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A phenomenological study of the experience of the spouse of a heart transplant recipient

Alice Hill McCurry

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To the Graduate Council:

I am submitting herewith a dissertation written by Alice Hill McCurry entitled "A phenomenological study of the experience of the spouse of a heart transplant recipient." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

Sandra P. Thomas, Major Professor

We have read this dissertation and recommend its acceptance:

Mitzi Davis, Howard Pollio, Patricia Droppleman

Accepted for the Council:

Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)


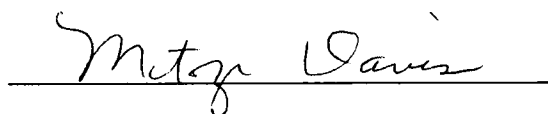
To the Graduate Council:

I am submitting herewith a dissertation written by Alice H. McCurry entitled "A Phenomenological Study of the Experience of the Spouse of a Heart Transplant Recipient." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.



Sandra P. Thomas, Major Professor

We have read this dissertation
and recommend its acceptance:



Accepted for the Council:



Associate Vice Chancellor and
Dean of the Graduate School

A PHENOMENOLOGICAL STUDY OF THE EXPERIENCE
OF THE SPOUSE OF A HEART TRANSPLANT RECIPIENT

A Dissertation

Presented for the

Doctor of Philosophy Degree

The University of Tennessee, Knoxville

Alice H. McCurry

December 1999

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DEDICATION

To my husband, Jim, and our son, Matthew

ACKNOWLEDGEMENTS

Many people have been involved in the completion of this dissertation process, and to each of them I owe a debt of gratitude. I have had the privilege to be guided by a superb dissertation committee whose dedication to education and scholarship is to be emulated. Dr. Sandra Thomas, committee chair, Dr. Howard Pollio, Dr. Pat Droppleman, and Dr. Mitzi Davis have mentored, encouraged, and challenged me throughout this process. For their guidance I am truly thankful.

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ABSTRACT

Heart transplantation is an increasingly common treatment for end-stage heart disease and often involves extended periods of waiting for the transplant, recovering from the surgery, and life changes related to compliance with subsequent perennial medical follow-up and treatment. Current research readily documents increasing success in cardiac transplantation and in the long-term quality of life of recipients. Relatively few studies, however, have explored the impact of this critical life event on the spouse and/or children of the transplant recipient.

The purpose of this study was to explore and describe the experience of spouses of heart transplant recipients. The study used a phenomenological design to describe the structure of the experience as related by seven female participants. Data was collected through phenomenological interview with audio-recording and verbatim transcription of the audiotapes. Analysis of the transcripts was done both individually by the researcher and within a phenomenology research group.

The thematic structure derived from data analysis describes the spouse's experience in the contexts of time and other people. Four major, interrelated themes emerged within this context: Death/Life, Vigilance, Change, and Gift. Findings are discussed in relation to nursing practice, education, and research.

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CHAPTER ONE

INTRODUCTION

Numerous studies address the physiological and psychosocial needs of successful heart transplant recipients. While current research documents the advancement of medical science in improving the success rates and longevity of transplant recipients, the impact of the transplantation experience and quality of life issues for recipients and family members, especially spouses and children, continue to be of major concern (Canning, Dew, and Davidson, 1996; Collins, 1994; Collins, White-Williams, and Jalowiec, 1996; Duitsman and Cychosz, 1993).

Heart transplantation is becoming an increasingly common treatment for end-stage cardiac disease and often involves long waiting and recovery periods for the potential candidate and his/her family. Beginning with the disease process that evokes the need for a heart transplant, potential transplant recipients and their families face periods of uncertainty and unpredictability which may dominate their lives and challenge their abilities to cope (Buse and Pieper, 1990; Mishel and Murdaugh, 1987). The experience of waiting for a heart transplant has been described by potential recipients and their spouses as "life on hold" (Williams, 1991). In many ways, this experience does not end with a return to pretransplant "normal" existence after the actual transplantation, but continues to affect the recipient and family members for an undetermined period of time (Mishel and Murdaugh, 1987).

A few studies directly address the effect of this significant life experience on spouses. In addition, some information can be gleaned from studies of heart transplant recipients that incidentally included data collection from the spouse as a factor affecting the recipient's pre- and posttransplant adjustment and compliance with the medical regimen. Results from the various studies are sometimes conflicting.

Mishel and Murdaugh (1987) studied pre- and posttransplant adjustment processes of heart transplant recipients and spouses or designated significant others. These authors described the posttransplant experience for the spouse as "passage" from immersing oneself in sustaining the transplant candidate's life for surgical intervention to "negotiation" of the spouse's regained independence and the couple's future life together. The authors describe the posttransplant period of adjustment as a "dynamic interaction between the patient and the partner" (p. 336) comprised of interpersonal conflict as their future life together is negotiated. Level of conflict and degree of family stability and cohesion reflect the success of negotiating the conflict. The authors note that resolution of the negotiation is a gradual process without identified time limits although ongoing negotiation was identified at one year posttransplant for some participants.

While this study presents valuable findings, some questions about the methodology remain. Study participants were members of various 12-week support groups conducted over a two-and-a-half year period of data collection. Although meetings were attended by the researchers, no clarification of the level of

researchers' participation in the meetings was provided. Data were compiled by recording and transcribing the researchers' memories of the meetings. For any needed clarification and/or verification, data were presented to other professional members of the support group rather than to participants. In addition, the time frame for the study is unclear: the support group included transplant candidates, transplant recipients, and spouses of candidates and recipients, although there is no distinction of the particular stage of the experience for any of the participants or of what portion of the participants' experience was included. These concerns may color the research findings and should be addressed in further study.

Buse and Pieper (1990) studied the effect of cardiac transplantation on the life, relationship, and perceived stress of the recipient's spouse. Thirty subjects completed three questionnaires relating to both pre- and posttransplant times and experiences. Although participants indicated that the posttransplant period had less overall effect and more positive impact than the pretransplant period, no difference was found in stress scores during pre- and posttransplant periods. These results may have been affected by the subjects' need to recall and give responses about experiences of as long as three years ago. The instrument also may have failed to adequately measure stress in this life experience. While this study differentiates the impact of the experience during pretransplant and posttransplant periods and notes continued and consistent levels of stress throughout, the study does not fully describe the experience of the spouse.

Collins (1994) investigated predictors of quality of life in spouses of heart transplant recipients and found that the spouse's physical health, coping ability and effectiveness, and family resources had strong positive relationships to quality of life. Sixty-five per cent of the subjects reported high stress levels, and increased stress was found to be negatively related to coping and quality of life. Spouses employed outside the home had increased stress scores, possibly related to their perception of increased socioeconomic responsibility. Increased stress was negatively related to the spouse's life satisfaction and effective coping. In another study of spouse stressors during the period of waiting for transplant, Collins, White-Williams, and Jalowiec (1996) found similar results. These two studies lend more support to the premise that this significantly stressful experience has great impact on the life and well-being of the spouse. However, their purpose was to identify and quantify specific aspects of the effect of the heart transplant on spouses, and these studies do not fully capture the specific aspects of their lived experience.

McSweeney and associates (1995) used both a naturalistic inquiry method and the Ferrans and Powers quality of life instrument to compare quality of life of ten heart transplant recipients and their spouses who were one to five years posttransplant. The participants were interviewed at length on two occasions and were asked to complete the quantitative instrument on a third visit. The Ethnograph computer software program was utilized for beginning data analysis and grouping of meaning units. Other unspecified methods of content analysis were used to complete

data analysis. Results were grouped in three large areas: perceived quality of life as measured by the instrument, personal concerns, and relationship concerns. Study results showed perceived quality of life was lower for spouses than for recipients. Additionally spouses in this study discussed such personal issues as financial concerns, future plans and personal desires, stress, and secrets not previously shared with anyone of their health care personnel or with anyone in the support group from which the participants were chosen. Relationship concerns included the recipient's posttransplant functional status, sexuality issues, other marital relationship concerns, burden of others also needing assistance or care of the spouse, and reaction of others to the transplant couple.

This study presented little positive data related to the spouses' posttransplant experience. Indeed, spouses generally responded that the transplant situation had resulted in continued personal stress and need as well as feelings of resentment and guilt. The authors suggested that findings should lead health care personnel to more fully prepare spouses for living with the heart transplant recipient. This study reported singularly negative findings overall and showed no positive outcomes for spouses. Without knowledge of the specific questions and process used in the interviews, it is not clear whether the participants' responses were freely elicited or were somehow inadvertently influenced toward the most negative of their replies. Some clarification of method might allay concerns about the lack of any positive finding among the experiences of the ten spouses.

Keenan (1992), in a study of adjustment and quality of life in transplant recipients, reported a significant relationship between psychological and marital adjustment of recipient and spouse: if the recipient reported increased distress, the spouse reported similar distress.

“In a sense, the recipient and their [sic] partner should be considered ‘co-patients,’ as they are both coping with the lifelong impact of a serious condition.... The needs of the transplant recipient and of their [sic] spouse are probably similar in many ways, but quite different in others. Given the importance of family support to the patient's adjustment and quality of life, it is crucial that adequate attention be given to ‘caring for the caregiver.’ Without this, it appears that we create a situation with increased risk of adjustment problems for the patient, a greater likelihood of marital distress, and a higher incidence of emotional problems among the spouses of the recipients” (p. 121-122).

It is evident that this experience is shared by recipient and spouse and has profound effects on both lives. Studies have shown that support from spouse and satisfaction derived from close supportive interpersonal relationships are essential to facilitating the recipient's adjustment throughout the transplant process. Hirth and Stewart (1994) found that social support from family, friends, and health care providers helped to maintain hope and contributed to coping while awaiting

transplantation. Duitsman (1991) demonstrated significant relationships between recipients' quality of life and marital and family life satisfaction. Duitsman and Cychosz (1993) note that family satisfaction is critical to successful recuperation of the heart transplant recipient and a major predictor of quality of life.

Lough (1986) indicates that family relationships, although stressed by transplantation, "return to normal over time". Hwang (1996) globally notes, "Most authors indicate that patients and families adjust well to heart transplantation" (p. 16). This author's brief review of some of the current literature is prefaced by a comment on the paucity of relevant studies. Current research and even the content of this article do not necessarily support her optimistic conclusion as to family and patient adjustment. Other researchers (Mishel and Murdaugh, 1987) indicate that the recipient and spouse must gradually develop a new "normal" posttransplant existence and must continually negotiate adjustment details in their situation.

Clearly, this critical life experience can be fraught with unpredictability, change, anxiety, and role variability which requires ongoing adaptation by recipient and spouse. The time component for adjustment of recipient and spouse to the posttransplant life situation also remains elusive. Conflicting findings as to role function of spouse and recipient, family dynamics posttransplant, and level of stress and ease of adjustment cannot be fully resolved by current research. Potential explanations of conflicting results are proffered by each author, but the matter remains ambiguous. A fully descriptive explication of the lived experience of the

spouse should provide insight and knowledge and help clarify some areas of ambiguity. This study attempted to resolve this insufficiency.

Purpose Statement

The purpose of this study was to explore the experience of spouses of heart transplant recipients during the posttransplant period. This purpose was accomplished by using a phenomenological interview process to describe the thematic structure of this experience for participants. In this type of research, experience is defined as the self-accounting of posttransplant life experiences of spouses of persons who received a heart transplant at least three months prior to the study. In in-depth interviews, each participant was asked to respond to the question, "Now that you have been the spouse of a heart transplant recipient for some time, what in that experience stands out for you?" Participants' stories allowed them to explore the meaning of the experience for them, and this information should prove useful to nurses and other health care providers in developing more holistic and individualized care of spouses of heart transplant recipients throughout the transplant experience.

Research Perspective

The experience of the spouse of a heart transplant recipient was the phenomenon of interest in this study. Because a clear description of the structure and meaning of the experience for the participants was the focus, a phenomenological approach was thought to provide the most appropriate method for this purpose. Polkinghorne (1989) notes that phenomenological research is distinguished from other qualitative approaches in its focus on the participant's experienced meaning rather than on his or her overt behavior or actions. The purpose of phenomenological research is to describe clearly and precisely the essential structure of a person's experience and its meaning to him or her.

Phenomenology, which refers to "the study of phenomena, the appearance of things" (Cohen, 1987, p. 31), had its beginnings in Europe in the middle of the nineteenth century as philosophers challenged the positivist (realist) worldview of objective reality and the Cartesian ideas of dualism of mind-body (Spiegelberg, 1971). This prevalent positivist worldview is based on the idea of an objective reality that can be known, measured, and understood through the use of appropriate instruments and by rigorous attention to the maintenance of researcher objectivity and separation from the phenomenon or object being studied. This worldview forms the philosophical basis for quantitative research methods.

Edmund Husserl, a German philosopher who is credited as the founder of phenomenology, renounced Cartesian dualism and the realist worldview. He insisted that one must return to the thing itself, the experience, to “come to an essential understanding of human consciousness and experience” (Valle, King, and Halling, 1989, p. 6). Similarly, existentialist philosophers such as Kierkegaard, Merleau-Ponty, and Sartre espoused the inadequacy of positivistic ideas and methods to elucidate basic human struggles and issues. The twentieth century existentialists found the methodology of phenomenology appropriate for the study of existential philosophy. Martin Heidegger, a student of Husserl, was among the first to combine existential ideas and phenomenological methods in a research method designed to understand human experience.

Both phenomenology and existentialism seek “a rigorous description of human life as it is lived and reflected upon in all its first-person concreteness, urgency, and ambiguity” (Pollio, Henley, and Thompson, 1997, p. 5), and the combination of these two philosophies is primarily concerned with describing human experience in and of the world. For the existential-phenomenologist, human existence is characterized by intentionality, concepts of figure/ground, and change and continuity (Pollio et al, 1997).

