

A STUDY OF SELECTED PSYCHOLOGICAL
RESPONSES EXPRESSED BY
LIVING-RELATED RENAL DONORS

A THESIS SUBMITTED
IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE
MASTER OF SCIENCE IN NURSING
IN THE GRADUATE SCHOOL OF THE
TEXAS WOMAN'S UNIVERSITY

COLLEGE OF NURSING

BY

MARGARET FRANCES BRUKS, B.S.

DENTON, TEXAS

MAY, 1974

Texas Woman's University

Denton, Texas

March 15 19 74

We hereby recommend that the Thesis prepared under
our supervision by Margaret Frances Bruks
entitled "A Study of Selected Psychological
Responses Expressed by Living-Related Renal Donors."

be accepted as fulfilling this part of the requirements for the Degree of
Master of Science

Committee:

Lois Hough

Chairman

Betty Henderson

Estelle D. Kurtz

Accepted:

Mary Evelyn Huey

Dean of Graduate Studies

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CHAPTER I

INTRODUCTION

Renal failure is responsible for a sizeable portion of deaths in America and, as a result, the demand for kidneys to be used for transplantation is growing. The subject of renal transplantation is complex and offers a large selection of topics suitable for study.

While the transfusion of blood has been universally accepted for many years and corneal transplantations are considered routine, other types of tissue transplants have generally been thought to be still in the experimental stage. Transplantation, however, is fast becoming a familiar aspect of patient care. Hamburger states, "Kidney transplantation has reached a cross roads. From the stage of tentative experiment, it is passing to the stage of routine therapeutics" (1972, viii).

Much attention has been given to the recipients of renal transplants; consequently, there is a large amount of medical and nursing literature regarding the physical and emotional needs of transplant patients. What of the donor? He is the other entity of transplantation. He, too, is a patient in need of psychological and physical care. Very

little has been written about this person, especially in the nursing literature. As primary care personnel, it is the nurses' responsibility to plan for and implement quality care. In order to provide full scope of patient care for the donor it is necessary to identify through research the relevant areas of physical and psychological needs. From these findings, then, a plan for patient care can be formulated.

Statement of Problem

The problem of this study was to investigate selected psychological responses of renal donors to renal donation and transplantation.

Purposes

The purposes of this study were:

1. To determine if there was emotional closeness prior to donation between the donor and recipient
2. To determine if there was any alteration in the emotional closeness after donation between the donor and recipient
3. To determine the motivating factor for the donor's decision to donate a kidney.
4. To determine if the donor felt any anger after donation

5. To determine if the donor perceived an increase in self-esteem following donation
6. To determine if the physical condition of the donor influenced his responses after donation
7. To determine if the length of time since donation has any influence on the donor responses
8. To determine if the family kinship between the donor and recipient had any influence on the donors' responses
9. To determine if the sex of the donors had any influence on the donors' responses.

Background and Significance

Kidney disease is fast becoming a major health problem. The National Kidney Foundation states that kidney disease is the fourth leading major disease in the United States (1973). This is evidenced by the growing number of persons seeking treatment for this disease. Schreiner states,

Specialty comes of age when it acquires a successful therapy for a previously untreatable condition, Uremia, the final common pathway for so many renal diseases is now treatable by . . . dialysis and transplantation (1969, 558).

and Aach comments,

In the last decade 30,000 patients a year reach end stage renal disease. Until the beginning of the decade each was destined to die. The situation changed in the 1960's with the introduction of

dialysis and transplantation . nine out of ten with progressive renal disease are candidates for either dialysis or transplantation (1969, 559).

Dialysis and transplantation, as the treatment for renal disease, has been met with much approval. Many authors have written about the growing acceptance of transplantation as treatment for renal disease. Hayes feels that renal transplantation is and must be considered a reasonable and acceptable form of therapy no longer regarded as an experimental maneuver (1969, 521). Fellner indicates, "In general, one can say kidney transplantation has become accepted medical procedure" (1970, 1245). Marchioro states that, "The treatment of chronic renal disease has been dramatically altered during the past nine years by the availability of renal transplants" (1969, 485). Zukoshi is more conservative about the number of persons needing the surgery, "In the past nine years 2,800 renal transplants have been performed; by conservative estimates there are some 6,000 who could benefit" (1971, 800). With the advent of transplantation emerged a new type of patient, the living-related donor.

Several authorities commented on the rationale for using living-related donors and the need to study them as a population. Kempf states,

Exchanging organs is a new and strange experience which stimulates fantasies rich in psychodynamic

meaning and it may be a psychological traumatic event for either the donor or recipient (1971, 123).

Crammond continues,

Because the possibility of success of renal transplant is improved if the donor is a blood relative and since it is in such a relationship that there exists a whole psychodynamic complex of integration, conscious and unconscious, with positive and negative forces in operation it was thought important for these to be explored and identified (1971, 116).

Statistics have shown kidneys from related donors to be better than cadaveric kidneys. The following tables indicate findings of various research groups.

TABLE 1

TWO YEAR SURVIVAL TIMES FOR DONATED KIDNEYS

Twins.87%
Related.75%
Cadaveric.41%

202. Source: British Medical Journal 3 (July 24, 1971):

TABLE 2

TWO YEAR SURVIVAL TIMES FOR DONATED KIDNEYS

Monozygote twins90%
Dizygote twins79%
Siblings68%
Parents.60%
Cadaver.38%

Source: Richard Aach and John Kissare, "Renal Transplantation," American Journal of Medicine 48 (January 1970): 93, table 2.

TABLE 3

ONE YEAR SURVIVAL TIMES FOR DONATED KIDNEYS

Related.87%
Cadaver.42%

Source: Richard Fine, et al., Seventh Report of Human Transplant Registry, "Renal Homotransplantation in Children," Journal of Pediatrics 3 (March 1970): 347, 349.

TABLE 4

ONE YEAR SURVIVAL TIMES FOR DONATED KIDNEYS

Sibling.91%
Parent83%
Blood Relative67%
Unrelated Live60%

Source: Boston Registry quoted in Wm. A. Crammond, "Renal Transplantation," Seminars in Psychiatry 1 (February 1971): 123.

There have been several contributory factors related to longer survival rates in the live-related population. One of these is the decrease in warm ischemia time with the use of live-related donors (British Medical Journal, 1971, 203). Hamburger explains the process of warm ischemia time as follows:

Tissues and organs removed from the body soon undergo irreversible destruction of their cellular ultrastructures: devascularization, distension of the endoplasmic reticulum, and mitochondrial lesions. Metabolism continues but the supply of nutrients essential for this metabolism has been cut off. Under these circumstances, early tissue death is inevitable (1972, 64).

In the live population the warm ischemia time is less than ten minutes and total ischemia time less than sixty minutes (Fine, 1970, 349). Dr. B. Amos outlines a second factor contributing to high survival rates,

The intensity of the reaction (between the host and graft) depends upon the extent of the difference between the host and the graft . . . the goal, (in transplantation) select a donor who is as compatible as possible.

The author goes on to explain that the likelihood of a good match in unrelated donors is less than 5 percent while in siblings, 25 percent (Aach, 1970, 97, 99). Crammond and Amos agree that original studies provide evidence that the survival of recipients at the end of one year depended on consanguinity (1971, 123). A study by Penn states,

One justification for continuation of this practice (using live related donors) has been that superior results have been obtained in recipients of intrafamilial renal transplants as compared to recipients of kidneys obtained from non-related or cadaver donors. Another justification might be the demonstration of an accepted risk to healthy, well motivated donors who are exposed to the major operative procedure of a nephrectomy (1971, 226).

Hayes comments that the practice of using live-related donors is possible because the kidneys are paired and the loss of one still leaves the donor with more than adequate renal tissue to maintain homeostasis (1969, 527). The use of living-related donors is widely accepted by many authorities. However, there is more to be considered

in this population than excellent tissue match and adequate renal function.

There have been several studies regarding the attitudes and reactions expressed by families and donors.

Simmons found in her study,

The need to donate a kidney frequently creates considerable tension in the family of the recipient and family members, on occasion, are ambivalent about donation Unlike many situations of family stress that have been investigated, selecting a donor can be a crisis for the entire family.

In the same study, Simmons explored donor motivation and found that in general, children do not generate as much crisis in the decision to donate as adults do. Parental sacrifice for a child is culturally expected. Parents, especially mothers, accepted donation as part of their role obligation. Adult siblings, on the other hand, because of the obscurity of role obligation in society, appeared unclear about their obligations. In American society no other family member has a clear-cut obligation to make this type of sacrifice. Simmons found at times much ambivalence and withdrawal accompanying the decision to donate. Simmons also found that relatives not in the immediate family did not regard donation as part of role obligation (1971, 909-912).

Selected pre-operative and post-operative feelings of the donors have been studied. Kempf found pre-operatively that:

Donors tended to withdraw and appeared harrassed as the operative date approached, the loss of a body part becoming a reality. Many had fears of damage to sexual organs and the vital danger of the operation.

Post-operatively, Kemph found,

Feelings of loss were experienced by the donor . . . depressive reactions usually occurred following surgery precipitated by the feeling of having gotten little reward, sometimes openly expressing hostility . . . there was obviously more investment in the recipient than in the donor by the medical team. Most donors suffered moderate depression one to two weeks post transplant. The donor found very little reward for maximum sacrifice while the recipient usually enjoyed improved cognitive power and greater sense of well being . . . both had fantasies of body disfigurement . . . (1967, 627).

Crammond reported only on the post-operative responses of donors. He found the donors had feelings of rejection as a result of attention, once focused on the donor, fixed once more on the recipient. The donors also experienced feelings of possessiveness toward the recipient as a result of their sacrifice (1970, 1217).

Kemph found, as Simmons, that sibling donors had misgivings about donating an organ, while maternal donors had little or none. In fact, the parental role, especially the maternal role intensified the feelings of obligation to donate (1969, 1250). Another study by Kemph and Berman regarding donation supports the previous findings. The usual pattern in families faced with donation was for a few members to offer to serve as donors. After agreeing to

serve and being praised by other members, the donors reappraised the situation and many had misgivings. However, they usually stuck to the original decision. The study found that mothers were usually most willing and able to serve, fathers were second, siblings least willing and more reluctant than parents (1967, 1486).

Regarding emotional investment of the donor in the recipient, the study showed that the donor's attitude toward the recipient depended somewhat on their previous emotional relationship. Donors were also found to be in an "emotional bind"--that is, part of themselves keeping a close relative alive so there is an intense emotional investment, but at the same time they know that rejection is likely, the relative will die, and the donor will lose his love object. The donors tended to resolve this emotional conflict by adopting the attitude that they had done everything possible. It was observed that parent donors, especially mothers, were consistently concerned about their children and to a lesser extent concerned about themselves. The need to see their children healthy again seemed to be reward enough for their sacrifice. Sibling donors, although somewhat altruistic, were able to express hostility toward the recipients in a more open manner. Kemph states, "The more probing with the living related donor . . . the more one uncovers the hostile side of

their ambivalence toward the recipient and the family." In many cases Kemph studied, the relationship between the donor and recipient changed after transplantation (1969, 1487). Kemph, along with Eisendrath and Wilson, noted several instances in which the black sheep of the family offered to donate a kidney in order to reinstate himself into the family (Kemph, 1969, 1251; Eisendrath, 1969, 247; and Wilson, 1968, 505).

Fellner and Marshall, in contrast to Kemph found in most instances the decision to donate was made immediately. Many of the donors stated they made the decision over the phone when they were first contacted. The authors found that the act of donation had turned out to be "the most meaningful experience of (the donors') lives . . . it had brought changes within themselves that they felt beneficial." Fellner and Marshall found two overlapping phases that the donors went through which contributed to this feeling; prior to and after the surgery, sometimes up to one to two months post-operatively, the donors received a great deal of attention from the family and friends. The donors stated that the attention made them feel "noble, good, and increased their self-esteem." In the second phase, when the donors were no longer celebrities, they continued to have changes in their attitudes about themselves. "I feel like a better person" (Fellner and Marshall, 1971, 1245-1255). Simmons

in her study also states that, "In many, perhaps most cases, donation is a relatively smooth and satisfying procedure" (1971, 112).

Hayes, in contradiction to Fellner, found that the decision to donate was not an immediate one. Rather, the decision was made only after the donors had an opportunity to examine the problem carefully with their spouses (1969, 528)

Wilson, in commenting on donor motivation, states that education and socioeconomic status did not seem to play a part in the decision to donate. He found kinship, sense of duty, and/or altruism were the crucial factors in donation. "A donor's motivation was based on the Golden Rule in most cases" (1968, 505). Sadler in a study done on non-related donors, found that the reason to donate, for most persons, was a desire to "help someone in distress or give further life to a hopelessly ill person" (1971, 94).

As evidenced from the literature, donation of a kidney involves a complex set of feelings and emotions. Most of the studies thus far have been done by psychologists and psychiatrists and are published in their journals. There is a large deficit of nursing literature pertaining to the living donor. It is through appropriate research

conducted by nurses, looking for what nurses need to know, that these deficits will be filled.

Definition of Terms

For the purposes of this paper, the following terms were defined:

1. Altruism: regard for or devotion to the interests of others, unselfish devotion.

2. Anger: a strong emotion of displeasure resulting from a physical or emotional insult.

3. Donor: a person who has met all the criteria for donation and who has donated a kidney to a relative.

4. Emotional closeness: feeling of intimacy, nearness, or familiarity with another person.

5. Family pressure: a compelling force on one member of the family to donate a kidney by other members of that same family.

