...for example, that each family member expresses the same unvoiced concern" (Weiss, p. 45). I have used "issue focused" analysis of the interviews, interpreting all the responses from the participants for any issues that arise within the interview, rather than one issue or one respondent (Weiss, 1994). I wrote memos for each interview to record additional information about the context of the interview, non-verbal cues and my responses. The interviews were coded for thematic material, which arose from the interviews as well as the interviewer's experience and background research. The questionnaire was adjusted for any new material uncovered in the interview as the study proceeds. The interviews were transcribed from the audiotape verbatim. Each interview lasted between 45 minutes to one hour, including the completion of the consent form. Identifying information was deleted from the transcripts to protect the confidentiality of the participants. The tapes were stored in a locked file cabinet during the data collection in the researcher's home and will be destroyed a year after the study is completed. Qualitative studies are ideal for discovering "themes and patterns that underlie developments in every sector...for example, that each family member expresses the same unvoiced concern" Weiss, p. 45).

Ten interviews with a variety of transplant staff, to include social workers, nurses and physicians who are familiar with living donation, were completed. The interviews took place in

each staff members' respective hospital at the convenience of the transplant staff. All interviews were audiotaped. They were performed in a private office or at the team member's choice of location. As previously indicated, all interviews were transcribed and coded for thematic material.

Participants

The inclusionary criteria for participation in the study: membership of a transplant team at a major teaching hospital. I used a purposive convenience sample of ten people on different teams.

I interviewed ten members of the transplant team at large urban teaching hospitals on the East Coast who have worked with living donors as they moved through the transplant process. Most of the professionals interviewed were known to me from previous clinical involvements. The data was analyzed using qualitative issue-focused methodology (Weiss, 1994). I used line by line coding to produce concepts, categories and themes. As the transcripts were coded I wrote memos about the coding process and also kept an interview journal about my thoughts regarding the interviews, so as to have maximum reflexivity.

Data Management

Transcripts and tapes were kept in a locked file in the interviewer's home and the results will be kept confidential from the team and other hospital personnel. An interview journal was kept as well as memos. The journal was to keep notes about the interview, and the memos were for thoughts as interviews are transcribed and coded. Identifying data was deleted from the transcripts after completion. Consent forms were kept in a separate file from the tapes and transcriptions so that there was no possibility of linking identities to the consent form. Tapes, notes and transcriptions will be destroyed a year after the study is finished.

Benefits/Risks

There were no immediate benefits to the participants except to add to the field of knowledge about living donation. The risks to the participants were primarily increased stress or anxiety or depression. If any of these effects had occurred the interview would have been stopped and if necessary, referral to a mental health practitioner would have been provided. Participation in the study was voluntary and this was explained in the interview.

Human Subjects

Approval from the hospitals' IRB was required to proceed with this study and obtained. The participants' privacy and confidentiality will be protected in case of a review. Participants signed a consent form (Appendix B) assuring them that their participation was voluntary and that nobody from the transplant team would have access to information that they participated in the study.

Chapter IV:

Findings

The field of living organ donation is in its earliest stages. The concerns of the team members seem to be centered on assessment and evaluation in order to avoid situations of coercion, financial incentives, and other ethical dilemmas. The research questions asked earlier in the paper are: “How do transplant staff members perceive the process, consequences and rewards of living donation for the patient and family? How do they feel about their participation in living donation? Would deep contextual information about donors and their families be beneficial in choosing live donor-recipient pairs? Would an emphasis on family dynamics and family culture improve a team members’ ability to detect coercion when deception is present?”

In this chapter I have organized the results of 10 interviews into groups of similar themes that occurred frequently in the interviews. The chapter is organized to first discuss general aspects of living organ donation, following that is a discussion involving the team, and finally particular themes about the family and the donor are explored. The first theme is transplant as a family illness, where respondents emphasize the family context of an end stage liver or kidney disease, which can be treated by transplantation and living organ donation. The second subject is about family dynamics between generations, although each case example in this chapter revolves around different family dynamics. The third theme encompasses donation as a redemptive act, to fix a relationship that is broken, and to account for past or other motivations. The fourth topic describes the staff’s concerns for the recipient. The fifth theme is about the authority that emanates from the team once they tell the patient that they will improve with a living donor. The fifth theme is a discussion about paternalism. Section six depicts aspects of the medical excuse. The seventh theme concerns coercion. Section eight is about guilt and its effects on living

donors. The ninth topic features a discussion of pediatric cases. Section ten considers deception and its impact on living donation. Ethnicity and religion comprise the eleventh section, and a discussion of ethical dilemmas is the twelfth subject. The thirteenth topic consists of the emotional aspects of living donation, including rage. The fourteenth theme is about financial incentives and coercion and the fifteenth subject is about the aftermath of living donation. The sixteenth theme is a discussion about living donation being in its early stages. The last section provides advice to other team members. I have interviewed 10 team members including coordinators, social workers, hepatologists, psychiatrists and surgeons. Their ideas and feelings about living donation are the scope of this chapter.

Theme 1: Transplant as a Family Illness

A key theme that emerged from the interview was whether or not the professional views the family as one complex unit or one sees two independent actors: the donor and the recipient. One participant stated, “Transplant is a family illness.” This statement represents the opinion of a team member who does not consult with individual patients but always meets them within the context of the family. However some transplant professionals prefer to perceive donors to be separate individuals who offer their organ. If one subscribes to the latter viewpoint, one can observe donation as an isolated event. Most transplant teams emphasize family support as criteria for listing and want as much deep contextual information as possible. With living donation, the family develops into a prominent feature in the foreground. Living donors need their own support system to help care for them post transplant, and in most cases the living donor comes from the structure of the family. One team member Olive Groff, a psychiatrist, says:

I don't ever evaluate recipients alone and I see the transplant as a family illness. Social workers never see people alone it is always the unit, we don't believe we can isolate the patient from the family so we incorporate the family from the beginning as a team. I will not see them alone. I guess you didn't read the letter, come back when you have a care

team.

Does the issue of transplant as a family illness discriminate against single people or those who are without family? The ideal candidate has a support system, but there are those in need without resources. A donor could not be without support in this transplant environment. Olive Groff said:

See, I feel it's a gift exchange within a family and you as a donor team have to know the family you have to know where it's not just about taking a piece of liver but that...he is cared for, that you're looking at the big picture; it's not just the donor evaluation in a sterile environment.

There are donors who decide to donate in order to save other family members from grief and loss. One young woman, a professional athlete in her twenties wanted to donate to her father in order to ensure that her younger brother would have a father, since their mother had died years before. Similarly, Eric Pierce, a psychiatrist, recounted an incident with another donor who felt as though her own life with her mother was worth less than her father's life with her mother should the father die. This donor said Eric Pierce:

was convinced she was going to die as a result of the donation and that actually was her goal and she never made it known to anybody...in exploring the family dynamics one aspect of her heading in that direction was I think she felt very disappointed in herself for not emulating and following in the footsteps of her own father. In other words her father had children and a steady job at a much younger time in her life than the patient did...her father was also closer to her brother in terms of his growing up and the donor was closer to the mother. I interpreted this as her need to be closer to her father.

Eric Pierce also discussed a donor who was emblematic of an "intergenerational responsibility thing" where the primary motivating force is for an adult child to donate to their parent. Sandra Morrison, a social worker, said that:

very often we expect parents to donate to children but more often I see patterns of children wanting to donate to parents and often it's a way for them to pay back what the parents have given them and done for them over their lifetime...people who want to be donors may not be as financially well off as their parents were at their age, people who are 30- 40 now are struggling with jobs, saving and in and out of living at home or starting a second marriage...I find they want to donate to say thank you and help their

parents and they can't help them in other ways like sending them on a trip like other generations used to be able to do.

Another reason for living donation is to do so to save a relationship for another person in the family. "I can't imagine depriving this person of their grandfather or this person of their parent."

These donors may have already experienced loss and want to protect other family members from the pain of bereavement. Transplant teams will have to decide if this is this relevant in determining donor acceptability. Providers decide on an individual basis for each case, but would probably think this is a legitimate reason to donate.

It is important to place the donor in the context of the family in order to have a full picture of the living donor scenario. In a response to the question if donors are ever working out their past difficulties Barbara Nolan, a social worker for living kidney donors said:

I'll raise that as an issue and a lot of what my concern is how do their present families feel about it? Do they have support at home? I can think of two totally separate issues and it's actually sons... I can think of the son who said my mother and I never got along but I can do this. He was married, a good solid relationship he had children, he worked, everything was solid. I spoke to his wife too and she said I support him on this. I think he will feel better if he does it. Is it back issues? Yeah. But it's not obsession with him and that felt OK to me. The interesting thing is that later he and the mother developed a better relationship, not great, but they have a Christmas party every year and they came together, a budding of a real thing. Another one a wife who called me, actually a brother to give to a brother, and he was under pressure from his mother to donate to his brother and his wife called me and said this family has treated him terribly. He gives his kidney I'm divorcing him. I'll leave him. There were huge issues there and what ended up happening it didn't feel right to take someone as a donor with the wife threatening it felt really murky to me, believe it or not we lucked out and a cadaver donor became available...this is loaded stuff.

Alyssa, a hepatologist, talked about family dynamics of picking a donor out of a pool of potential donors:

Sometimes I think it's the family dynamic of how many kids they have... There was another patient um where the family had about seven donors, the recipient has had seven donors, maybe not seen maybe I'm exaggerating, five donors that had come through all at separate times and each person has ultimately not gone to the next step although when you meet with them they say they want to do it and they say oh it's my time in the

pecking order to do it they ultimately aren't the one to do it one of them wanted to know whether or not she could have her breast augmentation done before she could donate and she was a model and wanted to know a lot about the scars so you got the impression that although the family was like you're young and healthy why don't you step up, she wasn't ultimately going to do it because the scarring, the body image she had.

Do families target their young and vulnerable members to donate, because they are without the support of a spouse and less powerful than the mostly middle aged recipients? This concept relates to what Scheper-Hughes (2007) stated. "Families are often violent and predatory, as inclined to abuse and exploit as to protect and nurture their members...Organ capture within families involves an intensely private dynamic that often escapes the most careful medical professionals...The tendency is to choose the least valuable, least productive family member" (p. 508). Alyssa, the hepatologist, remembers another situation of a young donor who was to give his liver to his grandfather.

His grandson is twenty years old, typically we have 21 as the cutoff...and he's in the military so we thought well he's in the military and maybe he is able to hold a gun so perhaps we can go forward even though he's not 21 yet and um the family keeps saying oh he's really interested, every time we see him, he's really interested but then we can never get a hold of this guy, I think he has a prepaid cell phone so by the end of the month all his minutes are gone so you can't leave him a message he has no old phone number no one in the family knows how to get a hold on him which puts us in an awkward situation always having to call the recipient to reach the donor seems a bit unethical...he doesn't show up for appointments so you really wonder how much is he interested versus how much is the family saying listen you should be interested.

Clearly this donor was trying to tell the team he was not interested and possibly being coerced by his family. Scheper-Hughes (2007) discusses the trend of younger family members giving to the elderly. "An ethnographic study...identified a subtle practice through which children were recruited by transplant professionals to donate to their elders. This practice violates a cultural norm in American society where it is not generally expected that children be unstintingly devoted to their parents, something that immigrants from Europe were happy to leave behind." Not every family is part of the European immigration experience, But cultural norms are

evolving and being breached.

Lisa Cohen, independent donor advocate and social worker remembered a woman who was donating to her husband but was angry because other family members had not offered to donate:

one lady donating to her husband and she was appropriately motivated it was her husband but she was very angry at her husband's multiple siblings who would not step up to donate. If she had a sibling donor she would not donate because they had a child with the same potential for kidney disease so that her child could need her kidney in the future and she's giving it to her husband. One willing donor with and potential definite need for one kid and potential need for another one for a child.... it's interesting. She made no bones about it and said she was very angry with them she wasn't necessarily happy but she still wanted to do it.

This example shows how living donation is an issue for extended families. Living donation widens the circle of those who can be affected.

Ellen Moriarty, coordinator, says, "A lot of people do it because they love the person that they want to do it for..." Max Wilson, a social worker, says:

I ask what is the driving force. I even said you're about to jump out of a perfectly good airplane. It's kind of like skydiving. There's nothing wrong with you, it's kind of electively doing it, like a nose job. Whenever I ask of a husband a wife a mother a father a brother a sister they're donating to 'it's because it's my father, it's because it's my blank. I love them...9 out of 10 times it's when you have intrafamilial donation with immediate family, spouse, sibling, even grandparent it's an immediate it's automatic, they'll do it.

Olive Groff, a psychiatrist, feels it is important to treat the whole family and not to isolate the patient. She said:

I was definitely the link between, I met the whole family, the other brother that didn't donate...I helped to give him something important to do...Get out of the box and start looking at an illness as a family illness, it's a system and it's affected.

This is an example of a practitioner using the entire family system in the process to include and benefit each family member.

Theme 2: Generations

Specifically within families are pairs of parents and children, generations of a family that may need to be involved in living donation. We often see adult children giving to parents, or a parent giving to one of their children. Henry Marcus, transplant surgeon, has been observant of family dynamics with living donation and shared a story about a mother with an 18 year old daughter with cancer whose cancer goes untreated while her mother struggles with donation.

A daughter who is 18 years old developed cancer. The best of the parent is the mother who is scared to death of donation and she I think deep inside does not want to donate and her very young daughter has no choice with cancer so we are shopping around while we are working up the potential recipient and ...the mother went to Sinai where they are doing a procedure to see how the cancer is going to behave and wait and see how it will behave before going forward to a donation or surgery and I think that my gut feeling or my fear is that this kind of decision is tried by the mother's fears of donation now I'm not blaming the mother I'm not saying she's a bad mother or she doesn't do her duty but I can kind of understand and have the vision of someone who is scared to death of the surgery...they are so scared to death they are not going to stand up and donate to an 18-22 year old and look for all the reasons why to postpone and reasons not to...you can start to see how family dynamics affect plenty of those ...every case whether family or not necessarily family has enormous dynamics that we must still understand in order to...make sure we know what we are doing.

Another dynamic of interest to Henry Marcus and to others on the team is as follows,

The (previous) example I gave you is an exception. In general intuitively, intuitively, you can see parents are more willing to donate to children By the way we see much more not in adult to adult but from adult to child living donation. There the parents are jumping all over to give their young children organs...the other way around child to parent is happening quite a lot but I also see there is a resistance from the parent to accept from a child...they are under no circumstance to put their children at risk.