Intentionality is “one of the defining properties of human experiencing” (Pollio et al, 1997, p. 6). In philosophy, intentionality implies that “human experience is continuously directed toward a world that it never possesses in its entirety but

toward which it is always directed” (Pollio et al, 1997, p. 7). A person’s consciousness is always consciousness of something. Person and world are totally interrelated or indissolubly united. The individual and his/her world co-constitute each other. Both are viewed as having no existence apart from each other, and each is seen as giving meaning to the other (Valle, King, and Halling, 1989). It is in the dialogue between the person and his/her world that the personal lifeworld is co-created. For the existential phenomenologist, human existence always concerns an experience of “being-in-the-world.”

All experience is situated in the world: that is to say, all experience is perceived against a background of something. Both the focal experience and the background are simultaneously present and necessary for the defining of the experience. The concept of figure/ground is most familiar in the combined figures of faces-and-vase, beautiful woman-and-witch, or perhaps in more recent work, in three-dimensional art. Both figure and ground are constantly present although only one is seen at any one time against the background of the other. So it is for human experience: experience does not take place in isolation; it is always situated in its lifeworld.

Consciousness always involves expressions of both continuity and change. That is, consciousness is continuous in that it is always present and ongoing, although the object(s) of consciousness changes with change in that which becomes figural or ground when perceived by an individual.

A phenomenological research design allows the researcher to study selected human experience on the basis of detailed descriptions provided by participants. By analyzing data obtained through phenomenological methods, the researcher is able to discover the thematic structure of the phenomenon. The knowledge gained through phenomenological research is not sought for its generalizability: indeed, this is antithetical to the epistemology and ontology of phenomenology and qualitative research in general. However, it is expected that knowledge gained from such research may enlighten our understanding of the participants' experiences and enable us to provide more holistic care to those individuals whom we encounter in nursing. Pascoe (1996) states that "nursing is currently searching for alternative methods and approaches which allow nurses to explore and understand fundamental but often elusive phenomena in such a way that they are not stripped of their human relevance, and also, to deliver care related to these that is unique to the patient. In order to achieve this the nurse needs to enter the world of the patient and to understand their unique meanings" (p. 1313).

Phenomenology has been identified as "suitable for researching nursing questions about nursing phenomena" (Annells, 1996, p. 708). While many studies address the biopsychosocial needs of heart transplant recipients, there is little research concerned with describing the experience of the spouse of a heart transplant recipient. A description of the spouse's experience and nursing care needs is basic to the nurse's understanding of this phenomenon and to the provision of suitable

nursing care. A phenomenological approach seems most appropriate for understanding and describing the lived experience of the spouse of a heart transplant recipient. This approach was chosen because of the congruence of its underlying philosophy and purposes with those of the study of this phenomenon. It is expected that description of the spouse's experience will enlighten nurses as to the potential needs of, and interventions for, spouses of cardiac transplant recipients.

Delimitations and Limitations

The study participants were spouses of persons who had received a heart transplant at least three months ago. The spouses were English speaking and had no known cognitive impairment. Although the study was not delimited to female spouses, the eventual sample was comprised entirely of female spouses.

This study described the lived experience of the spouses of heart transplant recipients. The results are specific to this sample. The qualitative design does not seek to determine relationships between specific variables; rather, analysis is designed to reveal the structure of the lived experience as related by the participants. Studies of similar samples could potentially have different results. Interpretation of results could also vary depending on method of analysis, although some meaningful similarity across studies is to be expected.

Significance of the Study

Cardiac transplantation is a critical life event for individuals and their families. It is also the beginning of continuing challenges for both recipient and spouse. The spouse's current and future life is both directly and indirectly affected by the transplantation. Knowledge of the life experience from the perspective of the spouse will more fully illuminate the structure of the experience and the nursing care needs of the spouse as well as of the recipient.

The spouse has unique information which can contribute to the knowledge base which underlies nursing care of the heart transplant recipient and his or her family. As noted above, this is a shared life experience in which the support of the spouse may be critical to the successful adjustment and ongoing self-care and compliance of the recipient. The knowledge of this experience will bring a new dimension to care that can be provided to the transplant recipient and to other family members including the spouse.

The study also has implications for nursing practice and education. More fully understanding the life situation and perception of reality of the transplant recipient and the spouse will identify potential needs that can then be addressed through anticipatory guidance and education. This enriched understanding should more specifically direct care planning and implementation and allow for evaluation of care in a more holistic fashion. Nursing education could also utilize the knowledge gained

from this study to broaden the student nurse's understanding of the complexity of effect of a heart transplant on the recipient, the spouse, and other family members. Accurate education concerning the needs of the family of the recipient and the spouse should lead to a more holistic understanding of the effect of heart transplantation.

The study will inform potential future research in the longitudinal effects of heart transplantation on individuals and their families. It seeks to bring a fresh understanding of the process of transplantation from the spouse's perspective and may apprise researchers of further areas of needed study. Findings of this study may also direct other follow-up studies of significant phenomena.

Summary

The impact of heart transplantation on the spouse of the recipient has been inadequately studied to this point. Since the heart transplant has significant implications for the life of the spouse as well as for the transplant recipient, a better understanding of the complete experience is needed. A phenomenological approach would seem appropriate for studying the lived experience of the spouse of a heart transplant recipient; such a study will result in a description of this life experience. It should also serve to illuminate a dark corner in the knowledge base with which we

understand the needs of others and allow us to meet these needs through appropriate nursing care.

CHAPTER TWO

LITERATURE REVIEW

The purpose of this study was to explore phenomenologically the lived experience of spouses of heart transplant recipients. In this chapter, a brief overview of the history and current status of heart transplantation will be presented as a background to the phenomenon of interest. Following this, a selected literature review related to heart transplantation and the spouse's experience before and after the transplant will be presented. In addition, this review will include significant literature related to the spouse's experience during the mate's experience of myocardial infarction, surgery of the heart, and/or other critical cardiac illness.

Heart Transplantation: History and Status

The history of heart transplantation may have had its beginnings in ancient civilizations as body parts were experimentally grafted from person to person (Kesling, 1987). During the nineteenth century, grafting of tendon, cartilage, and skin was attempted (Kesling, 1987). In the early twentieth century, experimental grafting of hearts in dogs was done at the University of Chicago; these heterotopic transplants left the original heart intact and grafted the transplanted heart into the neck of the recipient dog (Williams, 1991). The procedure for orthotopic

transplantation, removing the original heart and replacing it with a transplanted organ, was developed in the late 1950's and 1960's (Williams, 1991). In addition, transplantation of kidney, heart, lung, liver, pancreas, and other organs were attempted at this time with varying success (Kesling, 1987). In 1964 Hardy attempted a xenograft of a chimpanzee heart into a human recipient. The first allograft of a heart was performed by Christian Barnard in 1967; the patient survived eighteen days before dying of problems of infection and rejection (Duitsman and Cychoz, 1993; Kesling, 1987; Williams, 1991). The first transplant performed in the United States was done in January, 1968 (Porter, Bailey, Bennett, Catalfamo, Daniels, Ehle, Gibbs, Krout, and Luers, 1991). The next fifteen years of transplantation had generally poor results, with most patients surviving only short periods, perhaps no longer than if they had not had the transplant (Duitsman and Cychoz, 1993).

With the discovery of a new immunosuppressant drug, cyclosporine, in 1981, a transplant recipient's chance of survival was markedly improved (Duitsman and Cychoz, 1993; Kesling, 1987). As pharmacological control of rejection and infection continued to advance and as refinement of surgical techniques and medical follow-up of transplant recipients significantly improved, the success rate of heart transplants increased. Associated costs were also lowered, and acceptable levels of posttransplant quality of life and rehabilitation were demonstrated. Consequently, the U.S. Department of Health and Human Services declared the procedure no longer

experimental, and private and public insurance agencies included transplantation in their policies (Williams, 1991).

Once considered experimental, heart transplantation is now an accepted therapeutic option for persons with end-stage cardiac disease (Mai, 1993). General registry statistics report increasing numbers of heart transplants from 190 in 1982 to 3,048 in 1996; currently there are 297 transplant centers which have performed a total of 40,738 heart transplants. Current overall survival rates are 78.1 percent at one year posttransplant, 63.4 percent at 5 years, 43.9 percent at 10 years, and 30.9 percent at 13 years (International Society for Heart and Lung Transplantation, 1997). Due to the limited supply of donated organs, however, the number of transplants in one year has not exceeded 4000 worldwide (Saad, 1997).

Over the past twenty years, then, heart transplantation has evolved from an experimental attempt to prolong the lives of patients with end-stage cardiac disease to a successful therapeutic regimen. With funding from public and private insurance, it remains a viable option for many who would otherwise die prematurely. These transplant recipients are required to name a primary support person who will agree to share both the transplant experience and the responsibilities for ongoing care in the immediate posttransplant period (for six weeks to several months). In most instances this support person is the recipient's spouse. As supported by the above statistics, the population of spouses of heart transplant recipients is ever enlarging; despite this,

medical and nursing literature hardly addresses the experience and care needs of this group.

The Spouse's Experience in Heart Transplantation

A literature search quickly reveals thousands of studies related to heart transplantation. Initial studies reflect ongoing concerns about surgical procedure/technique. Research also addressed such problems as early detection and control of infection and rejection and continued improvement of patient care in all stages of the process. More recent studies focus on patient stress, coping abilities, and quality of life posttransplant. A few studies have addressed the effect of the transplant on the spouse/family of the recipient; these can be generally categorized by their focus on the pretransplant or posttransplant period, spouse/family stressors and coping strategies, or quality of life issues.

Prior to Transplant

The transplant process is often divided into three stages: the pretransplant period (including the evaluation for candidacy and the subsequent wait for the donor heart to become available), the transplant operation itself, and the posttransplant period (including postsurgical hospitalization of varied lengths and extending indefinitely). In two studies using grounded theory approach, the waiting period

before transplantation was labeled "life on hold" by candidates and their spouses (Williams, 1991) or "immersion" by researchers (Mishel and Murdaugh, 1987). Both studies describe initial spousal behavior of "freeing self" and "making life the transplant" or "immersion," that is, the spouse's disengaging from usual responsibilities to concentrate on maintaining the candidate's life for the transplant. Often this means temporarily giving up important aspects of the spouse's life and possibly relocating to the area of the transplant center to wait for a donor organ to become available.

Both studies note that the spouse relinquishes his/her separate identity to focus on the partner's health maintenance. Mishel and Murdaugh (1987) detailed two aspects of this stage of the spouse's response: "symbiosis" and "trading places." Symbiosis is described as destructive to the spouse as the spouse relinquishes a sense of self to identify totally with the partner's situation and to act constantly to maintain the partner for anticipated transplant. "Trading places" refers to the spouse's assumption of roles and responsibilities that previously were performed by the partner. It is hardly surprising that the pretransplant period has been studied from the perspective of spouse or from that of family stress and coping. Degree of stress during the period of waiting for heart transplant has variously been reported as low, moderate, and high in different studies (Buse and Pieper, 1990; Collins, White-Williams, and Jalowiec, 1996; Nolan, Cupples, Brown, Pierce, Lepley, and Ohler, 1992). This variation in reported amount of stress may have been affected by a

number of factors: the instrument used for measuring perceived stress; a retrospective design which asked subjects to report on memories of stress levels for as long ago as three years; the effectiveness of coping strategies in dealing with stress; and the method of sampling and lack of clarity of time frame of study (Collins et al, 1996; Nolan et al, 1992). The importance of social support to the candidate/recipient before, during, and after the transplant has been noted. Indeed, lack of adequate support may be a contraindication for candidacy (Keenan, 1992). Quality of relationships with family, style of coping, and psychological reaction to transplantation have all been identified as risk factors in recipient compliance with postoperative regimen. Lack of compliance is related to morbidity and mortality in the posttransplant period (Dew, Roth, Thompson, Kormos, and Griffith, 1996).

Psychosocial adjustment of candidates and transplant recipients has been an ongoing concern (Dew, Roth, Schulberg, Simmons, Kormos, Trzepacz, and Griffith, 1996; Hirth and Stewart, 1994; McAleer, Copeland, Fuller, and Copeland, 1985). Transplant recipients with increased depression and anxiety were likely to have poor social support, less effective coping skills, and poor self-image; this finding underscores the critical roles of spouse, other family members, and friends (Dew et al, 1996). Social support and hope have been found to be important in mediating stress and in facilitating the candidate's coping in the pretransplant period (Hirth and Stewart, 1994). Social support is not limited to spouses, although subjects identified families as significant sources of emotional support and practical aid. It was noted

that support from friends and family decreased after three months: the authors surmise that such support must be costly to the support person. Although the authors did not define "costly" in their discussion, it could potentially have been understood as cost in money, emotional/social support, and/or actual time. The research literature documents the value of a spouse's support for the recipient's health status and medical compliance. Despite these results, there are no specific reports of the cost of the ongoing support of the candidate/recipient for the spouse who is involved in the entire transplant process from initial evaluation through long-term survival. Such information could only come from the spouse's accounting of this experience.

During and After Transplant

The time frame of the surgical procedure of heart transplant and hospitalization for postoperative recovery is relatively short for the patient who does not require continuous life support prior to transplant or as a result of complications. The mood of the transplant recipient in the immediate postoperative period has been described as initially euphoric with gratitude to the donor's family. Reliance on the heart transplant staff diminishes as increased strength and endurance allow the recipient to take a more active role in recovery (Keenan, 1992). The euphoria may be negated, however, by an occurrence of infection or rejection: the recipient may become depressed with the realization of the tedium and chronicity of the expected posttransplant followup (Keenan, 1992). The effect of the perioperative period on spouses has been partially described by Mishel and Murdaugh (1987). Labeling this

period "passage," and noting that it culminates with hospital discharge, these authors delineate three parts of the process: 1) catharsis (discharge of pent-up emotions from the pretransplant period), 2) vacillation (acknowledging the unpredictability of the immediate posttransplant situation), and 3) awareness (recognizing that the transplant has created a new life situation with a new "normal" concerned with ongoing vulnerability and unpredictability).