6. Psychological responses: a feeling or emotion of the donor toward donation or transplantation.

7. Related: anyone within direct blood lines with the recipient: mother, father, brother, sister, uncle, aunt, cousin.

8. Role obligation (sense of duty): that which a person is bound to do as a responsible person or that which is

ascribed that person due to the part in life assumed by that person.

9. Self-esteem: a feeling of self-respect or self-importance.

10. Two-year survival rate: may be used to indicate the survival for two years of the recipient of a kidney or the survival of the kidney itself.

Limitations

The limitations of this study were:

1. The donors may have had a myriad of physical and emotional experiences that influenced their responses to donation.

2. The current physical condition of the recipient may have influenced the donor's responses to donation.

3. The prior relationship of the donor and recipient may have influenced the donor's responses.

Delimitations

The following delimitations were observed in this investigation:

1. The participants were living related donors who had donated a kidney.

2. All participants were able to read English.

3. The donated kidney was functioning at the time the inquiry was mailed.

4. The tool was sent to all donors in the Dallas city/county hospital population who had met the above criteria.

Assumptions

As a basis for this study the following assumptions were made:

1. Renal transplantation is a definite, acceptable aspect of therapy for end-stage renal failure.
2. Kidneys from living-related donors have the longest survival time and are the best matched.
3. Donation of a kidney will affect the donor.

Summary

Renal disease has been established as a major cause of illness in the United States. An acceptable mode of treatment for end-stage renal failure is renal transplantation. In order for transplantation to take place there must be an acceptable donor. Statistically it has been shown that kidneys from living-related donors have been the best suited for transplantation.

Very little study has been done concerning the donor. Existing studies show some disagreement in the findings. This study was undertaken to determine those responses expressed by the Dallas Center population of donors in order to plan better care of future donor patients.

Chapter II, the review of literature consists of an in-depth study of living-related donors and the attitudes expressed by them. Chapter III, the procedure for collection and treatment of data, contains the development and validation of the tool as well as the method of data collection.

Chapter IV is concerned with the analysis of data. Chapter V contains the summary with recommendations, implications and conclusions resulting from this study.

CHAPTER II

REVIEW OF LITERATURE

Introduction

The present era of homotransplantation began with three areas of endeavor which proceeded simultaneously. These areas were earlier animal research in transplant, development of histocompatibility testing, and immunosuppression methods. The first enduring transplant in humans between non-twins was performed in 1959. Since that time many advancements have been made and renal transplantation is now considered to have emerged from an experimental stage into that of a generally accepted medical practice (Bernstein, 1970, 109; Herdmen, 1968, 894; Hamburger, 1973, vii).

Transplantation has brought with it moral, ethical, philosophical, and legal issues, especially in the area of donation. With the use of living-related donors, two-year survival rates of 80 to 90 percent are being achieved (Bernstein, 1971, 109). However, more than survival statistics of recipients must be considered regarding the use of living-related donors. The reactions of donors to the experience of donation and the adjustment after donation

are just two areas in need of study. The family dynamics in donor selection is another such area. Existing studies have revealed emotional and psychological phenomena to be present in the process of donation. In many of the studies, however, there has been major disagreement between the findings of different authors. Chapter II deals with a review of the literature pertaining to the living-related donor, donor selection, emotional experiences of donation and the long-term results of donation.

Medical Selection of Donors

The major rationale for the use of living-related donors is the high survival rates of the recipients. The overall results of transplants obtained from close-blood relatives have been considered better than those from unrelated donors. Histologically, this is due, in part, to transplant antigens which are inherited in a similar way to the red cell antigens. The chances of matching these antigens between the recipient and donor are higher within the family population than from the random population (British Medical Journal, 1971, 202).

The use of living-related donors has gained acceptance in many of the large transplant centers. The two-year survival rates for live-related kidneys is between 80 and 90 percent. This is one justification for the use of these

people as donors for transplantation (Fine, 1970, 347; Bernstein; 1971, 109; Penn, 1970, 226, 230). Another justification for the use of living-related donors is the fact that the motivated donor accepts the risk of nephrectomy and anesthesia (Penn, 1970, 226). A third justification for the practice of using living donors is that the renal organs are paired and the loss of one leaves the donor with more than sufficient functional tissue (Hayes, 1969, 521).

The surgical advantages of using living-related donors are that the ischemia damage suffered by the kidney is likely to be minimal and the surgery can be planned without the element of emergency or rush (British Medical Journal, 1971, 202). The use of living-related donors along with improved graft function and survival has also resulted in a reduction of immunosuppressive agents required post-transplant by the recipient (Whalen, 1972, 61).

The best results in non-twin-related donors are from sibling donors with parental donors ranking second. In 1970 one-year survival rates for recipients of sibling kidneys were 88.4 percent, with 82.8 percent still functioning. Recipients of parental kidneys had 88.1 percent survival with 69.0 percent still functioning (Ninth Report of Human Renal Transplant Registry, 1972, 256). It is further reported that in all cases the duration of

function of familial grafts was superior to cadaver regardless of year (1972, 257).

As discussed above, the use of living donors increases the chance of success since optimally preserved tissue can be maintained in the living donor. Moreover, the use of kidneys from blood relatives improves the prognosis since there is greater probability of obtaining a good donor-recipient histocompatibility match. The best donor, short of a twin, is likely to be a sibling or parent. Transplantation performed under these conditions provides the best prognosis for the recipient (Starzl, 1966, 388).

There are ethical as well as technical questions raised with the use of living-related donors. Because the use of living-related donors involves a major surgical operation for the donor with risks of morbidity and mortality, the physical and psychological evaluation of each donor is important. Treatment has always been directed toward a balance between the intended good expectations and the potential adverse effects. For the healthy donor there is no physical benefit (Eisendrath, 1969, 243). The healthy donor has to undergo an operation from which he cannot possibly derive benefits for the sake of another. The donor has to face risks which may threaten his life and there can be no absolute certainty that the

transplant will succeed (McGeown, 1968, 711). Conn states that morally the decision to injure one person by taking a kidney is only justifiable if the survival results are considered to be high for the recipient (1969, 49). Nolen says that justification for removal of kidney from a healthy donor must depend on the generally accepted idea that it is a good thing that a man should be prepared to sacrifice his life for fellow-man (1966, 681). The benefits to the uremic patient receiving a familial kidney must be balanced against the potential harm that may be inflicted upon the donor (Penn, 1970, 230).

Simmons discusses the role of the physician in the donation process. "Having to ask a relative to donate a kidney is stressful and goes against medical precepts which say- 'first of all do no harm'." The physician must ask the donor to assume a surgical risk with no benefit to himself. The physician is placed in an ethical conflict between his obligation to the donor and his commitment to save a life. As a result, the donor is informed of the statistical need for a related donor and further contact with the physician is kept to a minimum until the decision is made (1971).

After a candidate is determined to be a potential donor, he is carefully evaluated both psychologically and physically (Penn, 1970, 226). An objective account is

given concerning the risk to the donor and the chances of salvaging the recipient patient. The donor is made aware of the statistics regarding the transplant success and failure and the fact that it is impossible to predict the long-term results is emphasized (Penn, 1970, 226). The risks to the donor are considered by many authors to be minimal. Penn states that the donor nephrectomy is an exceptionally safe procedure and to date the mortality of donor nephrectomy has been zero (1970, 230). Conn says that the risk of donor nephrectomy is approximately .05 percent,--that is, 5 out of every 1000 kidney donors will suffer complications or even face death. Furthermore, donation of a kidney alters life expectancy very little. He estimates that the life expectancy of the donor changes from 99.3 percent to 99.1 percent. This is a negligible amount and life insurance policies consider it such a small risk that donation does not alter the premium rate (Conn, 1969, 50). Katz has a somewhat different statistical breakdown of the donor risk.

The immediate operative mortality risk for unilateral nephrectomy in healthy individuals is 0.05 percent, the long-term risk of disease and development of kidney stones is 0.07 percent giving a total risk of 0.12 percent (1970, 82).

McGeown has an opposing outlook regarding donor risk. She says that

the operation entails certain risks, including those of anesthesia. The donor, although healthy, has to undergo an operation which is more extensive and potentially more injurious than most therapeutic nephrectomies, as considerable lengths of blood vessels and ureter must be carefully removed.

The donor has to face unpredictable later risks which may, in the long run, shorten his life. There may be decreased renal function or the remaining kidney may be affected by disease or injury (1968, 711). Woodruff agrees saying that later the donor may have a need for the part given up (1964, 1458).

Concurrent with informing the potential donor of the risks involved is the physical evaluation. When a transplant situation arises all possible donor relatives are asked to come to the hospital or clinic for ABO blood grouping and histocompatibility tests. Great care is taken to inform all volunteers that this is a preliminary procedure and that no commitment is involved. Those with compatible blood groups are then given a complete physical examination and additional history is obtained. Included in the physical exam are: a complete blood count, electrolytes, Blood Urea Nitrogen (twice), Creatinine clearance (twice), urinalysis with microscopy, urine culture, leukocyte antigen profile, electro-cardiograph, and chest X-ray. Those who are still considered to be potential donors are asked to return to the hospital for an intravenous pyelogram and

renal arteriogram and aortogram (Fellner, 1971, 78; Penn, 1970, 226; Bois, 1968, 1238; Hayes, 1969, 521).

The physical conditions that must be met in order for donor selection include:

1. Donor must be in good physical condition and health
2. Donor must have ABO compatability with the recipient
3. Donor must have a good tissue match with the recipient
4. All laboratory values, blood and urine, must be within normal limits
5. The donor must be free from hypertension, renal disease or other systemic diseases
6. The donor must have a normal urinary tract
7. Both kidneys must be normal in size and have normal arteries, veins, and ureters
8. The donor must be of legal age (Katz, 1970, 83; Whalen, 1972, 60; Aach, 1970, 97; Woodruff 1964, 1457).

It is only after complete evaluation and consultation regarding the risks and the chances of success that the potential donor is asked to make a decision and give informed consent (Fellner, 1970, 12). Fellner outlines the ethical guidelines adopted by the American Medical Association for informed consent.

The decision to donate must be a reasoned, intellectual decision, not an emotional one arrived at entirely voluntarily free from pressure and based on full awareness of all the relevant information (Fellner, 1970, 14).

The concept of freedom from external coercion and informed consent was referred to by several authors (Crammond, 1970, 1214, Eisendrath, 1969, 244). The other factors considered in acceptance of a living donor are that it must be established beyond a reasonable doubt that the recipient has terminal renal disease and that the chances of success must be reasonably certain (Woodruff, 1964, 1457; Nolen, 1966, 681; Starzl, 1967, 388; Penn, 1970, 226). Frequently during, and even before the medical selection of a donor takes place, donor self-selection has already taken place.

Donor Self-Selection

Fellner takes issue with what he calls the medical assumption regarding the decision to donate. He says that the medical profession assumes that the decision to donate occurs at the end of adequate information gathering and weighing of the pros and cons. However, members of the transplant team are aware that most potential donors are ready to make a commitment before the team has made its decision. Fellner charges that the spontaneous, often immediate character of the decision to donate, is interpreted by the medical profession as "emotional or impulsive

and therefore symptomatic of psychopathology" (Fellner, Schwartz, 1971, 584). Fellner conducted a study and found that the decision to donate was made immediately when the potential donor was first contacted. Of the forty patients studied, thirty-three stated that they made the decision over the phone in "a split second, or right away." Fellner states that, "the immediacy of the decision-making process with regard to donorship often contrasts markedly with the usual way in which a person makes other important decisions" (Fellner, 1971, 82). Fellner and Schwartz outline three conditions necessary for a moral decision and say that these conditions are met at the moment of appeal. The conditions are:

1. Some sense of moral obligation to donate to a member of the immediate family.
2. Awareness that serious consequences for the welfare of another are inherent in one's decision.
3. Acceptance of personal responsibility to self, rather than denial of consequences is assured by the knowledge that the better the match the better the chance of success (Fellner and Schwartz, 1971, 585).

Fellner feels that the speed of the decision, the apparent lack of conscious, intellectual weighing of alternatives by donors, and failure to seek the kind of information the transplant team feels they should be seeking, does not necessarily mean that the decision to donate a kidney was not based logically on other influences (Fellner, 1971, 82).

Sadler, in his study on non-related donors also found that the decision to donate a kidney was immediate (1971, 87). However, Hayes and Gunnels found the opposite to be true. In their study, the genuine donor usually reserved his or her decision until he had an opportunity to examine the problem carefully and to discuss the future decision with their spouse (1971, 521).

In a study of family non-donors, it was found that many of the members experienced feelings of ambivalence and long periods of indecision, even to the point of volunteering and then withdrawing (Simmons, 1971, 912). Kempf found that although some members did volunteer immediately, there was some reluctance and withdrawal after the primary decision. The usual response by the majority was to stick to their decision to donate. However, on occasion a donor would find reasons why he should not donate his kidney, such as family obligations or financial loss from missing work (1969, 1486).

Regarding motivation for donation, Fellner states that the "willingness to donate might reflect a healthy altruism derived from genuine moral concern rather than psychopathology" (1971, 82). The author found that the prospective donor's sense of his own moral obligation was an excellent predictor of who would donate. Anticipated guilt was found to be a poor predictor of intentions to

donate (1971, 585). Kempf found that each donor has his own combination of altruism and underlying needs which motivate him, but at the same time he is concerned about losing part of his body (1971, 624). Sadler and Wilson in their studies agree that the overwhelming reason to donate was to help someone in distress and to give further life to someone who would die otherwise. The donors felt that it was their duty to donate and that they had no other choice (Wilson, 1968, 504; Sadler, 1971, 87). Wilson further elaborates on donor motivation saying that education and socioeconomic status did not seem to exert an influence on motivation (1968, 505).

