

THE MEANING OF LIFE IN  
ORGAN TRANSPLANT RECIPIENTS

by

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Submitted to the Faculty of the School of Graduate Studies  
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ORGAN TRANSPLANT RECIPIENTS

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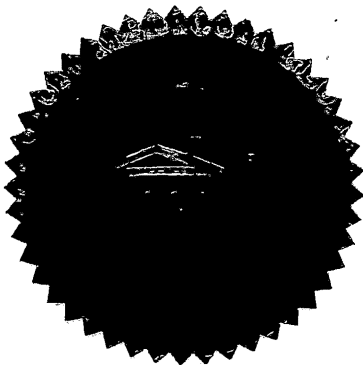
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The Meaning of Life in Organ Transplant Recipients  
(Under the direction of JOYCEEN S. BOYLE)

The purpose of this study was to explicate the meaning of life as experienced in a population of renal, cardiac, and liver transplant recipients. The method used was two-fold: A phenomenological design to explore qualities of the lived experience in subjective terms. A questionnaire provided measurable information for corroboration and validation.

The theoretical perspective of will to meaning (Frankl, 1969) served as a basis for the study. This view suggests that the search for personal meaning is a primary motivating force for continued survival in human beings.

A convenience sample of eleven vital organ transplant recipients participated in the study. Initially, the Life Attitude Profile-Revised (LAP-R) (Reker, 1992) was completed by each participant. This is a multidimensional, Likert-type instrument measuring attitudes toward life. Questionnaire completion was followed by semi-structured interviews.

The two sets of data were examined separately. Interviews were analyzed according to phenomenological guidelines set forth by van Kaam (1966), leading to structural definition of the meaning of life for organ transplant recipients. LAP-R data were then analyzed. Analysis culminated in a syncretic integration of findings from both data sources. This provided a rich, contextual description of the indomitability of the human spirit.

The meaning of life for organ transplant recipients was a complexity of interconnected aspects, reflecting a paradox of emotions and great intensity. It was at once evolutionary and revolutionary, comedy and tragedy, struggle between dependence and independence, and dream tempered by reality. Important themes described included drawing on internal sources of strength; having the support of family and friends; a desire to help others; acknowledgement of the contributions of a "greater force" to continued survival; some semblance of inner peace; a need to achieve one's purpose in life; and a sense of renewed responsibility for oneself and one's health.

Findings from this study afford new insights for clinical nursing. These insights are grounded in improved mutual understanding between persons, which is a critical element for efficient health care planning and effective intervention.

INDEX WORDS: Meaning of life, organ transplant recipient, phenomenology, triangulation.

## **DEDICATION**

This dissertation is dedicated with love to my family and dear friends, all of whom provided endless support and encouragement. Special tribute is also offered to my parents, who I know would have been very proud of this accomplishment, and are looking down from above with wonder and joy.

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## **CHAPTER I**

### **INTRODUCTION**

The goal of this study was to explicate the meaning of life as experienced in a population of renal, cardiac, and liver transplant recipients. The method used was two-fold: A qualitative, phenomenological design to interpret qualities of the lived experience; in addition, data was triangulated through the use of a questionnaire to provide measurable information for comparison and validation purposes.

#### **Problem**

The literature is replete with references to physiological considerations in organ transplantation but provides little substantive information related to post-transplant biopsychosocial adaptation. The multiplicity of variables which potentially impact upon the psyche of the person facing this experience can be overwhelming. This surgery is performed on persons across the life-span--ages range from less than one year to 65 years. That range is broadening as life expectancy increases, surgical techniques are refined, and pharmacologic advances improve organ rejection statistics. This combination of factors may have previously precluded precise nursing research efforts designed

to uncover the meaning of the overall experience and the meaning of life as humanly perceived.

Transplantation is generally preceded by a period of illness, sometimes long-term and often life-threatening. Cardiomyopathy, chronic renal failure, and idiopathic cirrhosis are all chronic illnesses indicating potential need for organ replacement. Medical indications for transplantation precipitate feelings of perpetual uncertainty (Mai, McKenzie, & Kostuk, 1986). As the candidate awaits a suitable organ, illness is complicated by the stress of fear that one may not be found. This stress is coupled with anxieties related to a physically disabling condition.

The post-surgical transplant patient is faced with similar unpredictability in life. The possibilities of infection, organ rejection, and other complications always loom on the horizon. Predominant feelings experienced by heart recipients have been described (Mai, 1986) and these include denial, euphoria, gratitude, curiosity, ambivalence, guilt, anxiety, and change in body image. Denial has been suggested as the primary protective and adaptive function for this population (Mai, 1986).

### **Societal Concerns**

Numerous concerns arise from the expanding practice of organ transplantation as treatment for otherwise fatal illness. Economic considerations are crucial. Cost estimates range from \$135-230,000 for liver, \$57-110,000 for heart, and

\$25-30,000 for kidney transplants, excluding some pre- and post-surgical expenses, such as evaluative procedures, outpatient visits, subsequent hospitalizations, and immunosuppressive therapies (Lindsey & McGlynn, 1988). Third party payers vary in coverage of these costs. The burden of absorbing uncovered portions of the procedure and subsequent expenses rests, in general, with society. Detailed investigation into the lived experience and meaning of life in organ transplant recipients is crucial in order to provide more definitive data on which to base clinical practice. Effective nursing interventions and educational programs will result in sound health promoting behaviors in this population, thereby leading to more fiscally responsible patient care.

Ethical issues in organ transplantation are also of paramount importance. Scarcity of resources is not limited to the financial realm. Criteria for allocation of available organs varies among transplant centers, as there are no state or national guidelines to aid in the selection of recipients. Indeed, the transplant team or center makes the decisions regarding distribution of all vital organs. Criteria may be based on age, tissue match, issues of "need," chance of success, ability to comply with post-operative care requirements, absence of psychiatric illness or substance abuse, and the presence of family support. Some centers rely solely on a first-come first-served ethical basis (Levine-Aruff, 1987). Implications for nursing practice in the area

of organ transplant ethics, based on the above criteria, include: (a) responsibility to effectively and objectively assess biopsychosocial dimensions of the recipient, (b) versatility in the development and application of interventional strategies across the life span, and (c) the ability to integrate family and social support aspects of care to enhance health behaviors of the individual. Post-surgical adherence to the therapeutic regimen is critical.

### **Significance**

Complexity of the discipline dictates that the nurse scientist and clinician have a broad understanding of numerous variables within the context of the human sciences. Nursing literature is lacking in reports substantiating the professional and/or social utility of many extant nursing theories. Neither do published research findings adequately address needs of the organ transplant patient from a holistic perspective. The most recent publications focus on cardiac transplantation (Mai, 1986; Mai, McKenzie, & Kostuk, 1986). Little information is available in regard to liver transplant, and much of the literature related to renal transplant is not reflective of current practice. Substantive nursing research is mandated to augment this knowledge base.

Roles and interplay of relevant variables must be sorted out to develop a sound foundation for nursing practice. Biopsychosocial phenomena must be investigated from a holistic perspective to provide a broad framework on which to build

effective and efficient strategies aimed at supporting development of sound health practices in the transplant population.

Salient information is gleaned from this study of the phenomenon of **meaning of life** in the organ transplant population. More specifically, it is necessary to uncover and explicate the perceived personal significance of life when one is faced with a medical illness that is best, and often only, treated by organ replacement. The literature has reflected no such global study, nor have life-span and human development issues been addressed. These latter concerns both impact upon and are affected by the organ transplant experience. They have bearing on health behaviors, and consequently, on long-term graft and recipient survival.

The availability of such information provides nursing science with insight into the salient biopsychosocial mechanisms which modify the transplant recipient's self-concept and feelings of personal significance. Explication of these mechanisms is of importance in facilitating health promotion behaviors and positive attitudes toward the recovery process.

#### **Research Question**

The research question guiding this study was: What is the meaning of life for individuals who have experienced transplantation of a kidney, liver, or heart?

The findings of this study provide a multidimensional portrait of the global experience and meaning of life for individuals who have undergone organ transplantation. The questionnaire component provides corroboratory data; the qualitative information proffers confirmatory evidence. Further, this study tests the Life Attitude Profile-Revised (LAP-R) questionnaire (Reker, 1992) in the clinical setting.

### **Theoretical Perspective**

Meaning of life was the major construct of interest and provided the theoretical basis for the study. Finding meaning in life, and in a selected experience of life, is a mental process suggesting serious introspection into feelings, thoughts, and perceptions. Meaning has been described as what is meant by a person who asks a question, or by a situation which implies a question and calls for an answer; a person is free to respond to life's questions, but this freedom must be interpreted in terms of responsibility--giving right answers and finding true meaning (Frankl, 1969). Personal inner significance is the key to finding meaning of life. Frankl (1959) noted also that the search for meaning is a primary motivating force for continued life in humanity.

A basic tenet of existential philosophy holds that existence precedes essence; that is, a person exists and only afterwards defines the self (Sartre, 1978). This is relevant to a discussion of meaning when attempting to relate it to human science issues, because this philosophy suggests that

drawing meaning from any situation has a temporal element. Inner significance is most effectively evaluated and conveyed from retrospection. Thoughts and feelings one might have during or after a given event can be anticipated, but cannot be known for sure until the event has actually transpired. This does not discount themes of hope and planning for the future, but rather puts thoughts into perspective. Intuitive reflection on the past influences and complements future direction and aspiration.

The concept of meaning of life in the organ transplant population is important to health care, and indeed, is of significant concern in any interpersonal relationship. An important contributor to explication of the concept of meaning of life was Frankl (1969), a psychologist who drew upon personal resources both in the concentration camps of Nazi Germany and in later years in professional practice. Groundwork was begun which led to the acknowledgement and acceptance of all facets of the individual, but especially the spiritual or inner self.

Frankl (1969), in discussing experiences in psychotherapy, noted that drawing upon the spiritual resources of the patient can be immensely revealing: "In other words, I left the psychological dimension to enter the noological dimension, the dimension of man's concern with, and search for, ultimate meaning" (p. 123).

Further analysis of this tactic caused Frankl to question whether a different (less desirable) outcome would occur with patients if a more orthodox psychoanalytic approach were used, which might confine interpretation of a patient's case to underlying dynamics--amounting to "dodging the actual issue and reinforcing the patient's escapism" (Frankl, 1969, p. 124). Sharing of the spiritual self by the organ transplant recipient provides numerous insights into personal meaning, but is also beneficial and therapeutic to the individual patient.

The construct of meaning of life is important to the human sciences, and especially to nursing, because identification of its underlying implications will lead to improved mutual understanding between persons. An abstract concept, meaning of life involves both intellect and spirit.

Constructs related to meaning of life have been abundantly addressed in the literature. The most significant of these are hope, despair, and spirituality.

**Hope** has been defined as a "multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant" (Dufault & Martocchio, 1985, p. 380). It has been further described as a fundamental necessity for continued life, without which illness and even death may result (Engel, 1968; & Hickey, 1986). One who gives up psychologically and emotionally and

fails to find hope for the future may lack a sense of meaning. This is a crucial element in the transplant recipient.

**Despair** is precipitated by unrealistic and exaggerated expectations which lead to false hope (Green, 1977). The bitter disappointment and desperate frustration of false hope often lead to despondency and inability to find personal meaning in lived experiences.

**Spirituality** is yet another component to consider in contemplating the construct of meaning. Spirituality encompasses but is not limited to religiosity, and may include love and relatedness, hope, and purpose in life (Ellerhorst-Ryan, 1988). Hiatt (1986) noted the spiritual dimension is that part of the person concerned with meaning, and is therefore a principle determinant of health-related attitudes and the worldview of both physicians and patients. This view should be expanded to include perceptions of all health care providers and significant others.

Soul has been hypothesized to be an entity which has real and permanent existence beyond mortal life in theology; but aside from religious connotations soul is described as the emotional qualities, as opposed to intellectual or rational qualities, of the human being (Chaplin, 1975). A fundamental requirement for determining meaning was previously noted--that of "mind-work" or cognitive, intellectual processes. Emotionality is an equally significant element.

These constructs, either individually or collectively, have relevance to a study of meaning of life in organ transplant recipients. A basic understanding is critical in sorting out individual perspectives in an effort to grasp the essence of the whole experience.

Benner (1985) stated "extreme objectification and subjectification cannot capture the lived experiences of health and illness because human beings are never fully object or fully subject; they exist in a network of concerns and relations" (p. 13). This may well provide the essence for examining individual meaning of life, with integrating themes of being and becoming in the process of health.

The importance of recognizing individual subjectivity and biomedical objectivity and their impact upon success (or failure) in health care has been recognized in the medical literature, as well:

Because biomedical science tends to blind health professionals to questions of illness and differing versions of clinical reality, social science teaching is necessary to train professionals to deal competently with these essential, but nonbiomedical, aspects of clinical practice. To be adequately conceptualized, clinical science must be thought of as both a biomedical and social science. (Kleinman, Eisenberg, & Good, 1978, p. 255)

Contemplation of the above excerpt in terms of meaning of life in the organ transplant recipient affords the opportunity to integrate both empirics and the historicist approach in best serving each individual.

### **Assumptions**

Assumptions underlying this research are:

1. Wholeness of being in the individual is an integrative effort of mind, body, and spirit;
2. Mind, body, and spirit of each human being interface and can impact upon the function of one another;
3. Perceived quality of life, purpose in life, and existential fulfillment are accurate indicators of some aspect of meaning of life;
4. The organ transplant recipient's explication of meaning will foster understanding of the sense of self and the impact of medical illness on that self;
5. The nurse clinician and scientist have an obligation to the transplant recipient to explore, accept, and at times reaffirm perceived meaning in the process of enabling health; and
6. Explication of the meaning of life of transplant recipients will ultimately lead to more effective nursing interventions.

### **Guiding Definitions**

The guiding construct of this study is the meaning of life in organ transplant recipients. **Meaning of life** is

defined as that contextual, subjectively perceived personal significance, reflecting cognitive and emotional processes, as portrayed by the individual. **Organ transplant recipients** are those invited to participate in this study on the basis of meeting entry criteria: Having received a heart, liver, or kidney transplant at some point prior to entering the study, who are at least 18 years old, and who read, write, and speak the English language.

### **Limitations**

The major limitation of this study centers around potential weaknesses in bias control of the investigator. Efforts to avoid this are evidenced by bracketing, tests of rigor, and methodological triangulation. Phenomenological research calls for simultaneous collection and analysis/comparison of data, which augmented endeavors to eliminate possible bias in sample selection, interviewing, and field notes, through repeated review of data.

The small sample size gives rise to questions concerning generalizability of the Life Attitude Profile-Revised (LAP-R) data. Salient information was gleaned on an individual basis, and from this particular sample, provided corroborating evidence of phenomenological findings. The intent of this study was **applicability** of the overall explication of meaning of life in this sample of organ transplant recipients.

## CHAPTER II

### REVIEW OF THE LITERATURE

#### Meaning of Life

Foundational instruments have been developed which purport to measure the concept of meaning, but these almost invariably involve the evaluation of related dimensions as well. Crumbaugh (1968) devised a measure of purpose in life, attempting to determine the degree to which a person experiences a sense of meaning; it is a ten item one-dimension measurement. Its use has led to the linkage of meaning and purpose in life in the literature, describing both the relationship between perceived purpose and self-destructive activity, and the association between purpose and psychiatric illness (Padelford, 1974; Pearson & Sheffield, 1984; & Sheffield & Pearson, 1974).

One study (Reker, Peacock, & Wong, 1987) sought to investigate the search for meaning and the psychological significance of meaningfulness by quantifying the amount of meaning and purpose that existed in healthy individuals. Differences were found both across the life span and between genders.

### Quality of Life and Life Satisfaction

Quality of life and life satisfaction have been proposed as indicators of perceived meaningfulness. The former has been defined in some tools both in pure objective (income, housing, physical function) and subjective (aspirations, frustrations, and attitudes) terms (Frank-Stromborg, 1988). Campbell (1976) noted that there has been an emphasis on the use of social indicators (education, occupation, etc.) in the evaluation of life satisfaction, and stated that more subjective measures should be used in this assessment because a sense of well-being extends to less concrete, less tangible aspects of life.