During a short period of time, the spouse and recipient must also learn much about the posttransplant followup and medication regimen in order to cope satisfactorily with the demands of the postoperative period outside a hospital setting. There is an unusual dearth of literature related to the needs of the nuclear dyad during this time period.

The final stage of the posttransplant period has been labeled "negotiation"; unlike the stages of immersion and passage, this stage moves from a focus on the spouse's evolution from the new "normal" to ongoing interactions between recipient and spouse as they realign role function, life goals, and power within the dyad (Mishel and Murdaugh, 1987). This stage is characterized by interpersonal conflict and may be variably prolonged. Successful resolution of this stage allows for the needs of both recipient and spouse as they "redesign the dream" of their future together.

McSweeney and associates (1995) used a combination of a quantitative instrument and a naturalistic inquiry method to explore this period and presented a

generally negative report of the spouse's posttransplant experience. The participants in this study, who were one to five years posttransplant, reported continued personal stress and concerns about fulfilling personal needs as well as resentment of their life alterations as a result of the heart transplant. These participants generally indicated a great deal of dissatisfaction with posttransplant life and its ongoing limitations and future ramifications. The authors concluded that the spouses should be more adequately prepared for the realities of the posttransplant experience.

Further studies of the first 6-12 months of the posttransplant period have focused primarily on the transplant recipient's compliance, psychosocial and emotional adjustment, and quality of life (Bohachick, Anton, Wooldridge, Kormos, Armitage, Hardesty, and Griffith, 1992; Dew et al, 1996; Dew, Simmons, Roth, Schulberg, Thompson, Armitage, and Griffith, 1994; Jones, Taylor, Downs, and Spratt, 1992; Kuhn, Davis, and Lippman, 1988; Lough, 1986; Lough, Lindsey, Shinn, and Stotts, 1985; Mai, McKenzie, and Kostuk, 1990). One study (Baumann, Young, and Egan, 1992) focused on adjustment in the posttransplant period through interviews with both transplant recipients (from five months to five years posttransplant) and significant others (78% were spouses); results of this study, however, were presented with primary emphasis on the adjustment of the recipients with the significant others' support. Very little information was reported in relation to the spouse's experience or life satisfaction posttransplant.

In summary, some studies of spouse experience during the heart transplantation process have used grounded theory to describe the stages of spouse experience, whereas other studies have primarily been directed at the measurement of spousal stress during the waiting period. The importance of the role of the spouse also has been emphasized in studies of psychosocial adjustment, compliance, social support needs, and quality of life of the transplant recipient. Questions remain as to the experience of the spouse in the posttransplant period.

Spouse Experience in Other Significant Heart Disease

In the absence of extensive research related to the spouse's experience in the posttransplant period, examination of related literature on spouse experience in other serious disease conditions may be helpful. Myocardial infarction is a common, life-threatening problem that has been studied from the perspectives of patient and spouse. The experience of the spouse seems somewhat similar to the experience of the spouse of a heart transplant recipient. This perhaps is because similar concerns were investigated: stress, psychosocial factors, marital relationships, coping abilities and styles, as well as the need for support and information to deal with post-myocardial infarction life (Beach, Maloney, Ploccia, Sherry, Weaver, Luthringer, and Utz, 1992; Bedworth and Molen, 1982; Caplin and Sexton, 1988; Croog and Fitzgerald, 1978; Hentinen, 1983; Mayou, Foster, and Williamson, 1978; Miller and

Wikoff, 1989). Findings indicated that the event of myocardial infarction was life-threatening and therefore very stressful for patient, spouse, and family both at the time of the event and in the recovery and adjustment period. Additionally, while the significance of the spouse's roles in the patient's recovery and compliance were noted, the spouses often were impersonally treated only as factors in relation to the patient. Results also indicated that spouses experienced role change and marital dysfunction in the period after the patient's myocardial infarction and that the quality of marital and family life seems to be a determinant of the patient's overall social and psychological outcomes.

Studies of spouses of patients with critical cardiac disease or heart surgery also resulted in findings of significant stress, anxiety, and/or depression in spouses. Research noted the potential for residual marital/family dysfunction postoperatively. Spouses were found to use a variety of types of coping responses with variable levels of success. Some studies also documented the spouse's need for information, social support, and anticipatory guidance regarding postoperative concerns. Other studies noted the long-term effect of the experience (Artinian, 1991; Artinian and Hayes, 1992; Bohachick and Anton, 1990; Gilliss, 1984; Gilliss, Neuhaus, and Hauck, 1990; Monahan, Kohman, and Coleman, 1996; Nyamathi, Jacoby, Constancia, and Ruvevich, 1992; Radley and Green, 1986). These findings parallel results of studies of spouses of heart transplant recipients and spouses of patients with myocardial infarction. The overall findings suggest that these experiences have great potential

for initial and prolonged impact on the lives of those involved, and that each situation significantly affects both patient and spouse.

CHAPTER THREE

METHODOLOGY

The purpose of this study was to explore and describe the experience of spouses of heart transplant recipients after the first three months of the posttransplant period. A phenomenological interview design was used to discover the structure of this experience for participants. The present chapter reviews briefly the underlying assumptions and characteristics of the existential phenomenological design used in this study. The role of the researcher in this process, data collection and recording procedures, and the process of data analysis are discussed. Finally, issues of validity and reliability in qualitative research and reporting of findings are addressed.

Existential Phenomenological Approach

Phenomenology is both an abstract philosophy and a methodology of qualitative research that deals primarily with the practical aspects of living in the world. While phenomenological philosophers attempt to describe existence as "being-in-the-world," phenomenological researchers endeavor to describe lived experience (Swanson-Kauffman and Schonwald, 1988). To accomplish this goal, they seek a rich description of lived experience that provides insight into the phenomenon and increases the potential for further action and/or research (Boyd, 1993).

Existential phenomenology yields a method of research that results from the blending of existentialism and phenomenology, two complementary yet distinctive approaches (Valle, King, and Halling, 1989). Kierkegaard, who is generally credited with the founding of existential philosophy, felt that philosophy should address itself to an individual's concrete existence and attempt to elucidate fundamental themes of human life (Valle, King, and Halling, 1989). Husserl, a German philosopher credited as the originator of phenomenology, emphasized the study of "things *as they appear* so that one might come to an essential understanding of human consciousness and experience" (Valle et al, 1989, p. 6). Heidegger, another German philosopher and student of Husserl, was among the first to combine the concerns of existentialism with the methodology of phenomenological study. In combination, existential phenomenology became a philosophy which sought to understand human existence in a manner as free as possible from cultural presuppositions such as the themes of Cartesian dualism and other natural science views of the topic (Valle et al, 1989). When existential phenomenology was specifically applied to studies in human psychology, existential-phenomenological psychology became a sub-discipline that sought to explicate the form or structure of human behavior and experience through descriptive techniques (Valle et al, 1989).

Phenomenology as a method of research was developed most fully within the discipline of psychology. It is based on the assumption of an indissoluble interrelationship between the human being and his/her world. Both the individual and the world co-constitute each other. The two do not exist apart from each other, and each is the basis of

meaning for the other. Thus, existence or being-in-the-world is a relationship of dialogue between person and world, and the person's life-world is co-created within this dialogue. The psychologist who ascribes to the philosophy of existential phenomenology uses descriptive techniques to reveal the structure of human experience. Structure is commonality seen in various appearances of this phenomenon of interest and is disclosed as meaning (Valle et al, 1989). The objective of phenomenological research is precise, clear, and systematic description of the meaning of human experience (Polkinghorne, 1989).

Pollio, Henley, and Thompson (1997) describe a specific phenomenological methodology (see Figure 3.1) using the phenomenological interview as a major procedure for attaining a significant and rigorous description of the lived human experience. "The method... that seems natural to attain a proper description of human experience is that of dialogue in which one member of the dialogic pair, normally called the *investigator*, assumes a respectful position vis-a-vis the real expert, the subject, or more appropriately, the co-researcher" (Pollio et al, 1997, p. 29). The authors note that this method encourages realization and clarification of meaning as the individual describes his or her experience.

After a topic is chosen and prior to the interview of the participant, a bracketing interview is performed to enable the researcher to talk about presuppositions concerning the phenomenon and to become sensitized to any potential for imposing the researcher's own views on participants. In this way, the investigator experiences the interviewing

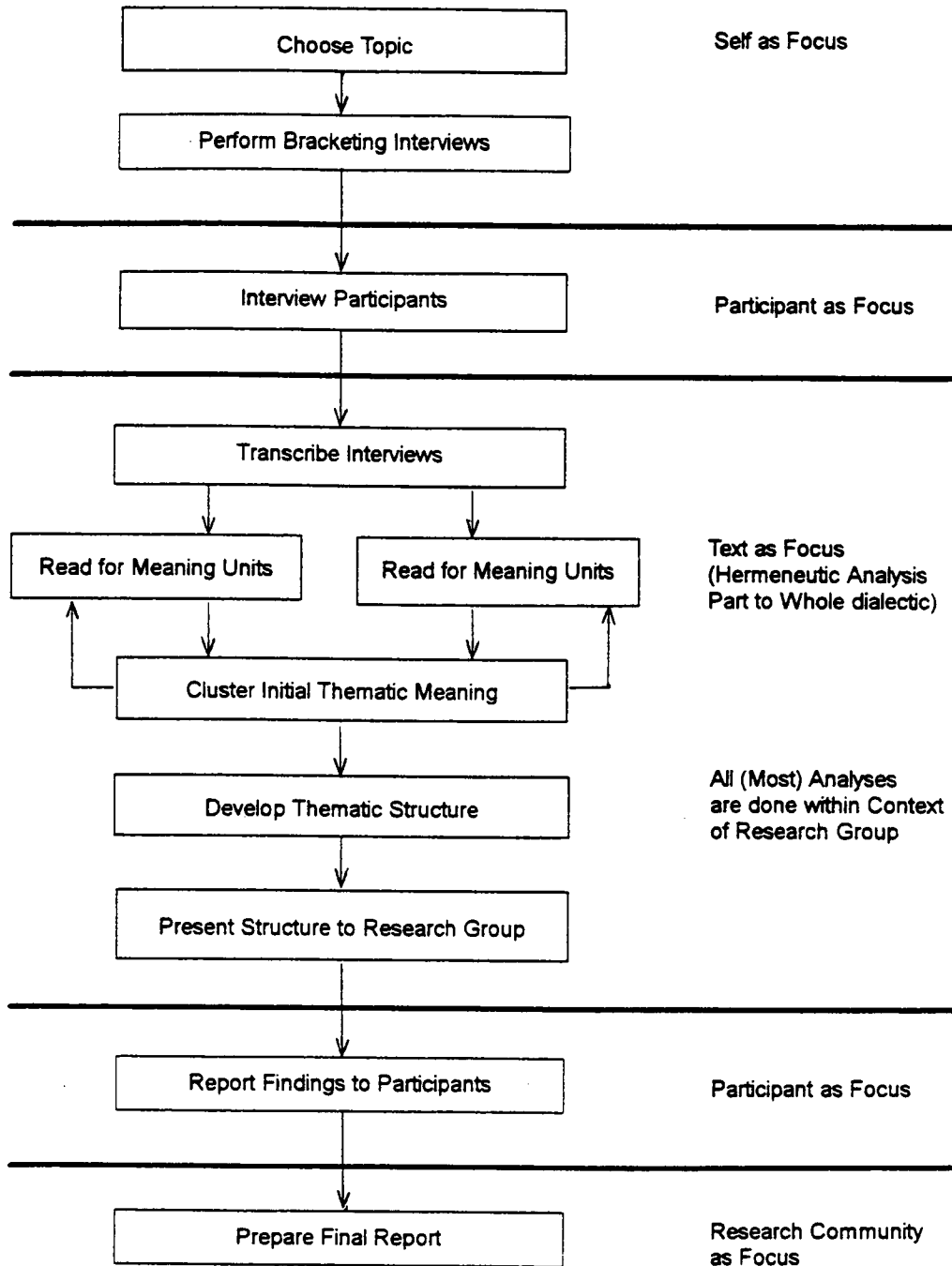


Figure 3.1. Steps for Doing a Phenomenological Research Project

Source: Pollio, H.R. Henley, T., & Thompson, C.B. (1997). The phenomenology of everyday life. Cambridge, United Kingdom: Cambridge University Press.

process and obtains a thematic description of his/her current comprehension of his or her experiences of the phenomenon of interest. An interview involving a research participant generally begins with a minimum number of prespecified questions because the goal is to obtain a description of human experience, with the course of the dialogue set by the participant. A broad general question requests the participant to describe what the experience was like. Further questions or comments are used only to facilitate further description. Such questions generally ask what a specific detail was like or how the participant felt at the time. These questions are used to facilitate a full description of the experience of interest (Pollio et al, 1997).

All interviews are audiotaped or audiovisually recorded and subsequently transcribed verbatim to create a text. The text then is read by the investigator for a sense of the whole and reread for analyzing meaning units. A hermeneutic analysis is employed to cluster thematic meanings and to develop an overall thematic structure. Analysis may initially be done by the investigator, although many of the texts also are read in a research group for a different set of perspectives on the texts analyzed. When all interview texts have been analyzed and a thematic structure is agreed upon by the researcher and the research group, the findings are reported to study participants for review and revision as appropriate. Finally, a report of the study is disseminated to the research community (Pollio et al, 1997).