Transplant teams in Great Britain take an interesting stand on donor motivation. Due to the risk of surgery and family distress they play the Devil's Advocate; the donor must come to them and persuade the doctors that they feel deprived if denied this opportunity to help a loved one (British Medical Journal, 1971, 202).

Parental donors, especially mothers, are looked on as unquestioning donors. Parents were looked on by their children as being expected to donate, although there are instances in which parental donors have revealed ambivalence about kidney loss (Bernstein, 1971, 1191). Simmons expands this theme in her study on family non-donors. Parental sacrifice, in our society, is culturally expected. Mothers,

especially, accept donation as part of their role obligation to their children (1971, 910). Fellner and Marshal present data to support this. Mothers unlike other donors, did not feel donation was an act of heroism, but rather an expected component of the mother role (1970, 10). Kempf found that mothers were usually the most willing and able to serve as donors, fathers second, and siblings were the least willing and most reluctant to serve as donors (1969, 1486). In general, it has been the impression of Korsch et al., that great care should be taken in selecting a parent who appears over-identified with the child recipient. At best, the psychological situation between donating parent and child is complicated; but when a parent who already feels that the child is a part of himself with no true differentiation, transplantation of an organ will further complicate future differentiation (1970, 16). Further observations by Korsch indicate that if a parent was truly motivated to donate a kidney, this was readily observable in terms of quick follow-through on all recommended procedures. The absence of spontaneous inquiry and follow-through usually indicated more than the usual ambivalence about donation. The reluctant donor often did not keep appointments for the blood testing or physical examinations (1970, 17).

Eisendrath found that sense of duty was the most frequent motivating factor. Interviews with twenty-five

donors revealed such responses as "I had no choice, the patient would have died and I couldn't have lived with myself." "I felt I was called to donate and I was unable to refuse," "I'd do anything to save a child." The parental donors in this study did express increased anxiety, but this was due to fear for success and fear of being rejected as donors. Many donors felt that the recipients would have done the same for them (1969, 245).

Sibling donors were found by several authors to be more ambivalent about donation, although they had the best genetic qualifications. In the face of unclear norms, the primary motivating factor is probably the emotional relationship of the donor to the recipient (Simmons, 1971, 910). Katz makes the comment that sibling motivation is almost always less sound than parental motivation. However, he does not qualify this statement (1970, 80).

A questionnaire given to the general public regarding the use of living donors found the following:

1. Younger persons were more willing to donate a kidney to strangers.
2. Substantial numbers of the public, especially the young and well-educated consider the use of living donors to be a reasonable procedure for which they themselves might volunteer.
3. Guilt contributed nothing to the explanation of stated intentions to donate.
4. Intentions to donate were a result of a desire to fulfill one's sense of moral obligation, regardless of the intensity of guilt feelings (Fellner and Schwartz, 1971, 584-5).

The self selection by the prospective donor is not the only method by which a donor is chosen. In addition, the family plays a major part in this process of donor selection.

Family Selection of Donor

The pre-selection of donors within the family is largely determined beyond the view of the transplant service. The problem of motivation is complex, for no family is completely free of obligations based on guilt, shame, debt, or fear. The donor, who finally presents himself to the transplant team, has undergone careful family determination (Eisendrath, 1970, 244).

The family system of donor selection is clearly most efficient very early in the total selection process and works primarily in the direction of excluding some family members from participating. Once the potential donors are known and made available to the transplant team, the power of the family system to influence the medical selection process diminishes greatly (Fellner, 1971, 82). Fellner points out that the role of family members in donor selection is suspect by physicians: "undue pressure and scapegoating is assumed by the transplant team." Fellner and Marshall found instead competition for donorship (1971, 585). Crammond agrees with the preselection

of donors by the family. "Even before transplantation is mentioned by the team, it has been discussed by the family members who have often selected likely donors." He disagrees with Fellner's finding of competition by saying that those who refuse to donate after the family has selected them, risk rejection from that family and are made to feel guilty (1970, 1214). Kemph studied the families of transplant patients and reported a great many changes in family dynamics. The usual evolution of family investment was found to take the following course. There was initial concern with the recipient because of his fatal illness. When the donor was selected, the family provided much support to him as their representative. Soon after transplant, when it was apparent that the donor was going to recover, the recipient became the center of attention. In many families the transplant was perceived as a rebirth for the patient and served, at least in fantasy, as an opportunity to redeem or considerably alter identities and roles that family members had played within those families for many years (1969, 1488-90).

As previously mentioned, there were several cases in which the black sheep of the family offered to donate in order to be reinstated in the family's good will. Kemph found that in some cases it was successful and in others it was not. In one case the parents of a young recipient

were divorced and the mother had happily remarried. The natural father agreed to donate a kidney hoping to win his wife back. He was disappointed post donation when his wife refused to remarry him (1969, 1489).

Simmons did a study on the family tension involved in the search for a donor and dealt mainly with those members who did not donate. The findings are outlined below.

1. Selecting a donor is a crisis for the entire family. The family is asked to donate the kidney of another member. The donation will cause the donor discomfort and anxiety as well as the loss of two to four weeks of work time. The immediate and extended family are affected in that the recipient will often look beyond the immediate family for an available donor.

2. In the adult recipient, the family crisis was much greater and more frequent than in children. Spouses who were the most willing to donate often were not biologically suited and the societal norms are not as clear for other family members regarding this kind of decision.

3. In thirteen out of nineteen cases of adult sibling donation, ambivalence of potential donors and conflict between family members were noted.

4. In many of the cases studied it appeared that one family member was particularly influential in selecting a donor. The recipient would inform one member to whom he was close, and that person would approach the other family members. Many times this person was the recipient's spouse. The solicitation of donors by the spouse was accepted by other members of the family as part of his or her marital obligations. The donor's spouse on the other hand, frequently exerted pressure against the donation (Simmons, 1971, 909-12).

Fellner also found the role of intermediary to be present in the initial family-selection system. He found that the selection system was made possible by the haphazard communication between the medical staff and the family of the recipient. Future donors often heard about the transplant over the phone from another family member. This was usually how all future communication was carried out. Thus, one person would assume the role of intermediary and exert the greatest influence for donor selection (1971, 82). McGeown adds one comment regarding family selection, "It may be difficult to discover whether a donor is truly willing to give a kidney, as he may be subjected to hidden pressures amounting to moral blackmail from other members of the family" (1968, 712).

Kahn found that family unity and cohesion affected the process of decision-making to a great extent. The families that were broken or had strained relationships or no external support (grandparents, aunts, uncles) had the most difficult time in arriving at the decision to donate (1971, 117). After the donor is selected by family and medical personnel, and found acceptable, the transplant takes place.

Experience of Donation

Kemph found that as the operative date approached, the donors tended to withdraw emotionally and appear harassed because the loss of a body part was becoming a reality. Kemph found that many more sibling donors had misgivings about their donation than did maternal donors. This was probably due to the absence of role obligation and societal norms. Kemph found that given an opportunity to discuss these feelings, the donors reaffirmed their desire to serve and were reassured that they were doing the right thing (1967, 623). Crammond and Kemph both found a fear of some sexual damage in the pre-operative period, due to the association of urination, genitalia, and sexuality (Kemph, 1967, 624; Crammond, 1970). Post-operatively the findings were varied. Kemph found that the donor felt the loss of the organ more keenly and was very aware that he

had made a great sacrifice. There was obviously more investment in the recipient than in the donor by the medical team. There was often considerable underlying resentment toward the recipient and those who suggested the transplant. "The donor came feeling well and now immediately post-operatively he feels sick and debilitated." During the post-operative week the donor went through transient mild to moderately severe feelings of depression. This depression was related to mourning for the loss of a part of his body and to underlying resentment. During this period the donor was even more concerned about the value of the procedure. He found very little reward for the maximum sacrifice. Kemph found that the recovery of the donor was hastened by the opportunity to achieve "catharsis" of underlying feelings through discussion (Kemph, 1967, 625). Crammond had similar findings in his study. After transplant the donors experienced depression lasting an indeterminant amount of time. This depression was related to the feeling that they were not adequately supported by the hospital staff. "Two out of five donors felt the renal team had lost interest in them." Four out of five felt ambivalent about the donor-recipient relationship that developed. The donor experienced emotional and physical investment and tried to overprotect the recipient. There was a hostile inter-dependency between the two. The donor felt his

sacrificial gift to be in jeopardy in the recipient did not act in a manner of which he approved. The recipient wanted to live his own life yet he felt obligated to the donor's wishes and guilty about having taken the organ (1970, 1227). Sibling donors were noted to be better able to express hostility toward the recipients in a more open fashion than did parental donors. This was felt to be due to the feeling of acceptance of role obligation by the parents (Crammond, 1971, 1215). Eisendrath was in agreement with Kempf and Crammond in that once the donor was on the road to recovery he felt he was of less interest to the medical team. The author also found that even though the donation had been an upsetting and painful experience, the donors were able to adjust to it and forget it (1969, 246). The psychological effects of donation do not end with discharge from the hospital.

Results of Donation

Following donation many studies have been done on donors. Several authors feel that there are absolutely no psychological benefits to the live donor as a result of donation (Hamburger, 1973, viii; McGeown, 1972, 1000). Fellner and Marshall have found results that contradict this. Reports from donors indicate that the act became the most meaningful experience of their lives and had

brought changes within themselves which they felt were beneficial. When the donors were asked to compare donorship with any other experience of equal importance, they were unable to do it (1971, 82). Eisendrath found similar experiences; "there was unanimity that the donor would do it again and that each had derived some sense of worthwhile accomplishment in helping to save a life." These feelings were shown to persist irrespective of the fate of the donated kidney and recipient (1969, 248). Many of the donor-recipient relationships were more closely cemented especially in the adolescent age grouping where a sibling had been the donor (Bernstein, 1971, 1192). Crammond found a hostile dependency between the donor and recipient in many cases.

If the relationship at all levels had been relatively harmonious the problem of obligation of giving and receiving was not of much significance. When the previous relationship had been ambiguous the dependency was very hostile and unhappy (1968, 624).

Muslin found that a strengthening in the relationship between the donor and recipient was a common happening (1971, 1188). Simmons' study indicates that for most, donation was a smooth and satisfying procedure and that even when conflicts existed prior to transplant, these were resolved by a successful transplant. There was an increase in self-esteem following the operation (1971, 910).

Kemph's studies indicate that the donor's attitude toward the recipient depended upon the prior relationship that existed. In one study it was clearly shown that one-fourth of the donors studied reported significant ill health and uncomfortable relationships with the recipients. The more probing Kemph did with the donors, the more hostility and ambivalence toward the recipient and family were elicited (1967, 627). Kemph also reported depression in the immediate post-operative period which lasted up to two to three weeks (1967, 628). Sadler's findings were similar to Fellner's. The donors in his study reported no depression following donation, and in fact, felt deep feelings of increased self-esteem and had no regrets about donating. There continued to be perceived changes in life style by the donors for at least five years post transplant (1971, 910).

Summary

It is evident from the literature that the reactions to donation take many courses ranging from depression and resentment to exhilaration and increased self-esteem. The medical selection of donors involves intense physical and psychological evaluation. Motivation to donate was reported to be due to several factors, altruism, sense of duty or role obligation, and family pressure. The family

played a large part in the donor-selection process. Various members of the family were found to exert pressure both for and against donation. The effects of the act of donation itself were found to range from depression (Kemph) to an increase in self-esteem (Fellner). In those donors who experienced depression following donation Kemph found that discussion about their feelings provided "catharsis" and speeded recovery.

CHAPTER III

PROCEDURE FOR COLLECTION OF DATA

Introduction

This study was undertaken to determine selected psychological responses of living-related kidney donors to the experience of donation. A Likert-type Attitude Scale was developed as the data collection tool. A mail out to donors was used as the method of obtaining the data for statistical analysis.

Locale

The Dallas Center transplant team agreed that the study was feasible. Since 1970, the Dallas Center has performed sixty-one living-related donor transplants. Donor statistics from other centers were incomplete, but indicated that the Dallas Center had the largest living-related donor population. The Dallas Center population was selected because of the availability of the donor list and the shorter time involved in the mailing process.

Population

The intended population was chosen from the list of donors obtained from the renal clinic of a large city-county

hospital. Of the forty donors found to meet the criteria (page fourteen), forty questionnaires were mailed out and twenty-one were returned. The population ranged in age from twenty-one to sixty. The relationships to the recipients were parental, sibling, child, and uncle. The length of time since donation ranged from two weeks to three years.

Development of the Measuring Device

For the purpose of this study a Likert-type Attitude Scale was developed. The Likert Scale is a summated scale. A summated scale consists of a series of items to which the subject is asked to react. The respondent indicates his agreement or disagreement with each item (Sellitz, 1967, 366). The Likert Scale was utilized in this study because it was developed especially for measuring attitudes and because it was less time-consuming and laborious to construct than the other types of summated scales (Sellitz, 1967, 368). The Likert Scale was used instead of interview in order to question a greater number donors and to assure anonymity.