Henry Marcus demonstrates his awareness of family dynamics in organ donation. These two examples are illustrative of how dissimilar families can be, from a mother who hesitates to donate to her daughter to a parent who hesitates to take a donation from an offspring.

Barbara Nolan, a kidney living donor social worker said

We certainly see parents to children, that's clear. Um, we do have now that you're saying

it a lot of children, adult children giving to parents in their 50's. What is interesting to me is the recipient's reaction sometimes, I see two separate reactions one is a group of parents who say there's no way I'm taking my child's kidney it's my daughter she hasn't had children yet that's not going to happen. There's another set of parents maybe because I'm from the it's my children school; they say I told him he can donate his kidney to me. I see two separate extremes.

Barbara Nolan is clearly biased towards parents who will not allow their adult children to donate as other team members may be. Mimi Delaney, research administrator and coordinator

remembered a case where a son was giving to his father:

So I think of family and I see guys who are lost mainly from alcohol, hep C or not, alcohol on top of hep C, ...I just think they have the audacity to not even bully their kids some are fine and some people, who was the last one, when I sat there and said, 'you can get a liver that's older' cause he had turned down a liver, (and he said) 'why would I want that when I can have his?' ... Some father.

Two extreme examples of parents who need a liver transplant are illustrated by the above quotes.

One sounds unselfish, the other one very much the other way. Mimi Delaney also discusses the recipients who have caused their disease, implying that they do not have the right to take a living donation from their children.

Theme 3: Donation is Multifaceted: Redemption

More than one participant pointed out that donors present themselves because they have problematic relationships that need to be worked out, or have the need to improve upon a relationship within the family, or as one participant put it, "clean up the relationship for past transgressions." This type of donor is often labeled the "Black sheep", who hopes to reclaim his place in the family or to become close to the recipient. But there are other types of conflicts that can arise. For example, Olive Groff, a psychiatrist, said:

I had a girl who lost her father at age 13 and she was not going to lose her mother...or we read a lot about the black sheep but I do think there are children who are making up for whatever past indiscretions or whatever they feel they did wrong to somehow regain the status.

Eric Pierce, the psychiatrist, stated “a lot of them [donors] either have the loss of a parent or loved one or some sort of relationship problem with one of those family members I don’t know if that’s ever been looked into but it’s something I’m starting to pick up on.” There is a lack of objective evidence in this field that calls for further research.

Donors Who Are Self-Oriented

Many donors are motivated by saving the life of their loved one to stave off grief for themselves. A team member, Max Wilson, a social worker, noticed that very often the donor would say, “It’s because it’s my sister, my mother, my husband, my wife.” There is another example, following, of a living donor whose thoughts were primarily about himself.

Mimi Delaney, a former coordinator and research director, had encountered a donor with unusual characteristics and was oriented towards himself:

He was in the same church or religious community as the recipient and they [the recipient family] were worried who was going to tell him he was not a candidate because he was going to be devastated that he couldn’t donate. This was the recipient. When I told him this he was like oh but I had been an alcoholic for so many years, and clean living. He had to do this, he had no concern for the recipient and it had nothing to do with it, it was all about him. It was completely inappropriate in my opinion.

Mimi Delaney had come across an unusual donor. He was disqualified for medical reasons.

Would he have been disqualified for psychosocial reasons? Mimi Delaney, research administrator and coordinator had thoughts about donor motivation:

The main question the donors should have if I don’t do this is so and so going to die? If there are other people around that would step up and donate an only child vs. one of five that kind of sit back and well let’s see who else will step up...also what they expect to gain. We had some donors who actually thought doing this would forgive them for former...some donors just wanted the attention and then you had some donors I’m going to do this because...maybe it’s not going to improve my relationship expectations but if I don’t do this I will regret the rest of my life or know that the rest of my life because I didn’t do this so and so will die and then other things. Some of them had nothing else going on in their life...did it happen to people who think they have nothing to lose anyway?

Mimi Delaney is alluding to donors who wish to make up for past wrongdoings or transgressions, as Kay Walker the social worker mentioned and as Eric Pierce the psychiatrist begins to see. People may become donors in order to atone for past mistakes, whether the mistake was pertaining to the recipient or to the world in general. She also touches on a point that is not usually mentioned, which is that some donors appear to have little going on in their lives, especially nothing positive going on in their lives, and this is a way to bring constructive energy and action and attention into their experience.

Barbara Nolan, a social worker, talked about an ethical dilemma that her team faced with a young mother:

We had a young girl who came in, 22, and had a young child; she said she wanted to give to her grandfather which we felt awkward. The grandfather was 72 she was 22 ...the age difference...when I talked to her it came out she's not the grand-daughter she was living with his grandson and grandparents who had a big house and all the kids were there and we felt like it was her ticket for a place to live. But it was a real ethical dilemma on one side the surgical people said she's a great candidate she wants to give what's the big deal, you know, on the other side we had a lot of the rest of us including medical staff who said they could take her kidney and throw her out the door, what's going to happen to that baby, you have to look at every donor to see what could happen to them. She had no family ties to these people, the recipient kept calling us what's the matter, and we didn't do it. You can go to another hospital but there was an ethical dilemma. We took it on ourselves; we did not rule her out medically if she wanted to go to another hospital we couldn't rule her out. Medically we said we will not do this. Because a 22 year old with a baby to someone not related, and it was very brief, like three months she was living there.

This illustrates the potential harm that can be done through living donation, as well as the friction between team members, especially medical vs. surgical. Without a careful psychosocial assessment, and attention to context, a bad situation could have become much worse. The young girl's motivation was to secure a place to live.

Many team members observe the process, consequences and rewards of living donation primarily as saving the life of the recipient and have discussed the results of the transplant for the donor with the same degree of enthusiasm. They are deeply aware that the donor is a healthy

human being who does not require surgery for their well-being and worry about the result for the donors and get engrossed in the motivations of the donors.

Donor Motivation

Each person who presents himself or herself as a living donor candidate for liver or kidney transplantation may have a different motive because each situation is somewhat different.

But there are stories that can be collected into clusters of similar motives. Barbara Nolan, a social worker, recounts various donor motivations:

It really runs the gamut. Everything from the positive which is understandable to me which is 'it's my brother I love him, we've always been close, the minute I heard I'm there.' Parents to children, children in their 20s, parents in their 40s and 50s 'it's my daughter, thank God I can do something. That's clear-cut motivation. I've certainly heard from other people a sense of duty, you know, 'it's my brother this is what I think he would do for me, we're not terribly close But this is what family members do, I've seen that...I've heard other people friends, colleagues, who say 'isn't this what you would do for anybody? I would. I've got two kidneys they need one, they're welcome to have it.' We've had altruistic kidney donors...I'm thinking of a man we did recently his mother had kidney disease she was too sick to be transplanted But he took her back and forth everyday to dialysis, he couldn't help his mother, she died, but he said, 'you know what, I saw those people and what they went through and you know what, if I can help them I'll do it.' There was a connection there. We've had people with altruistic who have had tragedies in their lives or maybe tragedies they've caused, car accidents and things like that where people have been hurt...But the one that was striking was the one who said, this will help me live with myself.

Henry Marcus, a transplant surgeon and director of a transplant institute, believes most donors do so due to altruistic reasons:

I do believe it's done in most of the cases that I see here for altruistic reasons. People are simply good and want to do it. Now some of them have very direct relationship with the patients with the candidate for transplantation some of them do not have it instead have indirect relationship and they still want to go ahead and do it because and I see it very often, they are really believing in what they are doing like it's a calling. Last week a patient donor wanted to do it because she did not know the recipient she knows the mother but she has children and she knew that the recipient has very small children and could not take it that she can't help someone who is a mother and ...she felt a calling to do that.

People who have been exposed to chronic illness or trauma may be predisposed to donate from

feelings of empathy or what some may describe as “survivor’s guilt.”

Theme 4: Providers Concerns Encompass Recipient

The other crucial component of living donation is the recipient’s needs, medical, psychological and social. The recipient must need a transplant and be an appropriate candidate, and be on the UNOS waiting list. He or she also has to be healthy enough to handle getting half a liver instead of a whole one which is what a patient receives from a cadaveric transplant. Team members have expressed some different concerns about recipients, which I will detail here. Ellen Moriarty, a coordinator, was concerned about how the recipient should ask someone to be a donor; “I would find it difficult to go to someone I love and say hey would you give me half of your liver?”

Helping recipients to ask the donor would also be a way to increase the numbers of potential donors to be worked up and possibly proceed with surgery. Kay Walker, a social worker says, “The team goes out of their way to see if there is a potential donor. It’s nothing to do with race religion or culture. They are vested in finding all potential donors.” Because of their obligation towards the recipients, the team, which is about saving lives, is committed to having as many transplants as possible. The inherent conflict in the role of the transplant provider is again expressed in this revelation. To save a patient, they risk harming another human being.

Olive Groff, a psychiatrist, noted that with adult child to parent:

the recipient struggles a lot more than the donor. The recipient first of all they’re tremendously guilty they’ve caused their illness whether it was alcohol, hepatitis C, and parents inherently don’t want to see their children being injured... I think the guilt of receiving gifts from your children for the recipient is enormous and I think that we have not really focused upon this.

This statement points the way to an unexamined aspect of living donation, that is, the guilt and reluctance of a number of recipients to allow their children to give them this life saving gift.

Many recipients do not allow the donor discussion to go forward once they realize their children are the best and likeliest for donation, even when they are informed that living donation is their best chance at getting an organ at an opportune moment, or else they could die waiting for a liver. Does the provider have an obligation to encourage consideration of donation by a child to parent? Most providers feel this raises the question of paternalism by the provider. Gifts from children are also mentioned on page 8 by Henry Marcus as an unexplored family dynamic, which may prevent people from using living liver donation.

Theme 5: Emphasis from the Team, or “The Voice of Authority” and Paternalism

The physicians are charged with giving patients information about the nature of their illness and the options. It would be remiss of the team members not to offer the option of living donation to suitable recipients. The proposal of living donation a priori may bring apprehension to the available likely donors in the family. Alyssa, a hepatologist, mentioned that “I’ve heard that uh the coordinators here encourage them to sit down and say listen you have six people, which of your six do you want to have come forward as your first donor, how do they decide who that first person is going to be?” Ellen Moriarty, a living donor coordinator, initiated sending a letter to recipients with MELD* scores Between 15 and 22 because those scores are good for living donation. “So I’d send the letter to the recipient and look to see their next appointment and say if you have any living donor this is the time this would be a great appointment for them to come to.”

The team promotes living donation to the most appropriate recipient and their families because they feel that it is the best chance of survival. The recipient who will to get a living donor will reduce their waiting time on the UNOS list; otherwise the wait may be too long due to the MELD* score.

*MELD stands for Model for End Stage Liver Disease. The scale runs from 9 to 40. The higher the score, the closer the patient is to his

mortality, and the closer the patient is to transplant.

Ellen Moriarty also points out that:

...My responsibility is that the uh recipient in general designates or has a donor and they tell the donor to call me...once they come in it is my responsibility to get their blood type and preliminary lab work and then go through the process of what is expected of them once they agree to be a donor...Then we would get in touch with the donor and ask if they want to continue the process. From that point forward my role was to coordinate the various tests that they needed to accomplish before being a donor and that was a lot of in the liver program a lot of handholding where you met with the patient just to make sure they got everything done. It's a huge deal as you know it was really that was the program dictate, that you help them along because you wanted to make sure there was no problem.

Ellen Moriarty has differentiated the kidney program from the liver living donor program where the coordinator may only meet the donor three times prior to the surgery because there are fewer tests involved. There are more living donors in the kidney program.

Olive Groff, a psychiatrist says:

“There is no living donation without coercion. Nobody would do this in their right mind. I think there is internal, external coercion all the time. There is coercion when I introduce the concept of living donation...I can spin this, not that I'm looking at anybody directly but introducing the concept.”

Olive Groff is well aware that just the introduction of the topic is coercive to anyone sitting in the room with the patient who needs the donation. Alyssa, a hepatologist, describes the process from the team's point of view:

Um we make them contact us first and then after that we give them, we can contact them. What our policy sort of has been that we will contact them um after they contact us that they're interested we try to set them up for donor discussion and they come in that day for donor discussion, if they say they are interested but don't make that appointment for the donor discussion we usually give them a week or two and call them again, if at that point we haven't heard anything we'll send them a letter letters saying thank you for being interested, if you are still interested please contact us otherwise here is a bracelet for even being interested you know we send them a little thank you note just for even calling and the same things happens at every step of the line, if they come to donor discussion and then say yes I'm interested, we wait about two weeks if we haven't heard anything again we'll call them, if we don't hear anything we'll send them a letter once again saying thank you if you're still interest please contact us but we don't try and berate them um unless we hear back from them.

The team has a fairly elaborate mechanism to approach living donors and they are careful not to step over boundaries with a person who is considering donation. But the boundaries continue to change as time goes on. In the beginning stages of living donation, the team would never contact the donor unless he or she approached the team first, in each instance. At this point in time, the team calls and writes letters to the prospective donor once he or she approaches them.

Paternalism differs from authority. Paternalism is a style in relationships where the “the claim or attempt by a government, company, etc., to take responsibility for the welfare of its people or to regulate their life for their benefit”, whereas authority indicates the right or power to “power to enforce obedience, right to command or give a final decision” (Shorter Oxford English Dictionary). Transplant staff worry about a patient’s right to self-determination versus the more traditional paternalism of the medical professions. If a patient’s or recipient’s relative wants to be a living donor, does the transplant mental health professional have the right, or the responsibility, to prevent him or her from doing so? If there is a medical contraindication, the answer is clear. If a living donor is not suitable medically, the donor is rejected. If a recipient is too ill to survive a donor transplant, the transplant is cancelled. At times the psychiatrist, usually with the support of the social worker, will put a halt to the transplant based on psychosocial reasons. Eric Pierce, a psychiatrist, stated:

If you love someone and you think they’re going to die if you don’t help them, I don’t think it’s inappropriate to help them even if it means sacrificing something for yourself. I think it crosses the line if someone said I feel guilty if I didn’t. I push that and say define guilt, guilt is when you do something wrong and you feel bad about that, and you’re pushed to shame or responsibility, and if they continue on and say I’m doing something wrong if I don’t do this, I worry how to interpret that. Does it mean they’re altruistic or the familial responsible type or does it mean they’re going to suffer if they don’t do it? Are we taking something away from them by saying no to them, that they feel they deserve?

This statement demonstrates the ambivalence and tension that the transplant team feels about

their role. Denying a potential donor can and does often end in death of the recipient and a personal loss for that donor. This transplant team member recognizes his role as both facilitator and obstacle to the transplant. He sees the dual nature of his responsibilities and acknowledges that living donors, as human beings, are motivated by a multitude of feelings. This does not imply that some conflicts within the donor automatically disqualify him or her.