There is little research, either qualitative or quantitative, that documents the experience of spouses of heart transplant recipients. Within studies of transplant

recipients, notable references point to the significant effect of spouse involvement on the success of posttransplant medical compliance and recipient quality of life. The effect of this critical life event on the spouse is largely unexplored; this is particularly true of the extended posttransplant period. Qualitative research is particularly enlightening when there is a lack of previous research on the subject, when there is a need to describe or explore a phenomenon, or when the phenomenon would not be fully explicated with quantitative measurement (Creswell, 1994). Phenomenological studies examine human experiences "through the detailed descriptions of the persons being studied" (Creswell, 1994, p. 12). Thus, the phenomenological interview design was chosen to facilitate a basic understanding of the experience of the spouse of a heart transplant recipient.

Role of the Researcher

In any qualitative research design, the level of researcher involvement is of significance. Of initial import, the researcher is the data collection instrument through his/her own interaction with study participants. According to some methods, the researcher must always attempt to suspend or bracket any presuppositions he or she has about the phenomenon of interest: that is, the researcher must carefully attend to the reality described by each study participant without coloring the data by his or her assumptions or bias (Boyd, 1993; Creswell, 1994; Swanson-Kauffman and Schonwald, 1988). "The imperative to accurately interpret lived experiences is the phenomenological

researcher's guiding principle" (Swanson-Kauffman and Schonwald, 1988). The suspension of researcher assumptions is done before and during data collection in an attempt to depict the study participant's reality. Such bracketing is done by clearly stating researcher assumptions prior to the initiation of the study (Swanson-Kauffman and Schonwald, 1988). The process of bracketing one's own presuppositions has developed from Husserl's concepts of reduction in his method of phenomenology (Cohen, 1987).

Since the researcher in this study is the spouse of a heart transplant recipient, participation in a bracketing interview allowed the researcher to have an interview experience similar to the experience of the study participants. As a result, the researcher was able to be more sensitive to the participant's feelings and to give attention to not imposing the researcher's assumptions in participant interviews. The "inter-view" (Kvale, 1996) between the researcher and the interviewer evoked and clarified thoughts and feelings not previously fully enunciated. The interview also provided new insight into aspects of vulnerability experienced in sharing one's thoughts and feelings with a trusted other. As with some study participant transcripts, the bracketing interview transcript was reviewed within a phenomenology research group for thematization and structure. Unlike study participants, the researcher was present though nonparticipating in this review of the transcript. The experience elicited a new appreciation for the required level of participant trust and the responsibility of the researcher to accurately report the

participants' words and meanings in study results. The initial bracketing interview also demonstrated the need for ongoing bracketing by the researcher.

Some qualitative research methods do not negatively interpret the researcher's involvement or previous experience of the phenomenon of interest. Rather, the investigator's history of experience with the phenomenon is seen as having a sensitizing effect: that is, the researcher may more sensitively interpret/analyze the data because of this experience which he or she shares with the participant. Munhall (1994) asserts that personal experience of a phenomenon of interest prior to research of the phenomenon does not necessarily preclude doing the research. Indeed, this author notes that hearing another person's experience of the same phenomenon "can raise your level of sensitivity and contribute enormously to your understanding of other perceptions and ways of being in an experience" (Munhall, 1994, p.69). However, she cautions that, while phenomenological research may increase personal understanding of a significant life experience, "it should not be used in an effort to resolve conflicts about personal issues. We may have had the experience under study, or be close to it; yet it is essential to evaluate the readiness to study the phenomenon" (Munhall, 1994, p. 69). This readiness, according to Munhall, can be evaluated by assessing the researcher's emotional reaction to discussing the experience: if tearfulness and pain seem to be evoked by the discussion, the research should be delayed until the researcher's emotional sensitivity is diminished.

Sample Selection

Purposeful sampling (Lincoln and Guba, 1985) was utilized for this study. Study participants were spouses of heart transplant recipients whose transplants were done at least three months prior to the study. This time frame was selected to avoid the hectic medical follow-up schedule that may be in effect for the first three months posttransplant. The basic criterion for selection was that the participant was the spouse of a person who received a heart transplant at least three months prior to the interview and was willing and able to talk about the experience in an unstructured or open-ended interview.

The sample of seven female spouses of heart transplant recipients was chosen by snowballing technique. All participants were to some extent known to the researcher. Some participants were known through mutual membership in a transplant support group. Other participants were known through transplant medical care at mutual health care facilities.

Protection of Human Subjects

Prior to initiation of the research study, approval for the study was obtained from the University of Tennessee College of Nursing Human Subjects Review Committee and from the university's Institutional Review Board. Participants were asked initially if they would be willing to participate in the research study and were given opportunity to

decline. One person declined to participate. Prior to the interview, the consent form (see Appendix B) was reviewed with each participant, and oral informed consent was audiotaped as the participant read the consent statement included on the consent form. Each participant was informed that she could withdraw at any time from the study without penalty. A copy of the consent form was given to each participant. Audiotapes of each interview were identified only by number. The tapes were transcribed verbatim by the researcher with the removal of any names of persons or places that were mentioned by the participant. For purposes of clarity, pseudonyms were used in one of the three transcripts that were read within the research group. Before transcripts were read in the research group, all members of the group signed confidentiality forms (see Appendix C). The audiotapes, demographic data forms, transcripts, and signed confidentiality forms will be stored for three years in a secured data storage room at the University of Tennessee College of Nursing. Tapes will be destroyed at the end of three years as indicated in the participant consent form.

Risk to the subjects was anticipated to be minimal. Subjects were informed of possible emotional distress at the recalling of sensitive information and experience. The interviewer is a veteran nurse with 28 years of nursing experience and is also the spouse of a heart transplant recipient. She is well prepared to intervene in the event of participant distress. At the end of the individual interviews, each participant thanked the interviewer for the opportunity to share her story. No untoward effects were noted. One participant did reveal a history of intermittent professional treatment for depression but denied

current problems or treatment. This participant was encouraged to maintain contact with her care provider and indicated that she would do so.

Bracketing Interview and Pilot Study

Prior to the beginning of data collection with study participants, the researcher was interviewed by another member of the research group. Because of her personal experience as the spouse of heart transplant recipient, the researcher was asked the initial research question which was used with study participants. The bracketing interview was audiotaped, transcribed by the researcher, and reviewed within the research group. Following this, a pilot interview was done, audiotaped, and transcribed by the researcher and presented to the research group for thematic analysis.

Data Collection and Recording

Data collection consisted of a tape recording and full verbatim transcription of an unstructured interview with each participant. Transcription of each tape was done by the researcher and coded by number to enhance anonymity. The code is known only to the primary investigator. All names of individuals and institutions mentioned by participants during audiotaping were replaced by pseudonyms in written reports of the project. A copy of each participant's transcript would have been provided to the participant if

desired, although no one requested a copy of her transcript. Transcripts will be maintained in a locked filing cabinet available only to the researcher or anonymously to another researcher unfamiliar with the participants or the study.

Data Analysis

Analysis of data adhered to the format described by Pollio, Henley, and Thompson (1997). Generally, all transcripts were read by the researcher in an effort to gain a sense of the entirety of transcribed texts. Three transcripts were anonymously presented to the research group for analysis. Notes of generated ideas were recorded throughout all readings. Each transcript was then reread for identifiable themes and topics; notes of such findings were recorded on the margins of the transcripts. After all transcripts were thus scrutinized, themes, categories, or topics from each were compiled and clustered. The themes were reviewed for presence of an emerging pattern or structure. Initial findings were reviewed within the research group for additional clustering. Following this, a refined structure of the experience was presented to the research group for confirmation or refutation of the structure obtained. After confirmation by the research group, the structure was reviewed by a study participant who agreed that the structure seemed to accurately depict the experience of the spouse of a heart transplant recipient.

Issues of Validity and Reliability

Literature documents confusion as to how to apply ideas of validity and reliability to qualitative studies (Polkinghorne, 1989). Pollio, Henley, and Thompson (1997) note, "For purposes of phenomenological interpretation, the criterion of validity becomes whether a reader, adopting the world view articulated by the researcher, would be able to see textual evidence supporting the interpretation, and whether the goal of providing a first-person understanding was attained. This criteria does not preclude the existence of alternative interpretations nor does it require the reader to believe that the present interpretation is the only or even the 'best' one" (p. 53). These authors suggest that validity is evaluated by the rigor and appropriateness of the method and by whether the insight into the experience studied is both plausible (the reader can see the relation of data and interpretation) and illuminating. Internal validity of the study is maintained through rigorous and appropriate methodology; plausibility and illumination are evaluated through research group and participant feedback.

In a strong response to critiques of the usefulness and scientific status of qualitative research, Sandelowski (1997) asserts that claims of lack of generalizability of qualitative research findings are indeed false charges. She further maintains that "much if not most of human knowledge is idiographic; that is, human beings make generalizations all the time from particulars of their lives" (p. 127). She notes that generalization of findings from qualitative research provides idiographic knowledge which promotes transformation

of understanding of universal and cultural singulars and extends research beyond the confines of a single study. Additionally, knowledge obtained from qualitative research may help clarify and lend significance to statistically insignificant results in quantitative studies (Sandelowski, 1997).

External validity or generalizability differs in qualitative research in that findings are not expected to be directly generalizable to any other group of study participants in the way that quantitative research findings are presumed to be generalizable. By following the same qualitative research method with a similar group, similar findings are to be expected. However, qualitative research assumptions of multiple and individual realities indicate that the specific replication of the study is not to be expected. Although patterns of experience may be seen in various groups having similar characteristics and experience, this generalizability between groups of participants is not the primary concern of the phenomenological design. The primary concern is a faithful description of the lived experience of study participants.

Reporting the Findings

Findings of this study will be reported with support by sufficient quotes of the transcripts to indicate the decision trail of the researcher and to lend credence to the development of themes or patterns within the lived experience of participants.

Maintenance of confidentiality and mass of information prevent the inclusion of all of the

transcripts, although adequate support of findings can be demonstrated with appropriate quotation. In instances of similar findings in several transcripts, quotes will be used to show how a theme is repetitive. Similarly, unusual or unique findings will be discussed.

Summary

This chapter has discussed the underlying assumptions of qualitative research methods in general and the existential phenomenologic approach chosen for this study. The researcher's rationale for the choice of a phenomenological design for this study as well as the role of the researcher in this process have been reviewed. Methods of data collection and recording were briefly addressed. Aspects of reliability and validity in this qualitative research study were noted. Finally, a plan for the reporting of study findings was suggested.

CHAPTER FOUR

RESULTS

This study used phenomenological methodology to investigate the lived experience of spouses of heart transplant recipients. This method of inquiry allows for the development of a thematic structure describing the lived experience of participants. This structure is derived from verbatim transcripts of interviews with spouses of heart transplant recipients. As may be recalled, each participant was asked to respond to the following open-ended question: "Now that you have been the spouse of a heart transplant recipient for some time, what in that experience stands out for you?" Further questions were asked only to clarify the participant's response to the initial question.

The description of each participant's experience was thematized using the methodology described in the previous chapter, and a thematic structure was developed as it emerged from the data. In this chapter, some brief demographic data describing the participants will be given. The thematic structure will then be presented and illustrated by samples of participant expression of each theme.

Demographic Characteristics

The seven participants in this study were Caucasian females whose ages at the time of their husbands' transplants ranged from 43 to 65 years (average age at the time of transplant was 52.57 years). The transplant recipients' ages at the time of the heart transplant ranged from 45-66 years with an average age of 55 years. All transplants were done between 1990 and 1996. At the time of the interviews, the time since transplant ranged from 2.4 to 8.9 years with an average of 4.3 years. The couples had been married from less than one year to 47 years (average=25.6 years). The level of participant education ranged from eleven to sixteen years. Only one participant had not completed high school; two had completed high school, three had some college education, and one had completed an undergraduate degree.

Thematic Structure

The experience of the spouse of a heart transplant recipient was described by participants as being contextualized by issues relating both to other people and time. From this context arise four themes. The central core of the experience is a profound awareness of death, and of how close the transplant recipient was to death. This central theme is designated Death/Life. Three other themes under the aegis of this awareness of death and life are Vigilance (watching and letting go), Change (in

recipient, in self, in roles and relationships, in faith experience), and Gift (giving and receiving). Each theme is inextricably related to each of the other themes as these occur within a contextual ground defined by time and other people. A schematic representation of the experience and the interrelationships of the four themes and the grounds of time and others is presented in Figure 4.1. The interpretation of this diagram is briefly discussed before individual themes and grounds of the experience will be examined.