Lewis (1982) studied late-stage cancer patients, hypothesizing that personal control would be associated with a higher quality of life as measured by self-esteem, anxiety, and perceived meaningfulness. A total of 57 patients completed the study instruments: The Rosenberg Self-Esteem Scale; the Health Locus of Control Scale; the Lewis, Firsich, and Parsell Anxiety Scale; and the Crumbaugh Purpose-in-Life Test. Salient findings reflected that the most consistent correlate of the quality of life was perceived control over one's life, though the magnitude of this relationship was only moderate. It was noted that perceived control over the individual's health did not meaningfully covary with the other two measures of psychosocial well-being. The author suggested that well-being for these patients was not a function of

perceived control over health, but rather it was a function of a more generalized sense of control over their lives.

A study to describe and explain the impact of physical, psychological, and social factors on the perception of quality of life experienced by arthritics has been reported in the literature. Burckhardt (1985) developed a causal model using disease-related variables in interaction with demographic and social factors, hypothesizing these to indirectly affect quality of life through psychological mediators. Semi-structured interviews with 94 adult men and women were conducted, along with the completion of a battery of questionnaires including (but not limited to): A Quality of Life Index, a Severity of Pain Index, a Severity of Impairment Index, and the internal control over health subscale of the Multidimensional Health Locus of Control Scales. Path analysis resulted in the conclusion that psychological mediators--positive self-esteem, internal control over health, perceived support, and low negative attitude toward illness--contributed directly to a higher quality of life.

Flanagan (1982) utilized an empirical approach to define the main determinants of quality of life through interviews with small groups of individuals. Questions were broad, focusing on satisfying experiences and those that were disappointing in some way. Through the critical incidents technique, approximately 6,500 items were identified to have either positively or negatively affected the participants.

These incidents were divided into groups, with cross-checking by independent judges. Ultimately a set of 15 factors that comprised all critical incidents was devised. A survey of 1000 individuals (equal numbers for each gender) in three age groups (30, 50, and 70 years) revealed that the dimensions that most highly correlated with quality of life were material comforts, work, health, active recreation, and learning and education. It was noted that the measure seemed a good indicator for quality of life of people in general, but that similar techniques should be utilized for the development of measures appropriate for disabled populations.

Quality of life is a complex construct which may enhance or diminish one's personal meaning of life. This is an area well-deserving further exploration in the effort to provide for effective, long-term, collaborative health care for patients.

### **Related Constructs**

Quantitative studies to measure activity level, perceived impact of phenomena such as crisis or health-illness situations, and social support/interaction across the life-span are reflective of the desire to explain segments of a person's experience (Amster & Krauss, 1974; Fuller & Larson, 1980; & Guttman, 1978). A number of investigators have attempted to assess feelings and their source or impact upon life, coping behaviors, and level of critical thinking and information-processing abilities (Baldree, Murphy, & Powers,

1982; Beck, Weissman, Lester, & Trexler, 1974; Gurklis & Menke, 1988; Scott, 1983).

Methodologies of the studies on which these reports are based are appropriate for evaluation of components of meaning from a human science perspective, but none has been comprehensive enough to reach the depths of the meaning of personal existence and experience. Although some of these studies dealt with chronically ill populations, none addressed the organ transplant group.

### **Chronic Illness**

Transplantation is not an ultimate end of chronicity. The recipient continues to strive for a state of physiological homeostasis through immunosuppressive therapy, diet, exercise, and self-monitoring. Thus the essential state of chronic illness continues, even though prognosis and outlook may have substantially improved. The long-term implications of chronic illness necessitate multiple accommodations on the part of the patient, the family, and society (Larkin, 1987).

It has been hypothesized that persons who have a chronic illness, yet demonstrate adaptive behavior, have a personality structure differentiating them from persons who have a chronic illness and maladaptive behavior. This personality characteristic has been termed hardiness (Kobasa, 1979). Pollock (1986) studied three groups of chronic illness sufferers, only one of which was found to possess the hardiness trait. The relationships between personality

characteristics and psychosocial adaption have yet to be adequately substantiated in the literature.

Researchers have identified a variety of coping strategies employed by those with diagnosed medical illness and with families of ill individuals. A variety of variables across several domains accompany the use of a particular coping strategy; the specific choice of a strategy is multidetermined, and configuration of several variables associated with a particular strategy is likely to be different for each coping strategy employed (Feifel, Streck, & Nagy, 1987). Rehabilitation of persons with a chronic disease has been said to be contingent upon family assistance in facilitating the patient's adjustment and willingness to seek rehabilitation goals (Power, 1985). Early intervention by helping providers was found to positively impact upon the family's ability to deal constructively with the illness and improve patient outcomes.

Empirically validated hypotheses related to coping with stressful experiences associated with physical illness provide suggestions for nursing interventions. For example, observable coping outcomes and processes to explain why a particular intervention effects an outcome have been reported (Johnson & Lauver, 1989).

### Immune Response

A review of psychic distress and immune response literature yielded significant information regarding

mechanisms of immunomodulation in light of data implicating neuroendocrine and learning factors; evidence supports the supposition that immunosuppression occurs in states of psychic distress (Tecoma & Huey, 1985). A growing body of research suggests that the humoral concomitants of the immune response can affect central nervous system functions, and possibly, behaviors that might be adaptive during illness (Calabrese, Kling, & Gold, 1987).

The immune system is involved in resistance to any disease in which "non-self" elements (antigens) must be recognized and destroyed while "self" elements are spared; these include infectious diseases, cancers, allergies, and autoimmune disorders (Hood, Weissman, & Wood, 1978). Traditional immunologic reactions have been identified as two basic types: Humoral and cell-mediated. Humoral reactions occur rapidly, involving the synthesis and release of immunoglobulin (antibody) into the blood and body fluids. These antibodies act by neutralizing bacterial toxins or by coating bacteria to enhance phagocytosis. Cell-mediated processes do not involve antibody production; they instead are comprised of delayed hypersensitivity reactions, transplantation rejection, and defense against cancer cells and intracellular pathogens (Riott, 1977). It is important to understand and differentiate between these processes in the organ transplant population because of induced immunosuppression--its sequelae may result in either organ

rejection or septic conditions leading to graft failure. In any event, psychological implications are profound. The psychoneuroimmunology literature highlights some significant findings in this regard.

Stein (1989) provided a comprehensive review of stress, depression, and immunity. It was noted from a series of studies investigating stress-induced alterations of the immune system that altered immune system measures do not appear to be a specific biologic correlate of major depressive disorders, but may occur in subgroups of depressed persons. Disparity of findings among these studies were attributed to a variety of factors, including age and severity of the depression.

Given these findings, speculation may occur as to the compounding factor of induced immunosuppression as a means of organ preservation in the transplant recipient, and the potential consequence this may have on biopsychosocial adaptation. Numerous physiological factors, whose mechanisms are not fully understood, may influence the individual's perception of meaning.

One group of researchers sought to prospectively measure changes in immune and endocrine function on a group of healthy individuals before and after acute psychological distress (oral fellowship examinations), and to relate these alterations to psychometric measures of psychological stress, personality style, and coping strategies (Dorian, Garfinkel, Brown, Shore, Gladman, & Keystone, 1982) A control group of

16 similarly educated persons of comparable age and sex was used.

Seven different psychometric tools were administered, and blood samples were taken at several points during the study period. Serum was tested for total lymphocyte count, lymphocyte surface markers, mitogen-induced lymphocyte transformation, suppressor cell activity, natural killer cell activity, and several hormones (prolactin, growth hormone, and cortisol).

This study extended previous findings of depressed T cell function by demonstrating numerical and functional alterations of both T and B lymphocyte subpopulations--despite increased cell numbers, there was impaired lymphocyte function resulting in reduced antibody synthesis in the experimental group. Psychometric analysis indicated a higher level of perceived stress in exam candidates when compared with the control group. All measures of perceived stress returned to below levels of the control group in testing after the oral examination. Dorian et. al. (1982) concluded that stress may have significant deleterious effects on human immune response.

Findings of the above study are relevant to the topic at hand because they demonstrate some of the intricacies involved in the psychoneuroimmunologic reactions that are possible in healthy persons. As noted previously, one can only speculate as to the degree and severity of responses in an

immunosuppressed and psychically stressed organ transplant recipient.

### Transplantation

The organ transplant literature to some degree contributes to an understanding of the biopsychosocial challenges and adaptation processes faced by that group. These studies primarily address the renal and heart transplant populations.

Abram (1972) interviewed 30 renal homograft recipients in an effort to describe overall adaptation and the symbolic meanings and unconscious conflicts that affected responses to the way of life post-transplant. It is interesting to note that the sample was intentionally selected to include only those who had received cadaveric organs, so that attitudes toward the homograft could be assessed (fantasies and dreams concerning transplant, body-image changes and distortions, and thoughts and feelings about the donor). Interview questions centered on life/family history, history of renal disease, patient and family adaptation to dialysis and then to the transplant, and changes in life-pattern, work, sexual habits, etc.

Findings from this study indicated that, although the patient's existence was not anxiety-free, living with the new organ did not present overwhelming problems (Abram, 1972). Most patients expressed gratitude for a functioning kidney. More than one-half of these patients returned to work or

school, and less than 35 percent had some psychiatric complication or psychosocial upheaval.

Renal transplant candidates have a distinct advantage over those suffering from end-stage heart or liver disease. Hemodialysis is a life-sustaining alternative in the event of nonfunctional kidneys. The latter two groups do not have that option. There is, however, evidence that supports transplantation over dialysis in light of quality of life and rehabilitation potential of these patients.

A study of **survival rates and quality of life** (using measures such as work, activity level, psychological status, and sexual functioning) among both hemodialysis and kidney transplant patients was conducted over an eight year period by one group of researchers (Bonney, Finkelstein, Lytton, Schiff, & Steele, 1978). Quality of life indices suggested that dialysis patients had a substantial impairment in all parameters, and that the transplant patients achieved a better degree of rehabilitation.

Kidney rejection and failure and the subsequent readjustment to dialysis have been examined (Streltzer, Moe, Yanagida, & Siemsen, 1983-4). Twenty-five patients who had suffered kidney transplant failure during a ten year period were interviewed by a research team. Questions related to original reaction to the transplant (perceptions before and after surgery), feelings about having to return to dialysis, who assisted in the adjustment of returning to dialysis, and

how they would respond to the offer of another kidney transplant. Psychological adjustment to returning to dialysis was deemed good in 24 of the 25 patients. Fourteen were considered to have successfully grieved the loss of their transplanted kidney, while ten denied any psychological difficulty in returning to dialysis. Sixty-eight percent of respondents agreed that they would be interested in re-transplantation if that option became available. The authors concluded that denial as a coping mechanism should be supported when present, and that those who actually grieve the loss of their organ should be assisted through that process and followed up to ensure resolution and proper readjustment to dialysis.

An investigation of perceived **life satisfaction** and **quality of life** as reported by heart transplant recipients has been published, as well (Lough, Lindsey, Shinn, & Stotts, 1985). The impact of life change and problems associated with immunosuppressive drug side effects were also examined in this study. A questionnaire was mailed to 100 heart recipients, 75 of which were completed and returned. The instrument was an adaptation of one previously devised by other researchers, and items covered quality of life and life satisfaction, life change since the surgery, and symptoms related to immunosuppressive therapy. The last category included identification of symptom frequency and degree of emotional distress precipitated by the symptoms. Eighty-nine percent of

these patients reported good to excellent quality of life. Life satisfaction was reported as positive by 82% of respondents. Even though there was agreement on considerable change in life style as a result of transplantation, perceptions were positive. Physical side effects from medication regimens had little impact on the overall positive evaluation of life quality and satisfaction.

Another group of investigators reported on the **psychiatric assessments** of 33 heart transplant recipients (Mai, McKenzie, & Kostuk, 1986). Pre-operatively, anxiety and depression were found to be most prevalent. The physiologic post-operative course of some patients was tenuous, with 11 of the 33 expiring from medical complications. Six of the 22 surviving recipients experienced acute delirium, and half of these required intensive pharmacotherapy; all of them recovered. Four patients developed moderately severe anxiety, and three exhibited social and/or behavioral problems. Only five patients were seen at a 12-month psychiatric follow-up, and all but one (who had been diagnosed with clinical depression at 6 months) were reported to have made reasonable psychosocial adjustment.

One group of authors highlighted the need for effective **psychiatric evaluation** as a part of the pre-transplant work-up in cardiac patients (Freeman, Watts, & Karp, 1984). Using a case study format, eight patients were described in terms of pre-transplant psychosocial evaluation and findings of this

assessment were compared with each patient's post-operative medical and psychiatric/psychosocial adaptation. These patient's stories demonstrated how such factors as ambivalence, family pathology, dependence, substance abuse, non-compliance, anxiety, depression, psychosis, and cognitive dysfunction can have a major impact on the post-transplant course. These investigators summarized by postulating that some relationship exists between psychiatric factors and post-transplant outcome, possibly mediated by immune factors.

Early reports in the heart transplant literature have provided insightful information regarding neurological complications thought to be related to **immunosuppression**. Although the literature is not current, it posed questions that are as yet unresolved and therefore relevant.

Hotson and Pedley (1976) performed a retrospective analysis of 83 cardiac transplant recipient records. They noted that 54% of patients had at least one neurological complication, with 16% exhibiting more than one. Twenty percent of the patients in this study reportedly died because of these complications. Aside from infection, encephalopathy and acute psychosis accounted for a preponderance of the neurologic problems. This information substantiates the speculated effect of induced immunosuppression on psychoneuroimmune responses in the transplant population.

More recently, Packa (1989) sought to describe the **quality of life** after a heart transplant. The McMaster Health

Index Questionnaire was used to assess three dimensions of health; physical, emotional, and social. The Cantril Self-Anchoring Scale served to establish overall quality of life at three periods in the recipient's transplant experience; one month before transplant, at the time of interview (post-transplant), and that expected five years after transplant. Twenty-two subjects completed the study. The investigator concluded that the most satisfactory assessment of quality of life was in the physical index, followed by social satisfaction. The lowest scores were found in the emotional index. Cantril Self-Anchoring Scale scores revealed significant improvement in perceived quality of life from the pre-transplant to post-transplant interview time, with even more substantial **anticipated** improvement five years after transplant.

One group of investigators performed a study of 56 cardiac transplant recipients who survived six or more months after transplantation, with the purpose of determining **degree of rehabilitation** (Christopherson, Griepp, & Stinson, 1976). It was found that 51 (91%) of the subjects were classified as successfully rehabilitated, four (7%) suffered substantial physical disability, and one (2%) experienced psychiatric disability. Categories by which these patients were rated in determining success of rehabilitation included: Competitive employment, retirement by choice, school enrollment/student status, homemaking ability. Mastery of tasks for self-care,

accuracy/regularity of self-medication, adherence to diet, and compliance with other aspects of the medical regimen were evaluated as well.

Mishel and Murdaugh (1987) used a **grounded theory** approach to explore the processes that **family members** of heart transplant recipients use to **manage the unpredictability** elicited by the need for and receipt of a heart transplant. The sample consisted of 20 subjects who were participants in three different support groups. Thirty-six transcripts provided the data for constant comparative analysis, obtained over a two-and-one-half year period of support group meetings. The authors identified the basic social psychological process that emerged as **redesigning the dream**, which refers to cognitive and behavioral changes that occur in the partner (significant other or family member) from the time that the patient enters the heart transplantation program. The initial dream of return to a "normal" life is reformulated and reshaped to fit the reality of the treatment environment.

Molzahn (1991) noted that organ transplants are taking place with increasing frequency and are generally known to increase the length of life, but the author continued to question the quality of that life. A literature review was conducted to ascertain the current status of research in the area of quality of life in various types of organ transplant recipients. Findings of this review reinforced the fact that quality of life after kidney and heart transplantation is very

good, when compared with the pre-transplant state. It was suggested that more research is needed to examine the quality of life of recipients of other types of transplants. Issues needing further exploration were identified, and included: Definitions of quality of life, dimensions of quality of life, expectations of quality of life, and clinical assessment of quality of life.

The ultimate goal of organ transplantation is clear: To extend life that would otherwise be lost to organic disease. Medical science has made great strides to this end. What remains to be reconciled is the description of the numerous variables that are not amenable to treatment with "cc's and milligrams of medication" or "another surgical incision" or any other invasive procedure. The multiplicity of biopsychosocial implications of organ transplantation must be studied as they bear on the whole, and the individual's perception of the experience. This study of the meaning of life in these patients provides those insights.