Theme 6: Opting Out and the Medical Excuse

An important issue in living organ donation is the donor's right and method of refusing to donate. Donors can state to their potential recipient that they wish to be excused but often this implies letting the patient die and a simple refusal is most difficult. Furthermore, the potential donor often fears the reaction from other family members if they find out that she or he willingly refused to donate and by extension save the life of one of them. In this section I will discuss the key issues of how potential donors avoid donation and related issues.

Part of the professional paternalism that was discussed above also extends to giving cover for a patient's decision not to go forward. The "opt out" alternative often calls for an excuse to "save face" for patients who have decided they cannot go through with the donation. For donors it seems a medical excuse is always preferable to a psychosocial excuse. Kay Walker, a social worker on a kidney service, gives an example:

...he decided to opt out of donation...the only way he could have gotten through instead of a social reason he felt better if he could use a medical reason...so a medical reason was used as opposed to a social reason. Sometimes recipients feel much better when they hear not a social reason but a medical reason why the donor is not being used. And you also have to be protective of the donor's privacy. Recipients are only allowed certain information, not a lot of information, regarding donor's decision.

The medical excuse seems incontrovertible and airtight; it cannot be disputed in the same way as a psychosocial excuse. However, Olive Groff, a psychiatrist on a liver transplant team, only

gives psychosocial excuses for the purpose of the “opt out” unless there is a true medical issue so as not to falsify health information:

Let’s say the donor can’t do it; they’re frightened but there’s nothing that would preclude them. I wish I could say I looked at the MRI you have a great liver but we can’t use it. Team doesn’t want to use it. So how does the donor save face by coming forward and withdrawing now? I say you can blame me, tell them the psychiatrist had something it’s not your fault. You’re perfect, it’s the psychiatrist. I’ve got to give them something. If it’s medical reasons then it’s clear-cut. If it’s psychological, I have often hoped we would give them ‘the volume is too small’ or something. I wish I could do that but am ethically forced to be truthful so now I take the blame.

When asked if her team uses the “opt out” she said, “they don’t like to so then it’s me, it’s fine. It’s so humiliating to say sorry I changed my mind.” Olive Groff, a psychiatrist, takes the responsibility for most of the “opt outs” at her transplant center.

Every health center and even organ service is likely to handle the medical excuse in a different way. The cases that require the “opt out” option are often among those that cause ethical dilemmas for the team. Another example of a case that required a medical excuse is that of a brother to donate to her chronically ill sister. There were only the two siblings and the parents were too old to be donors. The brother was healthy and a match for his sister. He went through all the testing and had been hoping to be ruled out by one of them. His parents were against the donation, while the sister and her husband were pressuring him. The psychiatrist Eric Pierce discusses this case:

There was a very ambivalent intelligent young man who had a conflictual relationship with his sister who needed a liver. She was an attorney who was somewhat basically she wasn’t a nice person and had been chronically ill and he felt responsible for her children because he didn’t have any children and he wanted those kids not to be deprived and was motivated primarily by guilt and not by the desire to do this.

The brother took the medical excuse and the sister received a cadaveric organ. The brother was unable to rejoice fully in his sister’s success of a new organ transplant as he had confided to this interviewer that he felt guilty about taking the excuse. The unanswered question

is how does this affect him today, if at all, and how did it impact the family? Eric Pierce, a psychiatrist, said:

I think in cases like that I think it was early in our processes with him, if I had to do it over again; I would have stepped in much sooner now. I feel I have enough experience to see this is a real outlier and he couldn't make that decision and someone needed to. And this whole living donation thing really puts us in a to use a word, paternalistic position that we have tried very hard not to take in our fields of mental health, um, but it also seems like the right thing to do at this time for some people...

Eric Pierce raises the issue of paternalism with respect to medical excuses. He recognizes the power and determinism of the medical professional and struggles with his role in issues of life and death, not the usual concerns of a practicing psychiatrist. We can see that team members feel differently with respect to assisting donors to take the medical excuse, that is, to help or pressure people take the medical excuse for the purpose of self-determination. The team had decided not to allow the brother to donate and then he chose the medical excuse after a prolonged struggle. His case was complicated by the fact that his sister was an attorney who was well versed in medical vernacular, and she also sat on a board involved with transplant listing. The brother was worried that either she would see through the excuse or find out that he had taken it. The brother was willing to lie about a medical reason for donor rejection.

Another case of a person taking the medical excuse was a young woman, the third potential donor for her uncle, a police officer in the city. A different candidate for this man had taken the medical excuse. This young woman wanted to be a model and worked for a modeling agency. She had concerns about the scar that the operation would leave. She missed many appointments and then told us that the recipient had announced on *Facebook* without her permission, that she was going to donate her liver. This was a clear case of coercion as it appeared to the team. Ellen Moriarty, a coordinator, stated that:

she kept creating situations so that she couldn't come for her appointments till we finally

said ‘we don’t think you’re a good candidate’ we just said she didn’t meet the profile we don’t want to tell them that your liver enzymes are elevated if they go to a hospital we don’t want to have falsified their health history...She kept creating situations, it was snowing, she finally came out and said I don’t want to do it and we told her, just tell them you don’t fit the profile.

In this situation the providers did not falsify the medical data but said the donor did not fit the profile without being specific. This equivocation helped the providers deal with their own conflicts.

A patient who used the medical excuse was the daughter of a recipient, the second donor candidate to be evaluated for living donation for this recipient. The first candidate was the recipient’s grandson who had been raised by his grandparents. He was in his early 20’s and was injured by the liver biopsy, thereby disqualified as a donor. The forty-year-old daughter came through as the next candidate. By the time that the daughter came to the donor discussion with the doctors, the wife of the recipient who was the grandmother and mother of the two donor candidates was pushing the staff and leaving angry voicemails and emails for the coordinators.

Eric Pierce, a psychiatrist remembers this case:

I think the woman we did the sham biopsy on, remember, she was quite memorable. She was very anxious about this process and kept stressing it that she hoped it didn’t have to happen that a cadaver would be there stuff like that...

Ellen Moriarty remembers the same living donor. “For the daughter? Well so she came in and they did a charade with her and that was really not a good experience. The daughter had come in with her boyfriend and, during a meeting with the psychiatrist and social worker, admitted that she did not want to go through with living donation.” She was accompanied by her boyfriend who was a friend of the mother, and in order to protect her, an incision was made where a biopsy incision would have been so that she could go home with a scar and the results would be believable. The hepatologist acted in the best interest of the living donor candidate and

against his own self-interest. Every person interviewed on the team remembers this case.

Alyssa, a hepatologist, stated that:

the donor felt that in order for the family not to think that she didn't want to donate she actually had to go as far as coming in for a liver biopsy and having a nick of skin so she could have a Band-Aid put on her and then leaving because the family had medical people and that they would know if a biopsy wasn't done and so I would think that if she weren't feeling coerced to do it then she would have not even come. I mean, she actually underwent some "pain" for to prove that she wasn't the one who wanted to step out of it so I absolutely think that there are people who are coerced and that would be the most extreme example that I've seen...

This case stood out to Henry Marcus, the surgeon and director of the transplant institute as well:

We had a case where there was a bad coercion business. Such stress on the intended donor when they came to us requested that we'll nick the skin and do it as if we had a biopsy and say the biopsy shows the liver is not good. We did not do the biopsy we had a small incision in the skin for her to be able to go back to the family and say, "I did it." That happened...we definitely have people to love us to find something if not they want us to say we find something that prevents them of being a donor.

Interestingly not one of the providers mentioned their own personal distress with this case. They characterized the situation as "horrible, horrible" but did not or could not discuss their feelings.

Unfortunately the hepatologist could not be interviewed for this study.

Max Wilson, a social worker had a case of a young woman of 27 who was a potential donor for her father. She had:

a really rough time with the evaluation. She had a phobia of needles and it was really hard to get blood samples and do all the blood work. I think the surgery scared her but didn't deter her that much so we never really um when I asked if she was being pressured by her father she denied it...she continued to deny it until two weeks before the surgery when she was meeting with the surgeon going over final blood draw just before donation when she asked to speak with me and said 'I'm being pressured by my father who doesn't want to remain on dialysis.' She didn't want to go through with it. The anxiety she was feeling was based on the surgery, the potential risks of mortality and complications scared her. Even though she had a deep caring for her father the fears were outweighing her feelings towards her father so she decided to opt out due to family pressure. Just cause her father was really pressuring her he was calling every day asking how she was feeling ...we put up a smoke screen. I like to call it a smoke screen. We told her we

would document that she would have complications with high blood pressure in the future, that she was OK now but we have concern for the future.

Henry Marcus, transplant surgeon, is familiar with using the medical excuse for patients. He said:

We had donors who did not want to go forward and donate and we said to the family that their anatomy was not appropriate and things like that I don't think it's uncommon I can't again tell you whether it's 10% or something like that it's guessing But we definitely have people love us to find something if not they want us to say we find something that prevents them of being a donor.

Sandra Morrison, a transplant social worker has not had memorable instances of helping a patient to use the medical excuse. She said, "Sometimes the nephrologists um kind of decides to make her guidelines stricter, more strict, I think know with blood pressure oh we did get this reading, or we did you know, there's more concern...I think it might happen more in liver, because people are dying, you don't have dialysis." There is less pressure on kidney donors because the patients have dialysis as a life saving measure, there is no equivalent treatment for end stage liver disease.

Lisa Cohen, independent donor advocate and social worker only had one experience with medical excuse:

Oh yeah. The one who didn't want to donate to her father, there was a tiny glitch in the test and they just said they're kicking her out for that, something showed on those lab results it's probably nothing, and she said I'm not repeating anything. They said the result is unacceptable. That was the only one.

Barbara Nolan, social worker for both kidney and liver transplant, remembers two cases where the medical excuse was used. Both were intrafamilial cases involving marriages, and both cases could have caused marital problems or divorce:

We had a wife who I think felt enormous pressure to give to her husband was supposed to do it. It was the right thing to do and at the last minute the day before surgery called me crying I can't go through with it, I'm scared to death I'm this and I'm that and I know he wants me to and I'm scared to death. Last crossmatch incompatible. I can't face him and

tell him I can't do it. The other was when we had a son in law, years ago, I don't like my father in law but my wife will be furious if I don't help her father. And I don't want to cause a divorce.

Kay Walker, a social worker on the kidney transplant service, was working with an altruistic donor:

An altruistic patient wanted to donate to a business partner and the donor both the donor and recipient were fairly wealthy and the problem was that the donor didn't disclose to his wife. Waited until the last minute and I've discussed with him you can't go through the surgery without discussing with his family members, the family is going to be pretty miffed and he thought about it and went home and discussed with his wife and clearly wife wasn't pleased with the decision, Because she felt there was some-thing underhanded and because of that he decided to opt out of donation but the only way he could have gotten through instead of a social reason he felt better if he could use a medical reason. I think that it's very helpful, the support that the team gives patients who opt out of surgery, has to be consistent which I believe that it is, that the patients feel protection and comfort, and to say no to any level. And the recipient doesn't know why.

Mimi Delaney recalled that when she was the donor coordinator, she would offer "the out" every time she met or spoke with a donor. She believes that now the coordinator only offers it once:

...I do it differently than the other coordinators every time we spoke; every time we met I gave them the out. Ellen Moriarty only gives them the out once and the same as who else was there and back again, Phyllis Atwater? Same thing, she doesn't give as many outs. They have to believe us, you know.

How significant is the difference between offering "the out" once versus multiple times? Does this affect the number of people who take the medical excuse? The field and practice of living donation changes rapidly and what is best practice also frequently changes. Put differently, we do not know which option is better.

In this section I covered the theme of the medical excuse. The medical excuse is a paternalistic practice as it gives power to the medical team to falsify the truth and protect an unwilling donor. While not used too frequently, the medical excuse is estimated to be used for 10% of the cases. Some medical practitioners oppose the medical excuse and only work with

unwilling donors by providing and guiding them how to use psychological excuses. The people who oppose the medical excuse feel ethically correct though others feel that they expose the unwilling donor to family pressure and possible retaliation. Another issue in opting out and the medical excuse is how often the potential donor should be offered to opt out. As noted above, some coordinators believe that the option should be offered as frequently as possible and in every meeting while others believe that once is enough. Clearly there is no “best practice” in this field and the decision is idiosyncratic.

Theme 7: Coercion

The theme of coercion is closely intertwined with the medical excuse but not identical to it. Not every living donor who feels coercion uses the medical excuse. Every living donation that involves a relationship will have some degree of coercion involved. Relationships that involve family members will have increasing implications of coercion that are hard to contest. Team members recognize that living donation almost always includes some amount of coercion.

Mimi Delaney, the donor coordinator and research administrator, remembered a case of coercion:

How about that kid that was going to donate to his grandparents who had a bad complication?...and we had to lie about that one and it was horrible, horrible. He was only twenty and we didn't see that he was coerced not by the grandfather but by the grandmother.

Henry Marcus, surgeon and director of a transplant institute is fully aware that coercion exists in almost every situation to some degree:

I think it's there it's there more than we imagine it is. Coercion can be in different way maybe the emotional, the money, the threats, I'm pretty sure it's there. I don't have any illusion. It's not that we're in the business don't ask don't tell like in the army we don't do that. We try very hard to see if there's any coercion in our business but I think it's there more than we imagine it's not going to be surprising to me if it's more than we can imagine.

When asked for an example, Henry Marcus remembered a case that involved people who originate from different countries other than the United States who wanted to import their living donor. This kind of situation brings additional responsibility to the transplant team to be sure that no coercion is involved. Henry Marcus recalled:

A kidney donor who had a diamond dealer a very religious Jew who brought an Israeli who looked as if it to me I know them an immigrant from the Soviet Union the difference between the two is striking. I could not believe one is a cousin of the other and I'm pretty sure there was a money exchange and that's coercion right? There's no way to prove it. When someone is coming to me or to the team we never say to them bring your family tree or bring evidence from social security we take their word that they are related so I'm pretty sure in some cases there are things we don't know about and people are coming and presenting themselves and sometimes they are smart enough to convince you that there's nothing but maybe there's something behind financial incentives?

This case raises many practical yet unresolved issues regarding suspected cases of coercion. Should the transplant team require papers or official documents that are relevant to the relationship between donor and recipient? How far does the responsibility of the team go towards ensuring that the relationship is above board? In one way it is easier to be suspicious of cases involving foreign nationals but then is it not incumbent on the team to check in all cases?