The Likert Scale is a qualitative, ordinal-type scale. The over-all score is obtained by summing the values of responses to each item (Abdellah, 1965, 241). The procedure for constructing a Likert-type Scale is outlined by Sellitz.

1. The investigator assembles a large number of items considered relevant to the attitude being investigated either clearly favorable or unfavorable.
2. These items are administered to a group of subjects representative of those with whom the questionnaire is to be used. The subjects indicate their response to each item by checking one of the categories of agreement-disagreement.
3. The responses to various items are scored in such a way that a response indicative of the more favorable attitude is given the highest score. It makes no difference whether five is high and one is low or vice versa. The important thing is that the responses be scored consistently in terms of the attitudinal direction they indicate.
4. Each individual's total score is computed by adding his item scores.
5. The responses are analyzed to determine which of the items discriminates most clearly between the higher scores and the low scores on the total scale (1967, 367-8).

Wang states, "The success or failure of the scale depends upon how well the initial list of statements is completed and edited" (1932, 367). The following are recommendations compiled by Wang in formulating items for the scale.

1. An attitude must be debatable.
2. All statements on a given issue should belong to the same issue.
3. An attitude statement must not be susceptible to more than one interpretation.
4. Avoid "double-barreled" statements.
5. Attitude statements should be short, it should rarely exceed fifteen words in length.
6. Each attitude statement should be complete in denoting a definite attitude toward a specific issue.
7. Each statement should contain only one complete thought.
8. Avoid grouping two or more complete sentences as one attitude statement.

9. An attitude statement should be clear cut and direct.
10. Use with care and moderation such words as "only," "mere," "just," "merely."
11. Avoid colorless expressions or statements lacking affect.
12. Whenever possible, write an attitude statement in the form of a simple rather than complex or compound sentence.
13. When a statement cannot be made in the form of a simple sentence, write it as a complex rather than compound one.
14. It is usually better to use the active rather than the passive voice.
15. In general, use the term of the issue as the subject of the statement.
16. Avoid high-sounding words, uncommon words or expressions, or technical terms not ordinarily understood, etc. (1932, 368-73).

To develop a scale that would determine psychological responses of living-related donors, seven areas were selected from the literature regarding areas which were mentioned most frequently by donors and those persons studying them. The areas were:

1. Closeness prior to donation between the donor and recipient
2. Alteration in emotional closeness after donation between the donor and recipient
3. Motivation to donate due to family pressure
4. Motivation to donate due to role obligation or sense of duty
5. Motivation to donate due to altruism
6. Feelings of anger after donation

7. Feelings of increased self-esteem after donation.

One hundred and thirty items were written pertaining to these areas. These items were selected from the literature: either they were said by donors in the context of studies or were statements taken directly from certain tests measuring the areas described. The items were written in the form of statements that a donor might have said regarding the seven areas. The choice of answers to the items were: Strongly Agree, Agree, Undecided, Disagree, Strongly Disagree. The donors were instructed to check the words that best described how he felt about each item.

The 131 items were given to a panel of 5 judges. A panel of judges was considered appropriate in this instance since, "Polled judgments increase the accuracy of any rating scale. Any number of judges can be used but they should be selected on basis of expertness in relation to the continuum to be examined" (Goode, 1952, 256). The panel in this study consisted of: Beth Vaughn, R.N.M.S., a Clinical Specialist who developed a Likert-type Scale for her Master's Thesis; Dr. Tom Sampson, B.S., M.S., PhD., a clinical psychologist who does psychological testing of potential donors; Carolyn Atkins, R.N., a renal transplant nurse practitioner with eight years experience in working with renal donors; Dr. Tom

Parker, M.D., a nephrologist who is responsible for donor preparation; and Chris Harris, a renal donor, one year post-donation.

The judges were asked to:

1. Determine if each item was written clearly and concisely

2. Categorize each item according to the area he felt it best represented (Appendix A).

Any item that did not obtain agreement from four-out-of-five of the judges, or 80 percent agreement, regarding the two criteria above was discarded.

Random selection was utilized for the placement of the items in the worksheet given to the judges (Appendix B). The number of items written for each area and the results of the tabulation after the items were examined by the judges are shown in Table 5. Appendix C gives the results of the tabulation of the judges' answers. Many of the items categorized by the researcher in specific areas met with 80 percent agreement as being in another area. The number of items needed for each area to validate that area was eight to ten (Dr. Woodard, personal communication).

Ninety-six items of the 130 met with 80 percent agreement. Random selection was used to select eight items

for each area and was again used to place the items on the test page.

TABLE 5
TABULATION OF NUMBER OF ITEMS WRITTEN AS COMPARED
TO NUMBER OF ITEMS APPROVED BY JUDGES

Area	Number of Items Written	Number of Items Approved by Judges
I	19	10
II	20	9
III	13	12
IV	16	16
V	14	14
VI	21	23
VII	27	15

Methodology

Selected donors were mailed the Likert-type Attitude Scale. The donors were asked to complete it and the demographic data, and return the completed form in the self-addressed, stamped envelope. The cover letter accompanying the test acquainted the donor with the purpose of the study (Appendix D). The letter explained the importance of the donor's participation in the study in furthering nursing's knowledge regarding the feelings of

living-related donors. The test contained a series of statements related to the seven areas outlined above. Following each statement were five columns labeled: Strongly Agree, Agree, Undecided, Disagree, Strongly Disagree. The donor was instructed to complete the demographic data prior to taking the test (Appendix E). He was then instructed to react to each statement in the test by marking an "X" under the column that best described his reaction to the statement. The importance of honest answers was stressed. Anonymity was assured by having the donor omit his name and any other identifying marks.

Procedure for Treatment of Data

Due to the small number of participants involved in the study Lambda was used as the statistical tool. Lambda describes the degree of association between two nominal scales and imposes no restrictions on the number of classes in the scales nor requires unrealistic assumptions about the distributions of the variables. Lambda was used to determine the following:

1. To determine the degree of association between sex and the response patterns
2. To determine the degree of association between kinship and response patterns

3. To determine the degree of association between the length of time since donation and response patterns

4. To determine the degree of association between physical condition and response patterns.

These variables were chosen for study because they were the most frequently-mentioned variables in the literature as influencing the findings.

Summary

A Likert-type Attitude Scale was developed by the investigator and validated by a panel of judges. The Scale consisted of seven categories related to the process of donating a kidney. Each area consisted of eight items. Twenty-one donors participated in the study. Each donor was asked to consider each item in terms of agreement or disagreement. He was instructed to check the words that best described how he felt about each item. Each item was scored on a five-point basis--five being highest and one lowest.

CHAPTER IV

ANALYSIS OF DATA

Introduction

The following chapter provides a general description of the sample population and the statistical evaluation of the data which was collected. The statistical evaluation includes a discussion of the independent variables of sex, length of time since donation, and type of familial relationship. At the end of the discussion of each variable there is a summary which includes a synopsis of the findings. The conclusion of this chapter contains interpretations of the findings and possible rationale for the results which were obtained in this study.

General Description of the Sample

The sample population was comprised of twenty-one living-related kidney donors. The ages of the donors ranged from twenty-one to fifty-six. Length of time since donation ranged from three and one-half months to three years. The types of relationships to the recipients were parental, sibling, child and uncle. Seven males and fourteen females participated in the study.

For the purposes of data analysis, length of time since donation was categorized as zero to eighteen months and nineteen months or over. The distribution of these two categories was as follows: zero to eighteen months--eleven subjects, nineteen months or over--ten subjects. The types of family relationships between the donors and recipients were categorized as "parental-child" and "sibling or other." The distribution of these categories was as follows: parent-child--eleven subjects, sibling or other--ten subjects.

A limitation developed involving the variable dealing with physical health following donation. Since the over-all modal response of the donors fell into the good health category (twenty-one of twenty-one respondents), no statistical analysis was possible. Could this response have been anticipated in any way, a more discriminating manner of division (good, fair, poor health) could have been utilized.

Statistical Analysis of Data

Lambda or Guttman's coefficient was used to determine the strength of association between a series of independent variables and the dependent variable of response patterns of donors reflecting attitudes toward donation. Respondents were categorized on the dependent variable of donor attitude as follows: high scores were based on the numerical values

falling between 4.0 through 5.0, medium scores were 3.0 through 3.9, and low scores were 1.0 through 2.9. The independent variables were posited as follows: sex, length of time since donation, and type of familial relationship between donor and recipient.

Lambda is a technique for describing the degree of association between two nominal scales and belongs to that category of statistics known as "proportional reduction in error measures." The calculation of lambda yields the proportional amount of error which is reduced in predicting the dependent variable, given knowledge of the distribution of the independent variable. The range of possible coefficient scores is 0 to 1.00. Increasing ability to make accurate predictions of the dependent variable on the basis of knowledge of the independent variable is reflected by increasing values of the coefficient. Lambda allows the categorization of both the dependent and independent variables and the construction of a matrix which indicates the simultaneous distribution of both attributes of the variable (Freeman, 1965, 71).

Sex

When the variable of sex was employed as the independent variable, the strength of association between the independent variable and the dependent variables was

negligible. When sex was examined for its association to the degree of emotional closeness between donor and recipient prior to donation, a moderate to low association was obtained. As Table 6 indicates ($\Lambda = .25$) 25 percent of the error in predicting donor response in the area of emotional closeness was reduced given knowledge of the sex of the donor. Most notable was the tendency for females to respond "high" with respect to emotional closeness whereas no discernable patterns exists with respect to the male respondents.

TABLE 6
ATTITUDINAL RESPONSES ON AREA OF EMOTIONAL
CLOSENESS BY SEX OF RESPONDENT

Sex	High	Medium	Low
Male	3	4	0
Female	14	0	0
Total	17	4	0

$\Lambda = .25$.

When sex was examined for its association with changes in the donor-recipient relationship after donation no association was found. As Table 7 illustrated ($\Lambda = .00$)

there was a pronounced tendency for respondents to indicate low or little degree of change in relationship, regardless of the sex of the donor.

TABLE 7

ATTITUDINAL RESPONSES ON AREA OF CHANGE IN
EMOTIONAL RELATIONSHIP FOLLOWING
DONATION BY SEX OF RESPONDENT

Sex	High	Medium	Low
Male	0	1	6
Female	0	1	13
Total	0	2	19

$\Lambda = .00.$

When sex was examined for its association with the motivation to donate due to family pressure no association was found. As Table 8 illustrates ($\Lambda = .00$) there was a pronounced tendency for respondents to indicate low or little degree of family pressure as basis for motivation to donate, regardless of the sex of the donor.

When sex was examined for its association with the motivation to donate due to role obligation or sense of duty some deviation from the previous patterns of association was noted. Table 9 illustrates the association between sex and motivation due to role obligation or sense

TABLE 8

ATTITUDINAL RESPONSES ON AREA OF MOTIVATION
TO DONATE DUE TO FAMILY PRESSURE
BY SEX OF RESPONDENT

Sex	High	Medium	Low
Male	0	1	6
Female	0	0	14
Total	0	1	20

Lambda = .00.

TABLE 9

ATTITUDINAL RESPONSES ON AREA OF MOTIVATION
TO DONATE DUE TO ROLE OBLIGATION OR
SENSE OF DUTY BY SEX OF RESPONDENT

Sex	High	Medium	Low
Male	1	1	5
Female	0	9	5
Total	1	10	10

Lambda = .36.

of duty (Lambda = .26); this indicates that 36 percent of the error in predicting the attitude response to motivation due to role obligation was reduced given knowledge of the respondents' sex. This represents a slight increase in

association over the association between sex and closeness prior to donation ($\Lambda = .25$).

When sex was examined for its association with the motivation to donate due to altruism no association was found. As Table 10 illustrates ($\Lambda = .00$) the modal response pattern of both males and females fell in the medium score range.

TABLE 10
ATTITUDINAL RESPONSES ON AREA OF MOTIVATION
TO DONATE DUE TO ALTRUISM
BY SEX OF RESPONDENT

Sex	High	Medium	Low
Male	3	4	0
Female	4	9	1
Total	7	13	1

$\Lambda = .00$.

When sex was examined for its association with the area of feelings of anger following donation no association was found. As Table 11 illustrated ($\Lambda = .00$) there was a pronounced tendency for respondents to indicate low or little feelings of anger following donation, regardless of the sex of the donor.

TABLE 11

ATTITUDINAL RESPONSES ON AREA OF FEELINGS
OF ANGER FOLLOWING DONATION
BY SEX OF RESPONDENT

Sex	High	Medium	Low
Male	0	0	7
Female	0	0	14
Total	0	0	21

Lambda = .00.

When sex was examined for its association with the area of increased self-esteem following donation no association was found. As indicated by Table 12 (Lambda = .00) the over-all response of both sexes indicates little or low increase in self-esteem following donation.

TABLE 12

ATTITUDINAL RESPONSES ON AREA OF INCREASED
SELF-ESTEEM FOLLOWING DONATION
BY SEX OF RESPONDENT

Sex	High	Medium	Low
Male	1	2	4
Female	2	4	8
Total	3	6	12

Lambda = .00.

Summary of the Association Between Sex
and the Attitudinal Areas

As noted previously, the association between sex and the several attitudinal areas (closeness prior to donation, change in donor-recipient relationship following donation, motivation to donate due to family pressure, motivation to donate due to sense of duty, motivation to donate due to altruism, feelings of anger following donation, feelings of increased self-esteem following donation) was negligible. At best, low to moderate associations were found in two instances; a Lambda of .25 was calculated for the association between sex and emotional closeness prior to donation and a value of .36 was obtained for the association between sex and motivation to donate due to role obligation or sense of duty.