Diagram of the Experience

In Figure 4.1, the circles representing time and others define the larger context of the present experience as described by participants. The circles overlap to create a more present context for the spouse's experience. The major themes can be depicted as a pyramid with each significant theme located at a different point on the pyramid. The dominant theme, Death/Life, is at the apex of the pyramid. The corners of the pyramid's triangular base are named for the other three themes. The theme of Vigilance is described as watching (for signs of death's approach) and letting go of the watching when life becomes more figural. The theme of Change (as noted in the transplant recipient, in roles and relationships, and in the spouse's faith experience) is more notable over time and is located at the left corner of the pyramid's triangular

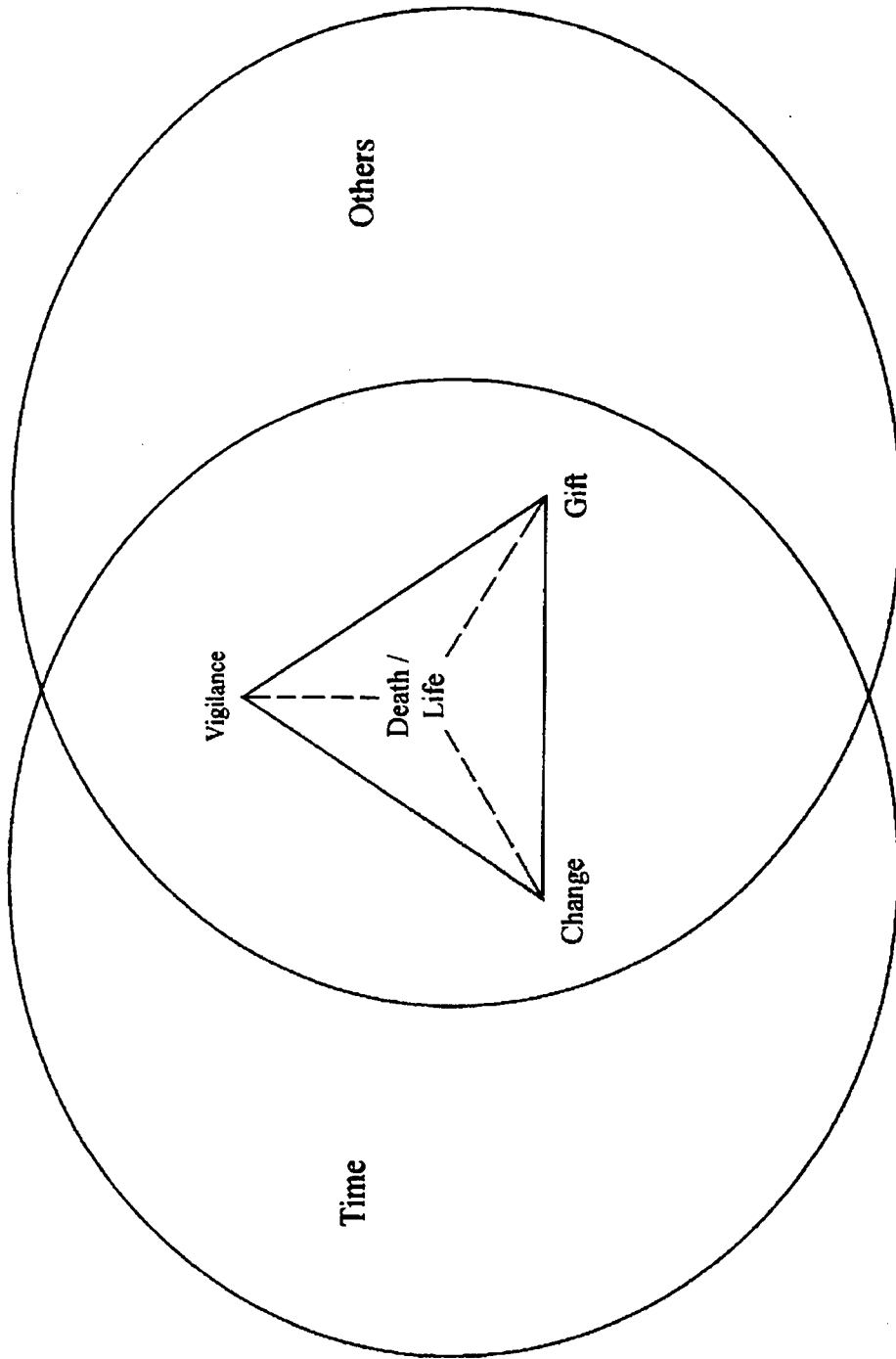


Figure 4.1. Thematic Structure:
The Experience of the Spouse of a Heart Transplant Recipient

base. The theme of Gift (giving and receiving) is more readily located in the ground of others and is placed at the right corner of the base of the pyramid.

The interrelatedness and blending of themes in various configurations can then be demonstrated in the triangles which form the base and each face of the pyramid. With a variation in any theme, other themes also vary. For example, if there is a movement toward death, vigilance is likely to increase with simultaneous variation in the spouse's awareness of change in the transplant recipient, in roles and relationships, and in the spouse's faith system. Conversely, when death becomes less figural, vigilance and notable change also recede in the participant's awareness. Similarly, when the gift of the donor heart is received, awareness of impending death should significantly diminish, renewed life should become more figural, and awareness of change should be noted in the recipient, the marital relationship, and in the participant's faith system. This reciprocal effect is true of all thematic configurations denoted by connecting lines in the diagram.

Contextual Grounds for the Present Experience

Time. All human life can be described as being experienced within the ground of time. However, time assumes more significance when it is seen as the line of demarcation of finite human existence and important relationships. For the spouses of heart transplant recipients, time demarcates significant events and becomes the

measure of continued life for the recipient and of the marital relationship. In this experience, time is described as a limited commodity that eventually can be extended only through successful cardiac transplantation. Following the transplant, time becomes more figural when life of the recipient is again perceived to be in jeopardy. Time is both ground and figure: time is the context for the life of the marital dyad, and time becomes most figural when its end (death) becomes a real possibility.

From the outset, study participants located their experiences within the ground of time. Time as a context of experience appears in each of the participants' stories in a variety of ways. References to time are prominent when the participants detail such moments as *time* of occurrence and circumstances leading up to the transplant recipient's diagnosis with end-stage heart disease and/or with the determination of the need for a heart transplant. One participant related the following:

“And he [a physician] told (my husband) that he wanted him to go in the hospital and have an arteriogram, that if his heart was the way he suspected, that he thought he had a year to live. And that was in 1974. Well, we couldn't get the arteriogram scheduled the first week, so we went, you know, we didn't want to go on vacation, we didn't want to do anything.”

For this couple, this event seemed temporarily to suspend and delimit time. The participant went on to describe the temporal sequence of fourteen years of medical management of the problems diagnosed as a result of the arteriogram,

subsequent surgery for a cardiac valve replacement, diagnosis of heart failure four years later, and heart transplant within the following year.

Time is such an omnipresent part of each participant's story that it soon became apparent that the entire experience is grounded or situated in time. One participant clearly defined the importance of time prior to transplant. After describing the chronology of events leading up to the transplant, this participant refers to the uncertainty of continued life:

"But when you get to that time, if it is possible, and with a lot of people it's not, I know that, but if it's possible, you want to spend what time you have left together."

The precarious quality of time is noted in this wife's description of her husband's condition:

"He had got really low. It was beginning to look like that, you know, it was the day's, a day's game, not week by week."

Throughout the experience, time assumes significance in terms of the lifespan of the recipient. When becoming aware of the deaths of other transplant recipients who have had several years of extended life, the spouse again becomes concerned with time for her mate. One spouse related her concern as she remarked, "So now it seems like there's almost a *new* time bomb starting up." This analogy to the suddenness with which time can explosively end is an apt reference to the uncertainty of time for living.

Each participant weaves time into the story tapestry whether in a detailed narrative or in specific reference to an explicit demarcation of time. Some participants responded to the opening question with a time-oriented narrative of the dyad's personal and medical journey before and after the transplant. This narrative situated the spouse's experience within the context of time. Other participants unfolded their stories in the context of time and used specific dates and measures of time (hours, days, weeks, years) to move the narrative along or to chronicle significant events. Other references to time include *time* of day or night of specific crisis situations; amount of *time* involved traveling to and participating in medical consultations; *time* of transplant and the *time* involved in the surgery; *time* in each area of the health care facility and living quarters posttransplant; *time* since transplant; and many other references to time which provides the context of the entire situation.

Indeed, the spouse's experience was easily situated in time from the acute awareness of the limited time available to the candidate prior to transplant through the experience of extended time as a result of heart transplantation. It is within this context of a heightened awareness of time, and the measurement of the potentially limited amount of time allotted to any human being, that the spouse experiences the (near-)death and (renewed) life of the heart transplant recipient.

Others. The spouse's experience also emerges from the context of the ground of others. Beginning with her relationship to her significant other, the marital partner,

the spouse's experience expands to include family, friends, medical and nursing personnel, transplant donor and donor family, and a variety of other people who are involved in the life situation of the heart transplant recipient and the spouse.

Within the ground of others, the spouse's primary focus is the transplant recipient. Participants' stories were often presented in "we" language, beginning with such phrases as "when we first found out" and continuing through the experience's timetable to "when we got the transplant" and "we can live with it." It is readily apparent from reading the present set of transcripts that this is an experience of the recipient and spouse together. One participant clarifies this idea in suggesting how health care personnel should recognize the impact of this experience on the spouse of the transplant recipient:

"...I am a person, I'm a spouse. I'm not the recipient, but it is my world. And to be a little, uh, more sensitive about my feelings, uh, and to know that I'm going to go through this. I'm not going to go through the physical part, but I'm certainly going to go through the emotional part."

Another spouse remarked, "...whatever comes, we'll, with the Lord's help, we'll handle it." This spouse reported her conversation with potential candidates and their spouses and advising them,

"You make sure that you can go through it. Or even your spouse because you're going to have to. It's going to take both of you. It takes both of you to get through it."

Participants' accounts give evidence that this is a shared experience primarily for the transplant recipient and his wife. A variety of other people, however, are vital to the possibility and success of the transplant and form the context for the experience. The donor and the donor's family are a concern although they are unknown to the recipient and the spouse. One participant related her thoughts about the donor family:

"And you remember that family, I guess, as long as you live for what they have, what they have done....And it comes at a time, uh, I mean they have to make that decision, and you know how broken hearted they are, and you wonder how they can even do it. It takes a very special person to...and I'm not sure that I would have been able to have done the same thing....I think as long as time goes on, that, when you are thanking the Lord for what He has blessed you with, you also ask a blessing for that family, to be comforted in their sorrow which you know they will always have."

Another spouse described similar feelings:

"I think he had a...the Lord gave him a second chance, and we are so thankful for that, you know. And for the young person that had to give his life, we think about the family. And, uh, it's hard sometimes for (my husband) 'cause you can see him tear up when he thinks about the young person. We think it's a young man, uh, what he did for him, and what his family did for

us... That family. What they did was very unselfish, and, uh, we have benefited from it.”

One participant had attended an annual Transplant Olympics celebration and described the wonder of seeing how many transplant recipients attended and participated in the competitions. She then acknowledged her amazement at the reverse statistic of the number of organ donors that this event celebrated:

“I just realized, you know, not much gets said about the donors all the time. You know, we always look at the living person, ‘Oh, look, he’s got a transplant,’ you know. Uh, but it’s the donors that make that all possible.”

This group of others is necessary for the transplant, becomes a part of the context of the situation, and is outstandingly memorable even in anonymity.

In some situations, the immediate and extended family is also significant to the transplant experience of the spouse. Family members are mentioned in decision-making about the transplant and as providing ongoing help and support throughout the experience. One participant spoke of the family’s discussion of treatment options including heart transplant: of one option, she stated, “And that surgery, uh, we debated as a family.” Another participant described the reluctance of the couple’s children to agree that their father should have a heart transplant: “No, they didn’t want him to have the transplant.” This fearful reluctance complicated the decision-making process but dissolved into positive support of the recipient and spouse after

the decision was made. Another participant described the comfort provided by extended family:

“And I was just so fortunate, uh, to have family there in town that we could stay with. I found that it was, uh, extremely comforting while we were there in town, because that was like our little cocoon.”

Another participant defined “family” to include many friends:

“And he (the transplant surgeon) was telling the whole family, when I say ‘family’ I mean all the (apartment house) friends that we had met. He... We had all these people down there (list of names) the whole bunch, they waited right there with us...Everybody at the (apartment house) just becomes very close-knit, and it’s just a god-send, you know, that they have something like that for us to wait at.”

For this spouse, this extended family group provided comfort and support within the context of the transplant experience.

While many individuals were recognized as giving positive support to the transplant recipient and to the spouse, some were perceived by the spouse as uncaring and not supportive. One spouse related an experience of her husband’s hospitalization far from home during which she experienced both supportive and nonsupportive others:

“And while we were there, they didn’t, they didn’t notify me. I was five miles at this lady’s house that took me in. And my number was on his chart. And I

would come in of the morning, and (husband's) bed would be made up. They hadn't called me. All his belongings were gone....I thought he had (pause) died, and nobody called me."

While she was helped by someone's providing a place to stay during her husband's hospitalization in an unknown environment, the health care personnel were seen as uncaring and nonsupportive. During the telling of this episode, the participant's outrage was expressed as though this incident had occurred recently instead of several years before.

In addition to help and support from immediate and extended family, some participants reported receiving positive support from the members of churches and community with which they were affiliated. Church and community members helped financially, prayed with and for the couple, visited, helped with driving on long trips, and assisted by maintaining the family's home while they were away for extended medical care.

The fabric of others as context includes many people who affected the life of the transplant recipient and the spouse at a critical time. Within the ground of other people, the spouse and the recipient received support and comfort; they also acknowledge the donor heart that provided extended life. Unfortunately, some spouses experienced actions of others, largely in the health care situation, that were less than caring.

Themes

The experience of the spouse of a heart transplant recipient is situated in the grounds of time and others. Within these contexts, four themes stand out as uniquely significant: a concern with Death and Life, a concern with Change in the context of before and after, a concern with Giving and Receiving, and a need to be Vigilant both in the form of watching and in the form of letting go of watching. These four themes are designated Death/Life, Change, Gift, and Vigilance. In the participants' words, vigilance would be called "watching" and "letting go"; change was noted in terms such as change or in ideas of same-different or before-after, as well as in terms of similar words that indicate change; Gift is seen in conversations about giving and receiving. All of these themes occurred within the grounds of time and others, and all were inextricably interrelated.

Death and Life. The spouse's experience is focally based on an acute awareness of the nearness and reality of death. This awareness of the possibility of death crystallizes as ongoing pre-transplant medical evaluation and followup inexorably move the transplant recipient ever closer to the inevitability of heart transplantation. This awareness is clarified as the spouse watches the transplant candidate's physical condition deteriorate over time and becomes an overt reality when observable signs of approaching death are apparent. One participant's initial

response to the research question directly addressed this theme. When asked what stood out in her experience, the participant replied:

“Well, the fact that my husband came so close to death, uh, which is very frightening. Uh, at the time, I, I knew he was close to death, but I didn’t process it, that he was that close, until later. And, uh, he is alive.”

This participant spoke of her new appreciation of life since the transplant.

