

Body Image in Renal Transplant Patients

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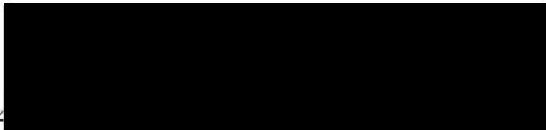
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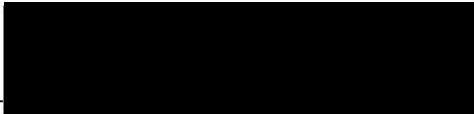
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CHAPTER 1

Introduction

Body image changes that occur with organ transplantation are a relatively new area of concern for health care professionals. Sexual dysfunction, steroid side-effects, and the physiological and psychological integration of a new organ, such as a kidney, may affect the transplant recipient's body image and thus threaten the person's adaptation.

Kidney transplants have been performed for approximately thirty years. Yet descriptive knowledge and explanatory theory regarding the impact of changes on patients are in their infancy. Due to the nature of the treatments for end stage renal disease (ESRD) pre and post-transplantation, the chronicity of the illness, and the constant threat of post-transplant rejection, the potential for body image problems is great. Because these problems affect self concept, and in turn health outcomes, it is essential for nurses to gain an understanding of body image dynamics in their patients. Since the knowledge base is limited, assesement tools are lacking that could assist nurses

in gaining that understanding. The purpose of this study was to explore the alterations in body image experienced by recipients of renal transplants with the goal of broadening the knowledge base of body image theory for this population.

Literature Review

The review of the literature is divided into four sections: (a) the relationship between body image and self-concept in general body image studies, (b) body image issues in a variety of patient populations, (c) body image issues for ESRD patients, and (d) body image changes for renal transplant patients.

General Body Image

Several studies related body image to self-esteem and self-concept. Secord & Jourard (1953) developed a Body Cathexis Scale to appraise persons' satisfaction with their body parts and functions. The scale was administered to college students along with an Aspects of Self Cathexis Scale, a homonym test of anxiety-related body cathexis, and the Maslow Test of Psychological Security-Insecurity. Results supported the study's hypotheses that feelings about the body are commensurate with feelings about the self. The

Body Cathexis and Aspects of Self Cathexis scales were significantly correlated. Low body cathexis was associated with anxiety in the form of concern regarding pain, disease, or injury and was also associated with insecurity. In 1955, Jourard & Secord used the Body Cathexis scale to explore the relationships between cathexis ratings for weight, waist, hip and bust size in 60 female college students, and three expressions of the size of those parts: measured size, self-estimated size, and self-ratings of size. Findings showed that measured and estimated size strongly correlated. The mean self-rated ideal size for weight, waist, and hip size was significantly smaller than the mean measured size of these parts, while ideal bust size measurement was larger than the obtained average bust measurement. Cathexis ratings for the body parts were found to vary with the extent of deviation of measured size from self-rated ideal size.

Berscheid (1973) reviewed data obtained from 2,000 respondents to a body image survey printed in Psychology Today, and found that for both sexes, body image was strongly related to self-esteem. Respondents

who had experienced more than one dramatic body alteration were less happy and confident, and reported poorer body images than those with one or no changes.

Champion, et al. (1982) used a convenience sample of 109 subjects for an investigation of several psychological constructs. Each person rated Present and Ideal Self on 42 semantic differential bipolar scales, and Present and Ideal Body on 28 semantic differential bipolar scales. Significant relationships were found between Present and Ideal Self and Present and Ideal Body. Major findings were:

1. For Present Self-Concept, subjects who scored high on happiness tended to score high on physical energy and low on social anxiety.

2. Body image dimensions of physical health and animation statistically predicted happiness in Present Self-Concept.

3. Present Body Image dimensions of strength, animation, and social anxiety were positively related to similar dimensions on Ideal Body Image.

One implication of the studies cited, is that if expectations of the body differ from actual appearance or performance, satisfaction with self is likely to be

adversly affected. In chronic illnesses such as ESRD this is always a potential problem.

Noles, et al. (1985) had 224 college men and women complete a Body Parts Satisfaction Scale, representing an affective measure of body image, and a Body-Self Relations Questionnaire, representing a cognitive measure. Subjects also completed a Center for Epidemiological Studies Depression Scale (CES-D) and a self-rated depression item. Subjects were classified as depressed (n=35) or non-depressed (n=42) on the basis of the depression scale and self-report. Subjects were video-taped and objective raters reliably (interclass correlation .95) evaluated a body pose of each subject on physical attractiveness. A distortion score was computed which represented the discrepancy between the subject's self-perceived physical attractiveness and that of the raters. The researchers found that depressed subjects were less satisfied with their bodies and saw themselves as less physically attractive than was reported by non-depressed subjects. These groups did not differ with respect to observer-rated physical attractiveness.

Fawcett (1980) reported on an exploratory study of body image dimensionality. Body perception was defined as the direct mental experience of the physical appearance of the body, and perceived body space was its empirical measure. Body attitude was described as encompassing a broad spectrum of feelings, attitudes, and emotional reactions toward the body. A Global Body Attitude Scale and Body Cathexis Scale were measures of body attitude used in this study. Fawcett viewed perception and attitude as conceptually distinct mental processes and the purpose of the study was to investigate the relationship between the two variables. The sample consisted of 62 voluntary subjects, 41 females and 21 males, between the ages of 18-40. Analysis of the results failed to demonstrate any relation between body perception and body attitude in this study. A possible conceptual problem with this study was the narrow definition of the empirical measure of the body perception variable, which included only the amount of space an individual perceived herself or himself to occupy.

With the exception of Fawcett's study, the literature supported a strong relationship between body image and self-concept. Poor body image was related to poor self-esteem, anxiety, insecurity, and depression. The studies cited in the general body image literature were done with healthy adult subjects. Those focused more on patient populations are reviewed next.

Body Image in Various Patient Populations

The body image boundary dimension was explored by Fisher & Cleveland (1968), and reported in a book entitled Body Image and Personality. Conceptually, they viewed the body as the individual's structural site for all past integrated experiences. They assumed that persons who saw their bodies as highly differentiated from the rest of the world and who were guided by definite boundaries would construct a different structure than persons who regarded their bodies as an area with indefinite boundaries. They devised measurements of Perceived Body Barrier, and Body Penetration based on responses to the Rorschach, Thematic Apperception Test (TAT), figure drawings, and intensive interviews. A series of studies with a variety of patient populations including those with

ulcerative colitis, dermatitis, arthritis, cancer, polio, and conversion hysteria were carried out.

One of the studies carried out by Fisher & Cleveland was with 25 male rheumatoid arthritis patients. Rorschach and TAT responses showed a tendency to self-protect and rigidly define boundaries. Furthermore, intensive interviews showed that these patients had difficulty expressing anger.

In another Fisher & Cleveland study of 28 polio patients, Perceived Body Barrier scores were correlated with adjustment to illness. Results indicated that individuals with definite boundaries adjusted better to the stress of serious illness than those with indefinite boundaries. Results were not related to length or seriousness of the illness.

Body Barrier and Body Penetration indices were scored in a Fisher and Cleveland study done with 89 cancer patients. Fifty-nine patients were categorized as having an exterior cancer site, such as breast cancer, and 30 as having an internal site, such as cervical cancer. Exterior and interior groups were significantly different in Rorschach responses. The exterior group exceeded the interior group in

Perceived Body Barrier responses at the .001 level and the interior exceeded the exterior group in Penetration of Boundary responses at the .01 level. Fisher & Cleveland concluded from this study that there was a link between site of cancer and boundary dimension.

Fisher & Cleveland generalized after their many studies that psychological patterns associated with a given type of body image boundary may create conditions which favor one body site over another as the focus for certain pathological events that they viewed as having a psychosomatic basis. People with more highly developed body boundaries were reported to have more external symptoms such as skin disorders and musculo-skeletal symptoms, and those with less defined boundaries, more internal symptoms such as colitis and cardiac problems.

Dropkin (1979) observed 10 male patients who had had radical surgery for cancer of the face and neck. Relationships between degree of disfigurement, social desirability, time spent out of the room, and compliance with treatment were studied. Patients were classified by degree of disfigurement by staff, and

rated themselves on the Crowne and Marlowe Social Desirability Scale. They were observed for 3-9 days post-operatively for 30 minute periods at random intervals to see how often they left their room and/or visited with other patients. Compliance was measured by an overall degree of self-care based on the optimum number of self-care tasks and times they were performed by each patient. Data analysis showed significant relationships between Social Desirability scores and number of self-care tasks performed, as well as between degree of disfigurement and time spent out of the room. Patients with the most disfigurement spent the least time out of their rooms. No significant relationship was found between disfigurement and need for approval. A major drawback of this study was the small sample size. Dropkin also reported the possibility of researcher bias. The study was included in this review because it was one of the few that looked at the relationship between body image and compliance, an important factor to consider with transplant patients.

In summary, studies of body image in patient populations found a relationship between body image boundary dimensions and type of illness contracted. A relationship was also found between social desirability and compliance, as well as time spent with others, following disfiguring surgery.

Body Image and ESRD Patients

Levy (1974) studied sexual adjustment to hemodialysis and renal transplantation, through a national survey conducted by mail. Sexual questions were aimed at comparing patient functioning at three different times: before developing uremia, after uremia but prior to dialysis or transplant, and at the time of answering the questionnaire. Responses were received from 519 adult subjects, 345 men and 174 women. A majority was married (78%), and white (91%). Fifty-six percent were on home dialysis, 27% on center-based hemodialysis, and 17% were transplant recipients. Both hemodialysis and transplanted male patients showed a marked reduction in frequency of sexual intercourse at the time of answering the questionnaire than they had had prior to uremia. Of the male dialysis patients, 59% considered themselves

to be either partially or totally impotent, compared to 43% of male transplant patients. Survey responses indicated that the problem might be even more prevalent than reported, as many of the patients who reported no potency problem also said they never had intercourse or their frequency of intercourse had been greatly reduced compared to a pre-uremic state. Females also showed a reduction in sexual intercourse at the time of completing the survey compared to pre-uremia. Frequency of orgasm was also markedly reduced in female dialysis patients, but not transplanted patients.