### CHAPTER III

#### STUDY DESIGN

The method used in addressing the research question was twofold: A qualitative, phenomenological design to explicate qualities of the lived experience; and a triangulated approach using questionnaire data to provide measurable information for corroboration and validation purposes. One type of this design is that which describes a single broad variable in a population; a basic assumption is that it proposes no cause-and-effect relationship and is therefore not a prediction nor the basis for a hypothesis (Brink & Wood, 1989). A prerequisite to this type of design is that the variable in question is understudied as evidenced by the literature. This is without question true of the global perspective of meaning of life in the organ transplant population.

The need for multiple triangulation techniques arises from the position that no single approach resolves the question of related factors. There is greater possibility that outcomes are valid when multiple methods are applied (Roberts & Burke, 1989; Sohler, 1988).

Field and Morse (1985) noted that triangulation is a particularly useful approach when the intent is to gain information about a single concept. The historicist

orientation encourages theory expansion through a process of integrating components from different research traditions, which results in a multidimensional understanding of the phenomenon studied (Silva & Rothbart, 1984). The research question lent itself well to multiple processes in understanding human perceptions post-transplant.

### Phenomenology

The phenomenological approach was used to uncover the qualities of meaning of life in transplant patients in order to arrive at a structural definition of the experience. The specific approach was semi-structured interview, recorded on audiotape. These qualitative data were analyzed according to the guidelines set forth by van Kaam (1966).

Phenomenology was chosen for this study because its goal is to understand human experience from the individual's perspective, viewing a phenomenon within its own meaning and structure (Knaack, 1984). This method was originally founded in the philosophy of Husserl (1973), who suggested that life and world are integral, and of greatest importance is a consciousness of being in the world.

Theoretical assumptions underlying this tradition include: (a) human and the environment are essential to each other; and (b) access to knowledge about the human being is gained by investigation of the conscious world (Dzurec & Abraham, 1986). Truth is viewed as a composite of individual's perceived realities and is conceptualized as

changing and context dependent rather than as fixed and inviolate (Dzurec & Abraham, 1986).

Phenomenology is geared toward enlarging rather than reducing life experiences. The individual is not an actor in isolated situations but is a person living in an ongoing process of experience, a process in which one "gets older" not only by the lapse of biological time, the aging of the organism, but in which one matures in experience (Wagner, 1973). Wholeness of being and its importance in living an experience are acknowledged. Research techniques are open-ended and suggestive rather than definite.

### **Researcher Perspective**

The role of the researcher is to study the life-world of others, not the life world from the researcher's own perspective. The researcher "attempts to transcend the everyday intentionalities in which he is the center of his own existence and adopt another point of reference" (Psathas, 1973, p. 9). Findings, then, are grounded in the data and are increasing levels of abstraction of the participant's views.

### **Bracketing**

Bracketing, or phenomenological reduction, is a means to acknowledge the researcher's own biases, enabling clear reception and interpretation of the phenomenon (Cohen, 1987). The process requires that the researcher make explicit personal assumptions, preconceptions, and presuppositions about the experience, to avoid misunderstanding the phenomenon

as it exists for the individual (Knaack, 1984). It is an explication of assumptions, or suspending beliefs in the reality of the natural world in order to study the essential structures of the world (Van Manen, 1990).

Very early in the research process, as the problem statement was refined and study methods were selected, the researcher recorded in a journal some thoughts, ideas, and preconceived notions regarding meaning of life as it might relate to the transplant experience. These notes were based predominantly on previous experience with liver and kidney recipients, and largely from thoughts reflective of the literature related to heart transplants. Throughout data collection and analysis, care was taken to induce phenomenological description based on the data and not on these thoughts and assumptions.

### **Sample**

A convenience sample was used for the study. Convenience sampling is a nonprobability technique, and one in which participants are accessed who are easy to identify and contact (Woods, 1988).

Participants were selected on the basis of their accessibility, on their ability to meet the study criteria, and on their willingness to participate. Three main sampling techniques were used. First, some participants were contacted who were known to the researcher through various experiences with the Transplant Program at a large medical center in the

Southeast United States. Second, others were introduced or recommended by colleagues familiar both with the particular transplant population and with the researcher's intended area of study. Finally, several transplant recipients contacted the researcher themselves, after hearing from other participants about the study, and requested the opportunity to participate.

All participants were residents of the same southern state. Transplant surgeries took place at several transplant centers throughout the United States. Participants were followed for health care at various medical centers throughout the southeast.

The sample consisted of eleven participants who had experienced the transplant of a heart, liver, or kidney at some point prior to being considered for the study. It was necessary for participants to read, write, and speak the English language.

Participants ranged in age from 22 to 73 years. The under 18 age group was eliminated largely because of potential difficulties in completing the questionnaire. Also, the experience of organ transplant is vastly different for younger populations with respect to physiological adaptation, and other characteristics such as growth and development level and social considerations (role in the family, friends, etc.).

It is recognized that though the sample size is small for questionnaire administration, the goal of this study was to

**explicate meaning of life** using a phenomenological approach with triangulation of methods. Sampling strategies in qualitative research call of **informational adequacy**, or researcher assessment of the relevance, completeness, and amount of information obtained, sometimes referred to as saturation (Morse, 1989). The desire for phenomenological explication superseded the desire for questionnaire generalizability. Additionally, non-parametric analysis of the Life Attitude Profile-Revised data was planned since it was recognized that sampling methods precluded the use of parametric procedures.

### **Setting**

Time and place of interview were at the convenience of the participant and mutually agreed upon with the researcher. Six of the transplant recipients chose to participate in a private office in the hospital, one was an inpatient in the hospital (interviewed in the patient room), and four opted for participation in their homes. The in-home encounters were private and generally uninterrupted, with only the participant and the researcher present for the questionnaire completion and interview. The times of each meeting ranged from forty-five minutes to one hour and forty minutes.

### **Instruments**

#### **Demographic Profile Questionnaire**

A researcher developed **demographic profile** was obtained for each participant. Items included age, gender, employment

status, income (reported as a dollar range,) educational level, marital status, date of transplant, and type of organ transplanted. (See Appendix A).

### **Investigator Journal**

A journal was maintained by the investigator which reflected descriptive accounts of the interview process not recorded on audiotape during the actual interview. This included notations regarding the setting, nonverbal behavior, physical appearance, and similar characteristics. Some notes were handwritten and some were recorded on audiotape immediately after the interview, depending on location and circumstances.

### **Life Attitude Profile-Revised**

The measurement portion of the study involved administration of the Life Attitude Profile-Revised (LAP-R) (Reker, 1992) to all participants. Responses are reported on a seven-point Likert-type scale ranging from strongly agree to strongly disagree. The scale is reported to require a fifth grade reading level (Reker, 1992). Participants had no difficulty in completing the LAP-R, and took between 20 and 40 minutes to finish it.

The LAP-R was used to ascertain the individual's perception of meaning and purpose in life. Reker and Peacock (1981) originally developed a multidimensional instrument, the Life Attitude Profile (LAP), to measure meaning and purpose based on Frankl's (1978) theory of "will to meaning." The

LAP-R is the latest revision of this instrument by Reker (1992), who considers it a "fine-tuned version" (p. 16).

There are a total of 48 items in the LAP-R, with eight items representing each of the six dimensions. The six dimensions are explained below:

**Purpose** (life goals, a mission in life, sense of direction from the past, present, and future)

**Coherence** (logically integrated and consistent analytical and intuitive understanding of self, others, and life)

**Life Control** (freedom to make life choices, exercise of personal responsibility, internal control of life events)

**Death Acceptance** (lack of fear or anxiety about death; acceptance of death as a natural aspect of life)

**Existential Vacuum** (lack of meaning in life, lack of goals, lack of direction; boredom; apathy)

**Goal Seeking** (desire to achieve new goals; welcome new challenges) (Reker, 1992).

Scale scores were obtained simply by summing item scores for the respective dimensions. The scoring scheme for each response was:

- |                        |     |
|------------------------|-----|
| a. Strongly Agree      | = 7 |
| b. Agree               | = 6 |
| c. Moderately Agree    | = 5 |
| d. Undecided           | = 4 |
| e. Moderately disagree | = 3 |

f. Disagree = 2

g. Strongly Disagree = 1

The possible range of scores was 8-56. The higher the score in a dimension, the higher the degree of the attribute in question.

Two composite subscales have been identified in this latest edition of the LAP-R (Reker, 1992). Explanation of these subscales follows.

**Personal Meaning** is a dual-component construct including life goals, mission in life, sense of direction, **and** having a logically integrated and consistent understanding of self, others, and life in general. The personal meaning index is derived by summing the Purpose and Coherence dimensions of the LAP-R (Reker, 1992, p. 23).

**Life Attitude Balance** is a global measure of attitudes toward life that takes into account both the degree to which meaning and purpose have been discovered **and** the motivation to find meaning and purpose. It is the sum of scores on the dimensions of Purpose, Coherence, Life Control, and Death Acceptance, and subtracting the scores of Existential Vacuum and Goal Seeking (Reker, 1992, p. 23).

Reker (1992) provided specific scoring instructions for the instrument. Scale scores are obtained by summing item scores for each dimension, with a maximum possible score of 56 in each area. A high total score on each dimension indicates a high degree of the respective attribute. The subscale

indices allow for a possible score range from 16 to 112 on Personal Meaning, and 80 to 208 for Life Attitude Balance.

Internal consistency and stability coefficients for each dimension have been reported (Reker, 1992). Cronbach's alpha ranged from .77 to .84, with the highest in the dimensions of purpose and death acceptance. Results were similar across three data sets. Composite scale alpha coefficients were reported as .89 to .92.

Test-retest coefficients ranged from .75 to .88, with the highest in the coherence, purpose, and existential vacuum dimensions (Reker, 1992). These data provide evidence for the short-term stability of the LAP-R.

Validity issues were addressed by developers of the original LAP instrument, and are currently in progress for the revised tool. For the original LAP, there were significant correlations with other tests for each concept/dimension (Reker, Peacock, & Wong, 1987). **Life Purpose**, for example, was reported to significantly correlate with internal locus of control, self-concept, and positive perception of life at present. **Life Control** was noted to correlate with internal locus of control measures. **Death Acceptance** was reportedly compared with a semantic differential rating of death, also reflecting positive correlations. A comparison of dimensions in the LAP and the LAP-R suggest validity for the revised test will be similar, because changes in the theoretical

foundations were minimal and specific item changes reflect clearer and more concise elements.

Since the LAP-R was revised based on substantial research, it is important to note the historical context of the original instrument. Literature on the LAP denotes the dimensions were "factorially derived" (Reker, Peacock, & Wong, 1987). Validity reports for this tool suggested that its developers used both mathematical and theoretical operations in order to interpret the fit between the items as they loaded onto the factors **and** to integrate the theory that motivated the definitions of each dimension.

The instrument was noted to be free of social desirability threats, except in the **Life Control** subscale (Reker, Peacock, & Wong, 1987). This is likely an accurate assessment, because that dimension is concerned with a personal, subjective judgment regarding how effectively one deals with life events. This may be a sensitive issue and one a person may respond to in terms of how it is thought that one **should** deal with life events rather than **actual** performance.

### **Procedure**

Written informed consent was obtained prior to any data collection. (See Appendix B). Upon agreement to participate, the demographic data was collected, then the LAP-R was administered, and finally the semi-structured interview was conducted and recorded on audiotape.

### Semi-Structured Interview

Tone for the interview was set by some introductory comments clarifying the study purpose and the goal of the interview. Interview questions included:

(1) I am interested in what your life was like before the transplant... ....before you became ill.

(2) What does receiving this new [organ] mean to you?

(3) What has this experience meant for your family? ...role in the family? ...relationships with friends?

(4) What do you think is the meaning of your life?

(5) Do you think this is different from what you thought before you needed a transplant? ... from before you were transplanted?

Based on interview experience, it is important to note that the interview guide was truly a "guide." Questions specified above were found helpful, but did not all apply in every situation. Some participants needed little or no prompting once they began talking. The guide posed no constraints on the course of the interview. Flexibility was crucial in dealing with this sensitive topic. A time limit was not set on the interview. No participants expressed objection or reluctance to be audiotaped.

Approximately two weeks after the initial encounter, participants were contacted either by telephone or in person for follow-up. Questions at this time were primarily intended to confirm and validate information gleaned during the first

interview. The participants were also afforded the opportunity to expound on thoughts and feelings that may have occurred subsequent to the initial interview. These encounters lasted a maximum of 20 minutes. Few new thoughts were added by the participants, and there was overwhelmingly positive response to the investigator's identified key themes and interpretive descriptions.

### **Ethical Concerns**

Human Assurance Committee approval was obtained prior to any data collection (See Appendix C). Audiotapes, transcripts, computer diskettes, and LAP-R data were stored in a locked file cabinet in the investigator's office. Anonymity was assured through investigator assigned codes for all pieces of data.

### **Data Analysis**

#### **Demographic Profile**

Demographic data from the profiles were summarized. Categories included age, gender, economic group, employment status, marital status, length of time since transplant, and type of organ transplanted.

#### **Phenomenological Analysis**

The Ethnograph (Seidel, Kjolseth, & Seymour, 1988), a qualitative software program, was used to manage and store interview data. Transcription was done predominantly by the investigator, however clerical assistance was sought for two of the final interviews. Auditability of data was ensured

through systematic organization and storage of data. Tapes, transcripts, codes, etc. were available for confirmation of analysis by another expert, in accordance with credibility recommendations by Guba and Lincoln (1981).

Once interviews were transcribed, phenomenological analysis proceeded according to Van Kaam's (1966) scientific phases of explication. These included:

- (a) listing and preliminary grouping of data;
- (b) reduction (to descriptive terms);
- (c) elimination of non-applicable data;
- (d) hypothetical definition (description of the feeling);
- (e) application (to selected cases of the sample);
- (f) final identification of the definition (p. 314-315).

van Kaam (1966) noted that these operations are not necessarily sequential, and tend to overlap one another. They are a set of ordered abstractions reflecting complicated mental processes the phenomenologist experiences.

A hallmark of qualitative research is that data analysis is an ongoing process, and data collection and analysis go hand-in-hand (Taylor & Bogdan, 1984). Steps in the process took a circuitous route until data saturation was achieved.

This means of analysis views the study participant as a co-researcher (Knaack, 1984). It is important, then, to consider potential interpretations of data in light of the impact that both the investigator's and the participant's historical contexts have on a life experience. The technique

of bracketing accounts for the author's acknowledgement and abeyance of forethought on the subject.

### **Life Attitude Profile-Revised Analysis**

**LAP-R Analysis.** The study design, the small nonrandomized sample, and the use of ordinal level data all preclude the possibility of using parametric statistical procedures, because the assumptions of parametric methods are violated. Nonparametric maneuvers were therefore used in the analysis of the data. These foundational statistics provided confirmatory data, augmenting phenomenologically derived information. A matrix reflecting dimension/subscale percentages for each participant is presented in Chapter IV.

**LAP-R Instrument Reliability.** Internal consistency of the LAP-R was estimated by use of Cronbach's Alpha for each of the six dimensions of the scale. Alpha is a measure of the extent to which performance on any one item on a scale is a good indicator of performance on any other item in the same scale. Brink and Wood (1989) noted that alpha does not provide a very good estimate of reliability when the number of items is small, and under this condition alpha will be smaller than the true internal consistency of the scale. Each subscale of the LAP-R contains eight items. This small number of items may lead to the risk of lower than actual internal consistency. This was deemed an acceptable risk since this was a study involved a small number of participants, and

because comparative data was available from the instrument's previous use by other investigators.

### Triangulation

Sohier (1988) suggested that by setting nursing research questions firmly in the contextual and conceptual fields of their origin, nurse researchers can increase consistency between epistemological and empirical elements. This, in turn, facilitates research that is meaningful for nursing science.

The researcher learns far more by using all of the information available from multiple sources than by use of any one method alone. Polkinghorne (1983) stated "human science research can reap significant benefits from using multiple procedures for its research designs" (p. 252). The process produces a new dimension of understanding, and a dimension of depth in findings. It is possible to capture a more complete, holistic, and contextual portrayal of the phenomenon of interest (Jick, 1979).