“I think it makes us both appreciate more of what we have and that we’ve got to...there’s other things to worry about, to fuss about, uh, than to, uh, to go to the little nitty-gritty things. I think we appreciate more of, of everyday living with each other and keep in mind that we need to take advantage of things.”

She further said, “You’ve got to realize that you’ve got to, uh, uh, be in control of your life and know that you don’t have any promise of tomorrow.” In another part of the interview this participant graphically described her empathic understanding of the experience of another heart transplant spouse: in reference to the pre-transplant observation of the transplant candidate, she said, “I know that you see your, your spouse laying there dying inches by inches.” This participant openly discussed death and life as a preeminent theme.

Another participant discussed the possibility of the recipient’s death with family members who were initially opposed to the transplant. When family members expressed their fear that the recipient would die during or after the transplant, the

participant reported, "I had to, uh, come right out and say, 'Well, he is going to die if he don't [sic] have it. And this is giving him a chance.'" In this declaration to family members, the participant clearly verbalized the certainty of death without the transplant as well as the uncertainty of its success in continuing the recipient's life. She reiterated this awareness when she stated that the family members "finally came to terms or did come to terms, and maybe they realized it had to be that way or there would be no way."

Another participant stated that the most outstanding aspect of her experience "is just how sick and how weak and just how far they can go and be so sick and then receive a transplant and come back and be so healthy." Although this participant did not directly speak of death, the weakening and deterioration would ultimately lead to death if the transplant were not available. Another participant rather directly addressed the subject of death in describing her experience of the subsequent deaths of three others who received heart transplants at the same time as her husband: "He's the only one living...of that day. And we thought, you know, you get fairly close to people, and you just see a lot, you see a lot of people die. And, uh, you just can't help but be touched by that..."

Another participant spoke of her continued gratitude for her husband's life: "And sometimes I look at him, and I just cry...well, tears, tears just come up, 'cause I know how close he came to dying." Later in the interview, this participant spoke of

life: "It is, it is very fragile. Uh, one, you know, one heartbeat. You could be one heartbeat away from death."

Still another participant summarized her experience of her husband's progression toward death prior to transplant,

"...he kept feeling worse and worse, and, um, he would ask me at night to take him to the hospital, and (my husband) is not somebody that wants to go to the hospital. You know, it was like, I thought he was dying, dead and gone, you know."

This central theme of death and life was apparent in each spouse's story. This awareness may recede with renewed vigor and health of the recipient, although its impact is also described in the posttransplant experience. One participant described the posttransplant clinic visits as a time of renewed fear: "And every time you go you're just terrified, you know, that something's going to go wrong."

Another participant spoke of her repeated experiences of the ultimate reality of death and its potential sudden intrusion. While attending the funeral of a friend who had died quite unexpectedly, she said, "And when I went to the funeral, I just sobbed and sobbed and sobbed. Uh, it was like, I was struck with the reality that you can be here one minute and gone the next minute." While this experience might seem a common realization for anyone who loses a friend to death, this death was made more poignant and significant by the fact that the deceased friend had also had an organ transplant and was overtly well just days before her demise. As in other life-

threatening situations, the transplant experience sensitizes recipients and spouses to the reality of death and the transient quality of life.

This pivotal awareness of the reality and nearness of death and life results in Vigilance, Change (in the transplant recipient, in the role of the spouse, in the relationship between the recipient and the spouse, and in the spouse's faith experience), and in an appreciation of the ongoing process of giving and receiving which occurs in this life situation.

Vigilance. The spouse's experience is one of vigilance. As described by participants, the spouse is very aware of Death and Life and watches to make sure life is continuing. Vigilance includes paying attention to the transplant candidate's physical condition and often involves a protective stance against those whose interactions with the candidate are deemed dangerous. This vigilance begins in the period before the heart transplant as the spouse becomes increasingly aware that her husband's death is a distinct possibility. This experience of "watching" increases as the potential of death comes near, and the spouse engages in "letting go" as the spectre of death becomes less figural.

One participant describes an episode of her observation of her husband before the transplant:

"And that night, uh, (husband) couldn't breathe. You know, he just...I thought he had a bad cold. And I thought it was just congestion. But he was just gurgling and all that. So I took him to the emergency room, like middle

of the night because he, he just couldn't get his breath. He just coughed and coughed and...and , uh, they told us it was congestive heart failure."

Another participant described her pretransplant vigilance:

"...and you listen to him breathe and, you know, making sure he's all right, and, uh, I mean, it seemed like it was just like a 24-hour thing. You just, you know, catch a nap here, and you try to relax, and it was just a 24-hour thing...and, uh, for a long spell he couldn't sleep at all. Well, then he got to where he'd just sit down, and he'd drop off to sleep. And he, it...with his breathing, he would just not breathe for a while, and I'd, you know, have to punch him and get him to breathe."

Another wife described two years of pretransplant watching to ascertain that her husband was still living:

"I would really just jump up and stand there at the door and just watch. I was constantly watching. And I would feel guilty if I slept a little longer than 15 or 20 minutes at a time. And this was night and day. If, uh, while he slept during the day, I was still watching. (pause) I was afraid I was going to lose him."

Another participant acknowledges her awareness of vigilance juxtaposed against the need to move on with the living of life: "I know it's scary to leave them at home when you know they're sick, but you've got a job to go to. And then you're scared

to death to come back home for fear that you don't know what you're going to find."

Vigilance does not end with the transplant. As one participant stated:

"But still to this day, I, I do, I still watch him. And I guess I'll go on watching him until...I can't watch him no more."

This same spouse said of the watching, "It is a way of life. You have to, you have to be on top of everything, you know, just, uh, (pause) well, *watch*." Yet another spouse admits, "I watch, this is silly, I watch every morning to make sure that his heart's beating." Later in the interview she again states, "I do watch him. Uh, I think in the back of your mind there's always that thing, what if something would happen?"

Another participant states her ongoing fear of negative findings during clinic visits after the transplant: "And every time you go you're just terrified, you know that something's going to be wrong." Again she states, "So, you know, just waiting for that... 'course you're just a nervous wreck every time you go to clinic; you're just afraid that the EKG won't be right or the echo(cardiogram) won't be right, or there'll be some kind of problem. I don't think you ever get over that."

This participant related her lifetime of vigilance with her husband prior to and after the transplant. Having been sensitized and acclimated to constant vigilance, she found it difficult to "let go" of this behavior. When she spoke with her husband's physician about her ongoing concerns after the transplant, the physician "chewed me

out good” and told her that “that was my problem and not (husband’s) problem.”

She spoke of the difficulty she had in relaxing her vigilant stance:

“So I have had to learn a lot about relaxing how *I* feel, you know, and I have had to, and I guess everybody’s the same way, you’re just such a...I guess it’s the mother in you? You’re just so anxious to, to make sure everything’s right...to make sure that everything they do, the right kinds of things, that you’re the person that’s there, you know, trying to be referee....”

In contrast, another participant responded to the initial interview question by stating,

“I guess what really stands out is, uh, that (husband) is able to do anything he wants to do, uh, after the surgery. Uh, he’s doing all his farm work that he wants to do, uh, and I just let him go.”

This participant’s interview then chronicled the situation and history leading up to this “letting go” of the constant vigilance. Although she does not state her vigilance directly, the descriptions of her husband’s physical appearance and her observations of situational factors indicate her watching in order to intervene as needed. Her narration includes health care situations in which she assertively used her own knowledge to protect and to ensure appropriate care of her husband prior to the transplant. Reflecting on some of her assertive interactions with health care personnel, she admits, “I was really kind of, maybe overbearing. But I think behind that was a lot of fear.” In speaking of her current level of vigilance, she says, “You

know, it's like, now I don't complain about what he does. I worry about him. Uh, and he's going to do what he wants to do, and I can't stop him from doing it, so there's no sense in me getting all upset about it anymore." One wife reiterated similar concerns about the need to let go of her vigilant stance:

"...but basically I think the hardest, the hardest thing I, uh, just learning to turn loose, you know, being able to relax a little bit with it. And, uh, I'm not sure you ever get to where you just totally relax...."

For these participants, it seems the letting go of vigilance is an ongoing concern.

For the spouse of a heart transplant recipient, vigilance as an ongoing stance and behavior begins before the transplant as death is recognized as a possibility for the transplant candidate. The watching of the candidate/recipient by the spouse intensifies as the awareness of death increases and begins to wane as the candidate/recipient's health status moves more steadily toward life. While there is a perceived need to let go of the watching, this is not easily or readily done. Therefore, for most of these study participants, some form of vigilance remains.

Change. The experience of the spouse of a heart transplant recipient is one of change. Only one participant used this word directly to refer to the differences she perceived in her husband, although other participants described differences in their husbands, in their roles and relationships, and in their faith experience as a result of the transplant. These identified differences represent notable change recognized by

the spouses in their vigilant observation and reflection on this ongoing life experience.

Change in the recipient is noted primarily in terms of observable physical change and mood or personality change. Participants often attributed undesirable changes to side effects of medications required after transplant. As previous examples have indicated, the recipient's movement away from death and toward life greatly affects the recipient's physical ability to work and to do many things that were seemingly impossible prior to the transplant. One participant relates an example of the physical change she noted in her husband in comparing his condition before and after transplant:

"He is... (husband) is just on top of the world right now. He really is. Uh, to see him the way he was before, when he'd get up early in the morning and have to go right back to bed. Couldn't do anything. And now he has so much energy. Until two wee...two months ago, he did. But, uh, he can do almost anything he wants to do, work in the yard, help me in the house, drive, go anywhere he wants to."

In referring to medication side effects, this spouse said:

"Yeah, can't be out in the sun without all the sunscreens; and hairy, the medicine makes you hairy. But we'll take the side effects as long as it keeps the heart going... We've got to have it, we have got to have it. So whatever else, we'll take it."

One spouse briefly describes change in her husband's behavior after the transplant, which she ascribed to the medications he is now taking:

“And there's lots of times now that, uh, I mean, if you're on the sideline and watching and listening, uh, he wants things and he wants it done his way, no one else's but his. And that's, that's not like him.”

Another participant recounted her experience with posttransplant change in her husband which she attributed to side effects of medication. She initially said, “We had a few little temper tantrums with the prednisone.” She gave an example of her husband's refusal to cooperate with the usual daily routine. She went on to say that her husband of thirty years was “this man that was so laid back, so relaxed, never raised his voice, and suddenly, you know, I had this animal.” Although she was laughing as she spoke, she went on to say, “Yeah. And so thank goodness that disappeared, you know, when we tapered off and got pretty much off of the prednisone. But, boy, it was, it was difficult, we, uh, being housed in that little apartment, and uh, I guess I didn't, I guess I...I'm sure they probably told me, but I just didn't realize it would affect him that much.”

Yet another spouse related her perception of the effects of medication on their relationship when both she and her husband were taking prednisone simultaneously:

“I think the hardest time I had was right after he came out of the hospital from, uh, having his transplant, and he was on high doses of prednisone

(laughing), and I was on my prednisone. And I decided we can't live like this. We're going to kill each other. So I tapered real fast off my prednisone. And, uh, he was just *unreasonable*. Oh, I mean like, he, one night he couldn't balance his checkbook. And there was something that he hadn't added in, and I tried to explain it to him, and then he just went off the wall, you know. Or he would argue with me about what roads went where in (city), you know. 'No, it goes this way.' I thought, 'If this is the way that it's going to be, I'm not, I don't know if I can stand it.'"

Clearly the spouses felt that side effects of some medications increased the occurrence of discord within the marital dyad. Another spouse added her thoughts about some of the effects of medication on the marriage relationship:

"Prednisone I have found can be a very mean, vicious drug. Uh, and it can also be very hard on marriages, too. Because you have a lot of ups and downs as far as moods are concerned. Uh, a spouse can't understand why, uh, his or her head is being snapped off. When you open your mouth, then your head is, is snapped off, and it's all because you said, 'Hi, honey, how are you?' (laughing) And it's the medicine. And you realize it's the medicine, but you have to tell your heart it's the medicine. And it's hard for your heart, your, your *heart* to accept that your loving husband is now snapping at you (laughing)."

One participant spoke of her efforts to deal with the effects of the medications on her spouse and on their relationship:

“Well, after you realize that what you think is the worst part is over, then you still have, uh, to deal with your feelings for your patient because of all the medications that they’re on. And they have so many mood changes that it’s very hard for you to really, uh, become a neutral in it and accept things as they are. But yet you, if you have enough love, you can do it. But, it’s, it’s still, uh, very hard to adjust to that, to accept, uh, how, however they are, uh, in other words, their feelings because sometimes they get so angry without, you think, any just cause in which it is all associated with the medications they’re on. But at the same time, you have feelings, too. And you kind of have to back off once in a while and get yourself under control.”

The participants in this study attributed identified changes in their husbands to the posttransplant medications, particularly large doses of prednisone. These participants also indicated that these changes in the recipient were greatly diminished and tolerable when the dosage of prednisone was lowered. However, this situation of mood change clearly led to conflict with the transplant recipient and required the spouse to manage the conflict in order to maintain her support of her husband.

Within this arena of recognized change in the spouse and the relationship, some spouses also noted change in their roles within the marriage. In their life together prior to the transplant, when the husbands were physically unable to

continue in their usual roles, the spouse was required to undertake functions that were previously shared with the husband. One participant states:

“It’s, it’s really hard because suddenly you find yourself, you have *all* the responsibility. You have the responsibility of the bills, you have the responsibility of taking care of them. You have the responsibility of taking care of your house (pause) and your children, and in addition to that I had the responsibility of the farm.”

Another spouse placed this change of role and responsibility in the context of time:

“His, uh, situation started just getting worse. And I had to take over...everything.”