Beckman, et al. (1982) studied 32 married home dialysis patients to assess impact of their chronic illness on sexuality. A Index of Sexual Functioning (ISF) was developed to quantify five aspects of male genital function. The ISF was correlated with other major areas of sexuality including masculine self-concept, sex drive, sexuality, sexual relationship, and sexual satisfaction. There were significant correlations between genital function and sexual satisfaction, attitude toward importance of sex, sex drive, and positive feelings about the body.

Of the patients studied, 28% had full sexual functioning, 22% had moderate dysfunction, and 50% had severe dysfunction.

Basch (1980) looked at body image dimensions of ESRD patients on hemodialysis by using a modified version of the House-Tree-Person Drawing Test. A convenience sample of 16 patients on a dialysis unit participated. There was no control group. Drawings revealed that in these patients body concepts were distorted, incomplete and unintegrated. Some drawings revealed an instability, or insecurity more marked than was observed clinically. There was also evidence of sexual disturbance. Somatic preoccupations in these renal patients were categorized as: external disfigurement, alterations in internal body parts and organs, and changes in physiology or somatic function. Drawing responses of dialysis patients were reported as unique, differing from those previously obtained on cancer, colostomy, or cardiac patients.

Studies of ESRD populations addressed body image issues relating to sexual functioning and satisfaction, and somatic preoccupations. Sexual dysfunction was found to be frequent in renal patients

and had a negative affect on self-concept. Drawings revealed somatic preoccupation with body parts and functioning in dialysis patients. Body image studies of renal transplant patients were reviewed next.

Body Image and Renal Transplantation

Psychological implications of kidney transplantation began to be addressed, primarily through case studies, in the 1960's. This section of the literature review explores findings of eight authors who observed body image issues in their work with renal transplant patients.

Kemph (1966) did the pioneering work on the psychiatric aspects of renal transplantation. A major finding was that for cases in which the new kidney began to function immediately, the recipient showed a lifting of depression in the first few days following surgery. In long-term follow-up, recipients reported frequent periods of severe depression, and all recipients were concerned about possible body damage. Some feared sexual damage or impotence resulting from the operation. Kemph provided examples of fantasies of recipients that centered on receiving sexual traits from the donor.

Crammond (1967) studied the actual relationship which developed between donor and recipient after transplant. In four out of five cases he observed guilty indebtedness and ambivalence in the relationship. Also observed was a threat to recipient's sexual identity in cases of opposite sex donors.

Ferris (1969) studied 54 transplant patients, 34 living-related, and 20 from cadavers. Fewer incidences of depression and anxiety (31%) were observed in cadaver recipients compared to living-related (51%). Ferris reported that for cadaver recipients, as post-transplant hospital stay increased, the recipient tended to become more introspective and somatically pre-occupied.

Muslin (1971) postulated that the body's assimilation of new tissue has as a counterpart the psychological integration of a new organ. He described three stages of internalization of the transplanted kidney: a foreign body stage, a stage of partial incorporation, and a stage of complete incorporation.

Basch (1973a) collected data over a four year period between 1966-1970 as psychiatrist on a renal transplant team at Mount Sinai Medical Center in New York. Twenty-eight recipients were observed, 9 living-related and 19 cadaver. Post-transplant patients were followed in a weekly clinic with individual interviews as well as observed in group interactions. Of the 9 family donors, 3 were maternal, 2 paternal, and 4 were adult siblings. Pre-existing family conflicts were observed to enter into the transplant situation. Dependency conflicts were most striking in cases of parental donors. Basch relates that in some patients psychic conflicts about the new kidney and donor appeared to contribute to physiological changes, and in at least two cases contributed to the recipient's death. Both living-related and cadaver recipients attributed traits of the donor coming from the kidney. Basch concluded that transplant situations have the potential to interfere with normal introjection and identification processes that foster adaptation, and that integration is influenced by the relationship between the donor and recipient, real and fantasized.

He observed, on one extreme, individuals who appeared to incorporate the new object in a primitive, narcissistic way, in which it was difficult for them to separate the donated kidney from the donor. On the other extreme were those who continued to treat the new organ as an entirely foreign object, referring to it in third person, or as belonging to someone else. Assimilation was accomplished by most recipients somewhere between these extremes to varying degrees of stability. Basch cautioned that findings were based on clinical observation without pre-conceived research design, and that findings should be viewed as suggestive rather than conclusive, and as indication of direction for further research.

Basch (1973b) reported that in his experience with 50 transplantation patients, it was unusual for a patient to enjoy a complication-free post-transplant course, physiologically or psychologically. Basch related this in large part to body image changes that affected self-esteem.

Immunosuppressant caused changes such as cushingoid appearance, acne, and hirsutism were the subject of Korsch's (1978) study. Korsch found that

teenage girls, and young adult women often stopped steroids because of these effects.

Castelnuovo-Tedesco wrote a series of articles on body image issues in transplant patients (1973, 1978, 1980). Case examples demonstrated recipient indebtedness, fear of the donor wanting to reclaim the kidney, and attribution of traits acquired through the kidney including generosity, artistic talent, religiosity, physical size, and even capacity to speak a foreign language. An example was cited of a man who refused his "hippie" brother's kidney, feeling he would reject it because it would be incompatible with his "square" lifestyle. Castelnuovo-Tedesco reported that patients found it difficult to immediately regard the new organ as part of the body, and described it as "sticking out" or "feeling funny". Castelnuovo-Tedesco found that psychological integration ranged from pathologic fusion to no integration, a range of incorporating the kidney similar to that reported by Basch (1973a).

Viederman (1974) reported similar observations on integration issues and added that in some situations, a kidney accepted without conflict initially, could

become a source of conflict later by virtue of an experience which evoked an old conflict. Viederman cited 8 case studies that reflected integration conflicts.

Review and comparison of case study findings revealed rich data and repeated themes. Transplantation appeared to affect body image through sexual identity issues, the physiological and psychological integration process, fear of bodily damage, fear of rejection, perceived acquisition of traits, and changes due to immunosuppressants. Case study and clinical observations gave depth to quantitative research findings that alterations in body image affect self-concept and also appear to affect health outcome. One limitation of the findings in this section was their primarily psychoanalytic viewpoint, which would bias interpretation of patient's behavior and reported experiences. Further research was indicated that more directly recorded the patient's experience in their own language, setting aside a psychoanalytic interpretation.

Conceptual Framework

The case studies literature demonstrated that patients struggle to make meaning of their transplant experience. Two conceptual frameworks provided a basis from which to look at this phenomena. One was symbolic interactionism and the other developmental psychology.

Symbolic interactionism, as presented by Blumer (1969), rests on three basic premises:

- 1) Human beings act toward things on the basis of the meaning those things have for them.
- 2) The meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows.
- 3) These meanings are handled in and modified through an interpretive process used by the person in dealing with things that are encountered (p. 2).

Developmental psychology more specifically addressed the meaning-making process involved in developing a sense of self, and self in relation to others. Theorists from this approach provided definitions and developmental models for body image.

Schilder (1935) stated that "the image of the human body means the picture of our own body which we form in our mind" (p. 11). He included appearance, sensations, and mental representations in the concept. He also stated that the experience of our body image and experiences of the body image of others were closely interwoven. Van der Velde (1985) added that body images consisted of a physical component, which represented a given bodily feature, and a psychological meaning, which reflected a person's notion of the feeling, thought, or quality expressed by the bodily function or action.

Development of body image was viewed as a gradual and ongoing process with images formed through interaction of bodily experience with influential factors in the environment. Developmental psychology and symbolic interactionism provided a broad and flexible framework that helped guide the inquiry into body image changes for renal transplant patients.

Research Question

The research question was: What changes in body image do renal transplant patients experience? The question was based on a two assumptions: (a) a

person's body image is affected by renal transplantation; and (b) the form and degree of body image alteration have the potential to vary with each person, according to the meaning the experience has for that person.

CHAPTER 2

Methods

This section presents information about the study's design, subjects targeted, data collection, research procedures, and data analysis.

Design

The research question required a design that could provide a range and depth of responses. A non-experimental, grounded theory approach was selected for this reason.

Oiler (1982) described the phenomenological approach as an effort to relate the human experience as it is lived. Qualitative research provides descriptions that are thorough and often impart a sense of understanding that directs interest to further research areas. Tilden & Tilden (1985) noted that the interpersonal, observational, and assessment skills used by the nurse are the same skills needed to study "actors" in the field, making qualitative research well-suited to nursing.

Stern (1980) recommended the qualitative method of grounded theory in investigation of relatively uncharted areas like the one investigated here. Glaser

& Strauss (1967) developed the grounded theory approach, the name they gave to the process of discovering theory from data. "It provides us with relevant predictions, explanations, interpretations, and applications." (p. 1). Comparative analysis, used to develop grounded theory, is a continuous process of coding, categorizing, and conceptualizing incoming data. It emphasizes theory as process, an ever-developing entity. Comparative analysis can be used to generate substantive theory which addresses an empirical area of inquiry. Substantive theory is middle range theory which is most useful to nursing practice. With a focus on a substantive area, the generation of theory is achieved by comparative analysis between or among groups within the area.

Subjects

The population targeted for study was ambulatory care patients who had one or more renal transplants. Of that population, patients who received transplants at a major university hospital made up the sample. Over 1,000 kidney transplants have been performed at the hospital, and all are monitored on an outpatient basis by the transplant coordination unit following

discharge. The nurse-coordinator of the unit facilitated access to the patient population by making their records available and allowing contact with potential subjects during their visits to the out-patient clinic.

In keeping with the grounded theory approach, subjects were selected for their relevance for furthering the development of emerging categories. Diversity for the sake of discovering as many properties of a category as possible was the goal. Therefore the sample included both men and women. A broad range of patients from those three months post-transplant to those who had successfully retained a transplanted kidney for ten years or more was sampled. Patients who had had more than one transplant were included to increase diversity. Ideally, the sample number was to be dictated by theoretical saturation. This meant that as the data were collected and analyzed, and a point was reached where new data did not add to the properties of categories, sampling could end. Due to the time limits of the thesis project, a sample size of 12-20 was projected as a realistic number to interview.