In general, coercion is an existing influence in many cases of living donation. Ellen Moriarty, a coordinator remembers a case of a donor being coerced by a family member:

The recipient's wife got my phone number somehow and kept calling me and I was too new to know to just be authoritative and say this is inappropriate you need to call the recipient coordinator. And I would try to work through it and she told um that the son who was donating had given her permission like the email he gave was really her email so any communication I had with him was going through her.

This type of subterfuge is rarely encountered. At first the team was not aware that the emails were being forwarded to the grandmother. Mimi Delaney, research administrator and coordinator, remembered a case of coercion involving sibling and blended family relationships:

the dynamic when the new wife who is looking for the biological children to save the husband...we used to have one and she used to call and ask us to find the biological

children. There's the guy who got out of prison the wife wrote the letters pretending they were from him in prison and sent them to me I showed them to [psychiatrist] it was classic female handwriting and it was postmarked from where he lived as opposed to the prison. He ended up back in jail, at least he'll have health care follow-up. Yeah, he was a brother and they had contacted somebody else to donate. A coworker, niece's boyfriend, a little strange. Seriously, you're going to do this, you could die?

Coercion in families can involve subterfuge such as the above examples. Outright impersonation is unusual. These two examples demonstrate that family members desperately want to ensure that their loved one gets the medical treatment that will save them.

Olive Groff, psychiatrist for liver living donation remembers a case of family coercion:

...a physician with primary sclerosing cholangitis had several siblings, was married, wife was pregnant, and he was getting sicker and he wasn't going to get the best organ, the best organ to get was a living donor. He had a younger brother, not as successful, 24, an artist, no children, and there was clear pressure on this younger brother to become the donor for the older brother that the young donor came forward he was so torn about this and really did not want to donate, was afraid of needles, hospitals, nearly fainted giving blood and from the beginning was struggling with how he can deny this brother, a physician, how would he have fit into the family structure? He was obviously the youngest, the weakest, the not accomplished and I very strongly felt the brother was chosen and he was coerced and I didn't allow him to donate. He asked me directly, he put his head down, body language, if he could have moved his chair outside the room he would have. Not appropriate, psychologically coerced. Thank God a friend donated. A powerful brother wanting...

Within families there are spoken and unspoken obligations and expectations. The above is an example of a family pressuring the youngest, most vulnerable member as discussed earlier. Because of his youth and vulnerability, he is considered a good candidate for living donation to his more powerful brother. Scheper-Hughes (2007) said, "In societies characterized by a high degree of male dominance pressure is frequently exerted on lower status, poorer...relatives to 'volunteer' as donors. The tendency is to choose the least valuable, least productive family member" (p. 508). Sandra Morrison, a social worker remembered a case of an 18 year old donating to his father:

an 18 year old...we were concerned because he was so young and we asked him to take a cooling off period and think about it and go home and talk to his parents about it but you know his father brought him in and you know that alone feels like coercion ...I did talk to the father when I explained that we were concerned about the age, his age, and his health in the future, and he the father said that his son wouldn't listen to him, that he's concerned, that he had this concern as well but that the son needed to hear it from us....We're like why do we have this at age 18?

The issue of young donors in their 18 to mid twenties came up often with participants and most felt that they would prefer to use older donors. Another social worker Max Wilson described his concerns about young donors:

We won't consider anyone under the age of 21. 18 is a legal adult...Show me a stable 18 year old who can handle the psychological future implications of being a kidney donor I mean they can handle it normally but there's always a potential for risk. I read a study one time that high risk behavior is at its peak between 18-24...when they go skydiving, driving 80 miles per hour...high-risk behaviors peak at 24 years old that's why car insurance drops at age 25...

Henry Marcus, transplant surgeon and director of a transplant institute, remembers a situation where:

I think I interviewed someone who was an employee who wanted to donate to his employer a piece of liver and no connection it was a peculiar situation, and uh it was not a medical issue whether to postpone or reject him as a donor so I elected to reject him as a donor by the way the patient, my understanding, went to a different institution and was transplanted there as a living donor, I don't care about it so much but I thought that the input I got from the team was that something is not right there. So someone had to make the decision and under such circumstances I took the responsibility and made the decision.

The director of the transplant institute had to balance his feelings with what was ethically correct versus what was most profitable for the organization. Coercion is present in all types of relationships, siblings, employer and employee, grandson and grandfather, mothers and sons, and fellow nationals. It is the responsibility of the team to detect coercion although it can be a most difficult task.

Theme 8: Guilt

Is guilt a factor in deciding to donate an organ and is it used as a coercive means by relatives? Ellen Moriarty, a coordinator, found that some donors appeared to be acting out of guilt. "...I think some people do it because they feel guilty like they're guilted into doing it like 'your dad is dying.'" Eric Pierce, the psychiatrist said:

There was a case of people who backed out or we've said no to. I think that had a lot of intrafamilial dynamic issues doing things because they felt they had to or felt guilt or responsible to their partner like an in-law, but it seemed much more clear to me and I think to you as well that they were ambivalent and I think we decided not to go through with it with that individual. I don't think you can say an emotional connection to somebody and feeling a bit of responsibility but not guilt is a contraindication. In other words, if you love someone and you think they're going to die if you don't help them I don't think it's inappropriate to help them even if it means sacrificing something for yourself. I think it crosses the line if someone said I feel guilty if I didn't. I push that and say define guilt, guilt is when you do something wrong and you feel bad about that and you're pushed to shame or responsibility, and if they continue on and say 'I'm doing something wrong if I don't do this' I worry how to interpret that. Does it mean they're altruistic or familial responsible type or does it mean they're going to suffer if they don't do it? Are we taking something away from them by saying no to them that they feel they deserve?

Eric Pierce struggled with the notions of guilt, sacrifice and paternalism. If the team makes a paternalistic decision because of their superior knowledge of the surgery and its course, will the prospective donor suffer guilt if the recipient should die before a transplant becomes available?

Theme 9: Pediatric Donations

Another type of living donation is of a parent or an adult to an infant or child. These transplants are done for the sake of the child, the donor is worked up at the adult hospital, the child at the pediatric hospital, the adult's surgery takes place at the adult hospital and the organ is brought to the pediatric facility. The reasons for these donations are largely unexamined just because the justification is so self-evident. Olive Groff, a psychiatrist, states:

I think it's easier to donate to your baby as a mother as a father than if you are a distant family member or friend donating to another adult. The surgery is different the morbidity

is different and again your desire to save your child is empowering it's so great it encompasses everything correct?

This quote was already used above in reference to paternalism. I am using it here again as it here again as it also pertains to issues of guilt. Are the situations involving pediatric donation coercive because the young recipient needs it so badly? Alyssa, a hepatologist thought this to be the case:

...when a mom has a child or a dad has a child that's dying, you cannot tell me that they're not, in my opinion, they're the most coerced than everyone. Maybe coerced isn't the right word But they're the one who says, I would say it, 'do whatever you need to me to make my daughter, my child live, you know? I'm doing it because I love this child but if I, but because I love them so much I don't know, coerced isn't the right word, but they're often the ones that we do within a 12 hour period. How can you really make an informed, educated, non-emotional decision in a 12 hour period, how can any parent make a non-emotional decision when they're seeing their child some come in every week for a paracentesis, they're jaundiced, they have tube-feedings, I mean of course they're coerced by the child they love...I always find it interesting when parents who don't want to donate to their kids, that's another interesting group in my opinion.

Mimi Delaney, researcher and coordinator, questioned why we don't inquire more about donation to one's child:

The other thing that's funny is we don't think twice about parent to child? There's no thought and if anything there's like I can't believe you'd not donate to your kid or someone who steps back and says 'I don't know', what do you mean you don't know? But it's still a big surgery, I don't know.

Max Wilson, a social worker talked about a case of pediatric donation:

Yeah I had a really interesting case he just donated about a month ago; a really swell guy probably my age 30, 31, his son is three and has had major medical complications since birth. When I went through the 'why' section I almost felt like I was doing a disservice to the patient because going through the assessment I could understand why he was there he's three and wants to give him the best shot at life. And when I asked him he gave me all the answers and I apologized for even asking the questions.

At times, the providers are expressing their frustrations with the imperatives of societal norms. Max Wilson even felt apologetic for raising the question of the donor's feelings and interest. But not every parent is going to want to donate to a child, as the quote from Mimi Delaney suggests, and some will have second thoughts. The age of the child is relevant as well.

Is it easier to donate to a young child than a teenager? Are the decisions made for the teenager more conflicted than they are for a young child?

Theme 10: Deception

As discussed in Chapter II, donors often engage in “impression management,” putting the best part of themselves forward, downplaying aspects they think the team will disapprove.

Because of the power imbalance inherent in the relationship between the medical team and the donor and family, deception is almost to be expected. Olive Groff, a psychiatrist, says that:

...they're not going to tell you when they get angry. They're above average in mental health. Living with a sick husband, no, they are no better than you or I. Anxiety, anger, no not them, who in the world is going to tell you the truth they are so worried you will turn them down. They would rather have a panic attack the night before than call me and ask for an ambien they're driven and I hold the key so therefore I'm so good, no, never had pain issues, I tolerate pain.

The issue of deception requires a delicate equipoise from the team members who have a need to know as much as possible about the candidate and a need to develop a relationship with the donor at the same time. As demonstrated, this is an omnipresent problem in so many aspects of provider-donor interaction.

Sandra Morrison, a social worker with many years of experience on both liver and kidney transplant services, recalled a situation where the donor and recipient concealed their plans from the team:

You may never know. I had a donor and her husband who were thinking of separating at the time, that she and they were going through donation but she loved him and really wanted him to have her kidney and they stayed together for another year and then they separated and she told me, a little while ago, that she, that they knew because they did cover it up, although their relationship seemed, people kept saying they seemed more like sister and brother I mean they loved each other in that way, you could tell she really wanted to do it because she wanted to help him and said he fathered my children, I want him to be productive, I want him to be healthy, I don't want him to die...so I mean her motive, she wanted to donate and she was healthy enough to do it but she really, I think if

anything she wanted him to be ok I gave you a kidney now let me go kind of thing, but she didn't really she covered that up pretty well, I didn't have a sense... and she said to me I didn't tell you guys that I was thinking of separating, that we were thinking of separating but we had talked about it before the transplant she said because I know it would have complicated the whole process.

Was it necessary for the couple to deceive the team in this situation? Quite possibly, for it is conceivable that some social workers or team members might take a dim view of their plans.

And there must have been many similar cases of deception that the medical team was unable to detect.

In terms of rage prior to surgery, Eric Pierce the psychiatrist said, "I haven't seen that. If I did I'd probably rule them out." Henry Marcus, transplant surgeon and director of transplant institute, said "I truly did not see angry donor who was more angry or so or behaving in a different way after the procedure. Maybe because we are so careful with our selection I did not see." Perhaps because of "impression management" patients act to please the team and therefore no anger is detected.

Theme 11: Ethnicity and Religion

Most participants had little to say about ethnicity and religion. Sandra Morrison, a social worker is of the opinion that:

...it seems to me that Hispanic people seem to like and usually they are Catholic or Christian, seem to be uh willing or more you know come forward, you know if I'll see a family, a Hispanic patient with a large family, many of them will come forward and try to be tested, now unfortunately many times they have diabetes or hypertension as well as or obesity...it seems we that Caucasian would be the largest group then Hispanic and then African-American and again it's something talked about a lot many years in the social work realm, that is it because you're not educated or is it because they see themselves as having diseases as well or mistrusting the medical system.

Kay Walker, another social worker, said:

I find that there are more non-minority donors then there are minority donors. umm, it's a for several different reasons one reason is that often in minority families you may have familial diseases where the donor can't really donate because there is a strong history of

diabetes or high blood pressure that isn't to the same amount in non-minority patients. Culturally I think that there's not as much as a difference today. We do find a lot of Asian-Americans, Arab-Americans that are much more educated about living donation today than in the beginning than when I started working in the early '90s. Most religions and cultures are comfortable with living donation from a cultural and racial standpoint. I find it's more of a personal issue.

Most participants did not seem to notice or had not thought of how race or religion may have played a part in people's behavior about living donation. Eric Pierce, the psychiatrist said, "Certainly we know that we think its only 25% of African American make it to the point of work-up; I don't know what role that plays in what we're seeing but I think it's an excellent observation and wonder if it's the same at other programs."

The role of religion and religiosity also factor into living donation. Olive Groff, psychiatrist, told of an incident with a religious donor:

...that donor M kept saying every time these are risks, God protects me. God knows what to do...I could never penetrate her absolute faith in God. What happens? She donates. The recipient died unknown pulmonary complication, intubated 2-3 months later dies. That donor fell apart. Fell apart. Rageful at me and at the team. Why did we take the recipient if we knew as if we did know how could we not predict she would have lung problems how could we operate, what do you mean, immunosuppression, why didn't you tell me? ..Her rage at God, He didn't protect her but let recipient die, was fully directed at us. She was not psychologically minded so developed severe abdominal pain, depression, couldn't go back to work ... I think religion blinds them to religion can be protective you don't have to agonize Because God will protect you but the denial and inability to work and look at what could happen to you because you stop thinking, because God is there God will protect you so I think it's a danger. A little bit of religion is good, too much scares me.

Lisa Cohen, a social worker and independent donor advocate, talked about a donor who was religiously oriented. It seems that intense religiosity poses a problem in coming to an accurate assessment:

I needed more, I needed her to say it's more like God told me we're supposed to take care and I'm like really needed to know she knows what she was doing. I mean she was an adult But all the answers were clouded with religious motivation I just felt like I needed to talk to her again and to make sure I was clear on why she was doing it.

Further research could be done to determine more about ethnicity and religion, including research on the degree of religiosity and its impact on living donation and what different

behaviors are associated with different ethnic and religious groups. There is no evidence-based practice in living donation for race, ethnicity or religion.

Theme 12: The Involvement of the Hospital Ethics Committee

Olive Groff, a psychiatrist had a case involving pediatric donation that went to the hospital's ethic's board. The donor candidate was psychologically unsuitable but the team was under pressure to accept the donor for transplant by a wealthy influential family:

a young couple, not married, the mother lives in Israel, baby born in Israel, father is son of rich lawyer, lot of family conflicts and the baby is sick needs a liver, father comes forward and psychologically appears completely unfit, narcissistic, no plan, fighting with mother, tremendous conflict, I turned him down. The surgeon turned him down, something so wrong. We made the mistake of saying we can't use you as a donor. They are a wealthy law firm so they were capable of getting ethics team involved to the family and grandparents how could you say our son was not good? Ethics was called in and ethics contacted us I don't understand why you don't take the father to donate? The whole team went in front of ethics and I had to argue why and they finally agreed but it was horrendous, I felt ethics was being corrupted By the law firm...ethically we said no and the grandparents used the hospital to get back at us.