This spouse was very aware of the distress this situation caused the husband. “He’d be sitting there at the window, and tears’d be running down his face to see me having to carry and do all the stuff usually that he would do.” In discussing their different chronic health problems, this spouse notes, “And there’s still a lot of things that we just sort of have to do together, you know, to try to get things done around here.” It seems that as their roles became more fused in the experience of the transplant, this couple has maintained a unified stance in addressing their posttransplant life together.

For those participants who described change in their husbands’ behavior and in their marriage relationships and roles, the transplant experience was also a time of a less tangible change--an increased awareness of and/or reliance on their faith system. Some participants told of experiences of an unusual level of support from church members and times of desperate prayer and prayers of thanksgiving. Spouses

often situated the meaning of this experience in their religious beliefs. One participant described feeling alone as her husband's transplant surgery began before relatives could join her. It was during this time that she prayed.

“Uh, you know, it was really, really tough, uh, when I first got there to the hospital and they just whisked him right off, you know, and there I was by myself. And I'm sure that everybody feels that way, because it was, uh, oh, probably about five hours before our daughter and son-in-law could get there, you know, to be with me. And, uh, and it... so that was really tough. I think I just sat and prayed most of the time.”

In retrospection, later in the interview, this participant states, “I can't think of anybody that could have done better than (husband's name) because he's been so lucky, and we just feel so blessed.”

This spouse indicated some change in her reliance on her faith system when she spoke of coping with her ongoing need to be vigilant and to eventually let go of the vigilance:

“...you reach a point where you just turn everything over to God, you know? And then, and I think when you reach that point, then maybe you hassle a little bit with the daily kind of stuff, but the major part of it, you just feel like it's in His hands....”

One participant spoke of her reliance on God when she now has concerns about her husband's health status:

“So, I just...I pray about it. And, uh, I know he’s in good hands with the Lord, you know. The Lord has really blessed him. And, uh, with the prayers going up at church, family, and we look to God for everything, we really do.”

In reply to the interviewer’s question as to what stood out in this spouse’s experience, the participant acknowledged a new appreciation for the complexity of life in its everyday occurrence. She mused:

“...for me to have been a part of that and to see the change in him, uh, (long pause), I don’t know how to explain it. (Another long pause.) I think we take everything for granted. We know that everything is supposed to work the way God meant for it to be. And when it doesn’t work, we lose it a little bit. And we don’t appreciate what we have. I never took into consideration that I’m going to get up every morning, and, uh, not be able to go to work or do this or do that, my household chores or whatever. I just take it for granted. And one little thing could happen, and it would have me just like he, he is, you know, or the way he was. Or that we can get up and walk or hear or see. Those things are precious that we have, and, uh, like I said, we take them for granted. We don’t appreciate what we have. Everything, everything that the Lord has blessed us with. And I thank the Lord every morning.”

This sense of wonder and gratitude pervades the statements of faith made by this participant. This wife documents a change in her faith as she recognizes her new appreciation of the gift of life and individual abilities to perform activities of daily

living. She repeatedly refers to the great blessing of new life for her husband and characterizes the transplant experience as a miracle. She says later in the interview:

“It’s, it’s been a miracle for us. I’d put it in one word: it’s been a miracle. In many ways.”

In the closing part of her interview, she recounts her childhood instruction “to always believe in the Lord, and the Lord knows best. And, uh, if we’ve got that faith, just a little faith, the Lord honors that. That’s what I cling to, I cling to the Lord. Even in the bad times, ‘cause He’ll bring you right out.” Obviously, the meaning of this experience for this spouse is structured in her faith system which seems to have been strengthened and confirmed.

Another spouse participant identified faith as the basic strength for everyday living:

“...you’ve got to have confidence in your, in your faith, with the Lord or whatever belief that a person may have. You’ve got your strength, that brings you strength.”

This spouse imbued the transplant experience with one tentative meaning and purpose in a later statement: “And you just have to be thankful for what you have. And maybe that’s a lesson. Maybe that was, uh, uh, the Lord telling me, “(her name), you’ve got to appreciate more what you have, and appreciate it.”

One spouse identified her reliance on her faith as the basis for successfully going through the entire experience: “I, I don’t think if I, if I hadn’t known God that

I would have gotten half way through it. But (pause), well, He just made it all possible, and He has also went [sic] with us through it all. And without Him we would have never got to where we are now.” This spouse told of her initial struggle to determine whether organ transplantation actually fit within her belief system and of her answered prayer that allowed her to go forward in the experience. She interpreted the caring actions of others in her church as God’s provision for her needs and wonders aloud how others without this kind of faith in God can handle a situation such as the transplant experience. It is clear that her faith is the basis for her structure of meaning in this experience, and she confirms this faith in her attitude of gratitude.

Another participant clearly stated her reliance on her faith: “The main thing for anybody, I would think, is to totally put your trust in the Lord and let Him see you through...He will definitely supply your needs. And he supplied the heart that (husband) needed, and he supplied the strength that I needed to take care of (husband).” The interview with this participant is replete with expressions of the spouse’s reliance on God for every need and her gratitude for His provision. She states:

“We’re just thankful, and we’re just thankful that God gave the doctors the knowledge to know what to do. And we do give God the credit. A lot of people don’t give God the credit, but we totally give God the credit. He gives

the doctors the knowledge to know all of this about transplants. And, uh, without God in it, I don't, I don't see how it could work."

While some of these spouses do not clearly identify their expressed faith as change, the confirmation of their beliefs seems to bring strength for challenges of life and a renewed sense of faith. This can be interpreted as change in the sense of strengthening and confirmation of the faith system by application of belief in a life-threatening situation.

Gift. In their experience of increased awareness of death and life that requires heart transplantation, the spouses in this study also expressed their awareness of giving and receiving. As noted above, there is an awareness of the giving and receiving that takes place in the gifts of others, particularly in the gift of the donor heart. These spouses also acknowledge the gift of extended time and life. In listening to their stories, one becomes aware of the continuing gift of the spouse's caring support despite changes that occur in the recipient and in their usual roles and relationships.

The most outstanding gift to be acknowledged is that of the donor organ. As noted above, the spouses gratefully remember the donor and the donor family for the matchless gift that has been given. Having recognized the gift, spouses then verbalize the responsibility to use the gift to optimize the life that has been extended. One participant aptly noted:

“You know, this is, you’re given this, this gift, this wonderful, wonderful gift from somebody else. Uh, and you’ve got more, you know, you’ve got more time to spend instead of thinking about you’re going to die in six months, now you’re not sure when you’re going to die. I might be ten years, or it might be five years, but make the most of it. You live sort of each day at a time. You know, one moment at a time.”

The gift that is given is the donor heart. But more than that, the gift of life or extended time is a primary exemplar of giving and receiving.

The theme of giving and receiving is intermingled with that of caring and the giving of helpful others. It is also seen in the spouse’s awareness of having been blessed by God. Although they do not specifically name it as such, some spouses also are aware of a deliberate giving of self to protect the recipient, if only in surreptitious vigilance and protective actions of which the recipient may be unaware.

One spouse states, “I try to keep him stress-free.” She admits hiding her concerns about his health in order not to upset him. Another spouse speaks of her protection of her husband: “You know, I’m always jumping in there and doing a lot more than I, than I really should be doing, but to keep him from doing them.” These women deliberately give of themselves to protect their spouses from potential harm.

Another participant told of sharing with others some of the bounty which had been lavished on them by members of their home community. The transplant candidate and his spouse had moved temporarily to the large city where the medical

center was located in order to be nearby when a potential transplant became available. Some community members had come to visit and to bring fresh produce from their gardens at home. The spouse stated, "And we were going up and down the hall at the (apartment house) knocking on people's doors giving them fresh vegetables that they would carry from (home) to (city of transplant) to us. And we just divided with just anybody.... We'd share, and other people would share with us."

The theme of giving and receiving as seen in the experience of these spouses is multifaceted. Some spouses feel the need to reciprocate or give back in response to the great gift that they have received. One spouse told of participating in a research study over time and remarked, "Somehow we finished that up. And, uh, hopefully it helped somebody." The spouses in this study indicated that their participation also was based on a desire to help future transplant recipients and spouses in similar situations.

One spouse strongly expressed her desire to give support to those who are considering having a transplant or who have already had a transplant and to share the spouse's experience from a firsthand perspective. Her adamant desire to educate the community at large about the needs surrounding organ transplantation is evident in the following excerpt:

"I have no doubt that through education that that's why he was given, uh, a longer life to live, is to get the word out. And of course that affects me, and I will be getting the word out."

This spouse disclaimed her ability to address small groups for purposes of education about organ transplantation. However, she related her inclusion of informal education of the public in her daily work routine: as she checked driver's licenses for identification purposes, she also encouraged organ donation decisions which can be personally recorded on some driver's licenses. In speaking of her participation in this research study, she said,

“So I think that any kind of a survey people do is very important, anything to get the word out there is going to be important.”

This participant noted the absence of a support group for transplant recipients and their families at the time when her husband received his heart transplant. Of this couple's involvement in founding and continuing to be active in a support group, she noted: “...so that's one way that we feel like we can give back.” Being very aware of the gifts which she and her husband have received, she expresses a need to reciprocate by giving.

Thus, the theme of gift includes ideas of giving and receiving in a variety of ways. This theme is interwoven within the ground of others. Each participant is aware of the wonderful gift of the donor heart and extended life or time. Some participants speak of a variety of gifts which they have received from others: gifts of visits and financial support, gifts of prayer and specific acts of kindness in maintaining the family's home environment while the family relocated for the transplant, or even gifts of food supplies that could be shared. Most participants

were clearly aware of the need for reciprocal giving as a response to the gifts they received; this was most noticeable in their need to be responsible stewards of the time extended by the gift of a heart to their husbands.

Summary

The experience of the spouse of a heart transplant recipient takes place within the context of Time and Others. Within these contexts, the experience is one of Death and Life, Vigilance, Change, and Gift. As described by the participants in this study, the spouse is very aware of death and life and watches to make sure that her husband's life is continuing. At some point after the transplant, however, participants noted that they must eventually let go of the watching. Participants also reported an awareness of change before and after the heart transplant, of receiving a precious gift, and of the need to give back.

The central core of the experience is death and life. A heart transplant means to the spouse that the recipient will live, that there will be change in their relationship, that they are aware of giving and receiving, and that they will have to be differentially vigilant and ultimately will have to let go of vigilance. Each of these themes has been demonstrated in the words of the participants found in transcribed interviews.

CHAPTER FIVE

DISCUSSION

The purpose of this study was to describe the experience of the spouse of a heart transplant recipient. Seven spouses of heart transplant recipients were interviewed using a phenomenological approach. Interviews were transcribed verbatim and interpreted by the researcher and in research group meetings. The result of this analysis of transcripts was a description of the thematic structure that formed the meaning of the experience as described by the participants. The meaning of this experience was situated by participants in time and others; and it is from these grounds that the themes of death and life, vigilance, change, and gift arise. This chapter discusses the thematic structure of this experience and its implications for nursing practice, education, and research.

Thematic Structure

The experience of the spouse of a heart transplant recipient was grounded both in time and in other people. Each of the transcribed interviews was clearly situated by the participant in the context of time: each noted the limited time available to the candidate without the donor heart; and most participants situated particular incidents within temporal increments such as hours, days, weeks, months,

or years. Certainly each participant could recall specific times involved in life-threatening situations. Some even remembered the time of day or night of critical events in the historical trajectory of time leading up to the transplant and beyond. Other participants still calculate time since the transplant and continue to speculate about the amount of time yet available to the transplant recipient.

A few studies of the spouse's experience have been done using grounded theory approaches, and some quantitative studies have defined variables related to the spouse's quality of life in various epochs of the transplant experience (Buse and Pieper, 1990; Canning et al, 1996; Collins, 1994; Collins et al, 1996; Hwang, 1996; Mishel and Murdaugh, 1987; Williams, 1991). For research purposes, the transplant experience is usually divided into three temporal periods which delineate boundaries of the specific part of the experience of interest to the researcher: these periods are usually designated as pretransplant, transplant, and posttransplant. It might be possible to look at these study participants' experiences by artificially dividing the total experience into these segments. For participants in this study, however, time is presented not as a boundary that separates parts of the experience but as an organizing context that becomes more figural when it appears to be more limited and scarce. As participants described their experiences, all aspects of time seemed to be woven seamlessly from the past through the present. Participants seemed unable to look at the present without also seeing both past and future simultaneously.

The second context for the spouse's experience of heart transplant was that of other people. For the spouse, the foremost and most significant "other" in the transplant experience is, of course, the transplant recipient. In addition, other people were described as being able to lend physical and/or emotional support that was helpful to the spouse. Other people who do not effectively support the spouse were described as uncaring or worse. Of the health care staff who did not notify one spouse of critical changes in the husband's pretransplant health status, the spouse said, "They never had the decency to call me." In this same situation, the spouse confronted apparently uncaring others who seemed (to the spouse) to be endangering the bit of life left for her husband.

"I finally went to, I finally went to the top officials. I told them, I said, 'Listen,' I said, 'I didn't bring him up here for y'all to kill. I brought him to see if he needed a heart transplant.' And, uh, I said, 'You give him enough amiodarone, get it back in his system...' I said, 'for me to get him on the plane. I'll take him home.' (My husband) said, 'I can die just as good at home as I can here.' He gave up."

For this spouse, others were usually helpful but could jeopardize the health of the most significant other in her life. When support was needed and given, others became positive influences on the transplant journey.

In previous studies of quality of life in heart transplant recipients and the spouse/family, others are usually globally grouped together in the variable of "social

support.” The presence of a good support system has been positively correlated with recipient compliance, decreased anxiety and depression, and facilitation of the recipient’s coping during the transplant process (Dew et al, 1996; Hirth and Stewart, 1994; Keenan, 1992). When the major variable of a quantitative study is social support, the conceptualization of others appears more mechanistic and somewhat impersonal. For the present set of participants, the ground of others was described in terms of contrast such as caring/uncaring, supportive/nonsupportive, and helpful/unhelpful. In whatever situation, the spouse’s account of other people is more often presented as a positive influence when the spouse perceives a personal concern for the welfare of the transplant recipient and the spouse.