Certain extraneous factors that confound body image issues necessitated the use of exclusion criteria to attempt to control for some of them. There are critical developmental stages and situations that affect body image including adolescence, old age, and pregnancy. Young adulthood to middle age can be considered a fairly stable body image period. Therefore, non-pregnant adults between the ages of 20-50 were selected. Body image perceptions can also be changed by blindness, deafness, and restricted mobility and patients with these disabilities were excluded. Subjects were interviewed at least three months post-surgery so that trauma from surgery would not be as likely to affect body image perceptions. One extraneous variable that could not be controlled was the effect of chronic illness with which most transplant patients had lived for years. Threats to validity and biases were not controlled for. Instead every attempt was made to take them into account in analysis of the data.

Collection Methods

A convenience sample of subjects, selected from a list of those who fit the criteria for the project, were contacted in person at the outpatient transplant follow-up clinic. The project and nature of inquiry were explained. Anonymity was assured, and the subjects were given an idea of the time commitment involved which was a one-two hour interview. If consent to interview was granted, a time and place to meet was arranged. A second contact was made just prior to the interview to confirm. When possible the interview was conducted in the patient's home to increase comfort and convenience to them. Three interviews were conducted at the university hospital.

One-time interviews, conducted by this researcher, were the primary data collection method. This researcher had extensive interviewing experience as a mental health nurse in a clinical setting, and as a research assistant in a similar qualitative study. Interviews were tape recorded so that a verbatim account of the interview was available for analysis.

A face sheet with pertinent demographic data was filled out at the onset of the interview, after the patient had read and signed the research consent form.

Collected data were identified by a number system, rather than by subjects' names to protect confidentiality.

Interviews were modeled after the ethnographic interview that Spradly (1979) and Hammersley (1983) described. Spradly saw the ethnographic interview as a series of friendly conversations in which the researcher slowly introduced new elements to assist informants to respond as informants. The interviewer provided purpose and clarity, explanations about the project and process, and questions. Exact questions were not known in advance, although a list of topics and potential questions served as an interview guide. (See appendix D for interview guide.) Questions were primarily open-ended. As suggested by Hammersley (1983), directive questioning was used more toward the end of the data collection process to test out emerging themes.

The risk to subjects from this data collection approach was minimal. Questions could have evoked painful emotional reflections, and the interviewer was prepared to provide support, or make a referral to another resource if it was needed. It was not ever

necessary. Questions relating to sexuality were anticipated as a source of discomfort to subjects, and every attempt was made to reduce this risk. The following statement, or one similar, was used to introduce this topic: "It is known that sexual function problems frequently accompany renal disease. Would you be willing to discuss with me how your satisfaction with your sexual functioning has affected your view of your body during your illness and since the transplant?" If the subject was not comfortable with this question, which happened in one case, the interviewer proceeded to another topic. At the onset of the interview, participants were told that they did not have to answer all questions and could ask that the interview be terminated at any point.

Research Procedures

The interviewing procedure has been discussed. The logging of the data included:

1. A face sheet containing pertinent demographic and medical information.
2. Brief field notes of non-verbal observations.
3. Notes taken from the interview, and checked against the tape for accuracy; a verbatim typed

recording of relevant and descriptive responses.

Tapes were saved until the end of the research project in case clarification of notes was needed later in analysis.

Lofland (1984) offered practical suggestions for maintaining a filing system which were used in this project. Types of files included:

1. Mundane files kept on each subject which contained demographic and other pertinent data.
2. Analytic or category files contained pieces of data analysis. These files changed in the course of data analysis.
3. A complete set of data was filed in chronological order of collection to help answer questions of context that came up during analysis.

Analysis

Comparative analysis was an ongoing process as the data were collected. As Glaser and Strauss (1967) reported, lower level categories emerged during the early phases of data collection. Higher level, and integrating conceptualizations, and the properties

that elaborated them, tended to come later in the process. Accumulating interrelations formed the core of the emerging theory.

Taylor and Bogden (1984) provided clear guidelines used for analysis of the data that included discovery, coding, and discounting.

Discovery

Themes and concepts were delineated from the data using the following five steps:

1. Reading and re-reading the data.
2. Writing memos to track hunches, ideas, and initial interpretations.
3. Examining accumulating memos for themes, and listing them.
4. Constructing classification schemes made up of related themes.
5. Developing hypothetical propositions which are statements of relationships among themes, that are grounded in the data.

Coding

A systematic way of developing and refining interpretations of the data was provided by the following steps:

1. Developing coding categories by listing every theme, concept, interpretation, typology, and proposition, as discovered in all data.
2. Refining the coding scheme as data were coded by adding, collapsing, expanding, and re-defining the categories.
3. Sorting data into coding categories by putting pieces of data under any and all categories that fit. Storing data in analytic files.
4. Reviewing data that were left out and determining if they fit in an existing category or needed a new category.
5. Refining the analysis by developing themes that appeared to get clearer and discarding those that didn't seem true. Analyzing negative cases to deepen understanding of the concepts.

Discounting Data

Data were interpreted in the context in which they were collected. Some considerations made when interpreting data were:

1. Whether it was solicited or unsolicited.
2. What the observer's influence might have been on the subject and responses.

3. What influence the presence of others may have had on the subject's responses.

4. Possible biases of the researcher.

Analysis of the data through discovery, coding, and discounting processes resulted in the emergence of one central theme and seven secondary body image themes and a hypothetical model of the relationship of the themes to each other. The themes will be discussed in the following chapter on results, and the model of the relationship of themes to each other will be explored in the discussion chapter.

CHAPTER 3

Results

This section includes characteristics of the sample and research findings.

Sample Characteristics

Thirteen renal transplant subjects were interviewed, 8 males and 5 females. Ages ranged from 25 to 44 years. Eight were employed at least part time and 5 were unemployed. Additional demographic information is listed in Table 1.

Age at onset of kidney disease ranged from infancy to 36 years. A majority (n=9) began experiencing symptoms between 16 and 25 years of age. Duration of kidney disease ranged from 4 to 37 years. Glomerulonephritis was cited as the leading cause of the ESRD. Twelve subjects had been treated with dialysis, 11 with hemodialysis, and 1 with peritoneal dialysis (CAPD). A majority of subjects held a very negative view of hemodialysis. Additional disease specific characteristics are presented in Table 2.

Seventeen transplant experiences were represented by this sample. This was the first transplant for 10

Table 1

Sample Demographics

Characteristic	n
<hr/>	
Sex	
Male	8
Female	5
Age	
20-29 yrs.	3
30-39	5
40-49	5
Race	
Caucasian	9
Mexican-American	2
Japanese	1
Caucasian-American Indian	1

Table 2

Disease Specific Characteristics

Characteristic	n
Age at Onset of Symptoms	
Infancy to 10 yrs.	2
10-20 yrs.	6
21-30 yrs.	4
31 or older	1
Duration of ESRD	
1-10 yrs.	5
11-20	3
21-30	4
31-40	1
Cause of ESRD	
Glomerulonephritis	9
Diabetes	1
Polycystic Kidney	1
Alport's Syndrome	1
Congenital Problem	1

subjects, two had one previous transplant, and one subject had two previous transplants. Two of the multiple transplant subjects, whose previous transplants were short-lived, were in rejection at the time of the interview awaiting another transplant. The other double transplant subject had retained his first transplant for 20 years. Including only the most recent transplant experience, length of time from surgery to interview ranged from 3 months to 16 years. Nine subjects had received cadaver kidneys, and four were from living-related donors, two fathers, and two sisters. All the living-related kidney recipients in this sample were male. Additional transplant specific characteristics are listed in Table 3.

Every recipient was taking immunosuppressant medication of some kind. All 13 were taking prednisone, 12 were also on imuran, and 6 were also taking cyclosporine. Nine subjects took blood pressure medication and/or diuretics as well.

Table 3

Transplant Specific Characteristics

Characteristic	n
Transplant Number	
1	10
2	2
3	1
Donor Type	
Cadaver	9
Living-Related	4
Time Between Transplant and Interview	
3 mos.-1 yr.	7
1-2 yrs.	3
2-10 yrs.	1
10-20 yrs.	2

Description of Major Themes

One core theme and seven secondary themes emerged from analysis of the data that spoke to the body image changes experienced by renal transplant recipients. Kidney function was the core concern for all recipients. Data also clustered into seven secondary themes that were related to kidney function: Threat of kidney rejection, Body functioning, Appearance, Energy/Strength/Stamina, Control over the body, Integration of a new kidney, and Interaction with others. These secondary themes were not all noted by every subject, nor were they noted in separate, clear processes as they occurred. Often many changes were occurring at the same time. For the sake of clarity they are discussed separately.

Kidney Function

Loss of kidney function was the central problem for ESRD patients. Most other problems related to this one, making it a heavy focus for recipients when evaluating their body image. Kidney function was monitored in part by lab tests, but more obvious to patients were urinary output and color, and fluid retention. These barometers signaled trouble or success.

In the course of their illness, most subjects noticed a reduction in urine volume, and some a total cessation of output.

"When I first became ill I was still urinating, but there wasn't much to it, a lot of protein and some blood, but not any good stuff you're supposed to pee out. I was still using my bladder but it decreased over the years until none, and I hadn't urinated since 1983, about 3 and 1/2 years."

Those who maintained some output were grateful, although sometimes embarrassed by its scantiness.

"Even when the kidneys were down to 0% I was able to urinate. Never occurred to me a person would stop going. That to me would be scary."

"You can hear people tinkle and mine was always just a little bit. I would sit on the toilet (in public restrooms) and flush it so no one would hear."

Two subjects had periods in their lives when they could not urinate because they had a drainage tube and a bag from a ureterostomy. For both this was a very difficult time.

Several subjects noticed that the color of their urine changed.

"I did notice that urine was supposed to be yellow, one thing I noticed after the transplant. Mine had been clear...From a gradual change I never noticed it."

Decrease in kidney function resulted in increased fluid retention. While subjects noticed less external flow they felt great discomfort with the fluid building up inside.