Scientific knowledge derived by using different investigative approaches enhances the process of illuminating, uncovering, and providing rich description of human phenomena. The data are most appropriately analyzed according to prescribed tradition for each method, and then findings are conjoined in final analysis to provide a holistic perspective and a conceptually cohesive whole (Morse, 1991; Polkinghorne,

1983). This process culminates in comprehensive understanding and clarity of findings.

Triangulation of methods was a substantive strength in the process of uncovering the meaning of life in this study. A global perspective of the phenomenon was explicated. Phenomenological and LAP-R data were critically appraised. Journal entries facilitated and reinforced interpretation of interview data. These processes were facilitated by investigator triangulation. This occurred as corroboration with qualitative experts was achieved at all levels of interpretation and abstraction.

Joining of phenomenological findings with LAP-R findings occurred in the "Discussion" of the study, as linkages became clear and interpretations were solidified. The LAP-R findings were invaluable.

This study demanded the use of the LAP-R for several reasons. First, its theoretical base--Frankl's (1969) theory of **will to meaning**, is congruent with the philosophical foundations which led to the identification of the research question. Second, a description of the concepts of meaning and purpose in life in the organ transplant population are a valuable tool to clinical practitioners as they strive to care in a holistic manner for these patients. Insight may be gained into the individual's existential coping and adjustment processes during a time of major physical and emotional challenge. Third, the instrument validity is strengthened by

the technique of triangulation of methods. Interview data served to further clarify validity of the conceptual links suggested by the factor analytic procedures used in its development. Finally, the literature had not previously reflected use of the LAP-R in a triangulated study. Demonstration of its effectiveness in this instance is considered a strength, highlighting versatility and applicability in a variety of areas.

Triangulation techniques have been an issue of contention in the nursing literature for some time. Their value, however, can be assessed in light of a report published several years ago in which a comparison was made of two stress and coping studies (Bargagliotti & Trygstad, 1987). One study was qualitative, the other quantitative, and both looked at work related stress in nurses. Important differences in sources of stress and in coping patterns were reflected in the two studies. The authors of this critical appraisal suggested that the differences were likely the result of the diverse methodologies and not due to social realities. Their conclusion was that the findings of these studies may have been more comprehensive had combined methods been used, owing to the complex nature of the topic. The same is true of the meaning of life in organ transplant recipients.

#### Tests of Rigor

The study was conducted in accordance with recommendations by Guba and Lincoln (1981) for aspects of

rigor in naturalistic inquiry. Criteria include credibility, fittingness, auditability, and confirmability. Additionally, these criteria were supplemented by Leininger's (1990) recommendations for evaluating on the basis of meaning in context and saturation.

**Credibility** was related to issues of internal validity--the "truth value" or the confidence that findings are accurate reflections of the participant and context (Guba & Lincoln, 1981). Acknowledgement of multiple realities in naturalistic inquiry is critical. This investigator insured that the sources of information were credible and that sources concurred with the investigator's interpretations. Some participants were asked to review analyzed data--codes, categories, and definitions; they then attested to the accuracy of findings. Participants were selected for this process based on convenience and interest on their part. There was general agreement among those reviewing the data that an accurate description of their meaning of life was portrayed. Further, there was concurrence with the structural definition of the experience.

Guba and Lincoln (1981) have suggested triangulation as an effective means to establish truth value, as well. Multiple analytic methods and investigator triangulation substantiated this in the current study. These findings are elaborated upon in the "Discussion" section of this report.

An additional criterion in assuring the rigor of naturalistic research is **auditability**. This dealt with the reproducibility of categorical sets by another competent judge (Guba & Lincoln, 1981). The code list and definitions, together with a sampling of the interview data, were presented to an experienced qualitative researcher for review. The data were coded by that expert, and substantial agreement was demonstrated.

**Meaning in context** refers to "data that are understandable and relevant within certain situations, settings, life experiences, or within specific or total frames of reference" (Leininger, 1990, p. 43). The frame of reference surrounding participants in this study is the unique experience of vital organ transplantation. These organ transplant recipients shared views of life and lived experiences within that context. Descriptions were rich and reflected depth of thought. They revealed a wholeness of experience and view previously unknown through scientific inquiry.

The criterion of **saturation** was achieved when evidence that all that could be known or understood about the phenomenon under study was uncovered (Leininger, 1990). This occurred as new interview data were examined and found to have "code" and "emerging theme" similarities with previously obtained interviews. There was a tendency toward duplication of participant descriptions and thoughts across interviews,

thus enabling progression through the final phases of phenomenological analysis.

### **Summary**

A detailed description of the research design was presented in this Chapter. Methodological triangulation was described, incorporating a phenomenological approach and a measurement instrument. The strategies for analysis of each approach were presented, along with an overview of the plan to draw findings into a cohesive whole in the discussion of the meaning of life of organ transplant recipients.

The sampling techniques, setting, semi-structured interview guide, and instrumentation, and tests of rigor were all described in some detail. Ethical concerns were addressed. Findings are presented in the following chapter.

## **CHAPTER IV**

### **FINDINGS**

Findings from data analysis are presented in this chapter. Initially, demographics of the sample are described. The interview data analysis is then presented according to van Kaam's (1966) method. Although depicted in seemingly sequential steps for the purposes of clarity and comprehensiveness, it should be noted that the process of analysis was actually circuitous--repeated review and return to original transcripts, audiotapes, codes, themes, and categories were necessary to arrive at a structural definition of the meaning of life in organ transplant recipients.

#### **Demographic Profile**

The sample consisted of eleven participants who had experienced the transplant of a liver (4), kidney (5), or heart (2) at some point prior to being approached for participation in the study. All participants could read, write, and speak the English language. Each also demonstrated capability and interest in discussion of the topic. A minimum age was set at 18 years. All participants were experiencing reasonably good health at the time of interview, and all had at some prior point experienced problems with organ rejection or infection. One person was

hospitalized at the time of participation, and was satisfactorily recovering from an episode of rejection.

The investigator contacted transplant recipients meeting the research criteria by telephone, and had knowledge of some of them from previous contacts as in-patients either before or after the actual transplant surgery. Others were referred to the researcher through professional contacts or study participants. All who were approached agreed enthusiastically to participate. Informed consent was obtained prior to entering the study. Anonymity was assured to each participant.

The **demographic profile** showed participants to be fairly diverse, and is summarized in Table I. There were six males and five females. Ages ranged from 22 to 73 years, with a mean age of 42.18 and median of 41. Five people were actively employed at the time of the interview; one was retired from a position after 50 years of service; the others had all stopped working at some point prior to the surgery for health reasons. Three had been physically disabled for quite some time, and had never really held long-term or "permanent" jobs.

**TABLE I**  
**SUMMARY OF DEMOGRAPHIC PROFILES**

<u>AGE in YEARS</u>	<u>MARITAL STATUS</u>	<u>GENDER</u>
Range: 22 - 73	Married: 4	Male: 6
Mean: 42.18	Single: 4	Female: 5
Median: 41	Divorced: 3	

<u>EMPLOYMENT STATUS</u>	<u>HIGHEST EDUCATIONAL LEVEL</u>
Employed: 5	High School Diploma: 3
Unemployed: 5	GED: 1
Retired: 1	Some College: 3
	College Graduate: 2
	Trade/Technical: 2

<u>ANNUAL INCOME</u>			
≤ \$10,000			3
> 10,000	-	≤ 25,000	4
> 25,000	-	≤ 40,000	3
> 40,000	-	≤ 60,000	1

Median Income: > 10,000 - ≤ 25,000

<u>LENGTH OF TIME SINCE TRANSPLANT</u>		
Range: 9 months - 7 years		
Heart	1 year	6 months
Heart		9 months
Liver	7 years	
Liver	2 years	
Liver	1 year	7 months
Liver		6 months
Kidney	6 years	
Kidney	5 years	2 months
Kidney	4 years	4 months
Kidney	1 year	2 months
Kidney		8 months

Income was assessed only by that money brought in by the transplant recipient and **not** as family income. This was deemed appropriate for the purposes of this study since the family/living situations were so divergent, with some households having as many as three financial contributors and others having no means of support aside from the participant. It is unclear from the literature and investigator experience as to whether or not financial status played a role in one's assessment of meaning of life. Incomes ranged from less than \$10,000 per year to a maximum of \$60,000 per year. The median range was \$10,000-\$25,000. Sources of income included employment, disability, and retirement plans.

#### **Phenomenological Findings**

Audiotaped interview data were transcribed by the investigator, with the exception of two tapes for which clerical assistance was sought. The investigator listened to each audiotape several times during the course of data collection and analysis, simultaneously reading over the transcriptions. This process served the dual purpose of both insuring accuracy of the written data, and enabling the researcher to more fully absorb and understand the contents. The latter allowed for careful attention to voice inflections which assisted in ascertaining and validating the more emotional comments and discriminating between less and more highly charged areas of concern.

The meaning of life for organ transplant recipients was found to have a multiplicity of interconnected aspects. Many paradoxes arose within the themes and descriptions. Most of these themes and descriptions cannot be viewed in isolation, except briefly for the purpose of explication. Thoughts and emotions tended to occur sometimes fleetingly, sometimes simultaneously, and at other times just on occasion throughout the interviews. Examples of the process of phenomenological analysis follow and are in keeping with van Kaam's (1966) guidelines.

Beginning with raw data generated through interviews, participant responses were examined in totality. "...The number and variety of their descriptions increase the probability that when combined, they will touch on the underlying necessary and sufficient constituents of the experience" (van Kaam, 1966, p. 314). Data analysis was initiated as each interview was completed, as it was important to ensure that interview questions were satisfactorily tapping the qualities of the experience. Once the investigator had reflected upon overall content of each interview, scientific explication was systematically performed.

#### Listing and Preliminary Grouping of Data

Listing and preliminary grouping of data began with extraction of descriptive expressions directly from the transcribed interviews. Careful effort was made to include in this listing process descriptions related to the entire

spectrum of ideas and comments, and emotions and feelings that each participant exhibited.

Data was then classified into codes. The Ethnograph (Seidel, et al., 1988) was employed as a data management tool at this point. These initial codes came directly from the data (see Appendix E). The investigator found that merely selecting one-word descriptions did not, in some instances, justly exemplify the many complex thoughts and feelings expressed. Rather than risk distortion of meaning, some whole segments of data were coded together; this included a line, sentence, or sometimes a whole paragraph of data. In this manner, van Kaam's (1966) "descriptive expressions" were extracted as complete thoughts, maintaining integrity and contextual description of participant ideas.

Initial codes and groups eventually encompassed every basically different statement in the transcripts. This listing reflected the predominant features of the phenomenon under study--the meaning of life in organ transplant recipients.

Examples of descriptions from the transcripts follow. These are verbatim quotes from the participants, and are linked to the codes.

"I usually have more time for friends and social stuff now that I'm not tied to that [dialysis] machine."  
{activities and social life} An appreciation for social activities and friends, and the contributions they make to

one's life and lifestyle are evident throughout the interviews.

The fear of death prior to transplant was less a concern for the kidney recipients than for those with heart or liver transplants: "I never really worried about dying before, but I did get scared that they wouldn't find a kidney and I would get too many problems with dialysis. I guess I just wanted it so bad I knew I couldn't give up." {how life and its meaning have changed}

The oldest participant (73 years of age at the time of interview) reflected on the possibility that transplantation would not be offered by the selection committee: "I was resigned to the fact that that [being turned down] was a good possibility because of my age...In fact I was a little bit reluctant really to make a decision, because I felt at 72, at that particular time, ah, were there some people that needed it more that have a longer life span ahead of them than I?" This participant acknowledged that the disappointment would have been great, but also that the decision could be rationalized in light of the "greater good to mankind."

Personal revelations were common, and often spiced with humor: "Just, whenever I think about it, I can't believe it was so exciting--I was so happy to wake up and find out that my new kidney was making urine. I get embarrassed now, 'cause it sounds silly to talk about. But it was like I was born again, that feeling. And now that I think about it, I even

acted like a kid. I can joke about it now, but I was a little afraid to back then." {what this new organ means and how it has changed life}

"I call my new liver my little friend, and I talk to him all the time. I know I wouldn't be here without him--it's given me a new life." {what this new organ means}

There was an component of collegiality throughout these rich descriptions of life after transplantation: "Knowing all these other transplants has given me a new circle of friends! I'm having a great time with them." {how life has changed}

Hope for the future was a predominant theme, as evidenced by the participant who noted: "I can make plans now. Before I was kind of depressed sometimes, and afraid; but I didn't want my family to know 'cause they'd worry. Now I know there may be problems, but there also may be solutions. I had hope, and I will keep hoping because it worked before." {how life is different now} Hope almost seemed a feature "learned" through the experience of chronic illness--what worked before may work again.

The conceptualization of a higher power, in a spiritual sense, came through clearly in **every** discussion. Some participants acknowledged belief in "God" and others referred to some "Supreme Being" who was a guiding, stabilizing force and a source of tremendous strength. "Before I was just tired of being sick. Five times I had bad bleeds and woke up in the ICU to find out I'd been in a coma, sometimes for a couple of

days. I wasn't afraid of dying, but if He [God] was going to let me live, I wanted Him to get on with it." {spirituality in light of what this new organ means}

Pre-transplant lifestyle was a source of frustration and sometimes despair, while the post-transplant life was viewed with a sense of planning and rebirth: "I hope I can get back to work. When I had to quit my job, I lost a lot--friends, money, a big part of my social life. Now I might be able to make a fresh start." {life before the transplant}

Concern for family relationships was common: "My family; I was afraid I was a burden to my wife and my dad. Things aren't perfect yet, but I seem to be more patient with them and with myself. Before I took things out on them sometimes. I was angry but I handled it wrong." {family relationships}

Yet another significant perception was that healthy people, indeed these very people prior to the illness precipitating the need for transplantation, tended to take **life and time** for granted. The transplant experience and the subsequent opportunity it presented for another chance at life was now treasured. The value was acknowledged both in terms of "another chance" and the personal revelation that one **never** has time to waste in life:

"I think I took almost everything in life for granted before. I don't do that any more. Life is just too, too precious." {how life has changed}

"I think that [illness and the care it required] took a lot of time before, valuable, precious time. But it's like I took it for granted before, that time...I feel like I've done more **real** living in that year or so [since the transplant] than I did for a long time before that."

These participants were very open in discussion of their perceptions of the meaning of life. The quotes and discussion above represent only a sampling of the values, the sentiment, and the conceptions that embody personal **meaning of life** for these organ transplant recipients. These examples represent the most prevalent expressions of perceived experience found in the original interview data.

Codes were clearly grounded in the data, and were actual labels chosen by the investigator that summarized or characterized a concept as appropriate to the context and content of a participant's statement or phrase.

Initial codes or groups eventually encompassed every basically different statement in the transcripts. This listing reflected the predominant features of the phenomenon under study: The meaning of life in organ transplant recipients.

Intersubjective concurrence with other experts was necessary for confirmation of accuracy of interpretations. Once the data had been coded, intersubjective concurrence with an expert colleague was sought. Original transcriptions, codes, and code definitions were presented to an experienced

qualitative researcher for review. This expert agreed, with few minor changes, in all of the investigator's codes.

**Emerging Themes** were identified based on the descriptive expressions. This process reflected the grouping of descriptions, and revealed the totality of experiences and statements made by the participants. The emerging themes were:

(a) drawing on internal sources of strength/renewed motivation from within;

(b) having the support of family and friends;

(c) acute feelings regarding perceived losses and the anger those losses precipitated prior to transplant;

(d) contributions of "God", a "Supreme Being", or "greater force" to continued survival;

(e) a tremendous desire to help others;

(f) a degree of comraderie with others who have had this very special experience;

(g) some element of inner peace coupled with the lack of a fear of death;

(h) a need to set and meet all goals; achieve one's purpose in life;

(i) responsibility for one's self, taking care of self/health and trying to make things (physical and psychological) better.

A specific example of an emerging theme is the transplant recipient's perception that life is a challenge to be faced

head-on, and death is to be neither welcomed nor feared--it just is. One participant noted that prior to transplant "I realized that I didn't die because God wasn't finished with me yet. I had a lot of serenity during that time." Another said "I prayed for another chance at living, to feel good enough to live again, but at the same time knew I may go [die] any day. Oddly enough, that was kind of ok, too."