The team faced pressure from the hospital ethics committee to agree to use a psychologically unfit donor. More evidence for practice interventions would have made it easier for them to defend their position to the ethics committee.

Theme 13: Emotional Consequences

Most participants had not noticed too much about the emotional aspect of donation.

Henry Marcus, surgeon and director of a transplant institute, said that:

I think that in the first several days they are all miserable they are in different situation and difficult situation where they were very healthy and then they had to donate and that's an extensive procedure which is associated with pain and things like that so in the first several days after I saw a lot of people who are almost in a state of shock what did we do to ourselves, however what I also see that many of them get over it eventually and you know there are studies to show you that some of them get exceptionally depressed and we saw we saw extremes we saw those who are unbelievably happy and stay happy for life and we saw people who never stay in touch with their recipient even though they did a great thing for them never stay in touch and get lost somewhere...

Henry Marcus has observed that pain predominates in the immediate aftermath, which affects the patients' emotions.

Olive Groff, psychiatrist remembered a patient who had an extreme emotional reaction to a transplant that went badly:

Anger? Disappointment? All the time yes. Again I think it depends on what the motivation was to donate. But for example I have a case right now it's not resolved yet where a sister donated to her sister who is two years older with hepatitis C and orthodox Jewish woman. The sister was Jewish but not orthodox course she felt she wanted to help her older sister and the hepatitis C was recurrent and the quality of life for the recipient did not improve that caused a tremendous psychological burden on the donor who had hoped that her gift would be well received and restore her sister to productivity and have more children. Instead she was back on interferon, ascites and cirrhosis and that donor to this day has not worked through this disappointment, felt very strongly it was her job to save her sister it was her duty to make her better. Nobody understands her, after all it's my sister, It's such a bond, and you never had a sister how could you understand my pain she's dying, the donor developed addiction and severe abdominal pain and probably irritable bowel and only narcotics are the way to go now she's addicted. I'm the only one who says 'you're addicted' and I'm the bad doctor and it will be a lawsuit. On top of it my sister is dying...if you are up to 160 mg of oxycodone for your intense pain and show to the world how much pain you have you don't understand how I'm suffering.

Olive Groff has shown us circumstances where a donor became angry post donation because the transplant did not go well and the recipient did not improve. This donor became addicted to a potent pain killer and developed irritable bowel syndrome possibly as a result of her intense anger and rage. Sandra Morrison, a social worker, recounts a story of a son who donated to his father:

He clearly wanted his relationship with his father to improve after donation. And he um would have times that he was angry at his father just because his father wasn't a father, didn't fulfill the father role as he expected him to and although I told him that and he knew, we had lots of conversations not that that was an unrealistic expectation, and he could always decide not to do this...I've seen him several times since the donation and at times...'I'm upset with him all he does is drink...and he doesn't talk to me or I have to call three times before he calls me back'...he was angry at times during the evaluation he kind of felt at times he couldn't do enough and that he wanted his donation to make a difference in their relationship...he didn't want to stay in the hospital very long and ...actually he was out of the hospital sooner and he did have more pain later than he came back in because of pain...he also went back to work sooner and then had to come out of

work because of pain and um blood pressure and ...he returned to smoking...

Do donors with difficult relationships with recipients, and donors whose recipients have poor outcomes, tend to have more somatic issues? On page 36, Olive Groff related the story of the donor sister who developed narcotics addiction and irritable bowel syndrome. This next donor had problems with compliance (earlier discharge, back to work sooner) and resulting pain and blood pressure and was disappointed in the relationship between himself and the recipient.

Barbara Nolan, a social worker for kidney transplantation, recognized that the outcome of the surgery will have a strong effect on a donor's feelings post-operatively:

We really try to talk about that, how would you feel if it didn't work? Remember we did talk about it, it wasn't 100% guaranteed. The only time people are angry is when the patient is not compliant. The recipient. That would be in the first months and in the first year if they don't take their medicine and don't follow up.

Within families, it is most likely that non-compliance would be able to be identified, while with an altruistic situation this issue would not arise. Kay Walker, a social worker for kidney transplantation recognized that donors become emotional when they feel underappreciated:

I have seen anger and anxiety because they're trying to prepare for the surgery uh sometimes donors may feel that the recipient doesn't clearly understand what it is that they're going through that there is the perception that the surgery from the recipient's part is not such a big deal particularly because we have a zero death rate, donors don't die, so it may be the perception on the recipient's part that this is something that you're doing for me, the hospital and surgeon will get you through and it shouldn't be an issue. The donor may feel I understand that this person does need my kidney but at the same time look at what I'm going through. I am going to take time from my job, I am going to feel worse than the recipient in the end, and the donor really has to reconstruct their lives for at least two months after surgery to make sure that they have support people and really changing everything around to suit the needs of the recipient and that can cause overwhelming feelings...They want to have some type of emotional reward.

Do patients who have unresolved anger and rage tend to have more somatic complaints? These few examples seem to indicate that further study is needed regarding this subject. Eric Pierce, the psychiatrist said:

I've seen one or two people who've had lingering medical complications and become depressed or anxious, we're trying to work that out I'm not sure that was so dramatic But I remember there's at least one case of a young woman who had some sort of complication after surgery it began to wear on her she was no longer functioning the way she hoped to and got depressed and wanted guidance and treatment.

Theme 14: Financial Incentives

It is illegal to pay for organs in the United States and it is illegal to accept money for organs. An example of a financial incentive occurs when an uncle pays for donor's dental work.

Alyssa, a hepatologist, remembered this case:

Later we learned that the recipient helped to pay for the grandson's teeth to be repaired, well but in the donation process, the grandson had to have most of his teeth removed in order to donate because of, he couldn't even donate blood his teeth were in such bad shape so you, I could hypothesize, that the donor, the recipient family said to him, listen we know that you're going through a lot we'll help you get these teeth repaired when all is said and done um do I think that that should've precluded him from donation had I known about it beforehand? To be honest I'm not convinced that should've precluded him. If he has to have his teeth removed in order for him to donate and he has to undergo this major surgery, and it's going to cost \$5000, and the guy says listen I'll help you out with that I'm not sure that's the wrong thing.

The National Living Donor Assistance Fund always asks for income information from the recipient before authorizing benefits to living donors. If the income of the recipient is over a certain amount, they are expected to cover the donor's transplant related expenses.

However there are other cases of financial coercion that have more clarity. Alyssa also remembers another example of financial coercion:

...The recipient is a biker...and he walked into the place where they all get together on the weekends to go biking...and supposedly he said 'listen I need a liver I'll give anyone \$20,000 if they give me a liver...um we heard about this later...he said oh I have someone interested in donating it was a woman and (she told the coordinator she knew him for a long time) so we thought sounds like a good plan. Well then two days later she called us looking for his cell number, which we thought was a little bit strange, I mean would you ever call a doctor's office for someone else's cell, then we get a voicemail...from donor's boyfriend, ...they just had a fight... prior to this the donor and donor's boyfriend were on the phone with us...so they had a fight that was pretty significant fight, the donor's boyfriend calls up and says I want to make an anonymous

phone call and we said well, we know who you are because we know your voice because we've only spoken to you on the phone two days ago and he goes well don't tell my girlfriend, my ex-girlfriend that I'm not speaking to at the moment she's getting paid for this, and we said well ..maybe a jilted boyfriend right now we need some evidence and he played a voicemail from uh the recipient to the donor the voicemail says thanks so much don't worry I'll get you your twenty thousand dollars...

Paying for organs in the present environment is strictly prohibited in the United States. In this one area guidelines are clear for providers. However the National Donor Assistance Fund routinely asks recipients to pay transplant related expenses before they will assist a donor.

Theme 15: Regrets for avoiding organ donation

Team members have wondered what happens to people who do not go through with donation. What is the effect of asking the question or stating the need for living donation? There are some cases where we can only speculate on the ripple effect that the topic must cause.

Henry Marcus, a transplant surgeon and director of a transplant institute recalled a wrenching situation:

...a very interesting and sad case where the mother came with the daughter to the clinic and say to me that the daughter is going to get living donation from her sister, the other daughter. The mother determined did not say she determined it was presented as a fact that the other sister is going to give this patient a piece of her liver and it had some very good immunological support because that sister already gave many years before a bone marrow to the recipient candidate and I said fine it was very peculiar when the sister came with the husband to my office to talk to me and the sister did not say much but the husband absolutely resisted that his wife is going to donate to the sister. Part of his resistance was from the fact that he was handicapped and needed someone to care for him I guess and he kept saying why the mother is not donating. In many ways the sister the intended donor did not say much. The mother was pushing for this donation to happen the husband of the potential donor absolutely resisted and the bottom line is we did not go forward with the donation and the recipient, the intended recipient, ended up dying. You can start to imagine what kind of dynamics there were before and the situation that was life saving between mother and two sisters and husband of the intended donor it's a terrible terrible situation this is one example I don't even want to think about the nightmares that people may have of this outcome something that's happening and now.

Mimi Delaney, researcher and coordinator stated that:

Just asking someone to donate will negatively affect someone for the rest of their lives. This guy's dad died, do you mean my dad's going to die if I don't donate, and you say no, I'm not going to donate to him, it's the circumstances. Are they going to be victimized by their families and friends?

Mimi Delaney remembered another situation where a daughter was going to donate to her father and she put it off for two weeks:

Oh my God that poor daughter who was going to donate to her dad and put it off to start the first week of school and the father died...she was like the only thing is I'd like to start school so I can get in, meet the kids, make a lesson plan and then do it. He sat with a MELD of 14 for 9 months (a medium score for "model for end stage liver disease", a score used to prioritize transplants) what's two more weeks going to do, bleeds out and dies. I can't imagine what she must feel and you can take it one way or the other was it meant to be or I made the wrong decision, if only if only if only.

Donors find themselves in the position of deciding life and death at times. Are we doing enough to help those caught in a vise of having no good choices? There should be further research in family dynamics and the effects on the donor when the outcome is poor or the recipient dies during the work-up process.

Theme 16: "Not a Lot of Data"

Eric Pierce alluded to living donation being in the early stages of practice:

I'm thrilled you're doing this because I think it needs to be done this is an area that has is really in its infancy and...I look at that poster over there that's the first NIH consensus conference that I was privileged to be at and I grabbed one of those posters and framed it. I just look at that thing a lot and think how amazing it is what we're doing and how intense and profound and I think all of us know it. But a lot like other important areas of medicine, we're at this point guided by the right thing to do, but not a lot of data, so it's wonderful what you're doing and I'm grateful and look forward to seeing the outcome.

Eric Pierce was frank and forthright in his assessment that living donation is in the beginning stages. Living donation is uncharted territory and practice varies from center to center because of the lack of evidence-based practice. For instance, Eric Pierce also said:

I think about capacity to make decisions as a psychiatrist and in order to have that

capacity, they virtually all do, it's a fairly broad definition when someone understands the purpose of the procedure, the risks and the alternatives and manipulate the data in their own mind and explain it to you then they have capacity. That seems, I'm almost beginning to see this as not a legitimate yardstick anymore. They all have capacity but there's more to it with respect to their decision-making. Other facets we don't know whether they should be concerning or not? But the simple bedside capacity that we used with dementia or delirium I don't think it applies and I don't think it's been discussed in the literature. I think we need to figure that out I mean I'm figuring it out as we go But um there's no clear guidelines right now as to what would make someone contraindicated or not other than something very obvious like somebody unable to consent or doesn't come to the appointments you know.

The field is in its early beginning stages and there is not enough knowledge at this point to use evidence-based practice, something of a concern for the psychiatrist. The standard tools he uses as a psychiatrist are not adequate to determine whether a candidate is suitable. Henry Marcus, surgeon and director of transplant institute said:

I think that most important thing for a surgeon team is that maybe the public is to believe in what you're doing and that it's a good procedure that the outcomes are as presented-good -that it's helping people. I think that under such circumstances you go ahead and do it if you to begin with don't believe in the procedure it's very difficult to impose it on others around you in the center.... A famous transplant personality Tom Starzl said it shouldn't be done in the liver setting because it's dangerous and it shouldn't be done. I mean I respect the opinion actually myself I myself was in the past more skeptical whether we should do it or not and I think now I am far more aggressive but now I see our results and see the nationwide results convincing me it's a good procedure...One thing for sure for whoever is doing this procedure going forward you cannot be afraid of your own shadow.

Living donation surgery is controversial and innovative. The physicians must take risks to perform it because of the risks to the donor, a healthy person with no need of surgery themselves.

Eric Pierce thought of other issues regarding evidence-based practice:

This is pretty serious stuff and I think we don't know what we're doing, (laughs) No it's actually not true I think we do know but I think more information is better in this case when I hear myself talking what we're talking about is experience based on our own experience talking in the meetings which is great but why not use other people's skills as to be available? I wonder if it would be better to have a psychologist do an PA (psychiatric and psychological assessment) than the IDA person, independent donor advocate, what do they do really...if we have standards and norms that we can go by that

would allow objective evidence with respect to motivations and own personality styles how they make decisions, and if we consulted industry we'd have those answers cause that's what they do. We don't.

Eric Pierce alluded to industry, that it encompasses a gold standard of psychological research as opposed to medicine. Should the techniques of industry be employed in order to build evidence-based practice for living donation?

Theme 17: Advice to Other Team Members

Eric Pierce, psychiatrist, had several points of advice to give to other psychiatrists and to other team members. He also thought of additional steps to take in the evaluation and assessment of living donors. Independently he arrives at a similar conclusion to the other team psychiatrist interviewed for this dissertation:

people say and what they do are not always the same thing and what they do is more important. How they behave actions speak louder than words in this case, how do they approach getting their blood drawn, to their appointments? How are they on the phone?...what I would say to the surgeons and psychiatrists, don't feel like you're the only one making this decision and don't feel that you know all the answers, and that other people can contribute to this process and need to. Another thing we don't do and probably we ought to it just occurred to me we don't do collateral interviews.... we don't interview family...whenever we make a decision about someone leaving my emergency room (Psychiatric Emergency Evaluation Center) we don't make that decision without talking collaterally in the same way we make a decision about an alcoholic coming in for transplant we almost always want to talk to the family members to find out their side of it. We probably ought to be doing this, and this is the first I've thought of it...