"It was starting to get critical before the transplant, lungs were filling."

This had a negative effect on energy level due to difficulty subjects had breathing.

"I've had so much water, I thought I was drowning."

It is no wonder that a successful transplant announced itself most obviously to patients with an increase in urinary output. This brought a great sense of well-being to those who had so anxiously awaited a working kidney.

"They couldn't keep enough water in me. I was putting out more than the IV was putting

in. It functioned immediately on the table."

"For two weeks after the transplant they measured intake and output. Got so I could fill a gallon."

"It felt so good (urinating again). It was ecstasy. I couldn't hardly make it to the toilet at first, because of the bladder being so small. I had to get up 3-5 times in the night to go to the bathroom but it finally tapered off. I never complained once."

A functioning kidney lent stability to body image, while a non-functioning or threatened kidney was very disruptive and made it difficult for recipients to hold a positive self view:

"I could only get a positive attitude on life if my kidney is good, and then I could build a foundation, could start building my body back up physically. And if I could do that, I could mentally start building myself back up."

The threat of rejection, the theme most closely tied to this core issue, will be presented next.

The Threat of Rejection

The threat of kidney rejection was perhaps the greatest threat to a kidney recipient's body image. Monitoring to detect kidney rejection, actual rejection episodes, and feared rejection, occupied several subjects.

Monitoring. For most subjects, monitoring the kidney through lab tests and clinic visits was "just part of what you had to do", or a mild inconvenience. Five subjects commented on being "poked with needles" which could be painful, leave bruises, or serve as a reminder of a bad time with needles on dialysis.

Lab results and clinic visits were welcomed by some. It helped them "know what was going on", "what to expect". For others lab results meant the possibility of confirming a rejection:

"Now every time you submit blood, 3 days a week, if the creatinine goes up you might be having a rejection. I have had 4 confirmed rejections. Constant."

Monitoring was seen as routine, reassuring, or threatening to the subjects, depending on the state of their kidney.

Actual rejection episodes and treatments.

Two-thirds of the subjects (n=9) had experienced at least one confirmed rejection episode. Two of these subjects were in irreversible rejection at the time of the interview and 2 or 3 others felt that their kidney was "tenuous". Four subjects had not had a rejection episode to their knowledge.

Most subjects had been told it was not unusual to experience a rejection episode soon after the transplant and were not overly concerned that they would lose their kidney if a mild one occurred:

"I had one minor rejection...Occurred right after the transplant. I kind of expected it."

Some subjects did not feel symptoms signaling rejection while others felt quite ill.

Half the recipients had experienced more than one rejection and this made them feel more "precarious".

In July I had my first transplant, then started going through rejection...My transplant is still precarious. The transplant has rejected four times...It was healthy prior to going through all that."

Finding out about a rejection episode caused fear and sadness over threatened loss of a life style:

"It was very scary, feelings of great sadness, lumps in my throat, felt I would cry. A lot of fear. I didn't want to face the fact that so soon it had come. I prayed it would help, didn't want it to end. It had been nice, the energy, eating, being able to work without hassles."

"The last rejection episode threatened my body image. I was beginning to get the feeling it was over and I could go back to a normal life...I would like to leave this behind me and go on, and I have the feeling I can't."

In addition to the threat to the kidney, rejection episodes meant an increase in immunosuppressants which could cause nausea and vomiting, achey joints, and increased susceptibility to infection, and alterations in mood.

Atgam and OKT-3 were medications used when the rejection threat looked serious. Reactions to Atgam included a rash and joint pain.:

"I couldn't move, my neck and joints were sore and stiff."

Some refused the Atgam due to its uncomfortable side effects. OKT-3 met with mixed reactions. Several saw it as reassurance that they would not lose their kidney. Its availability for use as an effective anti-rejection medication was what convinced some to try a cadaver transplant rather than remain on dialysis. OKT-3 also had side effects:

"It affects you differently each time. After the first transplant...I'd just as soon died: sweats, fevers, trembles, aches, pains. This year I had the shake and bake for 45 minutes the first day is all."

In spite of its uncomfortable side effects, no one said they would not take it again.

For the subjects who were in rejection, it was difficult to keep a positive perspective:

"I haven't had quality time in 8 years. But that doesn't mean I wouldn't do it again in a minute, the freedom is so important."

These subjects hoped the doctors would continue to see them as worth the risk for another transplant.

For most recipients rejection posed a threat to the health or survival of the kidney and thus to their life style. Recipients with few or no rejection experiences seemed to enjoy a more positive, stable body image than those with multiple rejections.

Feared rejection. In addition to actual rejection episodes, the fear of rejection was a threat to body image. Recipients who had not experienced a confirmed rejection had experienced something they were afraid was a rejection. Fever, and pain in the transplant area were commonly associated with rejection:

"This is the first year (in 8 years)

I haven't gone in for an attack of some kind and there's never a reason...I never think its my kidney, but I never know."

Some subjects tended to worry more than others and were acutely aware of rejection potential:

"I'm successful now, but for how long?

At the time I thought I'd be fixed and thats all there is to it. Now I'm older I wonder how long is this going to last? Then what? A lot of people would look at it as 'well, at least you're still alive'. Maybe I look

at it as, 'well, yes, but what is the quality of your life?'"

Other subjects were less concerned. They reassured themselves that the match was good, that they hadn't yet had a major rejection, or that their immune system was depressed after years of immunosuppressants.

The fear of rejection had an effect on all subjects whether they are mildly concerned or "terrified".

Body Functioning

Kidney transplant recipients often experienced health problems that focused their attention on the functional aspects of their body; how well systems were or were not working for them. Kidney failure was the biggest concern. Receiving and maintaining a functioning kidney became the top priority. Other systems were affected by the kidney problems and treatments. Of these the immune system, sexual/reproductive functions, circulatory system, musculo/skeletal system, and mental and neurological functioning played leading roles in impacting body image at one time or another.

Body functioning problems took a toll on body image.

"I feel my body is aging so much faster than it should be. I'm 31 and have had blood pressure problems, my kidney's failed, and I broke my hip which only happens to old ladies. I feel like a 31 year old in a 60 year old's body."

In this section findings that relate to the impact of body functions on body image are presented.

Circulatory system. Many transplant recipients had had hypertension and had been or continued to be treated with medication for hypertension. The major problem that arose after transplant was the need to adjust the medication dosage. Fluctuating blood pressure caused headaches and dizziness. Other circulatory system changes were fistula related and will be discussed later in this chapter.

Mental and neurological functioning. Although information about mental and neurological functioning was not directly solicited during the interview, at least half the subjects mentioned changes in these functions that affected their image.

For subjects who had been on dialysis, fear of mental deterioration, poor concentration, and mood fluctuations had been problems. The transplant improved this situation for some subjects.

"One of my priorities when I got off dialysis was to go back to school and prove that I had a brain, that I could absorb information and was intelligent."

Others who had had to continuously take high doses of steroids continued to experience short term memory loss, poor concentration and mood swings.

"It was like I couldn't make my mind work. It was scary."

Three subjects attributed neurological symptoms to cyclosporine. They had varying degrees of tremors, shaking, and involuntary movements.

"My nerves were completely gone. I tried to do something and I'd fall apart. Got shaking and couldn't even hold my arm still."

Symptoms were frightening and interfered with ability to perform daily activities. Adverse effects posed a great enough threat to two subjects that they stopped that medication.

Sexual/reproductive function. Results for this section are divided into male and female responses. Of the 8 males interviewed, one had not been sexually active, three did not feel they had had sexual function problems, two had experienced minor or short-lived problems, and two had experienced serious sexual functioning problems. One had had concerns about ability to produce children due to steroids.

Those with minor problems stated that they "lost it for a couple of months", or "slowed down but never stopped." Those with more serious problems achieving and maintaining an erection had also lost interest for long periods of time.

"Figure if your body's not going to function, why think about it, just let it go. After the transplant I started to feel better... My mind started functioning again. Sweeties looked better all the time, but there was nothing to work with."

A penile implant greatly added to the body image of one of these subjects.

"It has done very well for me. The mental aspect of it is great. A lot of other aspects

that are great. Gets you back to feeling somewhat normal."

Of the 5 females interviewed, one had not been sexually active, two had not experienced functional problems, and two had experienced moderate problems. Psychological factors, or reduced energy level did interfere with desire and frequency of intercourse. One subject who had no problems when engaged in intercourse prior to the surgery had stopped dating since the transplant for fear her boyfriend would think she was a "freak" if he knew she had received a transplant. Fear of contracting AIDS due to lowered resistance was another reason given for sexual inactivity. One subject felt she still had to prove to herself that she could be as sexually responsive as she had been before her illness. Another experienced occasional loss of bladder control during intercourse.

Women had more concern about reproductive functions than male subjects. One had conceived while on dialysis and lost the fetus at 5 months. Another had been very careful to avoid pregnancy on dialysis and after the transplant was still concerned about the adverse effect pregnancy could have on the renal system:

"I read that a 25% loss of kidney function occurs after you're pregnant. Twenty-five percent is a lot when you think about it."

With the placement of the kidney in the abdomen, it was also feared the fetus would put pressure on the kidney.

Females were generally more open than males in discussing sexual/reproductive issues. They were possibly more comfortable with a female interviewer than the males.

Immune system. For most people, a healthy immune system adds to the sense of having a strong, disease resistant body. For a renal transplant patient, a well functioning immune system can mean the loss of a transplanted kidney.

"I'm resistant to infection but it

battles the kidney, fights it too strong."

The immune system took on an identity of its own, a friend or foe depending on the situation. If rejection was the issue, a depressed immune system was seen as a plus. If a virus or infection was threatening to health, poor resistance contributed to the problem. Some subjects noticed a slower healing time for cuts

and scratches, others mentioned feeling more at risk of getting AIDS, or cancer. Many mixed emotions were expressed by subjects when they discussed the immune system.

Gastro-Intestinal function. One area of bodily functioning that was greatly enhanced by kidney transplant was eating and drinking fluids without "bloating up". Every subject mentioned how much enjoyment the lifting of restrictions brought them, and most experienced an improved appetite.