This was tied in some ways to the spiritual essence of **being**. As previously noted, all participants acknowledged the contributions of a "higher power" to their lives. A few were evidently deeply religious, very active in church activities, and with circles of friends and acquaintances from those churches who were sources of support and encouragement. Others, though, clearly struggled in discussing this sensitive aspect of their lives. It was impossible to determine whether this belief in God or a Supreme Being was actually a new experience itself, or if it was instead a lifelong belief but a new **topic worthy of discussion**. This speculation prompted phone calls to three participants to see if clarification of the researcher's thoughts could be attained.

All three participants contacted agreed that they had in fact been lifelong believers in God. They also conceded that talking about their beliefs was difficult. Interestingly, the difficulties centered around their uncertainty with how to approach discussion about so ineffable and transcendent a topic as "God." One person also expressed concern that others

would find amusement and actually laugh at the prospect that such an entity exists. This fear seemingly precipitated the difficulties in sharing thoughts about the "...God I believe in."

Another significant theme was the strain on family relationships during prior illness and since the transplant. This was recognized as having both positive and negative qualities. Most participants sought friendship, peace, and striving toward mutual goals with family members and friends. They concomitantly acknowledged, however, that "mood swings" (sometimes attributed to immunosuppressive therapy) and occasional bouts with anger at their health situations sometimes complicated these goals. Many of them identified a greater willingness to compromise, suggesting that this had not been their pattern or personal trait prior to transplantation.

Also within the realm of family and friend concerns was the idea that the recipient had often felt like a burden to loved ones before and throughout the actual transplant experience. A desire to alter this pattern, to become a source of strength and one who could **be depended upon** instead of being **dependent** on others was frequently mentioned. Some participants indicated a tendency to overcompensate in this area. They said that they sometimes tried too hard--to do the housework, to return to their jobs, to baby sit, and many similar activities--in an effort to make up for time lost

while ill or hospitalized. Most admitted that this was an area they continually sought to improve within themselves.

Feelings of loss prior to the transplant, and the anger these feelings caused, were another emerging theme. Losses were identified in the areas of friendships, employment, and especially the ability to work. The loss of health was by far the most common disappointment in the pre-transplant period, but generally was overshadowed by the improved post-transplant health the recipient was experiencing at the time of participation in the study.

The need to set and meet life goals and to strive toward achieving one's purpose in life was of paramount importance to this group of transplant recipients. Some goals were simple and perceived as easily achievable, such as taking a trip to visit relatives in another state or to attend more social functions or church-related activities. Other goals, more long-term but equally important, included things like returning to school, returning to work, initiating support groups throughout the state, getting married, and starting a family. Some goals related to "health conscious" activities, such as establishing a formal exercise program, writing a cookbook for transplant diets from the consumer's (recipient's) perspective, and engaging in sports--tennis, swimming, etc.--that the participant had engaged in prior to the illness and surgery.

Comments related to the desire to help others were varied. One person wanted to "repay" family members for their assistance and patience. Another hoped to start a new career in one of the health care professions so others could similarly benefit.

All participants identified goals and plans for the future, most of which were long-term. Paradoxically, all acknowledged the challenge of basic survival in the face of possible transplant complications.

Three **Thematic Categories** were identified from the emerging themes. These categories are presented in Table II, and represent elevation of conceptualizations to a higher degree. The themes were intensely studied and meanings were synthesized and drawn to a higher level of abstraction.

Resilience, courage, inspiration, spirituality, and peace embodied the notions of serenity and the ability to invoke meaning from within one's spirit or soul. Support, achieving, and acknowledging reflected substantive contributions to meaning that came from without. This included the support of family and friends; and the opportunities to do and to be that were presented **to** rather than sought **by** the participant. And finally, obligation, time, helping, and appreciating were drawn from the composite feelings and expressions that portrayed internal links to the external world. These signified a reciprocal relationship between giving and taking in survival and growth.

**Table II**    *Phenomenological Thematic Categories*

Resilience	Support	Obligation
Courage	Achieving	Time
Inspiration	Acknowledging	Helping
Spirituality		Appreciating
Peace		

Thus far, the analytic processed described accounts for the first step in van Kaam's phenomenological approach. Based on the transcripts, codes and descriptive expressions led to the identification of emerging themes. These themes were then synthesized and abstracted to the thematic categories. This process enabled movement to the next step in van Kaam's (1966) analytic operations.

### Identifying the Common Elements

Reduction to descriptive terms and identifying the common elements occurred next, wherein concrete, vague, intricate, and overlapping expressions were abstracted to more descriptive terms--more general categories were formed. Elements of clarity and organization shaped the data. This phase of analysis assisted the researcher in determining those elements that were actually reflective of the constituents of meaning of life as explicated by the participants.

It is recognized that the term "reduction" in the opening paragraph is suggestive of quantitative philosophies and strategies for scientific inquiry. It is, nonetheless, the term van Kaam (1966) used repeatedly to describe this step of the analysis. For purposes of the current research, it was considered conceptually logical to continue in this tradition, bearing in mind that the intent of this reduction process is to delve into the wealth of picturesque descriptions inherent in the data, and to examine them in detail for underlying thought and emotion. This process then became a revealing

one, in that segments of data were scrutinized for their potential contributions to the whole.

The phenomenological common elements were identified through extensive contemplation of the emerging themes and thematic categories. These elements represented further abstractions, and were statements that best described the major components of the meaning of life in organ transplant recipients. The common elements were:

**Facing the challenge of living day by day;  
treasuring opportunities and experiencing all that is  
offered; and  
cherishing precious time and helping others.**

Once again it was necessary to return to the original transcripts in order to affirm that these common elements were accurate reflections of the depth of meaning of this lived experience. As the investigator was satisfied that this was the case, and intersubjective concurrence was established, the next step in phenomenological analysis was approached.

#### **Elimination of Non-Applicable Data**

**Elimination of non-applicable data** became easier as the individual interviews and the sorted data were reviewed repeatedly. Initially, only pieces of conversation that were totally irrelevant were deleted. These included interruptions by another party during the interview and lengthy discourses not pertinent to the transplant experience or its meaning (e.g., one person stopped and told a joke that was not

particularly significant). Eventually, all data not related to the phenomenon under investigation were eliminated.

During this phase, responses related to **differences** in feelings before the **identified need** for a transplant and the **actual transplantation** were similarly eliminated, as these were determined not to contribute substantive information regarding meaning of life. A review of the interviews suggested that there were no discernible differences in these periods of time, or perhaps that the respondent could not rationally separate those time periods.

#### Formulating a Hypothetical Definition

Formulating a hypothetical definition of the phenomenon occurred as the common elements were joined to form an illuminating statement. This involved processes of intuiting and further abstraction. The resultant hypothetical definition was:

The meaning of life in organ transplant recipients is facing the challenge of living day by day, treasuring opportunities and experiencing all that is offered, all the while cherishing precious time and helping others.

#### Application of the Hypothetical Definition

Applying the hypothetical definition to the original **descriptions** for further analysis and evaluation yielded some changes. It was recognized that the definition could be strengthened and refined with the addition of a statement

regarding hopes and plans for the future. Another key perception that did not come through clearly in the hypothetical definition was that of "rebirth" and a second chance at life.

Returning to the original text brought several other important conceptions to light. These were examined in depth and compared with coded materials to ascertain their importance in the overall definition of the meaning of life for this group.

It was noted that comments related to family relationships and the newfound ability, and even desire, to compromise in an effort to preserve "peace in the family" was often mentioned in conjunction with expressions about the preciousness of time. A concurrent theme was patience--with self and with others: "I don't blow up anymore when they take too long in the grocery store check-out line." Although a seemingly small concern to many of us, this type of revelation was deemed important evidence of the participants' recognition that one cannot afford to take life or time for granted.

#### **Final Identification of the Definition**

Final identification of the definition took into account contemplation of necessary and sufficient constituents of the lived experience of meaning of life for organ transplant recipients. The hypothetical definition was accurate, but made stronger and further abstracted to best represent the

contextual richness of the phenomenon as humanly experienced. The structural definition that finally evolved was:

**The meaning of life in organ transplant recipients is a sense of rebirth after major life transition. The ability to face the challenge of living day by day in the face of one's own mortality is strengthened by cherishing people and opportunities, and attempting to quench the passion to accomplish.**

This structural definition encompassed thoughts that emerged from the original transcripts. It reflected the abstractions arising from the steps of van Kaam's (1966) process of analysis. The definition was applied again to the original transcripts, and then shared with several of the study participants, all of whom acknowledged that it enveloped and summarized their feelings. It comprises, in the words of van Kaam (1966, p. 316), the "necessary and sufficient constituents" of the meaning of life for this group of transplant recipients.

Reexamination of the tests of rigor substantiates the truth value of the structural definition. The criteria of auditability and confirmability were achieved by investigator triangulation. Reproducibility of code/categorical sets by another expert was demonstrated through both initial coding and the identification of common elements, thus insuring auditability.

Confirmability, wherein the information, or data itself, induced the definition, was attained as other tests of rigor were achieved. Recognition that human life experiences are never context free was an ongoing requirement throughout analysis. The researcher insured that all steps in the analysis approach were accurate interpretations of the data and not a personal representation of the way things are believed to be based on experience or conjecture.

### **The Life Attitude Profile-Revised**

#### **Findings**

The Life Attitude Profile-Revised (LAP-R), as discussed at length in the methodology section, is a 48-item Likert-type scale with choices ranging from "Strongly Agree" to "Strongly Disagree" across seven points. The LAP-R measures various attitudes toward life. The instrument is a refined version of the original Life Attitude Profile developed in the early 1980's (Reker, 1992; Reker, Peacock, & Wong, 1982).

The LAP-R was administered to all 11 participants in the study. Time to complete the questionnaire ranged from 20 to 40 minutes. None of the participants expressed any concerns or difficulties in completing it; all seemed to comprehend and give thoughtful answers. No questions were left unanswered by any participant.

Scoring was accomplished according to guidelines for the six dimensions and two composite scales of the LAP-R as identified by Reker (1992). Individual scores on each

dimension are exhibited in Table III, with notations regarding type of organ transplanted.

Table III Life Attitude Profile - Revised  
Individual Dimension Scales \*

	<u>Participant</u>											
	1	2	3	4	5	6	7	8	9	10	11	
<u>Dimension</u>												
Purpose	29	33	55	48	46	45	38	49	48	48	41	$\bar{X}=43.64$ s= 7.67
Coherence	30	40	53	51	48	50	45	50	45	44	40	$\bar{X}=45.09$ s= 6.59
Life Control	32	40	56	49	44	48	53	49	56	45	48	$\bar{X}=47.27$ s= 7.03
Death Acceptance	47	38	49	29	55	33	28	30	30	33	28	$\bar{X}=36.36$ s= 9.59
Existential Vacuum	33	41	20	25	31	24	32	31	32	18	16	$\bar{X}=27.55$ s= 7.58
Goal Seeking	50	43	48	46	51	47	43	48	47	42	41	$\bar{X}=46$ s=3.32

Type of Organ

1,2                      Heart  
3,4,5,6                Liver  
7,8,9,10,11          Kidney

\* Possible Range of Scores On Each Dimension: 8-56

Table IV reflects findings for the two composite scales. These subscales are Personal Meaning (PM) and Life Attitude Balance (LAB).

The **Personal Meaning** index was obtained by summing the dimension scores for Purpose and Coherence. Possible range of this index is 16 to 112. High scores signify a high perceived degree of Personal Meaning in life.

**Life Attitude Balance** was derived by summing scores for the dimensions of Purpose, Coherence, Life Control, and Death Acceptance, and then subtracting from that total the scores for Existential Vacuum and Goal Seeking. Scores for this index can range from minus 80 ( $4 \times 8 - 2 \times 56$ ) to 208 ( $4 \times 56 - 2 \times 8$ ) (Reker, 1992). Again, a high score reflects a high degree of balance in life attitudes.

Table IV *Life Attitude Profile - Revised*  
*Composite Scale Scores \**

Participant

	1	2	3	4	5	6	7	8	9	10	11	
Composite Scale												
Personal Meaning	59	73	108	99	94	95	81	99	91	92	81	$\bar{X}=88.36$ $s=13.84$
Life Attitude Balance	55	67	145	106	111	105	87	99	98	110	100	$\bar{X}=98.45$ $s=23.60$

\* Personal Meaning = Purpose + Coherence

\* Life Attitude Balance = (Purpose + Coherence + Life Control + Death Acceptance) -  
 (Existential Vacuum + Goal Seeking)

## The Six Dimensions

Reker (1992) noted that the **Purpose** dimension of the LAP-R represents one having life goals, having a mission in life, and having a sense of direction from the past, present, and future. "Worthwhileness" and what a person recognizes as centrally important in life are implicit in **purpose**. **Purpose** is essentially what provides direction in one's life.

Examples of items comprising this dimension are:

"In my life I have very clear goals and aims." and  
"Basically, I am living the kind of life I want to live."

Participants in this study scored moderately high on the **purpose** dimension. Scores ranged from 29-55 ( $\bar{X} = 43.64$  and S.D. = 7.67). No comparisons were made among groups, since that was not a guiding research question. Only one score approached the maximum possible score of 56, but none were close to the lowest possible score of eight.

**Coherence** was also a moderately high dimension for the group. Scores ranged from 30-53 ( $\bar{X} = 45.09$ , S.D. = 6.59). Item content for this dimension included statements such as:

"I have been aware of an all powerful and consuming purpose towards which my life has been directed."  
and  
"I have a sense that parts of my life fit together into a unified pattern."

Coherence reflected a logically integrated and consistent analytical and intuitive understanding of self, others, and life in general (Reker, 1992). A sense of order and perceived reason for existence are inherent aspects of coherence, along with a clear sense of personal identity and social consciousness. The scores of this transplant population suggested a fairly wide individual score range on this dimension, but overall appeared logical and consistent in understanding self, others, and life.

The **Life Control** dimension indicated a perception of freedom to make all life choices, the exercise of personal responsibility, and the internal control of life events; life control was described as an operational index of the degree to which a one perceives there is personal agency in directing one's life (Reker, 1992). Item content for this dimension included statements such as:

"My accomplishments in life are largely determined by my own efforts." and

"I regard the opportunity to direct my life as very important."

**Life Control** scores in this study ranged from 32-56 ( $\bar{X}$  = 47.27 and S.D. = 7.03). These again reflected moderately high perceptions of control, and the personal importance of control, in one's life.

**Death Acceptance** suggested absence of fear and anxiety about death and the acceptance of death as a natural aspect of

life (Reker, 1992). This dimension has been denoted as an indicator of one's achievement of death transcendence. Examples of items contained in this dimension are:

"I think I am generally much less concerned about death than those around me." and

"I accept death as another life experience."

The organ transplant recipients participating in this study exhibited a wide range of scores on this dimension: 28-55 ( $\bar{X} = 36.36$ ). Death Acceptance had the greatest variability of all dimensions, with a standard deviation of 9.59 (variance = 92.05). Three participants had scores in the 47-55 range, but six had scores of 33 or less.

This finding is particularly interesting in light of the clinical uncertainties faced by these individuals both before and since transplantation. Though many of them had come very close to death during their illnesses, clearly not all felt prepared or emotionally ready to die, nor were they altogether accepting of the prospect of death.

**Existential vacuum** was a relatively low scoring dimension. Scores ranged from 16-41 ( $\bar{X} = 27.55$ , S.D. = 7.58). Existential vacuum refers to having a lack of meaning in life, lack of goals, lack of direction, boredom, and apathy or indifference toward life; it is an operational index of frustrated "will to meaning" (Reker, 1992).

Items representing this dimension included:

"I feel the lack of and a need to find a real meaning and purpose in my life." and

"I daydream of finding a new place for my life and a new identity."

Low scores on this dimension were not necessarily interpreted as negative, since the dimension itself is defined by generally negative items. It is important to recall that this instrument is founded in Frankl's (1969) perspectives on "will to meaning" and to note that this dimension is in keeping with Frankl's (1963; 1969) theoretical position that a certain amount of existential tension is necessary to bring meaning to life. It is more significant in examining Existential Vacuum to note the consistency of individual responses within the dimension. As will be seen later, this dimension is balanced with the others in examining the composite scales--negative aspects of meaning and purpose were adjusted to attain the Life Attitude Balance score.

**Goal Seeking** is a measure of the desire to get away from the routine of life, to search for new and different experiences, to welcome new challenges, and an interest in getting more out of life (Reker, 1992). Examples of items from this dimension are:

"I feel the need for adventure and 'new worlds to conquer'." and

"I would enjoy breaking loose from the routine of life."