Length of Time Since Donation

When the variable of length of time since donation was employed as the independent variable, the strength of the association between the independent variable and the dependent variable was again negligible. When the length of time since donation was examined for its association with the degree of emotional closeness between donor and recipient no association was found. As Table 13 illustrates (Lambda = .00) there was a tendency for respondents to

indicate a high degree of closeness prior to donation regardless of length of time since donation.

TABLE 13

ATTITUDINAL RESPONSES ON AREA OF EMOTIONAL
CLOSENESS BY LENGTH OF TIME SINCE DONATION

Length of Time	High	Medium	Low
0 - 18 months	9	2	0
19 - over months	9	1	0
Total	18	3	0

Lambda = .00.

When the variable of length of time since donation was examined for its association with change in donor-recipient relationship following donation no association was found. As Table 14 illustrated (Lambda = .00) the over-all response indicates little or no change in relationship following donation regardless of length of time since donation.

When the variable of length of time was examined for its association with the area of motivation to donate due to family pressure no association was found. As indicated by Table 15 (Lambda = .00) there was a pronounced tendency for

respondents to indicate little or low degree of family pressure as a basis for donation.

TABLE 14

ATTITUDINAL RESPONSES ON AREA OF CHANGES IN
DONOR-RECIPIENT RELATIONSHIP FOLLOWING
DONATION BY LENGTH OF TIME
SINCE DONATION

Length of Time	High	Medium	Low
0 - 18 months	0	0	11
19 - over months	0	2	8
Total	0	2	19

Lambda = .00.

TABLE 15

ATTITUDINAL RESPONSES ON AREA OF MOTIVATION
TO DONATE DUE TO FAMILY PRESSURE BY
LENGTH OF TIME SINCE DONATION

Length of Time	High	Medium	Low
0 - 18 months	0	0	11
19 - over months	0	1	9
Total	0	1	20

Lambda = .00.

When length of time was examined for its association with the motivation to donate due to role obligation or sense of duty some deviation from the previous patterns of association was noted. Table 16 illustrates the association between length of time since donation and motivation due to role obligation ($\Lambda = .45$). This indicates that 45 percent of the error in predicting the attitude response to motivation due to role obligation was reduced given knowledge of the respondent's length of time since donation. This represents a more pronounced increase in association over the associations noted previously between sex and emotional closeness ($\Lambda = .25$) and sex and motivation due to role obligation ($\Lambda = .36$).

TABLE 16

ATTITUDINAL RESPONSES ON AREA OF MOTIVATION
TO DONATE DUE TO ROLE OBLIGATION OR SENSE
OF DUTY BY LENGTH OF TIME SINCE DONATION

Length of Time	High	Medium	Low
0 - 18 months	0	3	8
19 - over months	1	7	2
Total	1	10	10

$\Lambda = .45.$

When length of time was examined for its association with the motivation to donate due to altruism no association was found. As Table 17 illustrates ($\Lambda = .00$) the modal responses fall into the medium score range regardless of length of time since donation.

TABLE 17
ATTITUDINAL RESPONSES ON AREA OF MOTIVATION
DUE TO ALTRUISM BY LENGTH OF TIME
SINCE DONATION

Length of Time	High	Medium	Low
0 - 18 months	3	8	0
19 - over months	4	5	1
Total	7	13	1

$\Lambda = .00$.

When the length of time was examined for its association with feelings of anger following donation no association was found. As Table 18 illustrates ($\Lambda = .00$) there was an overwhelming tendency for respondents to indicate little or low degree of anger following donation regardless of length of time since donation.

TABLE 18

ATTITUDINAL RESPONSES ON AREA OF FEELINGS
OF ANGER FOLLOWING DONATION BY
LENGTH OF TIME SINCE DONATION

Length of Time	High	Medium	Low
0 - 18 months	0	0	11
19 - over months	0	0	10
Total	0	0	21

Lambda = .00.

When length of time was examined for its association with an increase in self-esteem following donation no association was found. As Table 19 illustrates (Lambda = .00) the tendency was for respondents to indicate low increase in self-esteem regardless of time interval since donation.

TABLE 19

ATTITUDINAL RESPONSES ON AREA OF EMOTIONAL CLOSENESS
PRIOR TO DONATION BY FAMILIAL RELATIONSHIP BETWEEN
DONOR AND RECIPIENT

Familial Relationship	High	Medium	Low
Parental-Child	10	1	0
Sibling-Other	8	2	0
Total	18	3	0

Lambda = .00.

Summary of the Association Between Length of Time
Since Donation and Attitudinal Areas

As noted previously, the association between length of time since donation and the attitudinal areas was negligible. A moderate association was found in one instance; a Lambda of .45 was calculated for the association between length of time since donation and motivation to donate due to role obligation or sense of duty.

Familial Relationship Between Donor and Recipient

When the variable of familial relationship between donor and recipient was employed as the independent variable the strength of association between the independent variable and the dependent variable was again negligible. When the familial relationship was examined for its association with the degree of emotional closeness between donor and recipient no association was found. As Table 20 illustrates (Lambda = .00) there was a marked tendency for respondents to indicate high degree of emotional closeness regardless of the type of family relationship.

When familial relationship was examined for its association with changes in donor-recipient relationship following donation no association was found. As illustrated by Table 21 (Lambda = .00) the prominent tendency was for

respondents to indicate little or low degree of change in closeness regardless of the type of familial relationship.

TABLE 20

ATTITUDINAL RESPONSES ON AREA OF EMOTIONAL CLOSENESS
PRIOR TO DONATION BY FAMILIAL RELATIONSHIP
BETWEEN DONOR AND RECIPIENT

Familial Relationship	High	Medium	Low
Parental-Child	10	1	0
Sibling-Other	8	2	0
Total	18	3	0

Lambda = .00.

TABLE 21

ATTITUDINAL RESPONSES IN AREA OF CHANGE IN
DONOR-RECIPIENT RELATIONSHIP
FOLLOWING DONATION BY TYPE
OF FAMILY RELATIONSHIP

Familial Relationship	High	Medium	Low
Parental-Child	0	1	10
Sibling-Other	0	1	9
Total	0	2	19

Lambda = .00.

When familial relationship was examined for its association with the motivation to donate due to family pressure no association was found. As Table 22 illustrates ($\Lambda = .00$) there was an apparent tendency for respondents to indicate low or little degree of family pressure as basis for motivation to donate regardless of familial relationship to the recipient.

TABLE 22

ATTITUDINAL RESPONSES IN AREA OF MOTIVATION
TO DONATE DUE TO FAMILY PRESSURE BY
TYPE OF FAMILIAL RELATIONSHIP

Familial Relationship	High	Medium	Low
Parental-Child	0	1	10
Sibling-Other	0	0	10
Total	0	1	20

$\Lambda = .00$.

When familial relationship was examined for its association with the motivation to donate due to sense of duty or role obligation a deviation from the previous patterns of association was again noted. Table 23 illustrates the association between family relationship and motivation due to role obligation ($\Lambda = .36$); this indicates that 36 percent of the error in predicting the

attitude response to motivation due to role obligation was reduced given knowledge of the respondents' familial relationship to the recipient. This represents the same association as found when sex was the independent variable ($\text{Lambda} = .36$) and a slight decrease from the association found when length of time since donation was the independent variable ($\text{Lambda} = .45$).

TABLE 23

ATTITUDINAL RESPONSES ON AREA OF MOTIVATION
DUE TO ROLE OBLIGATION BY TYPE
OF FAMILIAL RELATIONSHIP

Familial Relationship	High	Medium	Low
Parental-Child	1	7	3
Sibling-Other	0	3	7
Total	1	10	10

$\text{Lambda} = .36$.

When familial relationship was examined for its association with the motivation to donate due to altruism no association was found. Table 24 illustrates ($\text{Lambda} = .00$) there was a tendency for respondents to score in the medium-score range regardless of familial relationship to recipient.

TABLE 24

ATTITUDINAL RESPONSES ON AREA OF MOTIVATION
TO DONATE DUE TO ALTRUISM BY TYPE
OF FAMILIAL RELATIONSHIP

Familial Relationship	High	Medium	Low
Parental-Child	4	7	0
Sibling-Other	3	6	1
Total	7	13	1

Lambda = .00.

When familial relationship was examined for its association with feelings of anger following donation no association was found. Table 25 illustrates (Lambda = .00) there was an over-all tendency for respondents to indicate little or low degree of anger following donation.

TABLE 25

ATTITUDINAL RESPONSES ON AREA OF FEELINGS
OF ANGER FOLLOWING DONATION BY TYPE OF
FAMILIAL RELATIONSHIP

Familial Relationship	High	Medium	Low
Parental-Child	0	0	11
Sibling-Other	0	0	10
Total	0	0	21

Lambda = .00.

When familial relationship was examined for its association to an increase in self-esteem no association was found. Table 26 illustrates ($\Lambda = .00$) the general tendency for respondents to indicate low or little increase in self-esteem regardless of type of familial relationship.

TABLE 26

ATTITUDINAL RESPONSES ON AREA OF INCREASED
SELF-ESTEEM FOLLOWING DONATION BY
TYPE OF FAMILIAL RELATIONSHIP

Familial Relationship	High	Medium	Low
Parental-Child	2	3	6
Sibling-Other	1	3	6
Total	3	6	12

$\Lambda = .00$.

Summary of the Association Between Familial
Relationship and Attitudinal Areas

The association between familial relationship of donor and recipient and the attitudinal areas were found to be negligible. At best a moderate association was found in one instance; a Λ of .36 was calculated for the association between type of family relationship and motivation to donate due to role obligation or sense of duty.

Interpretations of the Findings

The following is a discussion of the results of this study with emphasis on the rationale for the findings. A fundamental objective of this research was to determine the nature of attitudes on the part of living-related kidney donors to the experience of kidney donation. Apart from the associations which were or were not found between a number of independent and dependent (attitudinal) variables, the over-all response patterns of donors warrants some attention. In this context, each of the attitudinal areas can be considered as a single dimension of the multi-dimensional construct surrounding the act of kidney donation. The various dimensions considered in this research will be discussed.

Prior to the discussion of specific reasons in relationship to the specific findings one aspect of this study must be explored as being a major factor influencing all the findings. That is, this research must be judged in the context of those persons who actually responded to the questionnaire. The generally favorable response on the part of donors to the areas (i.e. lack of anger, high degree of emotional fulfillment through donation) raises some questions about the responding population. A critical question relates to the motivation to respond to the

questionnaire, itself: the tendency to respond to the questionnaire may be dependent upon a favorable donation experience initially.

The general response of donors concerning pre-donation emotional closeness to recipient showed a tendency to indicate a high degree of closeness. Conversely, responses regarding emotional closeness post-donation indicated little change in attitude: most donors reported little change in their pre-donation relationship with the recipient. Perhaps an explanation for the findings of a high degree of closeness prior to donation can be found in the assumption that a relative would only consent to donate to a person to whom he felt close. It may be that the relationship did not change post-donation due to the over-all closeness experienced prior to donation.

The responses of donors regarding motivation to donate due to family pressure, indicated a low degree of pressure by the family members. In the area of motivation to donate due to role obligation there was little tendency for respondents to consider role obligation as having been a highly influential factor in the desire to donate: most responses being in the medium to low range. The over-all responses of donors on the matter of motivation to donate due to altruism indicated that altruism may have had some

influence on the decision to donate: the majority of scores falling in the high to medium range. To give explanation of these findings it is necessary to consider each aspect of motivation separately. In regard to family pressure, it may be that even though family pressure may have played a small part in the decision to donate, persons answering the questionnaire may have indicated low family pressure since medical personnel gave them a medical reason for deciding against donation; thereby reducing the factor of family pressure. Even though role obligation was not highly significant it did play a part in the decision to donate. This may be due to the fact that in Western Culture expectations of certain roles are usually clearly defined. Further discussion of this aspect will be included in relation to the independent variables. Scores of donors regarding altruism as a basis for motivation may have been due to the fact that persons are rewarded when they help their fellow man and the donation process is certainly an example of this concept.

Response patterns in the area of feelings of anger following donation indicated, overwhelmingly, little or low degree of anger following the donation experience. At the same time, the general response patterns regarding an increase of self-esteem following donation fell into the

medium to low-score range. The finding of low anger following donation may be attributed to the donors' feeling of an over-all favorable donation experience. A second explanation may be that the study involved living-related donors whose kidneys were still viable. A low to medium increase in self-esteem following donation was evidenced and may be related to the findings regarding role obligation and altruism. If the donors felt that the donation of a kidney was part of his duty or for the good of mankind, there would be no reason to expect an increase in self-esteem.

A secondary objective of the research was the determination of the extent to which certain variables were related to attitudes of the donors. Several independent variables were suggested as being associated with response patterns in each of the attitude areas: sex, length of time since donation, and type of family relationship between the donor and recipient.

The variable of sex was found associated to two attitudinal areas: pre-donation emotional closeness and motivation due to role obligation. Females exhibited a greater tendency to characterize their pre-donation relationships as "high" on the scale of emotional closeness than did the male donors. Females also exhibited a greater sensitivity to role obligation than did males in the matter

of motivation to donate. These findings may be attributed to the fact that in Western society females are allowed greater emotional freedom than males. This would also explain female willingness to attribute their decision to donate to be due to role obligation, whereas, males might be more reticent to admit role obligation.