"I never knew how good eating was. Before sometimes the smell of food nauseated me.

Now I have visions of what I can make tomorrow. I love every bite of eating!"

The joy of eating was dampened only by the tendency of patients to gain weight but, overall, was a great image booster.

Musculo/Skeletal system. Functioning problems in this area affected appearance with loss of muscle mass, and injuries from bone deterioration. Half the subjects pointed out the ill effects of prednisone on their muscle and bones:

"It has a tendency to eat your muscles.

"It deteriorates muscle and bone."

The results were muscle fatigue, weakness, achey joints, and broken bones. Some subjects tried exercise to get back in shape and met with some success if they were able to stick with it. Problems caused some subjects to refer to themselves as "puny" or "weak", neither of which added to a positive body image.

Appearance

Appearance changes included weight gain or loss, cushingoid features, hair loss or growth, and skin changes. The surgery itself added a scar or lump where the kidney was placed. The kidney was not in a normal position for a kidney. Scars from past procedures and remains of a fistula also continued to affect recipient's view of themselves. Each of these potential adjustments are reviewed in this section.

Weight gain/weight loss. Weight gain was a common occurrence for transplant recipients. About two-thirds of the subjects gained 10-70 pounds after their transplants. Five had gained over 40 pounds. One subject who was in rejection had lost weight. The rest of the subjects, who appeared to be of average weight, did not discuss weight changes.

An increase in appetite due to medication effects was named as the major factor in weight gain. Lack of exercise was another major factor. Several subjects found that as long as they kept up a strenuous exercise program they could maintain weight but that it crept back up when they slowed down. Decreased stamina made it more difficult to keep exercising.

Subjects who had had several years to adjust to the weight gain had resigned themselves to the change:

"Maybe when it first came on (it bothered me). Then I decided it doesn't bother others as much as it bothers me, so why let it bother me?"

Recent transplant recipients were more concerned about the change:

"I weigh in at 216 pounds and I never weighed that...I can't wear my clothes. I wear my mom's clothes or these all the time."

Scars from past procedures became bigger and deeper as weight was gained. All these factors had a negative impact on self image.

Of note is that several recipients who had experienced substantial weight gain since the transplant had also experienced a time during their illness when they were too thin and quite ill:

"I was a pile of bones with hair."

"I got down to a size ten. I had diarrhea, I had the flu."

"I wasn't healthy, was always light-headed."

For those who experienced a body image of feeling sick and "anorexic looking" at low weights, it is possible that too much weight was positive in comparison.

A striking feature of the weight gain/loss issue for transplant patients was the tremendous weight fluctuations many experienced throughout their illness and transplant, fluctuations that created major body image adjustments.

Cushingoid features. Most recipients in this sample had experienced cushingoid effects of steroids. Adjectives subjects used to describe this were: "chubby cheeks", "puffy face", "fat face", "rounded face", "distorted", and "my face blew up".

Some knew what to expect if they had taken prednisone before, and in some cases it was a deterrent to getting the transplant. After the transplant subjects did not care as much about the side effects:

"I didn't care what I looked like at that point. I was so ecstatic to have a working kidney and not going on that machine."

Three subjects commented that they did not recognize themselves in the mirror or in photographs after the transplant. Some subjects found that the cushingoid effects diminished or disappeared after a few months or could be reduced with proper diet. Subjects who had the effects for a long time had "grown accustomed" to the look.

Hair growth changes. About one-fourth of the recipients interviewed experienced hair growth changes of increased hair growth on the side of the face, arms, and chest, or hair loss on the head. Hair growth changes posed an adjustment for some but was generally experienced as minor. When subjects experienced both changes at once they were concerned:

"I'm losing my hair. One of the medication

side effects is loss of hair. I think its the imuran. Cyclosporine makes hair grow. I'm having that too...I asked the doctor if I would have to join the circus as the bald, hairy lady...I don't care as long as I feel good."

Skin changes. A few subjects noted skin changes in the form of pimples, rash, dry bumps, or oiliness. Two subjects reported bruising easily. Reports of skin changes and bruising were from subjects on high dose steroids whose kidneys were not functioning well at the time.

Kidney position. The placement of the transplanted kidney in the abdomen caused some adjustments in body image for subjects who saw this as "not normal". Some noticed a "lump", "puffiness", or "lopsideness", or that it "sticks out a little". A few subjects said they couldn't feel it. One subject had a particularly strong response to the abnormal position and had anticipated it would make her feel like a "freak". Another was concerned that if she got pregnant the fetus would put too much pressure on the kidney since it was "up front". For most subjects adjustment to kidney position or puffiness was not a major one.

Scars. The incision from the transplant surgery itself was considered "no problem" for subjects and "barely visible". Other scars were more pronounced and caused more self-consciousness. These included indentations in the back from where catheters had once gone to the kidneys, scars from removal of an original kidney, or scars from fistulas or shunts. These scars were also reminders of unpleasant procedures or events.

"It's ugly and an association of everything."

Some subjects were proud of their transplant incision, possibly because that was viewed as a positive event.

Fistulas. As with scars from surgeries, fistulas often remained with kidney recipients after the transplant. Most had adjusted to the appearance of the fistula while on dialysis, but still received comments from others because "it is a hump and looks like my hand was sewn on crooked". Often subjects feared complications from the unused fistula including infection and problems that could arise after it clotted off. Some subjects had to have their fistulas removed.

"I had nightmares about that. I had heard stories long ago about losing the arm if the fistula is not removed successfully due to the susceptibility to infection."

Results from circulation problems due to the fistula did not always disappear after it was removed. A subject who was experiencing increased redness in her hand remarked:

I just have this fear I'm going to lose my fingers if something doesn't happen. Especially being on my left hand. I'm not married but I will be one day."

It had become ingrained in subjects to protect their fistulas:

I'm still very careful of it. Will probably carry that with me if it works or not. Very wary of sharp objects. I don't sleep with my arms curled up...so it won't clot off."

The fistula was described by some as uncomfortable if anything was layed on it or they had to lift things. It also served as a reminder of dialysis, and subjects hoped they would never have to use it again.

In one or more ways kidney recipients looked different than before the transplant. Changes in weight and size could be seen as positive if the subject considered themselves before as too fat, or more frequently, too thin. But weight gain that was excessive had a negative affect on a recipient's self perception. Cushingoid features caused reactions ranging from hardly noticeable to inability to recognize oneself. This condition disappeared or adjustments were made over time. Hair loss or gain and skin changes were distressing but not a major concern to most subjects. Scaring from the transplant surgery was of little consequence, but scars from past surgeries remained more prominent and had more of an impact on body image, partially because they were reminders of unpleasant times. The fistulas were reminders of dialysis, and also presented potential for bodily harm. In spite of the many potential appearance adjustments that had to be made, the subjects in this sample felt that having a healthy, functional kidney was more important than how they looked and were willing to make those adjustments.

Energy/Strength/Stamina

A reduction of energy level, strength, and stamina was experienced by most subjects as their kidney disease progressed. More than half considered themselves to be particularly strong, athletic, physically active, and/or hard working prior to ESRD. Even subjects who did not hold this kind of image commented on their waning energy level as their illness progressed:

"I caught myself taking naps during the day at work. I didn't like that. My self image starting dropping. I started thinking something was wrong or I was lazy."

A few subjects found that they regained some strength once dialysis was started. For about one-third of the subjects, changes in energy level were more subtle and more easily adapted to:

"Its funny, when you get sick you tend to take it for granted that's how sick you are and change your life style so it becomes normal, like stopping in the middle of stairs."

For others a greater awareness of how tired they had been came after the transplant:

"That's when I first noticed that I must have really been tired before...because I can't ever remember feeling that good."

A majority of recipients felt the same or greater energy level after the transplant than during their illness. Only about a third felt the same or better after transplant than they did before their illness. A majority experienced some disappointment in the energy level, strength and stamina they felt after the transplant, even if their kidney was functioning well:

"I can't get up from the chair, my legs are too weak without pushing myself up."

(6 mos. post-transplant)

"Even now I need to rest when I come home from work...I will need to accept that is probably something I will have to deal with the rest of my life." (3 yrs. post-transplant)

Approximately a quarter of the subjects felt that their energy level was worse after the transplant than during their illness before it. Two were subjects in chronic rejection, and the others had experienced multiple rejection episodes.

"Since the transplant I haven't felt

worth a dang, felt real puny...Climbing stairs kills you. Walking up this parking lot just takes all day."

For all transplant patients in this study, changes in energy level, strength and stamina occurred as their illness progressed, they began treatment, and they received a kidney. Changes were drastic in some cases, making this area of body image adaptation one that is very pertinent to renal transplant patients. Weakness, and lack of stamina was cited as the major reason for being unable to work by those on disability. Loss of strength and energy interfered with identity as an athlete or productive worker.

Control Over the Body

One of the primary factors that contributed to subjects choosing a transplant over dialysis was the wish to gain more control over their bodies. Several indicated that they felt little control when on dialysis.

"Loss of control had a lot to do with the way I perceived my body. It was almost like I tried to deny it because it wasn't working for me...It was hard for me to love my body

during that stage." (After the transplant) "I became more in tune with it in a positive, loving way."

Self-awareness, or "tuning in" to the body was one way subjects attempted to gain some control over their bodies. They observed their body's reaction to various medications, and to symptom patterns. For some this awareness led to refusing or stopping medication, sometimes without the physician's blessing.

"I felt in tune enough with my own body to know that I couldn't take any more."

"I could tell. Off and on I'd slip up and miss it (cyclosporine) one day, and I'd feel better right away. Finally I said 'this is enough' and took myself off it."

Others took control by setting up their own exercise programs to regain strength or to lose weight. In some instances the exercise may have exceeded recommended limits. Exerting control over medication or exercise programs may have been potentially damaging but were attempts by subjects to maintain control over their bodies.

Becoming knowledgeable about lab values, medication purposes and dosages, and treatment options was another way recipients felt more in control. One subject put it this way:

"You have to (learn), can't just be a dummy. You'd wipe yourself out. Can't depend on others completely."

Several subjects felt that their attempts to take control and right something they saw as wrong were met by disapproval from the medical team.