Participants scored moderately high on Goal Seeking, with a range of 41-51 ( $\bar{X} = 46$ ). This dimension had the least variability, with a standard deviation of 3.32 (variance = 11). Scores reflected an overall desire to set and attain new goals, and even welcome new challenges as they were encountered.

**LAP-R Instrument Reliability.** Internal consistency of the LAP-R was estimated by use of Cronbach's Alpha for **each** of the six dimensions of the scale. Brink and Wood (1989) noted that alpha does not provide a very good estimate of reliability when the number of items is small, and under this condition alpha will be smaller than the true internal consistency of the scale. Each subscale of the LAP-R contains eight items. This small number of items may lead to the risk of lower than actual internal consistency. This was deemed an acceptable risk since this is a study of a small number of subjects, and because comparative data were available from the instrument's previous use by other investigators.

Reliability coefficients were calculated by a split-half technique. Coefficient alpha results are presented in Table V.

**Table V** *Coefficient Alpha for Life Attitude Profile-Revised  
Subscales*

Subscale	Study $\alpha$	Study 1 $\alpha$ (Reker, <u>1992</u> )	Study 2 $\alpha$ (Reker, <u>1992</u> )
Purpose	.81	.82	.87
Coherence	.85	.81	.84
Life Control	.87	.77	.79
Death Acceptance	.72	.84	.83
Existential	.59	.80	.78
Vacuum			
Goal Seeking	.77	.81	.75
	N=11	N=180	N=180

The alpha coefficients for the dimensions of Purpose, Coherence, Life Control, Death Acceptance, and Goal Seeking all approximate those obtained by Reker (1992) in developing normative data for the scale. There are substantial differences, however, in the coefficients for the dimension of Existential Vacuum (EV).

Reker (1992) cited EV  $\alpha$  .78 and .80 for two normative data sets. Differences in this dimension for the current sample may be reflective of the participants' relative uncertainty about long-term survival. An additional consideration in this regard is the degree of social desirability participants may have experienced in responding to items in this dimension. This has not been reported by Reker (1992) for the EV dimension, but should not be excluded as a possible source of influence as testing and refinement of the instrument continue.

### **The Two Composite Scales**

The **Personal Meaning** scale provided a more focused measure of personal meaning (Reker, 1992). It is a two component construct defined as "having life goals, having a mission in life, having a sense of direction from past, present, and future, and having a logically integrated and consistent understanding of self, others, and life in general" (Reker, 1992, p. 23). This index is attained by adding together the **Purpose** and **Coherence** dimensions of the LAP-R.

Therefore, total possible score on this index ranges from 16-112.

Study participants displayed a moderately high level on this composite attribute. Scores ranged from 59-108, with a mean of 88.36. This suggested the group had a sense of mission and purpose, along with some understanding of self, others, and life.

The **Life Attitude Balance (LAB)** index is a more global measure of attitudes toward life. It takes into account the degree to which meaning and purpose have been discovered, as well as the motivation to find that meaning and purpose (Reker, 1992). This composite scale is comprised of the sum of scores of several LAP-R dimensions: Purpose; Coherence; Life Control; and Death Acceptance. The combined scores of the Existential Vacuum and Goal Seeking dimensions are then subtracted from this score. The resultant total is the LAB index. Scores on this composite scale can range from minus 80 to 208.

Life Attitude Balance scores for the study group were again moderately high. They ranged from 55 to 111, with a mean of 98.45 and a fairly high standard deviation of 23.60. Few extreme scores were found in the raw data of each dimension, it is therefore congruent that the balance in overall attitudes was a mid-range value. The participant responses reflected insight into meaning and purpose and the desire to continue seeking meaning in their lives.

### **Summary**

This chapter explicated the phenomenological findings leading to structural definition of the meaning of life in organ transplant recipients. Participant demographics were described in detail. Richness of the data was reflected in quotations and varying levels of abstraction. Tests of rigor, as applied in this analysis, were presented.

Phenomenological analysis was followed by presentation of findings from the Life Attitude Profile-Revised. The instrument proved to be an easily administered, practical, and clinically significant measure of perceived meaning and purpose in life of this population of heart, liver, and kidney transplant recipients.

Discussion of findings from both research approaches is presented in the following chapter. The findings are jointly explored to determine the extent to which they are complementary and contributory to a unified whole in the understanding of the meaning of life for organ transplant recipients.

## CHAPTER V

### DISCUSSION

The previous chapters provided a description of phenomenological analysis and questionnaire findings regarding the meaning of life for eleven organ transplant recipients. A structural definition of this meaning of life was generated through phenomenological processes outlined by van Kaam (1966), based on in-depth interviews with all of the participants. Data obtained from the Life Attitude Profile-Revised, administered to all participants, were then presented and analyzed by Reker's (1992) guidelines.

Discussion in this chapter is multifaceted. Initially, demographics are described in terms of their relevance to the study and the population that they represented. Next, phenomenological findings are interpreted, and explicated as they relate to the literature and to philosophical foundations of the study. Findings from the Life Attitude Profile-Revised are similarly addressed. Findings from **both** qualitative and quantitative approaches are then integrated to form an interpretive whole in approaching an understanding of the meaning of life for this group of organ transplant recipients. It should be noted that points drawn from the investigator's journal are interspersed throughout the discussion of

integrated findings. These are relevant to interpretations drawn from both data sources. Decisions to include these thoughts and ideas were based on their contributions to the richness of the data and the unifying essence of methodological triangulation.

Implications for nursing science and practice are addressed. These implications are followed by suggestions for future research.

### **Demographics**

Several characteristics of the sample were interesting. One atypical and unanticipated finding was that of the older than average liver transplant recipient. The literature, and indeed practical experience, suggested that candidates are not generally considered for liver transplantation beyond the age of 65 years. As noted, one participant in this study was 73 at the time of interview (72 at time of transplant). This participant proved to be an invaluable source of enlightening information regarding the "waiting for a decision" and then "waiting for an organ" ordeals. Further, this participant provided mature insight into the notion of facing one's own mortality. Reflections on life as it had been lived prior to the illness were clearly heartfelt, with few expressions of regret. Not surprisingly, this oldest participant also seemed to be one of the most appreciative of having the opportunity for another chance at life. The view that "it [the liver] might have had to go to a younger person, and rightly so, as

I've had a good and full life" did not discount the fact that "I was in the right place at the right time."

A recurrent theme in the discussion of demographics with the participants was that of income, in terms of both amounts and sources. Five participants noted that they were caught in the "disability trap." These were situations where the participant collected disability income through private or governmental programs and also received health care benefits, which generally included both hospital and medication costs. The dilemma they faced was that if they sought employment--with or without benefits--their disability income and health coverage would cease. This was complicated by the fact that they all had extremely significant "pre-existing conditions" which would preclude new health coverage for extended periods of time. The frustration surrounding this issue was intense, and was portrayed as

Overwhelming, at times. I get so angry at the system. I'm doing better now, and I want to work, but I can't get out of this mess. I could never pay all of these medical bills. I could never get my head above water. But I **do** want to **contribute**.

The blessing of extended **life** gave rise to the burden of seemingly endless **dependence** on others.

Educational level was not unique or unexpected. The number of participants with aspirations to continue their educations was, however, surprising. All but two participants

in this sample stated or alluded to a desire to return to school. Some indicated hope for the opportunity to continue a degree program they had already been enrolled in; others wanted to change careers completely; still others wanted to take courses for personal edification--to learn a new language, or to engage in artistic endeavors. Motivation to achieve was reflective of perceived purpose and a mental outlook oriented toward the future.

Length of time between transplant surgery and participation in the study was quite diverse, with a range of six months to seven years. Expressive ability and willingness to share complex and profound thoughts and feelings did not appear influenced by this factor. Similarly, there were not remarkable differences in either interview or questionnaire data when examined based on this factor. The more pertinent revelations were in the level of support provided by the transplant recipients--those who had longer times since transplant indicated that they felt more competent and "experienced" and better able to participate in support groups or speak publicly about transplantation.

Type of organ transplanted was not a distinguishing feature of interview data. All participants were equally willing and able to respond to questions posed. All gave insightful and thoughtful answers. Many data codes appeared in the transcripts from participants across all three organ types during early stages of analysis. These were easily

elevated to higher levels of abstraction throughout the phenomenological process.

There were, as noted in Chapter IV, some suggestions that LAP-R findings may differ between organ types. Heart transplant recipients had noticeably lower scores on several dimensions when compared with the kidney and liver recipients. The small sample size precluded significance testing for differences, so this information is merely presented as an interesting observation.

### **Summary**

Demographic attributes of participants were quite diverse on all levels. This is a strength of the study, because findings ranged across the spectrum of life characteristics and attributes from which the transplant recipient comes--a group very similar to the population at large. They are not uniquely identified by social class, employment status, educational level, age, nor marital status. They are distinguished, for the purposes of this study, only by the fact that they have suffered an illness with few options for treatment except organ replacement.

### **Phenomenological Interpretation**

Phenomenology is the study of human experience from the actor's particular perspective, with the goal of greater understanding of the structure and meaning of lived experience (Knaack, 1984). Perceptions and actions are the meaningful expressions of **being-in-the-world** (Keen, 1975). **Being** is a

concept central to the philosophy and the research approach of phenomenology, as it represents acknowledgement of consciousness and the perceptive nature of humanity.

The search for meaning is a fundamental goal of phenomenology. In this tradition, meaning is recognized as contextually dependent and intersubjective. One's interpretation of being-in-the-world is the critical constituent. Creating meaning is individual, and occurs as a dialectical process in everyday interaction with others and with the world (Anderson, 1991).

Oiler (1982) summarized these views as they apply to nursing knowledge: Truth is "a composite of realities-the world is grasped in profiles dependent on an individual's perspective. Access to realities is a matter of locating and using forms of human expression" (p. 179). The knower shapes experience through subjectively being in the world.

Eleven recipients of vital organ transplantation have explicated the phenomenon of meaning of life as they perceive it, reflective of their being-in-the-world. Some of them were more articulate than others, yet many of the messages, explicit or implicit, were clear. Living with an "alien" organ, as one participant noted, is a never-ending physical challenge, sometimes like a best friend and other times like a worst enemy. The good aspects, the good days, and the good times that would occasionally last for only a few minutes, all clearly outweighed the bad. There was evidence of spiritual

serenity marred by occasional quiet desperation. There were numerous suggestions of underlying, yet pervasive, perpetual hope.

This group of transplant recipients repeatedly expressed the desire to live life to the fullest, not just to survive but to be productive and achieve new things. They did not suffer the same physical and emotional constraints as before transplantation, and the new constraints were portrayed as somehow much more tolerable. Newly discovered sources of strength came from within the self.

Participants acknowledged a lifetime commitment to themselves, to their loved ones, and to the health care community to take the best possible care of their new organs by leading the best possible life style. That new lifestyle involved following a medical regimen that included diet, medication, exercise, as well as frequent trips to the hospital or physician's office for check-ups and blood monitoring. It was a lifestyle not only accepted but embraced as "the way things are, and the way they must be."

Ties to significant others were among the most disparate of phenomenological findings. Some relationships became strained to the point of dissolution, either during the preceding illness or in the midst of the transplant experience itself. One participant noted "...She [my girlfriend] just couldn't take it anymore...sometimes I was feeling well, but other times I was kind of sick, and she said she just couldn't

live like that." This person also noted, though, that other family and friend relationships were much better, and was of the opinion that "I gave all I could, and if she couldn't take it then I guess we're better off without each other. I have my family, and they have me, and we seem to be doing okay."

A preponderance of participants expressed strengthening of relationships with family and friends. Further, they greatly appreciated their new friends--in the transplant recipient and health care circles. Support among and within these groups was perceived as vital to survival: "I couldn't have done it without them; and I can't continue without them."

Spirituality and the embracing of a "greater force" or Supreme Being or God appeared in virtually every interview. This was often coupled with discussion of inner strength, and suggested a transcendent and ineffable quality in the participants' life. This was perceived as a source of inspiration and hope, and a guiding force in decision-making. Moments of tranquility were seeded by this presence. Moments of desperation were usurped by it.

Probing into the contextual infrastructures of these organ transplant recipients led to identification of a definition of their meaning of life. Contextual infrastructure is what makes them who they are as individuals and what they think in their respective realms of existence. Their meaning encompassed hope, goal orientation and future-thinking, living day-by-day, and strong spiritual ties.

The hope described by participants was, within context, realistically possible and personally significant, in keeping with definitions in the literature (Dufault & Martocchio, 1985). Hope for a future good was a prevailing theme. Engel (1968) and Hickey (1986) both identified hope as a fundamental necessity for continued life which impacts upon the development of illness; without hope, even death may ensue. Participants clung to abundant hopes for health, prosperity, and sometimes basic survival.

These themes were also in keeping with notions of spirituality. Hiatt (1986) suggested that the spiritual dimension of a person is concerned with personal meaning, and as such is a principle determinant of health-related attitudes in one's worldview. Emotional qualities are tied to actions, behaviors, and thought processes. Organ transplant recipients in this study explicated spiritual awareness that served these purposes and more, as they embraced life with newfound fervor and sought happiness within the contexts of health and of "giving back."

Morse (1991) indicated that the qualitative research participant must be knowledgeable about the topic and expert by virtue of involvement in specific life events or associations. The participant must be able to reflect and provide detailed experiential information about the phenomena. Organ transplant recipients participating in this study met, and perhaps exceeded, these criteria. They were co-

participants in the research process as they provided insights, confirmed interpretations, and clarified confusing dialogue. Trusting, non-judgmental relationships were developed between participant and researcher. There was, as Knaack (1984) recommended, an absence of researcher "power" over the participant, enabling the uncovering of meaning in context. Participant relationships with the investigator also ensured researcher **faithfulness** to the phenomenon of interest and to the data collected, as they corroborated interpretations and validated findings.

#### **Life Attitude Profile-Revised**

##### **Interpretation**

Findings from the LAP-R data analysis suggested that these organ transplant recipients were highly inspired to find meaning and purpose. Responses in dimensions related to death and existential vacuum were consistent within each participant, though divergent across participants. Perceptions of control over life were most revealing. The composite scales of Personal Meaning and Life Attitude Balance measured senses of goals and mission in life and general attitudes toward life, respectively. Further interpretation of findings follows.

Participants overall scored moderately high on dimensions of purpose, coherence, and life control. The **purpose** responses suggested personal perceptions that include the establishment of goals and aims for the future, as well as

recognition of a satisfying life purpose. Most participants believed strongly that they had a mission in life which provided a sense of direction. Further, past achievements were strongly considered to contribute to meaning and purpose. The most tentative feelings were in the area of a life that is "running over with exciting good things." Responses in this area may be reflective of the day to day physical challenges of living, and the prospect of transplant complications that may infringe on perceived well-being.

In terms of **coherence**, which measured integrated, consistent, and intuitive understanding of self, others, and life in general (Reker, 1992), indices suggested a sense that life patterns fit expectations. That was interpreted as an indication that participants understand and accept the daily life struggles and necessary compliance with medical regimens, and in fact survive because of, and not in spite of, those demands. They have willingly adapted to post-transplant requirements for physical well-being, and in turn benefit through greater personal insight and identity. Disruptions in life-style seemed a fair exchange for the best possible health.

**Life Control** was held as extremely desirable by all of these organ transplant recipients. Several participants ranked low on items related to actual control that they perceived they have, which again may be related to strict medical regimens and subsequent changes necessary in personal

life style. Most indicated acceptance of responsibility for life choices, though, and welcomed opportunities to participate in determining what happens to them.

The wide range of scores on the **death acceptance** dimension suggested acknowledgement of emotional uncertainty related to death. This variability was interpreted as a simultaneous intellectual "knowing" how close some of them had come to death in the past, but concomitantly feeling apprehensive or ambivalent about whether or not they were truly ready to face it. Since the questionnaire was administered at a point **after** transplantation, it is impossible to know whether attitudes may have changed in the intervening time; that is, whether participants who had come nearest to facing their own mortality earlier had been more accepting of the prospect of death than they were after the transplant. This might further reinforce the notion that organ replacement is a source of renewed hope for the otherwise fatally ill person.

**Existential Vacuum** was a relatively low scoring dimension. Participant responses suggested that they were not generally affected by lack of meaning in life, lack of goals, or spent a preponderance of time mulling over "what might have been."