Donors are usually interviewed by themselves without family members being present, in order to give the donor ample time and opportunity to discuss matters in private. The transplant providers do not want to create extra hurdles for patients, such as requiring more than one meeting with a donor, and one with family members. It is unlikely that the center will mandate family or collateral interviews. Eric Pierce reaches a conclusion about another matter, that of psychological testing which is not currently being done at his center. Olive Groff, a psychiatrist, reaches an opposite conclusion. Eric Pierce said:

one possibility I just reviewed a disability claim for an insurance company as an independent medical examiner...they had a neuro-psychologist and he did an MMPI on a person? Is that the right test where they have the F score? It's a very long test But I would be curious to see if there might be smaller ones objective well validated tests of personality inventories and decision making like they use in hiring...something we have standards and norms that we can go by that would allow objective evidence with respect to motivations and own personality styles how they make decisions...

Olive Groff stated, when asked about psychiatric testing:

Bull---- It's all about the relationship it's just another way to be distant from the patient another way of saying I don't want to feel what you're going through take this test so I can be protected from the struggle and agony of to do it or not to do it. I am absolutely against it. ... use them. How can I? I have an hour to establish rapport...

Barbara Nolan, a social worker gives this advice for other social workers. She mentions the conflicts inherent in living donation and how best to handle them:

Sit in on a lot of interviews. Listen to other people talking to people. Trust your gut? If you've got a bad feeling I would really explore it. At the same time recognizing that there's people who can want to give and still be ambivalent, there's a lot of gray area in donation ...if you have someone who wants to give but is scared or anxious or ambivalent you need to be able to tolerate that ambivalence.

Barbara Nolan recognizes that ambivalence is part of living donation and that in her opinion best practices involve helping a patient with ambivalence. Many donors do make up their minds immediately and do not appear to be swayed by any amount of information. Psychiatry has often said that most donors have made up their minds as soon as they hear about the possibility of donation.

Social worker Max Wilson has the final word on advice for other social workers, "Be respectful. What they're doing, me personally, I think it's a great thing."

Findings Summary

Participants found multiple areas of concerns for living donors and their families as well as identified advice for future transplant team members who work with living donors and

recipients. The principal issues of family dynamics, donor motivation, coercion and the medical excuse were discussed in detail. Team members felt that the dynamics of the family portend to a great extent the way the family behaves during and after the surgery. There was recognition that donor motivation varies with each individual and that coercion is present to some degree in many instances. Evidence for practice interventions is scarce and needs to be developed with further research.

The first theme, transplant as a family illness, emphasizes the family context of the donation and argues for a family systems approach. The second theme, “Generations” illustrates the interplay between generations in a family and how the generations can involve living donation between them. The third theme is that donation has many aspects and individual variations. Donation as a redemptive act, donors who are primarily concerned about themselves, and donors who are mostly concerned with their families are described here. Providers have concerns that encompass the recipient is the fourth theme. The providers recognize that some recipients are reluctant to accept gifts of living organ donation from their children. Theme five describes the authority of the team and the existence of paternalism in the medical profession. The medical excuse is in theme six, a paternalistic practice that affords protection to an unwilling living donor. Theme seven is about coercion, which appears to be a common element in many living donation scenarios, in both familial and other types of relationships. Guilt in theme eight is another component, like coercion, that seems likely to be present in living donor situations. Theme nine is about pediatric donations and the motivations that parents have to donate to their children. Do we take for granted that parents always are willing to be living donors for their children? Is there more ambivalence for parents in donating to a teenager than for an infant? Deception, in theme ten, involves a discussion of “impression management” as practiced by

prospective donors. It also considers the power imbalance between patients and members of the medical team as a condition that enhances the climate for deception. The eleventh section covers aspects of ethnicity and religion and the need for further research in this area. The twelfth section illustrates what has happened when an ethics committee gets involved in decision in which a family does not agree. Emotional consequences of living donation, the thirteenth theme, attempts to show some instances of negative emotions dealing with the donation and its aftermath. The fourteenth theme is about financial incentives and the responsibility of the medical team to foresee and forestall financial considerations from living donation. The fifteenth theme, regrets for avoiding organ donation, conveys stories about when the surgical outcome is poor or the work-up took too much time. The sixteenth theme, “not a lot of data,” explores how living organ donation is in its infancy and that further research is necessary for evidence based practice in living organ donation. The seventeenth subject, advice to other team members, focuses on some new thoughtful ways to approach interventions with living organ donors.

Chapter V:

Discussion and Conclusions

As the participants in the study have indicated, this study can add to the findings of the literature and studies around the world that have explored the needs of live organ donors their families and transplant teams. The team members have generously shared many of the experiences and insights about living donation. The need expressed by some was to find “what we are missing” because the field is “in its infancy.”

Almost every participant discusses the challenges inherent in the assessment of prospective donors. One participant, Olive Groff, said “I have been doing this for 12 years, I’ve been burned.” Her learning experience was no more than trial and error. Manuals that would help to select an ideal donor from the psychosocial point of view do not exist, but would be welcomed by transplant professionals. “There is an inherent conflict in meeting the potentially competing needs of donor and recipient, and there is a lack of evidence-based data to help us objectively sort through that process” (Surman et al. 2005, p. 3). Although we will never perfect the circumstances for living donors, we can strive towards realizing a more ideal method for assessment and working with situations when living donation is part of the solution.

This chapter will begin with a discussion of the theories of Melanie Klein, D.W. Winnicott, and Viktor Frankl as they are relevant to living organ donation, both for donors and for recipients. The next section pertains to the preliminary stages of the donor work-up and how these can be improved to develop a fair and just prospect for the donor starting at the first meeting, usually called “donor education,” with the transplant staff. The next section is a discussion of education and training implications. Following that, there is a discussion about the study limitations. Next there is a section on implications for social work practice, and then

implications for future research. The next topic is a consideration of implications for liver donation practice. After this, the implications of paternalism and autonomy as they relate to living organ donation are explored. “Focus on donors” encompasses discussion on the need to focus further research on donors, to include the perspective of the hospital, transplant program, research and publications. There is a section on “The recipient” which explores the possibility of guilt after the transplant. A section on the issues of altruism in living donation and the growing numbers of altruistic donors is next. The last section is the conclusion.

Theory

The theories of Melanie Klein, Winnicott and Viktor Frankl can offer insights into issues affecting the psychological impact of living donation upon the donor. The theories apply to the events leading up to the decision to donate, and to the actual donation process itself on the donor. These theories may be instrumental in determining the suitability of a donor and inform the follow up interventions for any living donor.

As discussed earlier in Chapter II Melanie Klein imagined that the infant imagines that he or she injects parts of himself or herself into the mother to manage the conflicting feelings of the caregiver as “good” or “bad.” If this theory is germane and does influence the future development and maturation of an individual, the very act of offering oneself as a potential donor may be a method of coping with unresolved conflicts and guilt from infancy and childhood. This would not necessitate, by any means, that the donation had to be between parent and child.

Ramchandani, (2006), stated that there are:

positive psychological consequences of donation (suggesting that the act of donation binds unconscious conflict) but negative and persistent minor physical consequences for the donor (suggesting that it does so ineffectively!)...the possibility that covert psychological factors may exert a significant role in the motivation to donate and that the act of donation may be an attempt to resolve this conflict more or less successfully depending upon the maturity of the ego defenses displayed by the individual (p. 292).

At the core of the Viktor Frankl worldview is that to have a meaningful life, one must ask what does life demand of an individual, not what they want from life. The selflessness inherent in such an attitude lends itself to the offer of donating an integral physical part of one's self. Further studies must be performed to evaluate the donors themselves for the relevance of these concepts for them.

Decker et al. (2008), discuss psychic conflict and the integration of the organ at the time of the transplant by the recipient. "The function of the donor organ as a transitional object as described by Goetzmann (2004) supported by Winnicott (1969) can be confirmed as being a definite phase of the post-operative process. It is a non-personal possession of the patient in Winnicott's view and as such illustrates the quality of an object offering protection" (p. 250). The transplanted organ as a transitional object was discussed earlier in the second chapter. Goetzmann (2004), wrote that "a patient, years after receiving a lung transplant, still perceives the organ and donor as transitional objects, and how these have an important psychical function for him" (p. 280).

In addition, Decker et al. deal with the subject of the transplanted organ by citing Melanie Klein. They noted that:

Regarding the quality of the object it can be best understood in the terms put forward. By Melanie Klein (1946). The actually introduced object is burdened with archaic feelings of guilt in a highly ambivalent experience (p. 250).

Decker and colleagues described how a husband, the recipient of his wife's kidney, experienced the donation and the vicissitudes of his ability to integrate her organ, not only within himself but also within the relationship with his wife, the donor:

The wife as a donor is linked in the inner imagination of the recipient to the vision of a damaged, deprived mother image, whose revenge for this seizure is to be feared. Ambivalences towards the caring mother object can then lead to a qualitative change in

the experience of the donor organ (p. 250).

Goetzmann, (2004), based on a case study, described that the patient experiences the organ and donor as transitional object. “There are indications in psychosomatic transplant literature that the ‘transitional space’ (in the D.W. Winnicott’s sense) plays an important part in the psychic integration of a transplanted organ or its donor”(p. 279). He sees the organ being used as a transitional object by an adult:

...the idealization, omnipotence and magical vitality that are attributed to the ‘donor’ indicate its use as a transitional object...It remains in possession of both the donor and recipient and enables both persons to vitalize-both the living recipient and, in his phantasy, the living donor (p. 285).

Before the Initial Blood Test

The tension produced By the Hippocratic oath to “first, do no harm” occupies the territory of living donation for transplant team members. As one participant in the study, Mimi Delaney, said, “Just asking someone to donate will negatively affect them for the rest of their lives.” The statement of the need for living donation serves as the “first cut” of the living donation procedure and the process becomes more invasive as the work-up goes on. In a study performed in Brazil, the live donor protocol was divided into three stages:

Phase I: the cardiac and pulmonary clinical evaluation, surgical and psychosocial initial evaluation and ...abdominal Doppler ultrasound. In Phase II we performed tests [blood work] to exclude liver diseases...Phase III included a hepatic angiogram. Informed consents were signed in each phase (Araujo et al., 2010, p. 424).

The workup accelerates the physical invasion as it proceeds, but the introduction of the need for a living donor to the recipient is the first act of the living donor work-up. Russell and Jacob (1993) said “Health professionals should be aware that merely raising the issue of live organ donation may instigate powerful psychological processes beyond the potential donor’s voluntary control and leave little room for refusal without psychological cost.” (p. 89). Ross,

(2010) also points out that:

For provider efficiency, families are often educated about living donation as a group and they are encouraged to get... HLA-testing done before they leave, even before they have had time to reflect and make a fully informed decision. Because HLA testing is a simple blood test with minimal physical risks, many believe that they can test adults even before the adults have had the opportunity to reflect upon the broader implications of this test. This practice reveals a current error in the current process because this screening ought to be understood as the first hurdle in the donation process, a hurdle not to be approached without ensuring that the potential donor has adequate information about the risks, benefits and alternatives to make an informed decision whether or not to begin the process. This is particularly important given the empirical evidence that finds that passing the first hurdle may be a 'point of no return' for many potential donors (p. 734.)

Proceeding with an abundance of caution in these first few interventions is ethically fair and reasonable, although it may present an inconvenience for transplant teams.

If the donor decides to pass through these first obstacles, the complexity of his or her situation demands attention from the members of the team, especially the social worker and the psychiatrist. Currently the Independent Donor Advocate meets with the patients by themselves one time before the transplant, towards the end of the work-up. Some have advocated for the Independent Donor Advocate to be present at the initial living donor family discussion, well before the current practice allows. In some hospitals, groups of families with living donors meet with a transplant coordinator and a surgeon for their first meeting. Ross postulated:

To ensure that the potential donor has the opportunity to make informed decision prior to ABO testing, a donor advocate should be available at the introductory group meeting. This meeting should include an explanation of the transplant program's principles and practices including 1) the roles and responsibilities of the donor advocate, 2) the right of potential donors to be excluded at any time, and 3) the responsibility of the donor health care team to declare a donor ineligible without providing the rationale-whether it is medical (e.g. ABO incompatibility); psychological or donor directed and 4) the policy that the donor health care team will neither confirm nor refute any explanations provided by the potential donor to the potential recipient. That is, at this meeting, the donor health care team explains that its duties of veracity, privacy, and confidentiality are obligations to its patient-the potential donor- and this relationship is independent of the needs and interests of the potential recipient (and his or her family) (Ross, 2010, p. 734-35).

The empirical data, that is, the knowledge based on practical experience of treating living

donors, leads the transplant staff to assume a protective posture towards the donor, ensuring confidentiality and freedom of choice, freedom from coercion, and the right to self-determination. That is why some transplant centers have independent donor teams, which include a social worker, hepatologist, independent donor advocate and surgeon, rather than a sole independent donor advocate. The independent donor advocate team is solely responsible for the health and welfare of the donor and has no responsibility towards the recipient, who has his own team. The team method may be more advantageous than having just one independent donor advocate, providing support for its members and a more balanced interdisciplinary approach as opposed to one person. In Surman, Fukunishi, Allen and Hertl (2005), the evolution of the independent donor team is explained:

Death of a right lobe hepatic donor in 2002 at New York's Mount Sinai Hospital led the New York State Department of Health to formalize rules that supported state of the art care of the donor. One requirement is that live-donor liver transplant programs must have a 'donor advocate team' consisting of an independent medical specialist, a social worker who works with donors but not with their intended recipients, and a transplantation psychiatrist. The donor advocate team shares in an assessment of donor suitability and advises the donor surgeon. If the donor surgeon overrides recommendations of the donor advocate team, the reason for doing so must be documented and is subject to future review (p. 4).

Education and Training Implications

This study points to the need for objective evidence in the assessment of living donors. There are only subjective criteria in clinical work with living donors at this time. Psychological testing could add to the knowledge base on living donors to help transplant centers universally evaluate donors for the best outcomes. Russell and Jacob (1993) mention the psychic trauma of live organ donors and the administration of projective tests, which found that:

24 of those donors had experienced what they define as 'mild trauma' and that 'moderate to severe trauma' was experienced by 12.... Concerns for psychological risk to the donor leave the onus on the transplant team to weigh psychological with physiological factors in the selection of donors.... Of the factors that can be assessed at the time of selection, the researchers found that higher age of the donor, low level of education and perhaps

most importantly, lack of social supports, may be predictors of poor psychological outcome (p.92-93).