Attempts to gain control over the body were not always successful, particularly when it came to weight control. A sense of control was also very difficult for subjects to maintain when a kidney was threatening rejection.

When direct control of the body was difficult, recipients worked on controlling the mind in hopes of controlling the body. Most respected the effect mind had on body. Maintaining a positive attitude was identified as "half the battle" by many subjects. They found it hard to accomplish this, and fought depression when they "looked and felt awful". A positive attitude was seen as essential to achieving health by some.

"I have to believe in a positive self image, especially with all this stuff going on. Nerves and stimulus pick up on that. The mind is powerful."

Self-talk, visualization techniques, doing something positive, and focusing on caring for someone else were ways subjects worked on maintaining a positive attitude. Types of self-talk included, "if number 3 doesn't work, number 4 will", gratitude for survival and having treatment options, and telling themselves "I'm better off than others". Many subjects had felt close to death at one time or another, or watched others with ESRD die. They valued the "precious time" they had. Such positive attitudes, when they could be maintained, reduced fear, and provided more of a sense of control. When not maintained, subjects felt more frightened and out of control:

"What happens if?"

"It's scary."

"Is this the way I'm going to be?"

Whether it was lost or gained, most recipients identified the struggle for control over their bodies as a major issue, one that impacted body image and self esteem.

Integration of a New Kidney

Integration involved incorporating a new organ into the body image and, for some subjects, this included giving consideration to where it came from. Clues to issues involved in integrating a transplanted kidney were found in the ways recipients referred to that kidney. During the interview it was referred to as "my kidney" or "my new kidney" by half the subjects. "The kidney" or "the new kidney" was what it was called by two subjects. Three referred to it primarily as "the transplant". One subject referred to the kidney as "it" throughout the interview. A few had nick-names for the kidney. One recipient named his "Bummer" because it rejected so quickly. Another called hers "kiddo". One female recipient referred to the kidney as "him" in reference to the male donor.

Integration. Approximately one-third of the subjects reported that they immediately thought of the kidney as "mine". The following comments reflected this view:

"When it goes into my body, it's mine."

"It feels like a part of me. Has to do with wanting a kidney so bad, you'll accept anything that comes along."

About two-thirds of the subjects felt, or continued to feel, separateness from the kidney and viewed its integration as a process that takes time. For some that process was a matter of finding out that it was going to work for them, or protecting it for awhile.

Some subjects weathered rejection episodes before they began to feel the kidney was a part of them.

"Feels part of me most of the time now.

For awhile last year, it was touch and go."

For some the newness of the kidney and the fact that it was a "foreign object" added to the feeling that it was separate initially.

"At first the idea of my body accepting a foreign object like that was not acceptable."

Subjects used visualization or talked to the kidney to make it feel more a part of them:

"I did a lot of talking with my kidney and myself to try to get my body and my mind

to accept my kidney."

Expressing gratitude was part of the self-talk for successful transplants, and a scolding for the kidney that wasn't doing so well. One subject no longer talked to his rejected kidney:

"I won't get attached. It will come out soon and I'll get another one."

There was concern that ambivalence felt about the transplant was a kind of "rejection attitude" that might negatively affect the kidney.

For those who didn't immediately view the kidney as "mine", the feeling of being separate occurred when it was new or "foreign", when it threatened rejection, or when the subject was feeling very ill or dealing with other upsetting events. Recipients who were still integrating the kidney were 3 months to 3 years away from the transplant. Those who were more long term did not refer to this process and tended not to see the kidney as separate. Those recipients who had already rejected were on hold, waiting for a new kidney to integrate.

Donor issues. A majority of the transplant recipients in this sample received a kidney from a cadaver donor (n=9). Four male subjects had living-related donors. Female subjects tended to go into more detail when discussing donor issues and mentioned the donor's family in their discussion. With two exceptions, male subjects tended to be less curious about the cadaver donor, and none mentioned the donor's family. Recipients of living-related kidneys, all of whom were male, either did not feel that receiving a kidney from a relative affected their view of themselves or could not sort out what the effect was and did not pursue discussing it.

Of the cadaver recipients, one-third had little interest in knowing about the donor, or did not want to know anything. Reasons cited for not wanting to know included lack of curiosity, and concern that knowing more would make it feel more like the kidney belonged to someone else. One idiosyncratic response was from a subject who expressed feelings of guilt and indebtedness:

"The only thing I know for a fact is that somebody had to die. That's sad. Sometimes I

think it would have been better if it had been the other way around, maybe I could have helped someone by my death.. .If you knew (the family), how could you repay them?"

Two-thirds of the cadaver kidney recipients knew at least the age and sex of the donor and most wanted to know more:

"Stick something in your body from another human, you would like to know a little about it."

Age of the donor was important to these subjects. Most expressed that they were glad to have a younger kidney, feeling it would have a better chance of survival, or would last longer. Subjects joked about whether putting an organ in of a different age than they were changed their age.

One-fourth of the recipients had limited information about their donor and built onto that a more extensive picture of that person in their imagination of what they might have been like, their state of health, or how they died.

"I have a sister who told me about a man...who died the day before my transplant

who was an organ donor in his 50's. A neat man in good health, an avid fisherman...I feel like I need to know my roots and I think of that man. They told me it was a large kidney so I think of a man. A strong kidney."

"The kidney is so much like me, I wonder what their son or husband was like, what he liked to do, because a part of him is with me."

Aspects of the donor's life that affected the kidney was also a focus:

"I think sometimes of the violence of his death and could it affect how well the organ survived...The fact that two days after surgery, the kidney went into stun... and I was in the middle of a rejection."

The male recipients of living-related donor kidneys did not seem to feel that receiving a kidney from a sister or father had an impact on their body image, but that it possibly affected their relationship with the donor. Some felt closer while others felt a strain was put on the relationship.

When recipients were asked if the kidney felt a part of them, the answer varied from an unconditional "it's mine" to "it's a process". Some cadaver recipients found that knowing little or nothing about the donor helped them view it as theirs. Others preferred to know more about the kidney's origin and incorporate that image into the integration process. Recipients of living-related kidneys had little to say about their integration process.

Interaction with Others

This section presents the ways in which subjects related to others about their illness and how input from others affected their self view. Recipients varied in their openness to others knowing about their kidney problems, to input from others about their health, and to exposure to others ESRD experiences.

Telling others. Over a third of those interviewed preferred to keep their kidney problem quiet:

"On the outside world, no one suspects I have a kidney problem. Only those close know I have a problem. Something I try to keep quiet."

In contrast, others preferred to talk about their experience:

Everybody I know knows I've had a transplant. I don't keep it a secret."

Four recipients who had received transplants some years ago had newspaper article written about them. Often it was the donor who contacted the paper and was interviewed about the transplant. All four recipients found this kind of notoriety and public notice of their health problems "embarrassing", even those who liked to talk about their experience.

Recipients who preferred to keep quiet about their kidney problem did not want others to feel sorry for them and were "irritated" by that reaction. Some were embarrassed by their lack of stamina. They didn't want to be seen as "different":

"If they knew you had a transplant, they would look at you in a different light, as not healthy."

Input from others. Other people's reactions can be an assault to the image the recipient is trying to uphold:

"I had people tell me I was frail and

too thin. The word frail has stuck with me all these years because it implies to me a very sickling person...Responses from other people who called me frail or sick becomes a battle within my mind, 'Am I really sick?'"

A few recipients expressed confusion about whether they were disabled or not and input from others tended to confuse them more. Subjects reported that they would push to the limits to complete daily tasks and because their disability was not obvious would be met with the reaction of "there's nothing wrong with you". This made them question their disability status. Other recipients were not receiving disability and felt they could perform on the job. For them comments that suggested they were disabled put them on the defensive and made them question their capabilities.

Input from others was not always a negative force. It also served to bolster a person who was working on gaining or maintaining a positive body image:

"They tell me I look great. It gives me that umph, extra energy to do more for myself."

Comparison to others. Almost all subjects did some comparison of their situation to others they knew with ESRD. They had varying reactions to someone who was doing poorly, finding ways that they were "better off than" or "different from" that person to assure themselves it would not happen to them. Some were not successful in reassuring themselves. Unpleasant memories of other's experiences still haunted some subjects, making them feel more vulnerable to harm. a few found strength in watching someone go through a difficult time, perhaps losing a kidney, and return to try again.

Implications of the research results will be discussed in the next section. A review of the major themes and their components can be found in Table 4.

Table 4

Major Body Image Themes for Renal Transplant Patients

Theme	Components
CORE THEME	
Kidney Function	
SECONDARY THEMES	
Threat of Rejection	Monitoring Rejection episodes Feared rejection
Body Functioning	Circulatory system Mental/neurological Sexual/reproductive Immune system Gastro/intestinal Musculo/skeletal
Appearance	Weight changes Cushingoid features Hair/skin changes Kidney position Scars/fistula
Energy/Strength/Stamina	
Control Over the Body	
Integration	Integrating the kidney Donor issues
Interaction with Others	Telling others Other's input Comparison to others

CHAPTER 4

Discussion

Findings support the researcher's assumption that a person's body image is affected by a renal transplant and its treatments, and that the form and degree of change varies with each recipient. The effect of kidney function on body image was the core theme that emerged. The secondary themes that emerged which addressed the broad range of body image experiences were: Threat of rejection, Body functioning, Appearance, Energy/Strength/Stamina, Control over the body, Integration of the kidney, and Interaction with others. Comparison of findings to body image literature and theoretical implications of the research findings will be presented in this section.

Comparison of Findings to Body Image Literature

Findings in this study agree with the well established theory in general body image literature, that body image and self-esteem are linked. Patients experienced feeling better about themselves when they felt positive about their body. They had difficulty feeling good about themselves when their body "wasn't working for them".

Basch (1973b) observed that it was unusual for a patient to enjoy a complication-free post-transplant course physiologically or psychologically, and that complications often had an impact on body image and self-esteem. This phenomenon was also observed among subjects in this sample. There were numerous complications experienced after the transplant that affected body image including appearance changes, rejection episodes, muscle weakness, and medication reactions.