Two areas exhibited the greatest variability within this dimension. The first related to "daydreams about finding a new place for my life and a new identity" and the second

pertained to the feeling that the participant "experienced the feeling that while I am destined to accomplish something important, I cannot put my finger on just what it is." Responses in both of these areas may suggest differing interpretations of **item meaning**, as both could be perceived as hopeful about life for the future **and** some degree of uncertainty as to what the future may bring. Existential uncertainty or frustration, or a "frustrated will to meaning" (Reker, 1992) may be a motivating force for continued pursuit of meaning and purpose (Frankl, 1969).

Moderately high scores on **Goal Seeking** were interpreted as a major index of future meaning and the desire to achieve new things. It should be recalled that responses on this dimension exhibited the least variability. Participants in general consistently displayed positive attitudes about new challenges and adventures to be faced. These feelings were thought to arise from **and** complement the purpose and coherence scores. Participants were eager to both achieve and experience greater things.

It was interesting to note that heart transplant recipients scored lower than other transplant-types on several dimensions. Since the sample consisted of only two participants who had received hearts, these findings are certainly not generalizable, but fascinating nonetheless in that these participants were both relatively young people who clearly identified goals for the future and interest in making

the most of the lives they had. Further examination of this phenomenon in a more select sample of participants would be an engaging topic for further study.

Also intriguing is the fact that Life Control was a moderately high scoring dimension. Participants clearly valued the control they perceived they had in existential, decision-making, and life-directing activities and thoughts. Organ transplant populations are believed commonly in clinical practice and in the literature to have little control over their lives, owing to severe diet, medication, and sometimes social restrictions. Findings from this group of study participants suggest that professional perceptions may be considerably more restrictive than those of the organ transplant recipient.

**Personal Meaning and Life Attitude Balance**, as composite constructs, were based on scores from various dimensions of the LAP-R. Interpretation of these indices is therefore grounded in the findings from those dimensions. Participants exhibited moderately high scores on both composite scales.

These organ transplant recipients reflected positive feelings toward their missions in life, and sought to continue achieving previously defined life goals and setting new goals. They also demonstrated positive attitudes toward both existing meaning and purpose and the continued motivation to find meaning and purpose.

### **Integration of Phenomenological and Life Attitude Profile-Revised Findings**

Recommendations in the literature support the use of multiple research approaches in an effort to provide a basic, humanistic understanding of the multifaced complexities of human existence. **Simultaneous triangulation** has been described as the use of both qualitative and quantitative methods at the same time; there is limited interaction between the two data sets during collection, but findings complement one another at the end of the study (Field & Morse, 1985; Morse, 1991).

Polkinghorne (1983) stated that "human science research can reap significant methodological benefits from using multiple procedures for its research designs" (p. 252). The researcher can learn far more by using all of the information available from multiple sources than by use of any one procedure alone. Fullness of understanding is attained by bringing together different forms of knowledge. This new dimension of understanding, and dimension of **depth**, is the product of multiple approaches.

This complex form of inquiry required a step beyond analysis of each set of data. A final **syncretic** integration of findings into a new statement that combined the various dimensions of the phenomenon was necessary (Polkinghorne, 1983). Syncretism, by definition, is "the union of two parties to join against a third" (Webster, 1983, p. 1850).

Polkinghorne's application of syncretism in the research process places the process at a somewhat higher level than **synthesis**. Syncretism denotes the uniting of differences into an integrated statement or finding. This was a worthwhile strategy in examining the findings of the current study.

### **Integrated Findings**

Scrutiny of the emerging themes and common elements originally identified in phenomenological analysis of interviews showed many similarities with the dimensions of the Life Attitude Profile-Revised. Integrative descriptions follow.

The theme "drawing on internal sources of strength/renewed motivation from within" was related to several LAP-R dimensions. Internal sources of strength were tied to **Purpose**, as an indicator of sense of direction in life based on past, present, and future, as well as what a person recognizes as important in life. **Coherence**, or the logically integrated understanding of self, others, and life in general was also reflective of internal strength and motivation. Participant scores on these dimensions corroborated the phenomenological finding that these organ transplant recipients feel grounded by deep personal insight and commitment to themselves, to others, and to the world around them. Context dependent--living with the transplanted organ and its potential for adverse sequelae-- they draw forth the courage to survive with intensity and passion.

The phenomenological emerging themes of "a tremendous desire to help others" and "a need to set and meet all life goals; achieve one's purpose in life" bore commonalities with the LAP-R dimension of **Goal Seeking**. All participants spoke of aspirations for the future, most of which included the urge to assist others. Some hoped to help those in similar or more precarious health situations. Some sought to branch out and offer aid to the homeless, or to become involved in health teaching and illness prevention programs in their communities. Aside from these types of goals, there were also orientations toward careers or employment, advancing education, and traveling. The "future-mindedness" of this group was inspirational within both data sets. Two main pictures emerged from integration of these phenomenological and LAP-R findings. First, it became more important to **Give** of themselves even in the face of personal adversity. That is, they wanted to return something to others who had given to them and to assist those less fortunate or less capable or knowledgeable than themselves. And second, they welcomed the prospect of future challenges and aspired to new goals.

The LAP-R dimension of **Life Control** was revealed in the phenomenological theme of "responsibility for one's self/health and trying to make things (physical and psychological) better." Participants generally acknowledged ownership of their problems, and espoused the need to protect health as never before. There was a sense of perceived

guardianship for the new heart, liver, or kidney. This was tied both to appreciation for having received the organ and to the improved physical state it brought. When compared to Life Control in the LAP-R, the theoretical leap can be made as follows: These organ transplant recipients need and want internal control and responsibility over life events, but they also recognize that they may face physical complications. Again, following prescribed medical regimens is crucial. They must live a tenuously balanced existence physically, but are free within those identifiable bounds to live life as they choose. The cognitive paradox of internal locus of control is balanced with outside influences that enable physical health.

The **Death Acceptance** dimension of the LAP-R, as noted previously, reflected highly variable feelings. Comments from the interview data, which led to the description of "some element of inner peace coupled with the lack of a fear of death," provided a much richer understanding of the participants' feelings. Disparity of these findings was not viewed as negative. It was more importantly seen as appreciation for the amalgam of emotions that interplay in the contemplation of a sensitive and serious topic. Ambiguity of emotions may be a real and legitimate aspect in contemplation of one's own mortality.

These organ transplant recipients voiced acceptance of death as an inevitable part of life, and indicated that they would hopefully be ready when the time came. Some expressed

gratitude for the lives they had led thus far, but hoped sincerely for more in the future.

The themes "a degree of comraderie with others who have had this very special experience" and "acute feelings regarding perceived losses and the anger those losses precipitated prior to transplant" were not as clearly associated with any dimension of the LAP-R. They do, however, contribute to the participants' subjective assessment of the meaning of life. These themes appeared repeatedly across interviews. This was interpreted as an indication of the uniqueness in perceptions of the transplant group.

The transplant recipients felt a kinship with one another unlike other interpersonal relationships in their lives. Participants with same type of organ transplanted tended to develop relationships with each other, getting to know one another through pre-transplant counselling and post-transplant support groups. There was also expressed interest in meeting and learning about recipients of organ transplants other than the type each participant received. For example, liver recipients wanted to get to know heart and kidney recipients. This kinship enabled support and understanding through good and bad times.

Anger related to perceived losses prior to transplant was considered contributory to meaning, quite possibly related to the essence of purpose that is founded in past experiences. It was also a visage of growth, as the participants indicated

that they had long since let go of that anger and replaced it with hope and inner peace.

The issue of social support is not a specific attribute assessed by the LAP-R. This was, however, a powerful recurrent theme throughout phenomenological analysis. Participants felt tremendous ties to family and loved ones. They also felt strongly about relationships gone awry during illness and the transplant experience. Impassioned appreciation for and devotion to interrelationships were important contributors to perceived meaning as described by the participants. This reinforced the notion that meaning of life is context dependent and individually realized.

Another attribute not accounted for by the LAP-R but resounding throughout phenomenological analysis was that of "contributions of God, a Supreme Being, or 'greater force' to continued survival." These ethereal qualities provided spiritual motivation to continue living day to day. They also inspired hope and contributed to perceived internal strength of each participant. In this sense, such contributions were integral to the meaning of life for these organ transplant recipients. They did not separate this "greater force" from the self or life events, but embraced it as a part of themselves.

Similarly, conceptual links to the LAP-R dimension of **Existential Vacuum** were not clearly surmised from the phenomenological data. Examination of that concept through

repeated review of the original interview texts shed some possible light on this. None of the participants considered their lives "boring or uneventful" as one LAP-R item suggested. Most interviews indicated instead that participants were usually excited with the prospect of facing each new day. They withdrew from their surroundings only when physically ill or mentally "down in the dumps." Several participants noted that steroid and immunosuppressant medications led occasionally to labile emotions, and often attributed "down days" to this.

Existential vacuum was a relatively low scoring dimension on the LAP-R, and text data did not substantially reflect its presence in this population. The judgment in integration of findings for the two research approaches was to acknowledge that this was not a significant issue for participants. They do believe they have meaning, goals, and direction in life, and are not suffering from frustrated attempts to find meaning.

One aspect of life and meaning important to phenomenological context yet not heretofore addressed is that of humor. Virtually all participants engaged in laughter during the interview process, as they highlighted good times and recounted amusing anecdotes about their personal experiences. Investigator journal entries after most interviews suggested that it was important to participants to occasionally "lighten" intensely emotional topics. The good

natured approaches to humor were not perceived by the investigator as an opportunity for the participant to hide behind walls of illusion or fantasy. They seemed better judged as attempts to share a diversity of thoughts and feelings. This view was reinforced through repeated review of the original transcripts during final phases of analysis.

### **Syncretic Description**

Syncretic description, as previously noted, involved the uniting of findings into an integrated description about the meaning of life for these eleven organ transplant recipients. This description is drawn from all levels of analysis, and all levels of abstraction.

The meaning of life for heart, liver, and kidney transplant recipients is simultaneously evolutionary and revolutionary. It is comedy and tragedy. It is struggle between dependence and independence. It is dream tempered by reality.

This meaning of life is evolutionary in that it is context dependent and founded in the thoughts and experiences of the past, present, and future. It is revolutionary by virtue of the prevailing sense of gratitude with the dawn of each day and the formidable sensations of renewed appreciation for life and lifeworld. Time is both friend and foe. Good days do not last long enough, and bad days drag on endlessly. Time cannot be taken for granted.

The dichotomous nature of comedy and tragedy is exemplified by the range of emotions and experiences encountered by organ transplant recipients, and the eyes through which only they see those emotions and experiences. They seemingly have laughed in the face of death, but might yet be seized by it before they think they are ready. A part of their essence is life that continues from death--they know they have benefitted from someone else's passing. This has instilled or reinforced the need to be extra cautious in living.

The struggle between dependence and independence is an internal struggle mediated by external forces. Participants want all at once to be self-sufficient and self-secure, but know they must rely as well on the expertise and virtue of others as they face crises in daily life. Relationships are important and treasured, but do not discount the desire for personal control.

Dreams tempered by reality can be a source of comfort and woe, inspiration and disappointment. Aspirations provide evidence of perpetual hope; some are reinforced by thoughts of divine intervention. Day to day uncertainties necessitate acknowledgement of personal vulnerability. Often strength from within supersedes, though, and allows for many private victories. Participants were often able to transcend the adversities of physical uncertainty and think beyond the immediate horizon.

These paradoxical thoughts and emotions exemplified the tumultuous existence of organ transplant recipients. Universally, though, the best summation of meaning of life for this group was: "Life is precious, and over all, pretty good; I will do everything in my power to preserve it; I want to live, and I want to give."

### **Theoretical Integration**

Findings from both the phenomenological and LAP-R approaches as well as the integrated findings were consistent with the theoretical foundations identified early in the study. Frankl's (1969) theory of will to meaning was an invaluable adjunct to methodology and analysis. Ties of the theory to study findings were explored.

Previously it was noted that participants were able to effectively describe the meaning of their lives, both in current context and in terms of aspirations for the future. They were able to move beyond physical iniquities and discuss, with depth and feeling, many thoughts and emotions, many experiences and travails.

Frankl (1969) posited that existence is intentional, and that self-transcendence is the essence of existence. Further, it was noted that meanings and, indeed, the life of each individual as a whole, are unique. The underlying contention is that there is no universal meaning of life. There are, however, commonalities across situations which are shared by multiple human beings.

It was this type of common situation, the shared experience of organ transplantation, for which this study was designed in order to explicate the meaning of life. Participants were, in the final analysis, reflected as self-transcendent. They were found to have common emotions, feelings, and experiences. They expressed views individually, and in unique terms. These views were then elevated to various levels of abstraction through processes of scientific inquiry. Common elements were identified, and definitions and rich descriptions were provided. These were what is known by Frankl (1969) as "descriptors" of the human condition.

Frankl (1969) also observed that meaning and purpose cannot be imposed, again owing to the nature of the humanity. One cannot be mandated to hold something as important in life, but must, through processes of discovery, identify these things independently. The current study supports this view, as participants had no knowledge of each others' responses, nor the opinions of the investigator, and yet each felt free to share what were perceived as unbiased accounts of personal meaning. Nonetheless, common codes, themes, thematic categories, and common elements were easily identified, leading to abstractions of the summarizing definitions and descriptions.

Existential vacuum was a term used by Frankl (1969) to describe an "inner void" (p. 83), or a sense of meaninglessness or emptiness. Participants in this study did

not suffer from any substantive boredom or apathy, nor did they seem to lack meaning in their lives. There were, though, instances of frustration in day to day life and in the accomplishment of long-term goals. These may have represented ambiguities in questionnaire responses or overlapping ideas and goals in interview data. Frankl (1969) did not consider existential vacuum as pathological unless one became "neurotic" about it. More importantly, some degree of existential tension was believed to be beneficial in bringing meaning to life, in order to ensure dynamic existence.

### Summary

The syncretic description of the meaning of life was an advanced level of abstraction beyond that identified by each method alone. The view of reality was not limited. A singular reality does not exist in the qualitative methods, and oversimplification of reality is evident in the quantitative realm (Haase & Myers, 1988). Thus, study findings presented a unified view of reality--the reality of human experience.

Conceptually, aspects of the findings from each approach were integrated to describe the indomitability of the human spirit. Some attributes and components of meaning and life were extracted from both research approaches, and others, occurring in only one approach, would not have been found but for the use of diverse methods. Findings were not redundant

but complementary, and therefore, in keeping with the original goals of this study.

The two forms of data collected in this study enabled the explication of the meaning of life for eleven organ transplant recipients. The research approaches were different but complementary. They culminated in a rich, contextual, and illuminating definition. Descriptions were cognitively and emotionally embedded, and the essence of human subjectivity was valued as a foundational assumption of the study. The findings of each research approach were strengthened by the other. The integrated findings represented the reality, or the truth, of the meaning of life for these organ transplant recipients. The syncretic description epitomized the composite of study findings. Findings integrate well with Frankl's (1969) theory of will to meaning. This theory provided the theoretical base originally proposed for the study.

### **Implications for Nursing**

Clinical nursing practice may benefit from this study by consideration of its many facets. The structural definition it provided, the Life Attitude Profile-Revised findings, and the subsequent integration of findings from both approaches afforded invaluable insights into the complex and dynamic patterns that unite and interact to form the organ transplant recipient's meaning of life. Such insights allow for improved mutual understanding between persons, which is a critical

element for contemporary efficient and effective nursing practice. Implications for nursing arise from segments of the data as well as from the global interpretations.

The literature is replete with references to the need for improved clinical outcomes. Superior outcomes are achievable only when the patient and clinician alike are able to identify and plan for shared expectations. Understanding of "where the patient is coming from" is crucial, especially in the instance of a high risk group such as the organ transplant population. Interventions founded in individuality and uniqueness may be substantially more productive than those ascribed through "standard" practice. It is important to know, whenever possible, where the patient stands cognitively and emotionally.

More specific recommendations related to the study's findings include the need for evaluation of social support systems of transplant candidates, and continued reevaluation throughout the post-transplant period. Intricate changes in relationships may precipitate alterations in the patient's lifestyle/routine, and have consequences worthy of consideration and intervention.