More extensive training in trauma and post-traumatic stress disorder is indicated for social workers and psychiatrists. Hsu, Hwang, Lee & Chen, (2006) reveal that:

some donors were reluctant to reveal their anxiety about donation and that the donors seldom spoke with their doctors about this...They complained of tiredness and fatigue, indicating psychological tension and distress. Therefore, how to identify risk factors of psychosocial aspects and help the donors cope with anxiety, concern and stress related to donation will be an important priority in future studies. A better psychological preparation for the transplantation process and close psychiatric follow-up may reduce negative physical and psychological outcomes (p. 2105).

Social work is well positioned to be sensitive to a donor's unexpressed anxiety and tension during the hospital stay and at clinic visits. Close psychiatric follow-up may improve the quality of life for the donor post-transplant and should be recommended for all living donor programs.

Study Limitations

This focus of this study is obviously limited to providers and does not include the feedback of donors, recipients, and other family member participants. There were three transplant staff members from differing hospitals, the other seven were at the same hospital transplant center. It is also limited by the small sample size of 10.

The study was limited to one geographical area. The writer knew all but two of them professionally, and because of that, they may have withheld unconventional thoughts. Finally, if live donations were minimized, the subjects would be out of work and lose income for themselves, their administrative department, and their hospital, the employer.

Implication for social work practice

In this writer's opinion there must be psychosocial evaluation and services for both donor and recipient over several years post-operatively to know if there are any unforeseen

repercussions within the family or with the donor. Information is needed from long-term follow-up to improve our treatment of the patients and families. Transplant social workers and psychiatrists should remain available for living donors as long as they are needed. It may be that a more structured interval approach for assessment and further exploration of the psychosocial aspects of living donation will improve outcomes. What we learn about family dynamics in living donation will be important for the clinical practitioner as well as for policy decisions.

Both of the psychiatrists suggested that collateral or family interviews be done in the beginning stages of the psychosocial work-up. “At our center, a typical psychosocial donor evaluation, including a collateral spouse interview, is completed in less than 90 minutes... Wherever possible, collateral interviews with significant others should be included to assess the depth and breadth of the donor’s support system”(Olbrisch, Benedict, Haller, & Levenson, 2001, p. 44 and 53). This plan might necessitate more than one visit to the transplant center by the donor and family. The opportunity to glean deep contextual information about the family and support system may overshadow the risk of reinforcing coercion, as long as the donor has time to meet with each team member individually. Further research in this area is warranted to assist with various alternative combinations.

The very existence of a person in a family structure implies that an organ transplant involves family dynamics. How significant must this be in a situation such as living donation where family members are being evaluated as potential saviors of the patient? The aftermath of acceptance or refusal of an individual as a donor on subsequent family dynamics must be considered. The issue is so central and often determinative of donation that the requirement of an evaluator skilled in family therapy ought to be considered in the future for transplant teams:

There is clearly a need for rigorous accumulation of data regarding the long-term outcome and quality of life in donor surgery, especially in the case of the more recently

developed procedure of right lobe liver transplantation from live donors. Fukunishi et al. found in their one year post-transplant study of 40 partial liver donors that four experienced symptoms of post-traumatic stress disorder (Surman, Fukunishi, Allen & Hertl, 2005, p. 4).

Social workers must be alert for patients and donors who may be suffering from post-traumatic stress disorder.

Implications for Future Research

New research should explore the nature of the relationships between donors and recipients within families and whether it improves prospects for patients and families to use non-directed donation. Until recently only close and related family members were candidates for liver living donation. Intensive interviews with donors and their families can add to the knowledge which will help the transplant community come to terms with the difficult but life-affirming concept of living organ donation. Intensive interviews with donors about their families could bring new perspectives to living donation especially the relevant topics of family dynamics, family conflicts, coercion, or other aspects of family dynamics not yet identified. These topics need exploration in depth and an intensive interview is the best way to get description about these subjects.

Social work research can bring clarity to aspects of the expression of gratitude and help people negotiate the aspects of gifting. How can social work intervene to help individuals have a conversation with their donors and families about subjects including gratitude, obligation, danger, indebtedness, hazards and guilt?

One member of the team, Henry Marcus, wanted to do a study on adult-to-adult recipients who have a history of alcoholism to see how people feel when donating to adults who inflicted his or her disease on themselves. The alcoholic recipients often have stopped drinking within two years of listing, thereby having compromised themselves and their families until right

before the transplant. An area that warrants further research would study the adult children of alcoholics who donate to their alcoholic parent to see what dynamics are in play.

A longitudinal study of family dynamics of the patient and donor to track various changes over time would also be of interest. It is likely that the donation, at least temporarily, changes the family environment. The team should be sure to obtain baseline information on the family prior to the donor surgery, to see if the dynamics of the family change after the living donation. The feelings of the donor may change with the advent of the surgery and its aftermath. Knowledge about the long term effects of living organ donation might help us to improve the psychosocial outcomes of future families and donor recipient pairs.

An additional important area of study could be a trial using living donors who are not related and those that are related to the recipient in liver transplantation. Using non related donors who would be compensated in some way may render the “sacrificial nature of the gift” (Scheper-Hughes, 2007) archaic, relieve pressure on individuals and families to save the lives of loved ones and extricate them from the dilemmas in which they are entangled by modern life.

The anonymous nature of the cadaveric organ donor may allow for more idealization and positive cathexis than for the living related donor. It would be interesting to see a study on attitudes of the recipients and how they vary between cadaveric and living donors. Is there a significant difference in the regard between the cadaveric and living donor because, as Scheper-Hughes noted:

The gift the recipient has received from the donor is so extraordinary that it is inherently unreciprocal. It has no physical or symbolic equivalent. As a consequence, the giver, the receiver and their families may find themselves locked in a creditor-debtor vise that binds them to each other in a mutually fettering way? (Scheper-Hughes, 2007 p. 509).

Implications for Liver Donation Practice

The team was unanimously concerned with the donor’s rights to be free from coercion

and to be free to determine for themselves the best course of action. They were aware that almost every situation is coercive, some more than others. Some were aware that the team's actions themselves introduced some coercive element. They mentioned better screening and opportunities for the potential donors to find a way to save face when wanting out. The interviewees were divided regarding the use of the medical excuse. While some used it and went a long way with it (such as providing a scar) others were firm that the potential donor will face up to the pressure.

Transplant teams are very interested in increasing the numbers of living donors. More living donors mean more saved lives, and better outcomes for many recipients as well as more income and prestige for the transplant centers. As we increase the numbers of living donors who are being evaluated as potential living donors we will increase the numbers of living donations in the kidney and liver transplant services. There is a lack of objective factual evidence in the psychosocial aspect of living donation, therefore few ways to maintain evidence-based practice. The need for separate independent donor advocate teams will intensify as the numbers of living donors increase. Transplant and social work administration in hospitals will have to rise to the demand, and support independent donor advocates and advocate teams as well as support research to add to our knowledge about family dynamics and living organ donation.

The field of living donation uses heuristic techniques rather than empirical data and knowledge. Living donation is a procedure already entrenched in the repertoire of modern medicine. But the future and lasting effects of donation remain largely unknown throughout the medical community of the world, since the procedure is a relatively new one. Browne and Desmond (2007) noted that:

In 2006, the Irish government deemed the development of a national Living Transplant Programme a service priority. Such development is set against the backdrop of a recent

European Commission Communication (European Commission, 2007), which proposes expansion of living donation to increase organ availability... In light of recent EU Communications proposing the expansion of the use of living donors greater understanding of the determinants, psychological implications and ethical considerations in living donation decisions is necessary (p. 605-606).

Finally, there is some discussion about the language used for organ donation. Is the word “sacrifice” more descriptive than “gift?” Shaw (2010) said that:

gift terminology tends to downplay the sacrifice involved in tissue donation generally, as well as depoliticizing the exchange relations of tissue transfer in contemporary culture and in the global context (p. 609).

To Shaw, the word “gift” is a euphemism that disguises the sacrifice inherent in organ donation, including living organ donation. The sacrifice of a person who undergoes surgery to provide a life saving organ to another is intrinsically not reciprocal. Further study of the language used to describe organ donation may demonstrate that use of language will affect rates of donation, both cadaveric and living organ donation. Clarity in language may lead to less confusion and more simplicity in the field of living donation.

Paternalism and Autonomy

The tension between the inclinations in medical practice of paternalism and autonomy demands equipoise of the practitioner. One interviewee (Eric Pierce) raised the issue of paternalism with respect to medical excuses. He recognized the power and determinism of the medical professional. He cannot deny however, that in the power of the transplant team to approve or to reject a living donor, life and death issues are front and center. However, in this discussion, the principle of autonomy was neglected. In this respect, Surman, and colleagues (2005) noted that:

The impact of public opinion and growth of consumerism in American culture led to a decline in the primacy of Hippocratic paternalism. The zeitgeist in medical ethics has increasingly favored the principle of ‘autonomy.’ The growth in autonomy has come at a price. The greater burden of decision-making has shifted from the surgical team to

candidates for donor surgery (p. 2).

Patient autonomy is not part of the discussion here, but it should be incorporated. Eric Pierce continued:

Deferring to our own experience and our own skills as mental health professionals which I think is hard to understand for some people because a lot of what we go with our experience or our gut.

Dixon and Abbey (2000) wrote, “The living donor complicates the standard ethical dichotomy between autonomy and paternalism. A narrow paternalistic interpretation of the traditional ‘do no harm’ edict mitigates against the use of any living donor. Most clinicians reject this narrow view” (p. 409). Not mentioned in the discussion above by Eric Pierce is the principle of autonomy. Eric Pierce had been concerned with the lack of adequate psychiatric tools to establish a patient’s competence for living donation, however, autonomy is a principle that is prevalent and ubiquitous in medical practice today and it should be a part of the donor assessment. Biller-Adorno, Agich, Doepkens, and Schauenberg, (2001) noted that:

Autonomy provides the theoretical basis for both a free and informed consent and is usually considered the prerequisite for the ethical acceptability of living organ donation. Determining an individual’s decision-making capacity is thus a central, but insufficiently discussed task in the assessment of living organ donors...Some authors regard current assessment procedures as conceptually inadequate or deficient. They argue that strictly positivist approaches with their exclusive focus on a ‘patient’s ability to make independent, rational choices to consent’ can produce dichotomies of competent vs. incompetent persons that overlook gradations...other factors enter in the judgment if someone is regarded as ‘autonomous enough’ to be a living organ donor (p. 361-362).

These authors put forth an idea that might provide a more inclusive approach:

A relational concept of autonomy that sees humans as interconnected beings rather than as isolated individuals may be more prone to accept a donor who manifests such connectedness even if they lack high cognitive abilities. For individuals who care about one another, benefit for the recipient will also be a benefit for the donor. Such a view might have the effect of reducing the classic conflict between paternalistic protection vs. respect of choice (p. 363).

Focus on Donors

Eric Pierce had also referred to the need of the provider for evidence-based practice and the tension that results from making life and death decisions with a dearth of evidence and knowledge about the effects of living donation, both medical and psychosocial. Hsu, Hwang, Lee and Chen's study (2006), said:

Attention has focused on the quality of life of transplant patients, including stress, coping ability, and needs rather than on these factors among organ donors. In the United States, even though some reports have focused on the health status and medical complications of donors, few have assessed the effects on their quality of life. Furthermore, there are few reports on the physical and psychosocial aspects of living donors during the organ donation process (p. 2102-2103).

Transplant staff members are invested in living donation. From the transplant coordinators to the surgeons, living donation commands intense interest and commitment for its ability to save lives using resources beyond the deceased donor UNOS waiting list. Living donation is also positioned at the frontier of modern medicine, making it attractive to surgeons who want to be at the "cutting edge" of the diagnosis and treatment of end stage liver and kidney disease. Transplantation is dependent on interdisciplinary teamwork, although the surgeon has the final word.

The structure of medical care in the United States at the present time by necessity creates conflicts for providers. The desire to "cure" the patient is persistently influenced by the need to maintain survival of the program itself, i.e., its financial viability (and the university setting), the number and size of research grant support and publications.

Do these issues above affect the evaluation of potential donors, whether overtly or covertly? Studies of these special issues must begin with the topic under study here. What are the perceptions of providers with respect to their role in the selection of living donors? Do transplant providers overtly or covertly recognize the importance of these issues in their interactions and

evaluations of a donor?

The Recipient

Olive Groff, a psychiatrist on a living donor transplant team, was concerned with the guilt feelings of recipients. She stated that the:

recipient struggles a lot more than the donor. The recipient first of all they're tremendously guilty they've caused their illness whether it was alcohol, hepatitis C, and parents inherently don't want to see their children being injured... I think the guilt of receiving gifts from your children for the recipient is enormous and I think that we have not really focused upon this.

Psychiatric studies have reported that there exists in recipients a condition called Paradoxical Psychiatric Syndrome (PPS), which occurs in recipients despite a good surgical outcome. "The results of the present study suggest that this syndrome is related to guilt feelings of adult recipients who apparently develop increased concern for their donor offspring once the threat of death from end-stage liver disease has subsided" (Fukunishi et al. 2002, p. 2633). The diagnostic criteria are conflicts associated with the transplant, depression, anxiety, conversion disorders, somatization, and psychosis, which occur as a late complication following the transplant despite a good outcome. (p. 2632). They postulate that "PPS is closely related to recipient guilt feelings towards a living donor. Before LDLT, recipient's desire to escape from approaching death supercedes their conflicted feelings related to the prospect of living organ donation. Following LDLT, the fear of death subsides and concern for the donor becomes more pronounced" (p.2632). There is a need for this study to become more widely known to transplant team members so that they can better intervene with recipients before and after transplantation.

Altruism

Dixon and Abbey, (2000) wrote about the skepticism of transplant teams as it occurs with altruistic donors. Are transplant professionals suffering from a limited appreciation of altruism

and religious feeling thereby failing to value true expressions of human commonalities?

Kranenburg and colleagues (2008) said that:

...up until recently there has been great reluctance to accept the offers of Samaritan donors. The most important reason for this reluctance is the possibility that these donors may not be mentally stable (p. 178).

They explore the psychological evaluation of Samaritan kidney donors:

Why do we subject potential Samaritan kidney donors to a stricter psychological evaluation procedure than conventional living kidney donors? The underlying reason could be that we have insufficient data available yet that describe the differences between the conventional and the Samaritan donation experience (p. 183).

Are conventional and altruistic donors closer in motivation than we imagine? The benefit to the conventional donor is saving the life of their loved one, for themselves and for other family members. We must determine the benefit to the altruistic donor, and the risks:

The rationale for a well-defined psycho-diagnostic tool to screen Samaritan donors is to rule out cases where the psychological risks of donation are larger than the benefits. This is especially important because psychological benefits are generally seen as a major moral justification for the surgical practice of living donor nephrectomies (p. 178).