Kemph (1966) found that all recipients in his study were concerned about possible body damage. This finding was also supported. Subjects feared damage from fistula complications, muscle and bone deterioration, susceptibility to infections, reduction in mental functioning, and to sexual and reproductive functions. Fear of rejection was another concern mentioned in the literature and it too was raised as a concern by subjects in this study.

Korsch (1978) found in his study with teenage girls and young women that they often stopped steroids due to cushingoid appearance, acne, and hirsutism. Teenage girls were not included in this study, and the sample of young women was small (n=2). Those subjects reported valuing a functioning kidney over appearance

and did not stop steroids post-transplant due to steroid effects. In this sample, no subject reported stopping medications due to appearance side effects of immunosuppressants.

Integration of the kidney was another theme that existed in body image literature. Muslin (1971) described three stages of internalization of a transplanted kidney: a foreign body stage, a stage of partial incorporation, and complete incorporation. A process of integration resembling this description was reported by a majority of subjects in this study. That the new kidney was a foreign object was one of the ways it felt separate at first. Later in the process the kidney was described as "not feeling separate most of the time" indicating partial incorporation. Integration was threatened by rejection episodes. Subjects who were many years post-transplant did not identify a struggle with integration, indicating that they had incorporated it, or were no longer concerned about integrating it.

A third of the subjects reported that they saw the kidney as part of them instantly, and did not go through an integration process. It is difficult to assess whether retrospective recall was faulty or whether they indeed integrated the organ that quickly.

Donor issues was a popular theme in previous, psychoanalytically oriented, body image literature. Kempf (1966), Crammond (1967), and Castelnuovo-Tedesco (1973, 1978, 1980) all observed incidences of recipients feeling that they had acquired traits from the donor, or experienced sexual-identity problems if the donor was of the opposite sex. Subjects did not report such feelings in this study. A few subjects fantasized what the donor was like, or felt the donor may have been similar to them in some ways, but no one spoke of acquiring traits, or experiencing sexual identity problems.

The literature just cited also found that some subjects experienced integration problems due to conflicts with their living-related donors. Recipients of living-related donor kidneys did not feel that their relationship with the donor had impacted their body image, only that in some instances the relationship with that donor may have become closer, or strained. However all recipients were male, therefore gender differences related to this may have been in effect. It is possible that differences in reporting these donor issues was the result of different data collection methods and viewpoints.

Themes that were not well-developed in previous body image literature about renal recipients that emerged from this study included control over the body, energy/strength/stamina, interactions with others and a focus on body functioning.

Theoretical Implications

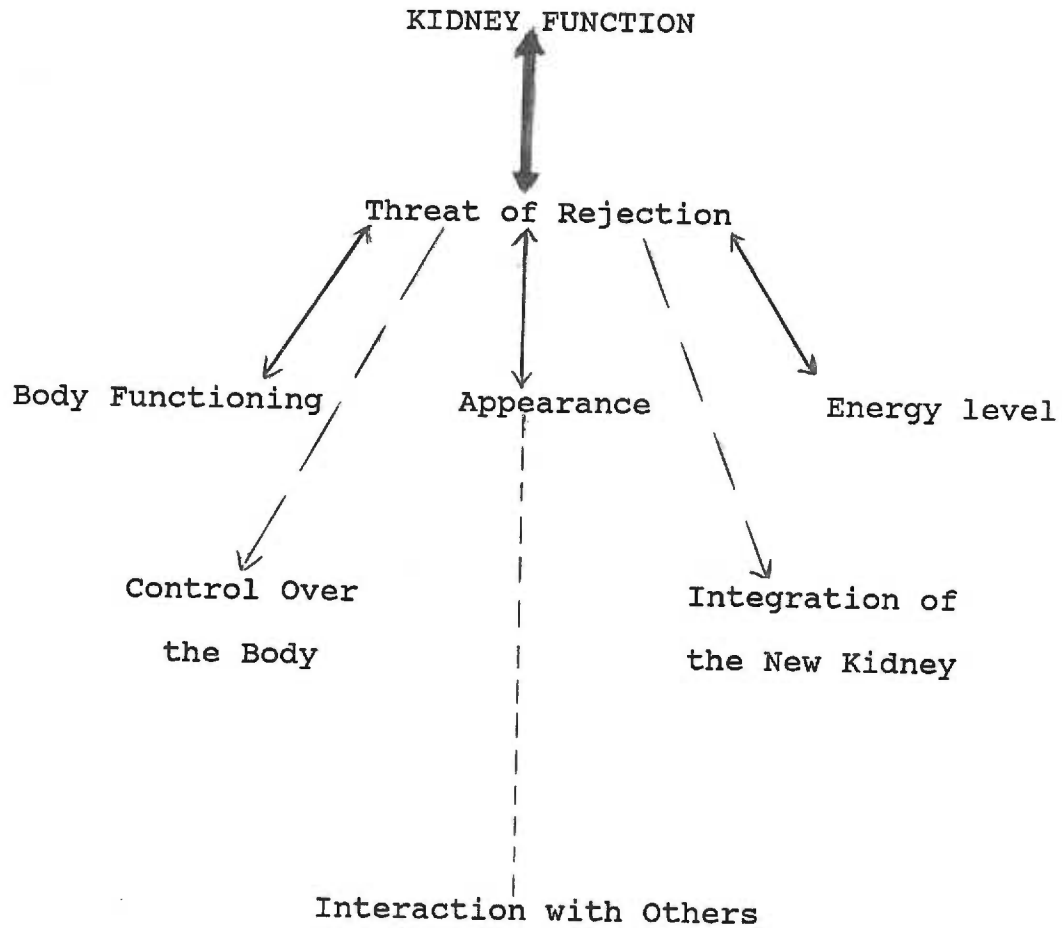
Inter-relationships among themes constitute an emerging theory of body image as impacted by renal transplant. This "grounded theory" is grounded in the data collected from 13 renal transplant subjects.

Figure 1 depicts the relationship of collateral themes to the core theme of kidney function in descending order from primary to more peripheral. The core theme, or central issue, that emerged for all recipients was kidney function. A functioning kidney greatly contributed to a positive body image. A non-functioning, or threatened kidney, had the opposite effect, making recipients feel more fragile.

Collateral themes that impacted body image were related to kidney function. One theme, threat of rejection, had a very central relationship to kidney function; the remaining themes were secondary and more peripheral.

Figure 1

Relationship of Themes Impacting Body Image for Renal Transplant Patients



Most directly related to the core concern of kidney function was the threat of rejection. Patients in chronic rejection suffered the biggest bodily threat, as they faced death, dialysis and accompanying change of life style, or a new transplant. Those in acute rejection were threatened with the same changes, but had hope of saving the kidney. Even those who had a functioning kidney were impacted by the fear of rejection. Thus, whether rejection was a reality or only a feared event, it loomed over all transplant patients as a central issue.

Secondary, in order of centrality to kidney function, were the themes of body functioning, appearance, and energy/strength/stamina. A functioning kidney directly improved the entire body's functioning, contributed to a healthier appearance, and increased energy level. When the kidney functioned well, lower doses of immunosuppressants could be used. This meant less impact was made on the immune system, mental/neurological functions, and musculo/skeletal system. In addition there tended to be fewer appearance changes due to cushingoid features, hair and skin changes, and weight gain. Components of body function that did not seem as directly related to

kidney function were sexual and reproductive concerns that varied in their origins. Likewise, the appearance components of scars and fistula complications did not have a direct relationship to kidney function.

Somewhat more peripheral in relatedness to kidney function were the themes of control over the body and integration of the kidney. A functioning kidney did give the recipient more control and provided opportunity for integration of the kidney. However, these themes were also strongly related to the attitudes or mind sets of the recipients that often pre-dated the transplant.

The theme that was most peripheral to kidney function was interaction with others. A functioning kidney contributed to patients feeling less vulnerable to the impact of input from others and exposure to other's ESRD problems. However, the recipient's style of relating to their illness and to others about their health problems usually existed long before the transplant.

CHAPTER 5

Summary

In this chapter a summary of the research study, its limitations, and implications for nursing practice and research will be presented.

Research Summary

Kidney transplants have been performed for approximately thirty years. Yet descriptive knowledge and explanatory theory regarding the impact of body changes on body image of renal transplant patients are in their infancy. The purpose of this study was to explore the alterations in body image experienced by recipients of renal transplants with the goal of broadening the knowledge base of body image theory for this population.

Review of body image literature addressing renal transplant patients revealed a small number of studies, primarily case studies, reported in the late 1960's and early 1970's. Themes that were reported in these studies included sexual identity problems, physiological and psychological integration processes, fear of bodily damage, fear of rejection, perceived acquisition of traits, and changes due to immunosuppressants. One limitation of the studies was their primarily psychoanalytic viewpoint. Further

research was indicated that more directly recorded the patients experience in their own language.

The conceptual framework included symbolic interactionism (Blumer, 1969), which addressed the meaning-making process of human beings, and developmental psychology, which more specifically addressed the meaning-making process involved in the development of a sense of self. Theorists from developmental psychology provided definitions and developmental models for body image. In this study body image was defined as a picture of the body formed in the mind which included physical components and psychological meanings. Formation of body image was seen as an ongoing process affected by interactions with people and events in the environment.

The research question was: What changes in body image do renal transplant patients experience? It was assumed that renal transplantation and its accompanying treatments affect body image and that the form and degree of alteration had the potential to vary with each person according to the meaning the experience had for him or her.

A non-experimental, grounded theory approach similar to that described by Glaser and Strauss (1967) was selected for the research design.

The population targeted for the study was ambulatory care patients who had one or more renal transplants. Subjects were selected on the basis of providing diversity so that as many properties of themes as possible could be discovered. Exclusion criteria were employed to attempt to control for factors that could confound body image issues. A convenience sample of 13 subjects was selected from patients attending an outpatient transplant follow-up clinic. Data were collected during one-time interviews, lasting from one to two hours, conducted by this researcher. Pertinent demographic data were recorded at the onset of the interview. An interview guide was employed when necessary to introduce topics and open-ended questions relating to body image.