The remaining instances in which any apparent association was discovered related again to the area of role obligation as motivation to donate. Both the length of time since donation and the type of relationship between donor and recipient were found to be associated with the attitude area of role obligation. Among those donors who had donated within the past eighteen months (at the time of the research) there was a pattern of "low" motivation due to role obligation: the donors who had donated over nineteen months previously (at the time of the research) were more likely to voice some sensitivity to the matter of role obligation and to treat role obligation as somewhat more influential. An explanation may be that the longer post-donation a person is, the more likely he is to forget or minimize the influences that family pressure or altruism played in his decision to donate. It then follows that role obligation remains fairly stable as an influential factor.

In parent-child relationships there was a greater tendency to voice motivation due to role obligation than in the sibling-or-other relationships. At the same time, however, the dimension of role obligation was not "highly" (on the basis of scores, i.e., high, medium, low) sensitive to either type of relationship. This finding is consistent with the literature regarding role obligation and donation. That is, parental roles are much more clearly defined in Western Culture and the obligation of siblings and other family members are less obvious.

Summary

After a description of the sample, statistical analysis was performed on the data collected for this study. Interpretations of the statistical findings were then presented on the basis of the findings. The findings of this research indicated that most donors expressed a high degree of closeness to the recipient prior to donation and no change in the emotional relationship following donation. The majority of donors expressed low family pressure as basis for donation while role obligation and altruism were found to be more influential in the decision to donate. Most donors expressed little anger or an increase in self-esteem following donation.

When the independent variables of sex, length of time since donation and type of family relationship were examined for their association to score areas all but four were found to be negligible. The area of closeness prior to donation was found to have a low degree of association to sex, and the area of motivation due to role obligation was found to have a moderate to low association to sex, length of time since donation, and type of family relationship.

CHAPTER V

SUMMARY, RECOMMENDATIONS, IMPLICATIONS AND CONCLUSIONS

Summary

This study was conducted to determine certain psychological attitudes of living-related kidney donors regarding the experience of donation. Both pre- and post-donation attitudes were considered and methods to determine these attitudes were developed.

The major purpose of this study was to determine the nature of attitudes of related donors within several attitudinal areas. They were: donor-recipient emotional closeness prior to donation, changes in donor-recipient relationship post-donation, motivation to donate due to role obligation, motivation to donate due to altruism, motivation to donate due to family pressure, feelings of anger on the part of the donor following donation and feelings of increased self-esteem following donation. To test these a method of measuring or rating the donors' attitudes was necessary. The rating was done with the use of a Likert-type Attitude Scale developed by the investigator.

In developing the Scale, seven areas were selected from a review of literature which described the various attitudes of kidney donors regarding kidney donation. From this review, statements regarding each area were formulated and compiled in test form. The initial compilation was validated by a panel of five judges. The validated scale, which included attitudes in each of the seven areas, was then mailed to the sample population.

Twenty-one living-related donors were included in the sample which was obtained from a large city-county metropolitan hospital. The donors were mailed the inquiry and instructed to read each statement carefully and then to indicate if they Strongly Agreed, Agreed, Disagree, Strongly Disagree, or were Undecided regarding each item. Each item was then scored on a scale of one to five--five being Strongly Agree, one being Strongly Disagree.

Appropriate statistical analysis was applied to the data received from the entire sample and interpretations of the findings were recorded. Further analysis was achieved through information gathered on a data sheet which included sex, length of time since donation, physical health, and type of family relationship to the recipient.

A proportional reduction in error measure, Lambda, was utilized to determine the association between the

dependent variable (high, medium, and low scores) and the independent variables (sex, length of time since donation and familial relationship). With respect to the basic purpose of this study, no significant over-all associations were found when exploring all the data; although, in four areas there were moderate to low association found.

Recommendations

Based on the findings of this research the following recommendations were made:

1. That a similar study be conducted using a larger sample population so that a greater degree of cross-classification by relevant variables would be allowed and there could be a more accurate examination of donor-response patterns
2. That a similar study be conducted which would include living-related donors whose recipient or kidney was no longer viable so that a full exploration of donor attitudes could be obtained
3. That a similar study be conducted to include donor populations gathered from various centers in which different methods of donor procurement is used and compare these results with those from the Dallas Center
4. That a similar study be conducted using interviews coupled with the questionnaires in order to obtain results

from that portion of the population who would not answer the mail-out inquiry

5. That longitudinal studies be conducted to allow for a diachronic examination of attitude change. In addition to offering insight into the process of attitude information and/or changes, longitudinal studies would also allow the researcher to gain greater specification on the matter of living versus non-living organs. In those instances in which the recipient or kidney died, pre and post "death" attitudes could be compared.

Implications

Current literature dealing with the care and treatment of living-related donors indicates that although donation may be a relatively benign procedure both physically and psychologically for some, many donors suffer definite psychological and emotional trauma as a result of donation. Results of the study indicate, however, that the majority of respondents donating kidneys from the Dallas Center have had positive donation experiences; indeed, most felt (nineteen out of twenty-one) it was the most rewarding experience of their lives.

In order to provide comprehensive care, nurses must be aware of the patient as a whole human being with physiological and psychological elements contributing to

his behavior. In the area of living-related donors one must view the donor as a complete human being rather than merely a potential kidney. He, like the recipient, has certain needs which must not be overlooked. Members of the health profession must focus on him as an individual with feelings and emotions even though he does not demand the closer, constant, clinical supervision which is necessary for survival of the recipient.

Even though the findings of the research at this time indicated that for the majority of donors the experience of donation was a relatively smooth process, it is not unrealistic to postulate that some future donors at the Dallas Center will have the types of difficulties outlined in the literature since there is an increasing demand for kidneys and renal transplantation. It is necessary, then, for nurses caring for donors to be aware of possible emotional as well as physiological problems related to kidney donation. How will nurses be made aware of these problems? One method may be specific in-service education programs which would provide time for all nurses, but particularly those involved with donors to review their knowledge of the effects of the donation procedure on man. A second approach may lie in a more effective use of current literature. Pertinent articles must be made available to

the nursing staff and emphasis placed on the importance of knowledge of the literature. Administration personnel must provide on-the-job time for nursing personnel to further increase the knowledge regarding living-related donors and appropriate rewards must be devised to encourage educational advancement. Continued emphasis on improvement of patient must, in itself, provide the impetus for nurses to constantly expand their knowledge.

In order to continue the preparation of nurses sensitive to specific psychological needs of the patient, nursing education must continue to provide curriculum rich in both behavioral and biological sciences. Student nurses must be able to apply the theory of these sciences and reflect their knowledge of the psychological needs as well as the physical needs of the patient in the giving of their patient care.

Nursing education must strive to implant within students an attitude of inquiry and learning, so that once formal education has been completed and a degree and licensure obtained, each individual practicing nurse will strive independently to reach new levels of intellectual awareness. In this way nurses and nursing will continually be expanding their basic store of knowledge.

Conclusions

This study was conducted to establish selected psychological attitudes of living-related donors regarding their donation experience. Based on the findings, the following conclusions were made:

1. Emotional closeness between the donor and recipient does seem to be a factor in the final decisions to donate. Following donation, the donor-recipient relationship was not affected either constructively or adversely

2. A low degree of family pressure as a motivating factor for donation was found which is in contrast to Kemph's findings of a large motivating factor

3. A high degree of altruism as a motivating factor for donation was found, which is consistent with the Fellner and Marshall study

4. A low degree of anger following donation was found which is in contrast to Kemph's findings of a high degree of anger following donation

5. A low degree of self-esteem following donation was found which is in contrast to Fellner and Marshall's findings of a high degree of self-esteem.

As can be seen from the study there are a variety of factors operating within each individual who decided to donate a kidney. It is only through careful observation

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and research that one can begin to understand the complexity of factors operating in each individual donor.

APPENDIX A

DIRECTIONS GIVEN TO PANEL OF JUDGES REGARDING CATEGORIZATION OF TOOL

This tool is being developed in order to determine selected attitudes about donation as expressed by living-related donors. The tool is composed of a series of statements to which the donor will be asked to respond on a five-point scale ranging from Strongly Agree to Strongly Disagree. In order to use the tool as an effective measurement for these attitudes it must first be validated by a panel of judges. As a member of the panel of judges, I am asking you to consider each statement carefully and respond to it according to the areas outlined below.

- A. Is the statement written clearly and concisely?
- B. Categorize the statement according to the area you feel that statement deals best with. To do this put the number which corresponds to that area after the statement. Keep in mind that the statements are stated both positively and negatively. Use ONE number only after each statement.

- I. Closeness prior to donation between the donor and recipient.
- II. Change in closeness after donation.
- III. Motivation to donate as a result of family pressure.
- IV. Motivation to donate as a result of role obligation or sense of duty.
- V. Motivation to donate as a result of altruism (Unselfish feeling to help mankind).
- VI. Feelings of anger felt by the donor after donation.
- VII. Feelings of increased self-esteem felt by the donor after donation.

Please consider these statements carefully and without consultation from others as this will effect the final outcome.

APPENDIX B

STATEMENTS GIVEN TO PANEL OF JUDGES

<u>Statement</u>	<u>A</u>		<u>B</u>
	<u>Yes</u>	<u>No</u>	
1. I donated my kidney because I felt it was my duty.	_____	_____	_____
2. After donation I wondered if it had all been worth it.	_____	_____	_____
3. After donation I didn't like to be around the person I gave my kidney to as much as I did before.	_____	_____	_____
4. The best reason to donate a kidney is because of love for the person who needs the kidney.	_____	_____	_____
5. Fathers are not obligated to give kidneys to children.	_____	_____	_____
6. After donation the person I gave my kidney to and I do more together.	_____	_____	_____
7. The best reason to donate a kidney is because it is the Christian thing to do.	_____	_____	_____
8. Most people are more willing to donate to children than to brothers and sisters.	_____	_____	_____
9. The main reason to donate is because it will make you feel like a better person.	_____	_____	_____
10. Every family member is responsible for every other member in the physical sense.	_____	_____	_____

<u>Statement</u>	<u>A</u>		<u>B</u>
	<u>Yes</u>	<u>No</u>	
11. Most people don't hesitate to go out of their way to help someone in distress.	—	—	—
12. After donation the person I gave my kidney to and I talk more together.	—	—	—
13. Most people donate a kidney so that other people will admire them.	—	—	—
14. Mothers and fathers are closer to children and are more willing to give a kidney than other members of the family.	—	—	—
15. After donation the other person's feelings toward me stayed the same.	—	—	—
16. I don't think I should suffer for other people's problems.	—	—	—
17. Mothers are not obligated to give kidneys to children.	—	—	—
18. It is not my duty to help someone out.	—	—	—
19. The person I gave my kidney to and I talk about the same things we always did.	—	—	—
20. Before donation, the person I gave my kidney to was someone I could have fun with.	—	—	—
21. After donation I felt lonesome.	—	—	—
22. If I would die today, I would feel my life has been completely worthless.	—	—	—
23. An individual most deserves the feeling of satisfaction with himself after he has done something to help someone else.	—	—	—

<u>Statement</u>	<u>A</u>		<u>B</u>
	<u>Yes</u>	<u>No</u>	<u> </u>
24. I feel the same about the person I gave my kidney to as I always have.	<u> </u>	<u> </u>	<u> </u>
25. Brothers and sisters are not obligated to give kidneys to each other.	<u> </u>	<u> </u>	<u> </u>
26. People pretend to care more about one another than they really do.	<u> </u>	<u> </u>	<u> </u>
27. I felt more important after donation.	<u> </u>	<u> </u>	<u> </u>
28. Most people will donate a kidney because it is their duty.	<u> </u>	<u> </u>	<u> </u>
29. Most people try to apply the Golden Rule even in today's society.	<u> </u>	<u> </u>	<u> </u>
30. Families expect too much from their members.	<u> </u>	<u> </u>	<u> </u>
31. Most people will donate a kidney because it makes them feel good.	<u> </u>	<u> </u>	<u> </u>
32. After donation I felt that nobody cared what happened to me.	<u> </u>	<u> </u>	<u> </u>
33. The person I gave my kidney to and I hardly ever saw each other before donation.	<u> </u>	<u> </u>	<u> </u>
34. The family would look down on those members who didn't want to donate a kidney.	<u> </u>	<u> </u>	<u> </u>
35. I was proud to have donated.	<u> </u>	<u> </u>	<u> </u>
36. The person I gave my kidney to and I do the same things we always did.	<u> </u>	<u> </u>	<u> </u>
37. It is only a rare person who will risk life and limb to save another's life.	<u> </u>	<u> </u>	<u> </u>

	<u>Statement</u>	<u>A</u>		<u>B</u>
		<u>Yes</u>	<u>No</u>	
38.	After donation no one paid any attention to me.	_____	_____	_____
39.	After donation everyone paid attention to the person I gave my kidney to instead of me.	_____	_____	_____
40.	After donation the person I gave my kidney to and I feel we are closer.	_____	_____	_____
41.	After donation I felt I couldn't do anything right.	_____	_____	_____
42.	Since donation I think more about the person I gave my kidney to.	_____	_____	_____
43.	I felt left out after donation.	_____	_____	_____
44.	Sometimes I have the feeling that other people are using me.	_____	_____	_____
45.	The main reason to donate a kidney is because it is a family duty.	_____	_____	_____
46.	Every person is his brother's keeper in the physical sense.	_____	_____	_____
47.	I like the person I gave my kidney to just as much as I always did.	_____	_____	_____
48.	After donation I just didn't seem to like the person I gave my kidney to as well.	_____	_____	_____
49.	Before donation the person I gave my kidney to was someone I could count on for help if I was in trouble.	_____	_____	_____
50.	The way we get along with each other did not change after donation.	_____	_____	_____
51.	After donation we are as close as we ever were.	_____	_____	_____