Henry Marcus, a transplant surgeon, spoke of altruism as it relates to living organ donation.

“I do believe it’s done in most of the cases that I see here for altruistic reasons. People are simply good and want to do it. Now some of them have very direct relationship with the patients with the candidate for transplantation some of them do not have it instead have indirect relationship and they still want to go ahead and do it because and I see it very often, they are really believing in what they are doing like it’s a calling. Last week a patient donor wanted to do it because she did not know the recipient she knows the mother but she has children and she knew that the recipient has very small children and could not take it that she can’t help someone who is a mother and ...she felt a calling to do that.”

Dixon and Abbey (2000) conclude:

...conceptions of altruism can be unduly restricted by an overvaluing of biological kinship and an undervaluing of religious motivation. By pathologizing an altruistic act that does not restrict itself to family, ethnicity, or friendship, only the most primitive conception of human relationships is left as the standard of mental health... [the generosity of an altruistic donor] presumes meaningful, caring relationships with others based on a common humanity (p. 410).

However, new social technologies such as the Internet, FaceBook, You tube, and other media uses such as billboards and even TV news programs, complicate the concerns for altruistic donors. At a conference in 2006 convened By UNOS, it was found that:

types of unrelated donors that have provoked heightened concerns within the transplant community: individuals solicited from Internet or media appeals, individuals in a superior/subordinate relationship with the transplant candidate (employers/employees, teachers/students), foreign nationals, members of organizations/faith communities, individuals involved in paired and list donation and individuals seeking to make a nondirected donation (Dew, Jacobs, Jowsey, Hanto, Miller & Delmonico, 2007, p. 1048).

Caution must be used in evaluating these situations to protect the donor's health, safety and well-being.

Conclusion

Recent developments in stem cell research indicate that organ transplants may become obsolete in the future, when stem cells can regenerate a new organ from a patient's own cells. In November of 2008, surgeons were able to take a windpipe from a cadaver and from the frame, add recipient's cells to grow a windpipe that was compatible. This type of intervention would do away with the need for immunosuppression medications.

As of this writing, in late August of 2010, two recent deaths this summer of living liver donors occurred in the United States. Is the current practice of living donation a blunt archaic instrument used to solve the problem of organ shortages? Dixon and Abbey (2000), wrote, "future generations of surgeons will look back on this phase of transplantation in which live

donors are used as a relatively primitive time” (p. 410). The family of the first donor mentioned above maintained their privacy and there is little known about the circumstances of that donor’s death. The second death occurred in a brother-to-brother liver transplant. The donor was 34 years old, married with three young children and we are waiting to learn of the cause of his death. On August 25, 2010, it was reported by Reuters that scientists in Cambridge have succeeded in growing liver cells from patients’ skin, which will likely advance treatment of end stage liver diseases and may one day preclude the need for living liver donors. Medical and surgical treatments for end stage liver diseases are in a state of lively flux and progression. Undoubtedly the need for living organ donors will vanish in the future but until that day arrives, we must contend with the circumstances in transplantation and living donation as they are in our time. Until the time that organs can be grown from one’s own stem cells, it behooves us to take extreme care with living donation, and “do no harm.”

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Appendix A

Interview Guide

I am going to ask you about your experience as a member of the transplant team who works with transplant donors and recipients. I am particularly interested in your perception of how donors make the decision to donate and what family dynamics are involved in the decision making process. There are no right or wrong answers; I am simply interested in your honest opinions and thoughts.

I will try to keep your answers confidential but given the size of the service someone may be able to guess who answered what. I hope that this is OK with you. None of the questions are about you personally, but they are all about the work experience you have with live liver donation. Thank you for your time and cooperation.

- Could you start by telling me about your role and responsibilities on the team?
- Based on your professional experiences can you tell me about the kinds of things that motivate people to donate an organ?
- In intra-familial cases of organ donation, where one family member donates to another, are there particular family dynamics you have noticed? Can you give me examples of how this played out with particular donors and their families?
- Based on your professional experience, have you noticed anything about race or ethnicity that may affect people's behavior regarding organ donation?
- Based on your professional experience, have you noticed anything about religion that may affect people's behavior regarding organ donation?

-
- Have you ever had or suspected a case in which goods or money were exchanged or promised to be exchanged to make the donor more willing to give? If so, please elaborate.
 - Have you ever had the sense that coercion of any kind played a part in a donor's decision to donate? Can you give me examples?
 - Can you talk about emotional reactions to organ donation that you have been aware of among the organ donors you've worked with? Examples?
 - Some of the research in this area has suggested that anger prior to surgery was a predictor of perceived stress following liver donation. Have you ever encountered such anger? Has this been your experience in working with donors?
 - Have you ever been involved in a case in which a "medical excuse" that deems the donor medically unsuitable was used to give the donor an "out" when he or she does not want to donate? If so, can you tell me more about these cases?
 - Can you talk about any ethical dilemmas the team has faced? Can you think of examples?
 - Is there anything you would like to add?

You have shared some of the advantages of having living donation. In these final questions we would like to hear your ideas about how to improve the way living donation is approached.

- What advice would you give another transplant surgeon, social worker, nurse or psychiatrist who is learning about living donation?
- What can transplant team members do to help donors and families navigate the process of donating an organ – financially, socially and psychologically?
- Is there anything you would like to add?

Appendix B

Consent Form

Introduction and purpose of interview

I am a graduate student in the DSW program at the University of Pennsylvania School of Social Policy and Practice. As part of the requirements for my doctoral degree in clinical social work, I am writing a dissertation which will include intensive interviews which I will conduct and analyze.

Please ask any questions that you have about participating at any time. I want you to have the information you need to make a decision that is best for you.

What is involved?

The interview will last about an hour to an hour and a half. I will make an audio recording of the interview and may take written notes. The area I am interested in studying is about living organ donation when involved with liver transplant. Social work is well positioned to have noticed different aspects regarding family dynamics of living organ donation. In addition it is important to know how living organ donation affects the individual donor as well as involved family members. These are the issues I plan to cover.

It is possible that we might forget to cover something important during this interview. In case that happens, I will also ask if I can have permission to call you in the next two weeks to see if there is more you want to add, or in case I have any questions. When I call, depending on how much you have to say, it is possible that I will ask your permission to have a second interview.

Confidentiality

The information you share will be kept confidential. I will not share information about whether or not you participate in this project with anyone, including any employer. I will never use your name, personal information or information about where you work in the class paper that I turn in. Anything with your name on it, such as signed consent forms, and any other documents that could be used to identify you, will be kept in a locked file cabinet, separate from your interview tapes and transcripts of those tapes. I am the only person except a transcriber who will listen to these tapes. Once I have analyzed the interview and written my final class paper for this project I will destroy an audio recordings, interview notes, interview transcripts and any other materials as related to this project. The final paper, including the transcripts, will only be viewed by my instructors, Dr. Ram Cnaan, Dr. Lina Hartocollis, and Mary Mazzola.

Benefits of participating:

Although being interviewed will not help you directly, your answers will assist me in developing, performing and analyzing an intensive interview. You may also find it interesting to share your own story.

Risks of participating:

There are no known risks of participating. If answering some of the questions makes you feel uncomfortable, please let me know. We can stop the interview for a few moments, or you can decide to stop participating entirely.

Compensation:

You will be reimbursed for any money you spend to travel to the interview site, including parking.

If you have any questions about the project, please feel free to contact me:

Laura Kotler-Klein, LCSW

University of Pennsylvania Hospital

Department of Clinical Resource Management and Social Work

3400 Spruce Street

Philadelphia, PA 19104

215-662-6637, or fax 215-662-4819

laura.klein@uphs.upenn.edu

If after talking with me you have other concerns, you can contact the professor who is supervising this work:

Dr. Ram Cnaan

3815 Walnut Street, Room 400

School of Social Policy and Practice

Philadelphia, PA 19104-6214

215-898-5523

You do not have to participate in this project. There will be no negative consequences if you decide not to participate. No one will know if you participated or not. If you don't participate, it will not affect your job or anything else.

If you do decide to be interviewed today, you can stop the interview at any time. You can also refuse to answer any questions that you don't want to answer. If you agree to be interviewed today, you do not have to give permission for me to contact you in the next few weeks. Even if you agree today that I can contact you in the future, you can change your mind at any time.

Please initial one:

_____ I DO give permission for Laura Kotler-Klein to contact me within the next two weeks.

_____ I DO NOT give permission for Laura Kotler-Klein to contact me within the next two weeks.

By signing this consent form, I am indicating that I have had all of my questions about this project answered to my satisfaction and that I have been given a copy of this consent form.

Participant/ Date

Appendix C

University of Pennsylvania
Office of Regulatory Affairs
Yvonne Higgins, Executive Director Human Research Protections
Emma Meagher, MD, IRB Executive Chair
3624 Market St., Suite 301 S
Philadelphia, PA 19104-6006
Ph: 215-573-2540/ Fax: 215-573-9438
INSTITUTIONAL REVIEW BOARD
(Federalwide Assurance # 00004028)
19-Mar-2010

Ram A Cnaan
c/o Laura Kotler-Klein
715 Station Avenue
Haddon Heights, NJ 08035
E-mail: laura.klein@uphs.upenn.edu
cnaan@sp2.upenn.edu
PRINCIPAL INVESTIGATOR: Ram A Cnaan
TITLE: Family process through the prism of living organ donation: courage, coercion calculus
and coalescence
SPONSORING AGENCY: NO SPONSOR NUMBER
PROTOCOL # 811369
REVIEW BOARD: IRB #8

Dear Dr. Cnaan:

The above referenced protocol and was reviewed and approved by the Executive Chair (or her authorized designee) using the expedited procedure set forth in 45 CFR 46.110, category 6, and 7, on 09-Mar-2010. This study will be due for continuing review on or before 08-Mar-2011.

Approval by the IRB does not necessarily constitute authorization to initiate the conduct of a human subject research study. Principal investigators are responsible for assuring final approval from other applicable school, department, center or institute review committee(s) or boards has been obtained. This includes, but is not limited to, the University of Pennsylvania Cancer Center Clinical Trials Scientific Review and Monitoring Committee (CTSRMC), Clinical and Translational Research Center (CTRC) review committee, CAMRIS committee, Institutional Bio-safety Committee (IBC), Environmental Health and Radiation Safety Committee (EHRS), and Standing Conflict of Interest (COI) Committee. Principal investigators are also responsible for assuring final approval has been obtained from the FDA as applicable, and a valid contract has been signed between the sponsor and the Trustees of the University of Pennsylvania. If any of these committees require changes to the IRB-approved protocol and informed

consent/assent document(s), the changes must be submitted to and approved by the IRB prior to beginning the research study.

If this protocol involves cancer research with human subjects, biospecimens, or data, you may not begin the research until you have obtained approval or proof of exemption from the Cancer Center's Clinical Trials Review and Monitoring Committee.

The following documents were included in this review:

- HS-ERA Submission (cjjjafc) submitted on 03/03/2010 - Cover Letter, dated 01/21/2010 - Consent Form- Email correspondence, dated 3/2/10 - CITI Social/Behavioral Basic Course Completion Report: Laura Kotler-Klein, dated 10/06/2009 - Interview Guide

When enrolling subjects at a site covered by the University of Pennsylvania's IRB, a copy of the IRB approved informed consent form with the IRB approved from/to stamp must be used unless a waiver of written documentation of consent has been granted.

If you have any questions about the information in this letter, please contact the IRB administrative staff. Contact information is available at our website:

<http://www.upenn.edu/regulatoryaffairs>.

Thank you for your cooperation.

Sincerely,

IRB Administrator

Consent Form

Introduction and purpose of interview

I am a graduate student in the DSW program at the University of Pennsylvania School of Policy and Practice. As part of the requirements for my doctoral degree in clinical social work, I am writing a dissertation which will include intensive interviews which I will conduct and analyze.

Please ask any questions that you have about participating in this project at any time. I want you to have the information you need to make a decision that is best for you. What is involved?

The interview will last about forty five minutes to an hour. I will make an audio recording of the interview and may take written notes. The area I am interested in studying is about living organ donation. In particular - how living organ donation affects the individual donor as well as involved family members. These are the issues that I plan to cover.

It is possible that I might forget to cover something important during this interview. In case that happens, I will also ask if I can have permission to call you in the next two

weeks to see if there is more you want to add, or in case I have any questions. When I call, depending on how much you have to say, it is possible that I will ask your permission to have a second interview.

Confidentiality

The information you share will be kept confidential. I will not share information about whether or not you participate in this project with anyone, including any employer. I will never use your name, personal information, or information about where you work in this dissertation.

Anything with your name on it, such as signed consent forms, and any other documents that could be used to identify you, will be kept in a locked file cabinet, separate from your interview tapes and transcripts of those tapes. Once I have analyzed the interview and written my dissertation for this project I will destroy any audio recordings, interview notes, interview transcripts, and any other materials as related to this project.

Benefits of participating:

Although being interviewed will not help you directly, your answers will assist me in developing, performing, and analyzing an intensive interview. You may also find it interesting to share your own story.

Risks of participating:

There are no known risks of participating. If answering some of the questions makes you feel uncomfortable, please let me know. We can stop the interview for a few moments, or you can decide to stop participating entirely.

If you have any questions about the project, please feel free to contact me:

Laura Kotler-Klein, LCSW
University of Pennsylvania Hospital
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3400 Spruce Street
Philadelphia, PA 19104
215-662-6637, or fax 215-662-4819
Laura.klein@uphs.upenn.edu

If after talking with me you have other concerns, you can contact the professor who is supervising this work:

Dr. Ram Cnaan
University of Pennsylvania
School of Social Policy and Practice
3815 Locust Walk
Castor Building
Philadelphia, PA 19104
215-898-5523

Your participation is completely voluntary

You do not have to participate in this project. There will be no negative consequences if you decide not to participate. While I will not divulge about your participation it is possible that other team members may become aware of your participation. If you do participate, it will not affect your job or anything else.

If you do decide to be interviewed today, you can stop the interview at any time. You can also refuse to answer any questions that you do not want to answer.

If you agree to be interviewed today, you do not have to give permission for me to contact you in the next few weeks. Even if you agree today that I can contact you in the future, you can change your mind at any time.

Please initial one:

_____ I DO give permission for Laura Kotler-Klein to contact me within the next two weeks.

_____ I DO NOT give permission for Laura Kotler-Klein to contact me within the next two weeks.

By signing this consent form, I am indicating that I have had all of my questions about the project answered to my satisfaction and that I have been given a copy of this consent form.

Participant// Date