Comparative analysis was used to delineate emerging themes and concepts from the data. Kidney function was the central issue that emerged from the data. Seven secondary themes emerged which addressed the broad range of body image experiences reported by subjects. These were: Threat of rejection, Body functioning, Appearance, Energy/Strength/Stamina, Control over the body, Integration of the kidney, and Interaction with others. Several of these themes had been reported in previous literature, others were

added or developed from a different viewpoint in this study. Kidney functioning was a core concept to which all others were related. The secondary themes were related to kidney function, and ranged from a primary relationship to a more peripheral relationship. A hypothetical model, based on the empirical data, was presented that described the relationship between the major themes.

Limitations

A major limitation to this study was that theoretical saturation was not completed due to the time constraints of the research project. Categories could be developed more fully by adding more subjects. A larger sample size would improve generalizability of results. Two notable gaps were present in subject type. One was that all the living-related donor recipients in this sample were males who either did not experience an impact on body image related to the relationship with the donor, or could not relate that experience. Female subjects tended to focus more on donor issues and inclusion of females who had had living related donor transplants would possibly have provided more information. The other group of subjects that was under-represented was recipients who had been transplanted 3-8 years. Subjects in this sample tended

to be grouped into more recent transplants (3mos-3yrs), or were long term (9-16yrs.). This gap sets limits on generalizing findings to the mid-range group. A limitation when saturation is not completed is that a theory may not hold up when tested further.

A limitation of the data collection method was that it was a one-time interview. A follow-up interview, or interviews, may have revealed further information after subjects had had time to reflect on topics introduced in the first interview. Data collection would also have been enhanced by field observation of renal transplant recipients over a period of time.

The research question was very broad, providing a great deal of diverse information. This was positive for representing a breadth of experience, but depth of experience for each category may have suffered as a result.

Until further testing proves otherwise, results can only be generalized to the population that produced them, renal transplant patients between the ages of 25-45.

Implications for Nursing Practice

Major themes that emerged could provide guidelines

for the clinician for assessing body image issues for renal transplant patients. The themes suggest that the first concern to address is kidney functioning and its impact on the patient physiologically and psychologically. Most directly it may be impacting other body functions, appearance, and/or energy level. Assessment could include a review of the components included in each of these themes in order to discover which changes are affecting the patient the most.

Bodily changes may be less directly affecting patients' sense of control over the body or be impacting on integration of the kidney. Components of control and integration could also be reviewed with recipients.

The patients' vulnerability to input from others regarding their illness, and exposure to other's with problems could also be evaluated. Information gained from assessment of the components of interaction with others can help the nurse make decisions about what, and how much, information or feedback should be presented and help staff in selecting appropriate roommates for patients.

Assessments can include observation of the patient's behavior, listening to their comments, and asking direct questions using the themes as a guide.

Knowledge from this kind of in-depth assessment could indicate nursing interventions which would help patients clarify and work through difficult body image problems.

Knowledge about the experiences of body image changes of transplant recipients could also be used in education programs to prepare future transplant patients for potential changes.

When using the themes as an assessment or teaching guide, it must be remembered that grounded theory is a theory generating method, not theory testing research. Use in clinical practice can help to test the themes, and suggest further research to define and refine them, but themes can not provide a proven basis for nursing practice.

Implications for Research

Grounded theory is designed to generate more questions than it answers, and in that respect, this research was quite successful. Each theme that emerged, and each component of each theme warrants its own more focused research study in order to gain more density in the knowledge base for each category and generate hypotheses. An expansion of the present study to include a larger sample which would provide better representation in areas under-represented by this

sample would also serve to further develop the themes and test their validity. The same study conducted with subjects of different age groups would provide information for further comparative analysis. Research that followed a similar approach with subjects who have had other types of organ transplants would further test generalizability of themes and the hypothetical models of their inter-relationships.

As data from this study were analyzed it appeared that patients followed a process of integrating changes into their body image. The process included evaluation of the change, an accomodating action or reaction, and integration or re-evaluation, depending on the results from the accomodation. This hypothetical model for integrating change could be explored futher in future research.

Body image changes in renal transplant recipients present clinical and research challenges to nurses. Research indicates themes from which assessment tools could be built. Elaboration of themes and discovery of areas that suggest further research could result from clinical use of assessment tools. Integration of practice and research would lead to improved health outcomes, mental and physical, for transplant patients.

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APPENDIX A

Consent To Be A Research Subject

The Oregon Health Sciences University

Consent To Be A Research Subject

1. Yvonne Boyer, RN, GSN is doing a research study called "Body Image in Renal Transplant Patients". The purpose of the study is to learn more about the body image changes that accompany end stage renal disease, particularly in relation to kidney transplants.
2. If I agree to be in the study, I understand I will be interviewed once and asked questions relating to my renal disease and kidney transplantation, and how they have affected my view of my body. The interview will last one to two hours and, with my permission, will be tape recorded.
3. I understand that answering some of the questions may be difficult because I may recall some unpleasant memories or embarrassing thoughts or situations. It has been explained to me that my answers will remain anonymous, and my name will not be recorded on the questionnaires or tapes. Tapes will be erased at the end of the study. The researcher is not aware of any physical risks or discomforts that may result from this research. I understand there will be no cost to me.
4. "It is not the policy of the Department of Health and Human Services, or any other agency funding the research project in which you are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions please call Dr. Michael Baird, M.D., at (503) 225-8014."
5. I understand there is no direct benefit to me, except the chance to talk about my experience. In the future, other people may benefit as health care professionals better understand how certain kidney treatments affect a person's body image.
6. I have talked with Yvonne Boyer and she has offered to answer any questions I have. I can telephone Ms. Boyer at 225-7827.
7. I understand that I may refuse to participate, or withdraw from this study at any time without affecting my relationship with, or treatment at, the Oregon Health Sciences University.
8. I have read the foregoing and agree to participate in the study.

Subject's Signature

_____ Date _____

Witness

_____ Date _____


APPENDIX B


Committee on Human Subjects Communication

THE OREGON HEALTH SCIENCES UNIVERSITY

MEMO 

Date: November 7, 1986

To: Yvonne E. Boyer, B.S..
Carol Burckhardt (Advisor) 

From: Donna Buker, Administrative Assistant 
Committee on Human Research

Subject: "Body Image in Renal Transplant Patients"

The above entitled study falls under category # 3 and is considered to be exempt from review by the Committee on Human Research. Therefore, I have put your study into our exempt files and you will receive no further communication from the Committee concerning this study.

If the involvement of human subjects in this study changes you should contact the Committee on Human Research to find out whether or not these changes should be reviewed.

If you have any questions regarding the status of this study, please contact Donna Buker at X7887.

APPENDIX C
Demographic Data Sheet

Demographic Data

Identification # _____ Interview date _____

Age _____ Sex _____ Race _____ Marital Status _____

Age at onset of kidney disease _____

Cause _____

Renal treatment prior to transplant _____

Date of transplant(s) _____

Donor: Cadaver _____ Living Related _____ Relationship _____

Medical problems _____

Medications _____

Field Note:

APPENDIX D
Interview Guide

Interview GuideGeneral

Recall the time before your illness and how you viewed your body then. In what ways, if any, has your view of your body changed over the course of your illness and medical treatments?

Expectations

How did you imagine the kidney transplant would affect your body before you received it?

How does this compare with what you have actually experienced since the transplant?

Appearance

Has your illness, medical treatments, or transplant affected your body size or appearance in any way?

Probes: Incision, shunt, medications

Functioning

Has your illness, medical treatments, or transplant affected your body's functioning?

Probes: Kidney or bladder functioning, energy level

Probe: Sexual functioning problems frequently accompany renal disease. Would you be willing to discuss with me how your satisfaction with your sexual functioning has affected your view of your body during your illness and since your transplant?

Rejection

Has a transplanted kidney ever rejected or threatened rejection?

If so, how has that affected your view of your body?

Do you ever think about rejection? If so, how does that affect the way you view your body?

Probe: Clinic visits for lab work, weight monitoring, abdominal pain.

Integration

How do you refer to your transplanted kidney?

Sometimes people with a transplanted kidney feel that the new kidney is a part of them, others view it as separate, and for others it fluctuates. How do you experience this?

Probe: If part of you, how long did that take, is that constant or does it change? If it changes, what contributes to changes? If separate, how does it feel separate? Is that constant or does it change? If it changes, what contributes to changes?

Donor Related

If cadaver donor:

Do you have any knowledge or guesses about what your kidney donor was like? If so, has that knowledge or the guesses affected how you view your body?

If living related:

Are there ways that receiving a kidney from your _____ has affected your view of your body?

Conclusion

Is there anything else you would like to share about your kidney transplant and how it has affected the way you view your body?

AN ABSTRACT OF THE THESIS OF
YVONNE LAROUCHE BOYER

For the MASTER OF SCIENCE IN NURSING

Date of Receiving this Degree: June 12, 1987

Title: BODY IMAGE IN RENAL TRANSPLANT PATIENTS

APPROVED: _____

Carol S. Burckhardt, RN., Ph.D. Thesis Advisor

The goal of this descriptive research study was to broaden the knowledge base of body image theory for the renal transplant patient population. The research question was: What changes in body image do renal transplant patients experience?

Subjects were selected from a convenience sample of outpatient renal transplant patients contacted at a transplant follow-up clinic. Thirteen subjects, 8 males, and 5 females, between the ages of 20-50 were interviewed. An interview guide was used to introduce topics when needed. One-time interviews, lasting from 1-2 hours were taped and transcribed. Comparative

analysis was used to analyze the data to delineate themes relating to body image changes.

One central theme emerged, kidney function. Seven secondary themes that emerged were: Threat of rejection, Body functioning, Appearance, Energy/strength/stamina, Control over the body, Integration of the new kidney, and Interaction with others. A hypothetical model of the relationship of the major themes to each other was presented.

Factors limiting generalizability of the study included a small sample size, and under-representation of certain recipient groups. The grounded theory approach increased understanding of the transplant experience as it is lived by recipients. Major themes have potential as a basis for an assessment tool and as a guideline for educating and preparing potential transplant recipients. Data analysis generated many questions deserving of future research in the area of body image changes for recipients of kidneys as well as other organ transplants.