	<u>Statement</u>	<u>A</u>		<u>B</u>
		<u>Yes</u>	<u>No</u>	
52.	Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries.	_____	_____	_____
53.	After donation the person I gave my kidney to and I see more of each other.	_____	_____	_____
54.	The typical person is sincerely concerned about the problems of others.	_____	_____	_____
55.	I felt I looked better after donation.	_____	_____	_____
56.	After donation I became very irritable with those around me.	_____	_____	_____
57.	It is not the duty of family members to give a kidney.	_____	_____	_____
58.	I liked myself better after I donated a kidney.	_____	_____	_____
59.	In making family decisions the strongest member should make a decision.	_____	_____	_____
60.	Most people who donated a kidney feel some sort of obligation toward the person they donated to.	_____	_____	_____
61.	The person I donated my kidney to was someone I really cared about.	_____	_____	_____
62.	I felt let down after donation.	_____	_____	_____
63.	I care about the person I gave my kidney to just as much as I always did.	_____	_____	_____
64.	After donation I felt like I wasn't getting as much attention as I should be.	_____	_____	_____

<u>Statement</u>	<u>A</u>		<u>B</u>
	<u>Yes</u>	<u>No</u>	
65. After donation I felt like I got a raw deal.	_____	_____	_____
66. After donation I talk more about the person I gave my kidney to.	_____	_____	_____
67. For some reason I felt mad at everyone after donation.	_____	_____	_____
68. Sometimes I feel it wasn't fair that I had to donate.	_____	_____	_____
69. After donation I felt shoved aside.	_____	_____	_____
70. Brothers and sisters will always give kidneys to each other if they can.	_____	_____	_____
71. After donation I felt depressed.	_____	_____	_____
72. After donation I found a good deal of happiness in life.	_____	_____	_____
73. I take better care of myself physically since donation.	_____	_____	_____
74. After donation I found myself mad or irritated at the doctor or nurses.	_____	_____	_____
75. The family put a lot of pressure on me to donate.	_____	_____	_____
76. I don't approve of spending time and energy in doing things for other people.	_____	_____	_____
77. I discovered my true purpose in life after donation.	_____	_____	_____
78. The best reason to donate a kidney is to give further life to a person who would die.	_____	_____	_____
79. After donating a kidney I really felt worthwhile.	_____	_____	_____

<u>Statements</u>	<u>A</u>		<u>B</u>
	<u>Yes</u>	<u>No</u>	
80. Before donation the person I gave my kidney to was someone I missed alot when they weren't around.	_____	_____	_____
81. Mothers will always give a kidney to their children if they can.	_____	_____	_____
82. The person I gave my kidney to and I really didn't know each other very well before donation.	_____	_____	_____
83. The best reason to donate a kidney is to help someone in distress.	_____	_____	_____
84. After donation I felt I did not have much to be proud of.	_____	_____	_____
85. Before donation the person I gave my kidney to was someone I could get mad at and still care about.	_____	_____	_____
86. Before donation the person I gave my kidney to and I hardly ever talked to each other.	_____	_____	_____
87. Although I didn't show it, I was jealous after donation.	_____	_____	_____
88. For some reason I felt mad at the person I gave my kidney to after donation.	_____	_____	_____
89. Before donation the person I gave my kidney to was someone I could have fun with but not tell my troubles to.	_____	_____	_____
90. After donation I was made at myself.	_____	_____	_____
91. The best reason to donate a kidney is because your husband or wife says you should.	_____	_____	_____
92. After donation I just didn't feel the same toward the person I gave my kidney to.	_____	_____	_____

<u>Statements</u>	<u>A</u>		<u>B</u>
	<u>Yes</u>	<u>No</u>	
93. After donation I felt forgotten.	_____	_____	_____
94. After donation I couldn't help feeling superior to most other people.	_____	_____	_____
95. After donation I didn't know who I could count on.	_____	_____	_____
96. I don't miss the person I gave my kidney to anymore than I ever did.	_____	_____	_____
97. I think about the person I gave my kidney to in the same way I always have.	_____	_____	_____
98. The person I gave my kidney to and I had very little in common.	_____	_____	_____
99. I never felt I could count on the person I gave my kidney to if I were in trouble.	_____	_____	_____
100. After donation I didn't seem to get what was coming to me.	_____	_____	_____
101. I don't approve of doing favors for other people.	_____	_____	_____
102. If I should die today I would feel my life was worthwhile.	_____	_____	_____
103. I feel like the person I gave my kidney to owes me something.	_____	_____	_____
104. After donation I felt like I was someone special.	_____	_____	_____
105. Even though I didn't feel it was my duty I still wanted to donate a kidney.	_____	_____	_____
106. People don't really care what happens to the next fellow.	_____	_____	_____

	<u>Statements</u>	<u>A</u>		<u>B</u>
		<u>Yes</u>	<u>No</u>	
107.	After donation I felt no anger or resentment toward anyone.	_____	_____	_____
108.	Most people inwardly dislike putting themselves out to help other people.	_____	_____	_____
109.	Most people would only donate a kidney to a person they cared about.	_____	_____	_____
110.	After donation I felt loved.	_____	_____	_____
111.	After donation I generally felt in good spirits.	_____	_____	_____
112.	It's pathetic to see an unselfish individual in today's world because so many people take advantage of him.	_____	_____	_____
113.	People in our society are just out for themselves and don't really care for anyone else.	_____	_____	_____
114.	After donation the other person's feelings seemed to change toward me.	_____	_____	_____
115.	Most people will donate a kidney if the rest of the family thinks they should.	_____	_____	_____
116.	Brothers and sisters who aren't close shouldn't give a kidney.	_____	_____	_____
117.	Before donation the person I gave a kidney to was someone I could talk to about my troubles.	_____	_____	_____
118.	Most people will donate a kidney when their parents say they should.	_____	_____	_____
119.	In making family decisions about donation all person's views should be listened to.	_____	_____	_____

<u>Statements</u>	<u>A</u>		<u>B</u>
	<u>Yes</u>	<u>No</u>	
120. I feel I'm a person of worth, at least on an equal plane with other people.	_____	_____	_____
121. When I look back on what has happened to me I feel cheated.	_____	_____	_____
122. The family controls who is going to donate.	_____	_____	_____
123. It wouldn't matter to me whether I cared about the person I donated to.	_____	_____	_____
124. In making family decisions parents ought to take the opinions of their children into account.	_____	_____	_____
125. After donation I found myself feeling mad at my family more than usual.	_____	_____	_____
126. It would have been all right with the rest of the family if I had decided not to donate.	_____	_____	_____
127. The person I donated my kidney to was someone I felt very close to.	_____	_____	_____
128. In order to get along with the rest of the family I decided to donate.	_____	_____	_____
129. Fathers will always give a kidney to their children if they can.	_____	_____	_____
130. After donation I felt people were apt to react differently to me than they would normally react to other people.	_____	_____	_____

APPENDIX C

TABULATION OF PANEL OF JUDGES' RECOMMENDATIONS

	<u>Statements</u>	<u>A</u>		<u>B</u>
		<u>Yes</u>	<u>No</u>	
1.	I donated my kidney because I felt it was my duty.	5		4,4,4, 4,4
2.	After donation I wondered if it had all been worth it.	5		6,6,6, 6,6
3.	After donation I didn't like to be around the person I gave my kidney to as much as I did before.	5		2,2,2, 6,2
4.	The best reason to donate a kidney is because of love for the person who needs the kidney.	5		5,1,5, 5,5
5.	Fathers are not obligated to give kidneys to children.	5		4,3,3, 4,3
6.	After donation the person I gave my kidney to and I do more together.	5		2,2,2, 2,2
7.	The best reason to donate a kidney is because it is the Christian thing to do.	5		5,5,4, 5,5
8.	Most people are more willing to donate to children than to brothers and sisters.	5		4,1,3, 4,4
9.	The main reason to donate is because it will make you feel like a better person.	5		5,7,5, 5,5
10.	Every family member is responsible for every other member in the physical sense.	5		4,3,4, 4,4

<u>Statements</u>	<u>A</u>		<u>B</u>
	<u>Yes</u>	<u>No</u>	
11. Most people don't hesitate to go out of their way to help someone in distress.	4	1	5,5,5, 5
12. After donation the person I gave my kidney to and I talk more together.	5		2,2,2, 2,2
13. Most people donate a kidney so that other people will admire them.	5		7,7,4, 7,7
14. Mothers and fathers are closer to children and are more willing to give a kidney than other members of the family.	4	1	1,4,4, 4
15. After donation the other person's feelings toward me stayed the same.	5		2,6,2, 1,2
16. I don't think I should suffer for other people's problems.	4	1	1,3,4, 2
17. Mothers are not obligated to give kidneys to children.	5		4,4,4, 4,4
18. It is not my duty to help someone out.	5		4,4,3, 3,3
19. The person I gave my kidney to and I talk about the same things we always did.	5		2,1,2, 1,1
20. Before donation, the person I gave my kidney to was someone I could have fun with.	5		1,2,1, 1,1
21. After donation I felt lonesome.	5		2,2,6, 6,2
22. If I would die today, I would feel my life has been completely worthless.	4	1	6,6,6, 6
23. An individual most deserves the feeling of satisfaction with himself after he has done something to help someone else.	5		7,5,7, 5,7

Statements	A		B
	Yes	No	
24. I feel the same about the person I gave my kidney to as I always have.	5		2,1,2, 1,1
25. Brothers and sisters are not obligated to give kidneys to each other.	5		4,3,4, 4,4
26. People pretend to care more about one another than they really do.	5		1,2,5, 3,3
27. I felt more important after donation.	5		7,7,7, 7,7
28. Most people will donate a kidney because it is their duty.	5		4,4,4, 4,4
29. Most people try to apply the Golden Rule even in today's society.	4	1	5,5,5, 5,5
30. Families expect too much from their members.	5		3,3,3, 3,3
31. Most people will donate a kidney because it makes them feel good.	5		5,7,5, 7,5
32. After donation I felt that nobody cared what happened to me.	5		6,6,6, 6,6
33. The person I gave my kidney to and I hardly ever saw each other before donation.	5		1,6,1, 1,1
34. The family would look down on those members who didn't want to donate a kidney.	5		3,3,3, 3,3
35. I was proud to have donated.	5		7,7,7, 7,7
36. The person I gave my kidney to and I do the same things we always did.	5		7,7,7, 7,7
37. It is only a rare person who will risk life and limb to save another's life.	5		5,7,5, 7,5

	<u>Statements</u>	<u>A</u>		<u>B</u>
		<u>Yes</u>	<u>No</u>	
38.	After donation no one paid any attention to me.	5		6,6,6, 6,6
39.	After donation everyone paid attention to the person I gave my kidney to instead of me.	5		6,6,6, 6,6
40.	After donation the person I gave my kidney to and I feel we are closer.	5		2,2,2, 2,2
41.	After donation I felt I couldn't do anything right.	5		6,6,6, 6,6
42.	Since donation I think more about the person I gave my kidney to.	5		7,2,2, 2,2
43.	I felt left out after donation.	5		6,6,6, 6,6
44.	Sometimes I have the feeling that other people are using me.	5		6,3,6, 3,6
45.	The main reason to donate a kidney is because it is a family duty.	5		4,4,4, 4,4
46.	Every person is his brother's keeper in the physical sense.	5		5,5,4, 5,5
47.	I like the person I gave my kidney to just as much as I always did.	5		2,1,2, 3,2
48.	After donation I just didn't seem to like the person I gave my kidney to as well.	5		2,2,2, 2,2
49.	Before donation the person I gave my kidney to was someone I could count on for help if I was in trouble.	5		1,1,1, 1,1
50.	The way we get along with each other did not change after donation.	5		2,1,2, 1,2
51.	After donation we are as close as we ever were.	5		2,1,2, 1,2

<u>Statements</u>	<u>A</u>		<u>B</u>
	<u>Yes</u>	<u>No</u>	
52. Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries.	4	1	6,6,6, 6
53. After donation the person I gave my kidney to and I see more of each other.	5		2,2,2, 2,2
54. The typical person is sincerely concerned about the problems of others.	5		5,5,5, 5,5
55. I felt I looked better after donation.	5		7,7,7, 7,7
56. After donation I became very irritable with those around me.	5		6,6,6, 6,6
57. It is not the duty of family members to give a kidney.	5		4,3,4, 3,4
58. I liked myself better after I donated a kidney.	5		7,7,7, 7,7
59. In making family decisions the strongest member should make a decision.	4	1	3,3,3, 3
60. Most people who donated a kidney feel some sort of obligation toward the person they donated to.	5		6,4,4, 4,4
61. The person I donated my kidney to was someone I really cared about.	5		1,1,1, 1,1
62. I felt let down after donation.	5		6,2,6, 6,6
63. I care about the person I gave my kidney to just as much as I always did.	5		2,1,2, 1,1
64. After donation I felt like I wasn't getting as much attention as I should be.	5		6,6,6, 6,6