Organ transplant recipients should also continue to be tapped as a valuable resource for their fellow transplant recipients. Support groups and individual conferences among recipients and/or candidates may strengthen personal awareness

and assist in adaptation to life throughout the post-transplant period.

An additional practice concern relates to occasions when the transplanted organ fails beyond hope, and death is imminent. Assisting the terminal patient through a dignified and meaningful death, when feasible, may be enabled by knowledge of how that person feels about death--how accepting or fearful, or whether or not death is viewed as a natural part of life.

Some implications that arise from this study are perhaps beyond the scope of traditional nursing practice. These primarily include socioeconomic issues, such as the "disability trap" that some participants addressed. It is incumbent upon professional nurses, though, to bring to the forefront these issues, and guide transplant recipients to appropriate resources. Further, nurses should become involved at the political level to resolve these problems.

Awareness of intricacies in perceptions and attitudes about meaning of life may enhance professional relationships between the organ transplant recipient and the nurse. The findings of this study augment that awareness, and can be cognitively employed in practice.

#### **Suggestions for Future Research**

Opportunities for future research based on the findings of this study are numerous. There is a need for studies that utilize qualitative methodologies to document more extensively

the meaning and purpose of life as perceived by organ transplant recipients.

The Life Attitude Profile-Revised provided many insights and corroborative data that enhanced this study's findings. Further testing with such instruments is indicated, especially in light of findings that suggest possible differences between organ types. Larger samples sizes would allow for statistical analysis of other variables. Comparison of dimension scores across participant ages or socioeconomic status may provide additional valuable data on which to base clinical practice.

Relevant information may also be gleaned from a similarly structured study examining families and significant others of organ transplant recipients. Since this study suggested that these people played a pivotal role in the participants' well-being, it would be interesting to ascertain family member's perceptions of their own lives. Examination of social support systems would provide a broader picture of this lived experience, and perhaps further augment clinical decision-making practices.

Nursing science may also benefit from examination of the links of this foundational study with concepts traditionally measured as indicators of quality of life and life satisfaction. These would include demographic variables such as socioeconomics, physical rehabilitation potential and status, or other published quality of life instruments. An ultimate goal may be refinement of meaning and quality of life

instruments to the point that they conjointly offer data on which individualized nursing interventions can be based.

Extending beyond the scope of organ transplant populations, it would be interesting to study meaning of life as it pertains to other life and health crises. Changes in perceptions over time could be explored by qualitative measures, again in the interest of more effective clinical outcomes and in the prevention of illness and disease.

### Summary

Scant published literature exists regarding the experiences of recipients of different types of organs. This study is innovative in that regard, and contributes to the growing body of nursing knowledge. Eleven vital organ transplant recipients--heart, liver, and kidney--participated in this study of the meaning of their lives. Participant demographics were diverse, adding richness to the data.

Complementary methodologies were employed, and included phenomenological analysis of interview data according to guidelines set forth by van Kaam (1966) as well as administration of the Life Attitude Profile-Revised (Reker, 1992). Findings were discussed separately, and then conjoined to explicate a sound description of the meaning of life for these eleven organ transplant recipients.

Nursing practice will be strengthened by mutual understanding between patient and professional. Individualized assessment and intervention based on detailed

explorations of the meaning of life will lead to more efficient and effective health care for the organ transplant population, and perhaps improve overall quality of life.

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**Appendix A**

**Demographic Profile  
Questionnaire**

**Demographic Profile****Questionnaire**

1. Participant Code # \_\_\_\_\_
2. Date of Birth \_\_\_\_\_
3. Type of Organ Transplanted \_\_\_\_\_
4. Date of Transplant \_\_\_\_\_
5. Educational Level \_\_\_\_\_
6. Marital Status \_\_\_\_\_
7. Gender \_\_\_\_\_
8. Employment Status \_\_\_\_\_
9. Annual Income \_\_\_\_\_

**Appendix B**

**Consent Form**

**Consent Form**  
**The Meaning of Life in**  
**Organ Transplant Recipients**

I have been invited to participate in a study which seeks to describe the meaning of life for patients who have had an organ transplant. I have been asked to participate because I recently had a liver, kidney, or heart transplant.

If I participate in the study, I will be interviewed twice by the researcher concerning some of my personal beliefs and thoughts. These interviews will be recorded on audiotape. I will also be asked to complete a short questionnaire. The time and place of the interviews will be at my convenience. The first interview will take place as soon as possible after I agree to participate. The second interview will be about two weeks after the first one.

I will not be paid, nor will I be charged anything for participating in this project. I understand that there are neither any direct benefits nor risks to me by participating. I will not be personally identified in any way on the recorded or questionnaire information if the results of this study are published. My participation will be kept confidential. I may withdraw from the study at any time simply by informing the researcher. Withdrawing from the study will not affect my care in any way.

I HAVE READ THIS DOCUMENT AND IT HAS BEEN EXPLAINED TO ME. I HAVE HAD AN OPPORTUNITY TO ASK QUESTIONS AND THEY HAVE BEEN ANSWERED TO MY SATISFACTION. IF I HAVE ANY FURTHER QUESTIONS, I MAY CALL ANN JONASON (792-7544 or 553-0675). IF I HAVE QUESTIONS CONCERNING THE RIGHTS OF RESEARCH SUBJECTS, I MAY CONTACT DR. GEORGE SCHUSTER AT (404) 721-2592. WITH THIS UNDERSTANDING, I HEREBY CONSENT TO PARTICIPATE IN THIS STUDY.

\_\_\_\_\_  
Subject

\_\_\_\_\_  
Date

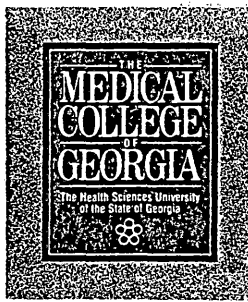
\_\_\_\_\_  
Principal Investigator

\_\_\_\_\_  
Date

**Appendix C**

**Human Assurance Committee**

**Approval**



Human Assurance Committee  
Institutional Review Board

February 2, 1991

Anna M. Jonason, RN, MSN  
P.O. Box 428  
Goose Creek, SC 29445

RE: The Meaning of Life in Organ Transplant Recipients

Dear Ms. Jonason:

The above protocol has been examined and found to be exempt from formal review by the HUMAN ASSURANCE COMMITTEE in accordance with the DHHS policy and the institutional assurance on file with the DHHS.

If VA patients or facilities are involved in this study, you must also have a letter of approval from the VA Research & Development Committee prior to involvement of VA patients or facilities.

Sincerely,

George S. Schuster, D.D.S., Ph.D.  
Chairman  
HUMAN ASSURANCE COMMITTEE

jfh

**Appendix D**

**Life Attitude Profile-Revised**

Permission for use of the Life Attitude Profile-Revised was  
obtained from:

Gary T. Reker, Ph.D  
Professor, Department of Psychology  
Trent University  
Peterborough, Ontario  
Canada K93 7B8

**LIFE ATTITUDE PROFILE-REVISED (LAP-R)**

(c) Gary T. Reker

This questionnaire contains a number of statements related to opinions and feelings about yourself and life in general. Read each statement carefully, then indicate the extent to which you agree or disagree by circling one of the alternative categories provided. For example, if you **STRONGLY AGREE**, circle **SA** following the statement. If you **MODERATELY DISAGREE**, circle **MD**. If you are **UNDECIDED**, circle **U**. Try to use the undecided category sparingly.

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	<b>SA</b> <b>STRONGLY</b> <b>AGREE</b>	<b>A</b> <b>AGREE</b>	<b>MA</b> <b>MODERATELY</b> <b>AGREE</b>	<b>U</b> <b>UNDECIDED</b>	<b>MD</b> <b>MODERATELY</b> <b>DISAGREE</b>	<b>D</b> <b>DISAGREE</b>	<b>SD</b> <b>STRONGLY</b> <b>DISAGREE</b>
1. My past achievements have given my life meaning and purpose.	SA	A	MA	U	MD	D	SD
2. In my life I have very clear goals and aims.	SA	A	MA	U	MD	D	SD
3. I regard the opportunity to direct my life as very important.	SA	A	MA	U	MD	D	SD
4. I seem to change my <u>main</u> objectives in life.	SA	A	MA	U	MD	D	SD
5. I have discovered a satisfying life purpose.	SA	A	MA	U	MD	D	SD
6. I feel that some element which I can't quite define is missing from my life.	SA	A	MA	U	MD	D	SD
7. The meaning of life is evident in the world around us.	SA	A	MA	U	MD	D	SD
8. I think I am generally much less concerned about death than those around me.	SA	A	MA	U	MD	D	SD

		SA STRONGLY AGREE	A AGREE	MA MODERATELY AGREE	U UNDECIDED	MD MODERATELY DISAGREE		
				D DISAGREE	SD STRONGLY DISAGREE			
9.	I feel the lack of and a need to find a real meaning and purpose in my life.	SA	A	MA	U	MD	D	SD
10.	New and different things appeal to me.	SA	A	MA	U	MD	D	SD
11.	My accomplishments in life are largely determined by my own efforts.	SA	A	MA	U	MD	D	SD
12.	I have been aware of an all powerful and consuming purpose towards which my life has been directed.	SA	A	MA	U	MD	D	SD
13.	I try new activities or areas of interest and then these soon lose their attractiveness.	SA	A	MA	U	MD	D	SD
14.	I would enjoy breaking loose from the routine of life.	SA	A	MA	U	MD	D	SD
15.	Death makes little difference to me one way or another.	SA	A	MA	U	MD	D	SD
16.	I have a philosophy of life that gives my existence significance.	SA	A	MA	U	MD	D	SD
17.	I determine what happens in my life.	SA	A	MA	U	MD	D	SD
18.	Basically, I am living the kind of life I want to live.	SA	A	MA	U	MD	D	SD

	SA STRONGLY AGREE	A AGREE	MA MODERATELY AGREE	U UNDECIDED	MD MODERATELY DISAGREE		
			D DISAGREE	SD STRONGLY DISAGREE			
19. Concerning my freedom to make my choice, I believe I am absolutely free to make all life choices.	SA	A	MA	U	MD	D	SD
20. I have experienced the feeling that while I am destined to accomplish something important, I cannot put my finger on just what it is.	SA	A	MA	U	MD	D	SD
21. I am restless.	SA	A	MA	U	MD	D	SD
22. Even though death awaits me, I am not concerned about it.	SA	A	MA	U	MD	D	SD
23. It is possible for me to live my life in terms of what I want to do.	SA	A	MA	U	MD	D	SD
24. I feel the need for adventure and "new worlds to conquer".	SA	A	MA	U	MD	D	SD
25. I would neither fear death nor welcome it.	SA	A	MA	U	MD	D	SD
26. I know where my life is going in the future.	SA	A	MA	U	MD	D	SD
27. In thinking of my life, I see a reason for my being here.	SA	A	MA	U	MD	D	SD
28. Since death is a natural aspect of life, there is no sense worrying about it.	SA	A	MA	U	MD	D	SD
29. I have a framework that allows me to understand or make sense of my life.	SA	A	MA	U	MD	D	SD

		SA STRONGLY AGREE	A AGREE	MA MODERATELY AGREE	U UNDECIDED	MD MODERATELY DISAGREE		
				D DISAGREE	SD STRONGLY DISAGREE			
30.	My life is in my hands and I am in control of it.	SA	A	MA	U	MD	D	SD
31.	In achieving life's goals, I have felt completely fulfilled.	SA	A	MA	U	MD	D	SD
32.	Some people are very frightened of death, but I am not.	SA	A	MA	U	MD	D	SD
33.	I daydream of finding a new place for my life and a new identity.	SA	A	MA	U	MD	D	SD
34.	A new challenge in my life would appeal to me now.	SA	A	MA	U	MD	D	SD
35.	I have the sense that parts of my life fit together into a unified pattern.	SA	A	MA	U	MD	D	SD
36.	I hope for something exciting in the future.	SA	A	MA	U	MD	D	SD
37.	I have a mission in life that gives me a sense of direction.	SA	A	MA	U	MD	D	SD
38.	I have a clear understanding of the ultimate meaning of life.	SA	A	MA	U	MD	D	SD
39.	When it comes to important life matters, I make my own decisions.	SA	A	MA	U	MD	D	SD
40.	I find myself withdrawing from life with an "I don't care" attitude.	SA	A	MA	U	MD	D	SD

		SA STRONGLY AGREE	A AGREE	MA MODERATELY AGREE	U UNDECIDED	MD MODERATELY DISAGREE		
				D DISAGREE	SD STRONGLY DISAGREE			
41.	I am eager to get more out of life than I have so far.	SA	A	MA	U	MD	D	SD
42.	Life to me seems boring and uneventful.	SA	A	MA	U	MD	D	SD
43.	I am determined to achieve new goals in the future.	SA	A	MA	U	MD	D	SD
44.	The thought of death seldom enters my mind.	SA	A	MA	U	MD	D	SD
45.	I accept personal responsibility for the choices I have made in my life.	SA	A	MA	U	MD	D	SD
46.	My personal existence is orderly and coherent.	SA	A	MA	U	MD	D	SD
47.	I accept death as another life experience.	SA	A	MA	U	MD	D	SD
48.	My life is running over with exciting good things.	SA	A	MA	U	MD	D	SD

## **Appendix E**

### **Data Codes and Definitions**

<b>DATA CODE</b>	<b>DEFINITION</b>
<b>ACTIVITY</b>	activities the participant engages in, including house and yard work, leisure, and exercise programs
<b>ANGER</b>	expressions of anger regarding illness, trauma, etc.
<b>CHANGES</b>	sense of physical or interpretive changes from pre- to post-transplant; changes in mental outlook
<b>CHOICES</b>	perception that one has choices, options, opportunities that were not available before
<b>DEATH</b>	what death means (may mean) during illness, before or after transplant; facing death
<b>FINDIF</b>	financial difficulties--personal finances, insurance problems, and challenges of bill management
<b>FINSUPRT</b>	financial support references (positive) regarding income, insurance, etc.

<b>FTRPLAN</b>	plans for the future--life plans, goals, expected achievements
<b>JOY</b>	references to laughter, sharing joy, good feelings about experiences
<b>LIFEHIS</b>	explanation /discussion of the way life was before illness and the need for transplantation--related to work, recreation (not specific family info
<b>LIFEVIEW</b>	how participant views "life"; differences pre- and post-transplant
<b>MEDTEAM</b>	any reference to the medical team having cared for or currently caring for the participant; building of a bond between recipient and team
<b>OPTIMISM</b>	expressions of optimism in life (different from specific "hope")
<b>ORGAN</b>	the experience, sensation, feelings related to having someone else's heart, liver, or kidney in one's body

<b>OTHVIEW</b>	views expressed by others regarding the participant or transplant experience and/or how participant feels about it
<b>PEACE</b>	expressions of peace or serenity either before or after the transplant
<b>PRFAMREL</b>	discussions of family/significant other/friend relationships prior to transplant
<b>PRFEAR</b>	pre-transplant references to fear, being scared
<b>PRHOPE</b>	expressions/experiences of hope prior to transplant
<b>PRILL</b>	events/experiences of illness prior to transplant
<b>PRPERSTR</b>	personal trauma (psychological) experienced by the participant prior to the transplant

<b>PTFAMREL</b>	references to family/significant other/friend relationships after transplant (understanding, physical strain, responsibilities)
<b>PTHOPE</b>	expressions/feelings of hope and being able to plan for the future after the transplant had occurred
<b>PURPOSE</b>	specific reference to one's purpose in life (perceived)
<b>QUESTION</b>	questions/leading statements by the interviewed
<b>RESILIENCE</b>	self-identified personal resilience in the face of adversity either before or after the transplant
<b>SHAREEXP</b>	a desire to share thoughts and experiences of transplant with other candidates or recipients
<b>SPIRITUL</b>	reference to God, Lord, Supreme Being, some higher power

<b>SPECULAT</b>	ideas suggesting what "might have been" without the illness and need for a transplant; speculation as to how this experience perhaps made "me" different
<b>STRUGGLE</b>	struggling to stay alive versus struggling to live--physical and emotional
<b>SUFFER</b>	references to suffering--physical and emotional; or related psychological hardship experiences
<b>SUMM</b>	summarizing statements, plans for future talks, other miscellaneous information
<b>TRANSPLT</b>	immediate pre-, during, and post-transplant experience
<b>TRDECIDE</b>	statements, issues, concerns regarding the personal decision to proceed with transplantation