<u>Statements</u>	<u>A</u>		<u>B</u>
	<u>Yes</u>	<u>No</u>	
65. After donation I felt like I got a raw deal.	5		6,6,6, 6,6
66. After donation I talk more about the person I gave my kidney to.	5		2,3,2, 7,2
67. For some reason I felt mad at everyone after donation.	5		6,6,6, 6,6
68. Sometimes I feel it wasn't fair that I had to donate.	5		6,3,6, 6,6
69. After donation I felt shoved aside.	5		6,6,6 6,6
70. Brothers and sisters will always give kidneys to each other if they can.	5		6,1,5, 4,4
71. After donation I felt depressed.	5		6,6,6 6,6
72. After donation I found a good deal of happiness in life.	5		7,7,7 7,7
73. I take better care of myself physically since donation.	4	1	7,7,7, 7
74. After donation I found myself mad or irritated at the doctor or nurses.	5		6,6,6 6,6
75. The family put a lot of pressure on me to donate.	5		3,3,3, 3,3
76. I don't approve of spending time and energy in doing things for other people.	5		5,3,5, 5,5
77. I discovered my true purpose in life after donation.	5		7,7,7 7,7
78. The best reason to donate a kidney is to give further life to a person who would die.	5		5,5,5 5,5

	<u>Statements</u>	<u>A</u>		<u>B</u>
		<u>Yes</u>	<u>No</u>	
80.	Before donation the person I gave my kidney to was someone I missed alot when they weren't around.	4	1	1,1,1, 1
81.	Mothers will always give a kidney to if they can.	5		4,1,4, 4,4
82.	The person I gave my kidney to and I really didn't know each other very well before donation.	5		1,2,1, 1,1
83.	The best reason to donate a kidney is to help someone in distress.	5		5,5,5, 5,5
84.	After donation I felt I did not have much to be proud of.	5		6,6,7, 6,6
85.	Before donation the person I gave my kidney to was someone I could get mad at and still care about.	5		2,2,1, 1,1
86.	Before donation the person I gave my kidney to and I hardly ever talked to each other.	4	3	1,2,1, 1,1
87.	Although I didn't show it, I was jealous after donation.	5		2,6,6, 6,6
88.	For some reason I felt mad at the person I gave my kidney to after donation.	5		6,6,6 6,6
89.	Before donation the person I gave my kidney to was someone I could have fun with but not tell my trouble to.	5		1,2,1, 1,1
90.	After donation I was mad at myself.	5		6,6,7, 6,6
91.	The best reason to donate a kidney is because your husband or wife says you should.	5		3,3,3, 3,3

	<u>Statements</u>	<u>A</u>		<u>B</u>
		<u>Yes</u>	<u>No</u>	
92.	After donation I just didn't feel the same toward the person I gave my kidney to.	5		7,2,2, 2,2
93.	After donation I felt forgotten.	5		7,6,6, 6,6
94.	After donation I couldn't help feeling superior to most other people.	5		7,7,7, 7,7
95.	After donation I didn't know who I could count on.	5		7,6,7, 6,7
96.	I don't miss the person I gave my kidney to anymore than I ever did.	5		2,6,2, 1,2
97.	I think about the person I gave my kidney to in the same way I always have.	5		2,4,2, 1,2
98.	The person I gave my kidney to and I had very little in common.	5		1,6,1, 3,1
99.	I never felt I could count on the person I gave my kidney to if I were in trouble.	5		1,6,2, 3,1
100.	After donation I didn't seem to get what was coming to me.	5		6,6,6, 6,6
101.	I don't approve of doing favors for other people.	5		5,3,5, 3,5
102.	If I should die today I would feel my life was worthwhile.	5		7,7,7 7,7
103.	I feel like the person I gave my kidney to owes me something.	5		5,6,6, 2,6
104.	After donation I felt like I was someone special.	5		7,7,7, 7,7
105.	Even though I didn't feel it was my duty I still wanted to donate a kidney.	5		5,4,5, 4,4

<u>Statements</u>	<u>A</u>		<u>B</u>
	<u>Yes</u>	<u>No</u>	
106. People don't really care what happens to the next fellow.	4	1	5,5,5, 5
107. After donation I felt no anger or resentment toward anyone.	5		6,7,7, 7,7
108. Most people inwardly dislike putting themselves out to help other people.	5		5,4,5, 7,6
109. Most people would only donate a kidney to a person they cared about.	5		5,5,4, 7,5
110. After donation I felt loved.	5		7,2,7, 2,7
111. After donation I generally felt in good spirits.	5		7,7,7, 7,7
112. It's pathetic to see an unselfish individual in today's world because so many people take advantage of him.	5		5,5,5, 5,5
113. People in our society are just out for themselves and don't really care for anyone else.	5		5,4,5, 5,5
114. After donation the other person's feelings seemed to change toward me.	5		2,2,2, 2,2
115. Most people will donate a kidney if the rest of the family thinks they should.	5		3,3,3, 3,3
116. Brothers and sisters who aren't close shouldn't give a kidney.	5		1,3,5, 3,1
117. Before donation the person I gave a kidney to was someone I could talk to about my troubles.	5		1,2,1, 1,1
118. Most people will donate a kidney when their parents say they should.	5		3,3,3, 3,3

	<u>Statements</u>	<u>A</u>		<u>B</u>
		<u>Yes</u>	<u>No</u>	
119.	In making family decisions about donation all person's views should be listened to.	4	1	3,3,3, 3
120.	I feel I'm a person of worth, at least on an equal plane with other people.	5		5,7,7, 7,7
121.	When I look back on what has happened to me I feel cheated.	5		6,6,6, 6,6
122.	The family controls who is going to donate.	5		3,3,3, 3,3
123.	It wouldn't matter to me whether I cared about the person I donated to.	5		5,5,5, 4,5
124.	In making family decisions parents ought to take the opinions of their children into account.	5		3,3,3, 3,3
125.	After donation I found myself feeling mad at my family more than usual.	5		6,3,6, 2,6
126.	It would have been all right with the rest of the family if I had decided not to donate.	5		3,3,3, 7,3
127.	The person I donated my kidney to was someone I felt very close to.	5		1,1,1, 1,1
128.	In order to get along with the rest of the family I decided to donate.	5		3,3,3, 3,3
129.	Fathers will always give a kidney to their children if they can.	5		4,4,4, 4,4
130.	After donation I felt people were apt to react differently to me than they would normally react to other people.	5		7,6,2, 2,7

APPENDIX D

LETTER OF INTRODUCTION TO DONORS

September 4, 1974

Peggy Bruks
700 South Story
Apt. 1009
Irving, Texas

Dear

I am a registered nurse currently working on my Master's Degree in Renal Transplantation at Texas Women's University. I have been working closely this year with Dr. Hull and Mrs. Atkins at Parkland Hospital. As a result of this work it has become apparent that not much research has been done in relation to kidney donors. For my Master's Thesis I have decided to do a study on living-related donors in an effort to help the kidney team at Parkland Hospital plan better care for donor patients.

Your participation in this study is extremely important in that it will help us understand the feelings and reactions of kidney donors. This understanding will help the nurses and doctors assist the donor patient throughout his experience of donation. In order to do this effectively, we must have the cooperation of all those donors who have had this experience of donating--remember YOU are the experts.

As you look at the questionnaire, you will see a page for specific information regarding your age, sex, relationship to recipient and other information. Please fill this page out carefully and then proceed to the rest of the questionnaire. When you have finished the test please feel free to make any additional comments about positive and negative feelings regarding your donation on the blank piece of paper provided. Please be as honest as you can. There are no identifying names or marks on these questionnaires and there will be no way of knowing from whom these responses came. Please reply as quickly and promptly as possible and mail your replies on or before September 19.

-108-

Your responses are much appreciated and thank you
for your participation.

Sincerely,

Master's Candidate, T.W.U.

Approved by,

Assistant Professor,
Lois Hough
Medical Surgical Graduate
Studies

APPENDIX E

TEST SENT TO DONORS

Data Sheet

Age _____

Sex: Male _____ Female _____

Relationship to kidney recipient (please check one of the following):

Mother _____

Uncle _____

Father _____

Aunt _____

Brother _____

Cousin _____

Sister _____

Other _____

Since donation I have been in: (Check one)

Good physical health _____ Poor physical health _____

Length of time since donation in years and months:

Directions: The following are statements that might be made by a living-related donor such as yourself. Please read each statement carefully and decide if you Strongly Agree, Agree, Undecided, Disagree, Strongly Disagree with the statement. Check the words that BEST describe your feelings at this time about the statement. There should be ONE mark and ONE mark only after each statement.

Code: SA - Strongly Agree
A - Agree
U - Undecided
D - Disagree
SD - Strongly Disagree

Example:

1. I donated a kidney. \overline{X}
 \overline{SA} \overline{A} \overline{U} \overline{D} \overline{SD}

Please Start!

- | | |
|---|--|
| 1. After donation I just don't feel the same toward the person I gave the kidney to. | \overline{SA} \overline{A} \overline{U} \overline{D} \overline{SD} |
| 2. In making family decisions about donation all person's views should be listened to. | \overline{SA} \overline{A} \overline{U} \overline{D} \overline{SD} |
| 3. Although I didn't show it, I was jealous after donation. | \overline{SA} \overline{A} \overline{U} \overline{D} \overline{SD} |
| 4. The best reason to donate is to give further life to a person who would die. | \overline{SA} \overline{A} \overline{U} \overline{D} \overline{SD} |
| 5. The person I donated my kidney to was someone I felt very close to. | \overline{SA} \overline{A} \overline{U} \overline{D} \overline{SD} |
| 6. I felt I looked better after donation. | \overline{SA} \overline{A} \overline{U} \overline{D} \overline{SD} |
| 7. After donation I don't like to be around the person I gave my kidney to as much as I did before. | \overline{SA} \overline{A} \overline{U} \overline{D} \overline{SD} |

- | | | | | | |
|--|-----------------|----------------|----------------|----------------|-----------------|
| 8. Most people will donate a kidney because the rest of the family thinks they should. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 9. Families expect too much from their members. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 10. I discovered my true purpose in life after donation. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 11. The family controls who is going to donate. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 12. After donation I felt like I was someone special. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 13. I liked myself better after I donated a kidney. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 14. Before donation the person I gave my kidney to was someone I could count on for help if I were in trouble. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 15. After donation I felt like I wasn't getting as much attention as I should be. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 16. After donation I just don't seem to like the person as well. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 17. Before donation the person I gave the kidney to was someone I could talk to about my troubles. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 18. The best reason to donate a kidney is because your husband or wife says you should. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 19. Before donation the person I gave my kidney to and I hardly ever talked to each other. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 20. Most people will donate a kidney when their parents say they should. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |

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|--|-----------------|----------------|----------------|----------------|-----------------|
| 21. Most people will donate a kidney because it is their duty. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 22. After donation I couldn't help feeling superior to most other people. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 23. After donation I found myself mad or irritated with the doctors and nurses. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 24. After donation the person I gave my kidney to and I feel we are closer. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 25. After donation I think more about the person I gave my kidney to. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 26. After donation everyone paid attention to the person I gave my kidney to instead of me. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 27. After donation I wondered if it had all been worth it. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 28. The main reason to donate is because it will make you feel like a better person. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 29. Mothers will always give a kidney to their children if they can. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 30. The best reason to donate a kidney is because of love for the person who needs the kidney. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 31. It would have been all right with the rest of the family if I had decided not to donate. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 32. Before donation the person I gave my kidney to was someone I missed alot when they weren't around. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 33. After donation I was mad at myself. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |

34.	I felt more important after donation.	— SA	— A	— U	— D	— SD
35.	The best reason to donate a kidney is to help someone in distress.	— SA	— A	— U	— D	— SD
36.	Before donation the person I gave my kidney to was someone I could have fun with.	— SA	— A	— U	— D	— SD
37.	After donation I didn't feel the same toward the person I gave my kidney to.	— SA	— A	— U	— D	— SD
38.	Most people don't hesitate to go out of their way to help someone in distress.	— SA	— A	— U	— D	— SD
39.	For some reason I felt mad at the person I gave my kidney to after donation.	— SA	— A	— U	— D	— SD
40.	The best reason to donate a kidney is because it is the Christian thing to do.	— SA	— A	— U	— D	— SD
41.	The family would look down on those members who didn't want to donate.	— SA	— A	— U	— D	— SD
42.	The person I donated my kidney to was someone I really cared about.	— SA	— A	— U	— D	— SD
43.	I donated my kidney because I felt it was my duty.	— SA	— A	— U	— D	— SD
44.	When I look back on what has happened to me I feel cheated.	— SA	— A	— U	— D	— SD
45.	After donation I found a good deal of happiness in life.	— SA	— A	— U	— D	— SD
46.	I take better care of myself physically since donation.	— SA	— A	— U	— D	— SD

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|--|-----------------|----------------|----------------|----------------|-----------------|
| 47. The typical person is sincerely concerned about the problems of others. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 48. Mothers are not obligated to give kidneys to children. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 49. After donation the other person's feelings seemed to change toward me. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 50. The person I gave my kidney to and I hardly ever saw each other before donation. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 51. After donation the person I gave my kidney to and I do more together. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 52. I don't approve of spending time and energy in doing things for other people. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 53. Most people who donated a kidney feel some sort of obligation toward the person they donated to. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 54. Fathers will always give kidneys to their children if they can. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 55. Brothers and sisters are not obligated to donate to each other. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |
| 56. The main reason to donate is because it is a family duty. | \overline{SA} | \overline{A} | \overline{U} | \overline{D} | \overline{SD} |

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