Death and Life. This theme was dominant both by its presence and its pervasiveness in all of the interviews. Though few in number, studies of the pretransplant period note that the primary stressor for the spouse is the possibility that the transplant candidate might die before a suitable donor heart becomes available (Collins et al, 1996; Mishel and Murdaugh, 1987; Williams, 1991). Williams (1991) termed the pretransplant period “life on hold,” and this description aptly depicts this stage of waiting hopefully for a donor heart. One might expect, however, that this stasis of the spouse’s life would end when the transplant is completed. Though posttransplant expressions of gratitude for longer life expectancy are abundant in the present set of interview transcripts, spouses in this study acknowledged a continued fear of complications that imply a drawing near to death.

Participants in this study rather forthrightly confront their ongoing concern and/or fear of death and the loss of the transplant recipient.

Phenomenological interviews allowed participants to describe their experience in their own words and with their own levels of significance. The theme of death and life is much more notably prominent in this study than in previous studies in which data are grouped and labeled as "stress." Quantification of the level of significance of this basic existential theme seems to minimize its magnitude and its importance in the spouse's experience of heart transplantation. The predominance of this theme is also reflected in the correlated themes of vigilance, change, and gift.

Vigilance. This theme was present in the participants' use of words such as "watching" and "letting go." Previous studies have not clearly identified this significant aspect of spouse perception and behavior. Most participants in this study echoed the words of one participant who stated that watching had become "a way of life." Within the transplant experience, the spouse learns to watch the recipient for signs of altered health. Certainly the spouse, as the designated support person in the posttransplant experience, is initially instructed by health care providers to monitor the transplant recipient closely for numerous signs of rejection and infection that can destroy the transplanted heart and the recipient. If the spouse had already experienced a state of hypervigilance prior to the transplant, this was not a new role, but it returned the spouse to those enervating behaviors of constant observation that were a primary role in the time immediately prior to the transplant.

As the threat of death became less figural, the spouses reported becoming aware of the need to “let go” of the vigilance in order to allow the recipient to resume a more “normal” life. Some participants had difficulty with the letting go. Most spouses continued the vigilant stance, and some attempted to conceal it from the recipient in order to alleviate any stress engendered by the watching. Thus, vigilance was reported to have begun for most participants prior to the transplant and to continue in some fashion to the present time. This ongoing state could be construed to be the result of the spouse’s inability to face the possibility of the recipient’s death, and this may be accurate. Alternatively, this facing of death reappears periodically and must be encountered on multiple occasions within the overall transplant experience. One participant whose husband received a transplant almost nine years ago seemingly had moved to a less vigilant acceptance of the negative aspect of the recipient’s longevity. She did admit, however, that the couple now faced a new anxiety as the spectre of death seemed once again to approach. She described this situation as “a new time bomb.” From her words, it is evident that vigilance remains to some extent over time and is closely tied to a fear of death.

Heidegger (1927/1962, as cited in Pollio et al, 1997) posits that only when one faces death, the impossible possibility of not-being-in-the-world, can one *choose* to live what Heidegger terms the “authentic” life. Thus one’s authentic being-in-the-world is necessarily a being-toward-death. For the spouse of the heart transplant recipient, an increased awareness of the possibility of death for the transplant

recipient and for oneself has the potential for allowing the *choice* of living each day with an increased appreciation of one's present being-in-the-world. These study participants echoed this recognition and appreciation of an extended life in its precariousness despite, or perhaps because of, the consciousness of the possibility of its end.

Change. The changes inherent in the transplant experience have not been fully described in previous studies. Again, these changes have been otherwise named as factors in quantitative investigations of the transplant recipient's "quality of life" and "coping" capacity. Changes also are included in a limited fashion in those few studies which address the spouse's quality of life at some point of the transplant experience. The descriptions provided by the present set of participants much more richly express the significance of the changes that affect the roles of the spouse and the marital relationship. These descriptions also reveal the importance of the spouse's faith system in helping to endure in a critical lifeworld situation.

Like the other themes, the theme of change is more apparent when there is a drawing near to death and a movement away from life. Change is inherent in the dynamic of the lifeworld that is constantly being co-constituted by people as they live in dialogue with their world. Change occurs over time and has the potential for being perceived as either a positive or a negative aspect of the transplant experience. Most of the spouses spoke of their coping with observed change in the posttransplant period. They described their own actions and dialogue with the transplant recipient

which helped to mitigate the disruptive and surprising effects of change. Some spouses leaned heavily on their faith system and prayer for strength to persevere. One spouse relied on daily solitary physical exercise to help her deal with the changes in her husband which also effected change in their usual relationship and roles. She described the therapeutic effects of her exercise: "That was my only thing that I really, really got to do that I felt like for my frustration." Another spouse humorously suggested the need for a specific type of home:

"So I've told people that one way of getting through a transplant is to have a bi-, a bi-level house. Have an upstairs and a downstairs. I don't know how on earth people make it through when they live on one level (laughing)."

Some previous research identifies conflict as a significant factor in the posttransplant period. While this set of participants indicated some conflict with their husbands, the participants always related the conflict to the increased dosage level of prednisone and other medications. Although most participants concurred that changes in transplant recipients related to medication side effects subsided somewhat as the amount of medication was decreased, the change was certainly significant enough to have indelibly implanted itself in the spouse's memory.

Gift. The fourth major theme described by participants was named Gift. In the participants' words, the theme could also be aptly titled as giving and receiving. Not all participants used these words, nor did they universally disclose an attitude of gratitude for the donor heart. Five of the seven participants, however, did

speaking of the wonderful gift of extended life, of the donor, and of the donor family who made this possible by giving to someone else in an almost inconceivable situation of grief and personal loss. Some participants expressed the compelling need to give in return for what they had received from others; this giving was variously seen in active efforts to support others in similar heart transplant situations and in the individual and group education of others as to the need for donor organs with which others could also be gifted with extended life. The theme of giving and receiving is almost totally blended within the ground of others, for it is within the ground of others that giving and receiving take place. It is difficult to speak of giving without speaking also of the receiving of the gift.

Attitudes of gratitude also are part of the faith system of some of the participants. As one participant stated, "We totally give God the credit. He gives the doctors the knowledge to know all of this about transplants. And, uh, without God in it, I don't, I don't see how it could work." This same spouse spoke of God's provision of strength for her caretaking of her husband and of God's providing the donor heart at just the right time. As with other examples cited above, the theme of gift is closely interrelated with other significant themes. It is the interweaving of all these themes in the context of time and others that fully exemplifies the complex human experience of the spouse of the recipient of a heart transplant.

Implications for Nursing

Implications for nursing practice. Heart transplantation has become a treatment of choice and almost routine in the treatment of end stage heart disease. The nurse must realize, however, that for each transplant recipient and spouse, this is likely to be the couple's only experience with this process, especially on such a personal level. Moreover the nurse should realize the complexity of the entire transplant experience for each of the individuals within the marital dyad as well as for their combined experience as a couple.

Often in nursing practice there is a great deal of emphasis on physical aspects of the client's situation which require a variety of technical skills to effectively maintain physiologic homeostasis. Nursing, however, also espouses a more holistic approach to caring for human beings which involves giving attention to the physical, social, emotional, and spiritual facets of the person. In nursing practice, the client may be a person, a group, or an entire community. When the client is more than one individual, the nursing care must move to another level of complexity.

The nurse who cares for the heart transplant recipient and the spouse must necessarily be technically skilled and knowledgeable in this specialized area of practice. These abilities are assumed as minimal requirements. Interpersonal skills and the ability to assess the client situation holistically are the foundation for data collection which underlies appropriate nursing care. Data collection generally

consists of hearing the client's story of the health care situation (client history) and then following this account with a more objective physical assessment. Much of the data needed to care for the client is contained in the client history and may or may not be confirmed in the physical assessment. Thus, the very most important part of data collection is the nurse's listening to, and hearing of, the client's account of the situation.

Emphasis must be given to the necessity of caring for both the transplant recipient and the spouse, since the two share this experience over time. While each of these individuals might have some needs in common, each also has individual concerns that require nursing attention. Participants in this study suggested several areas of concern. For example, they spoke about, or alluded to, their lack of knowledge about heart transplantation and their need to know many things that were unknown to them. The task of the nurse in this instance involves an assessment of the spouse's level of knowledge and then the provision of the knowledge required. Not uncommonly, the nursing diagnosis of "knowledge deficit" is followed by specific knowledge which the nurse deems necessary to meet the goals of nursing. While the development of care plans should be done in conjunction with the client, this is not always the case. It is very important for the nurse to communicate the desire and ability to assist in meeting the spouse's goals. If the nurse believes the spouse's goals to be inappropriate, good interpersonal skills are needed to discuss and resolve the difficulty in a way that is beneficial to all concerned.

One spouse clearly stated her need to be informed in her husband's immediate health care situation and the ongoing decision making: "And I always told them [the health care team], 'You give me the information, you give me the numbers that are pertinent, and I'll be a happy camper. Because if you don't, then I'm going to be upset.'" Certainly the spouse needs to be informed, and the nurse must assess the spouse's level of knowledge and intervene appropriately.

Another spouse described her reaction to being asked if she and her husband were willing to go for a transplant evaluation. She stated, "So we had no information." This state of not knowing can lead to erroneous conclusions or feelings of powerlessness on the part of the spouse and can be rectified by provision of needed information through client teaching. This same spouse clearly identified her major needs from health care personnel:

"But I think that what I would be more appreciative of is to educate the nurses and the doctors that I am a person, I'm a spouse. I'm not the recipient, but it is my world. And to be a little, uh. more sensitive about my feelings, uh, and to know that I'm going to go through this. I'm not going to go through the physical part, but I'm certainly going to go through the emotional part. Uh, and, uh, to give them, have them to give us more of a bedside manner, not be so clinical about this."

This comment points out the need for both excellent clinical and interpersonal skills. Further, and perhaps more importantly, the spouse asks to be recognized as a co-

participant in this experience who also needs caring attention for herself as a person. This attention to holistic nursing care is often conspicuous by its absence as the nurse focuses only on the physiological homeostasis and other concerns of the transplant recipient.

The results of this study speak directly to nursing practice: spouses in this study describe an experience of awareness of death and life. As death approaches, fear generates vigilant behaviors. The nurse who observes increasing recipient movement toward death is likely to also see increases in the vigilant behaviors of the spouse. Nursing interventions in this situation should include encouraging the spouse to verbalize her fears. The nurse must also demonstrate warmth and caring for the spouse as well as for the transplant recipient and must help the spouse and the recipient to understand the care that is planned to meet the recipient's needs. The spouse and the transplant recipient also need reassurance of the ongoing presence and expert support of the health care team. The nurse has the opportunity to care for the spouse and the transplant recipient through a variety of situations of celebration and perhaps of the great sadness and seeming ultimate defeat of death. In situations in which death approaches and becomes irrevocable, the spouse needs to see and to feel unrelenting concern for the transplant recipient and to feel the compassion of a caring professional who as a fellow human being can share the spouse's imminent loss from both professional and personal perspectives.

The spouse also experiences changes in the transplant recipient, in roles and relationships, and in the need for support. The nurse is optimally situated to be able to provide anticipatory guidance and client education, to listen to the spouse's concerns, and to plan appropriate interventions with the spouse and transplant recipient. Nursing intervention should include education and reinforcement of information regarding side effects of medications such as prednisone and encouragement that side effects generally will decrease with lower medication doses in the near future. Facilitation of open communication between spouse and recipient should also be helpful.

The nurse can be involved in developing or participating in support groups which are focused on sharing of common concerns and management of common difficulties such as conflict management and self-care activities for the spouse. The transplant couple often is some distance from their usual support system during the period leading up to the transplant and immediately thereafter. If needed in this situation, attention should also be given to helping the couple become familiar with their temporary new home and the surrounding area as well as the facilities available to meet their needs most effectively. The nurse might also help the transplant couple develop connections with local churches or other faith communities which may be a source of support and comfort.

As the transplant couple experiences the wonderful gift of the transplant and desires to express their gratitude, the nurse should be able to answer questions about

the process of thanking the donor family for their unselfish and courageous sharing of extended life. Often the nurse can refer the couple to local donor organizations which have established protocols for confidential communication between donor family and recipients. Donor services organizations also provide opportunities for reciprocal "giving back" that many spouses and recipients seem to desire.

Throughout the transplant process, the nurse should be a competent and caring resource person who can promote the health of both recipient and spouse.

Implications for nursing education. Nursing education provides the skills and knowledge that are the basis for nursing practice. Transplantation nursing is certainly a specialized area of practice and requires advanced knowledge of the transplant candidate/recipient's needs and appropriate nursing care. In addition to caring for the candidate/recipient, the nurse must recognize the primacy of the relationship of the marital dyad and include the spouse as the other client in this situation. As Keenan (1992) noted, this necessary caring for the caregiver not only promotes the health and compliance of the recipient but also decreases the potential for marital distress and/or conflict. It also should promote the emotional health of the spouse.

In the education of the generalist nurse, basic skills of client health assessment and communication skills must necessarily be developed with an emphasis on the nurse's ability to listen to the client's story and to draw appropriate conclusions which are verified by the client. Teaching the use of phenomenological interviewing techniques and interpretation of the resulting transcripts would be

helpful in this endeavor. Nursing education must emphasize the nurse's focus on the client as a holistic human being and on the nurse's role of assisting the client through appropriate nursing care and client education. Advanced practice nurses who function as transplant coordinators not only need an advanced knowledge base but also skill in caring for people in crisis situations so that the people emerge from the situation stronger and more capable for having had this experience.

As educators are often role models for learners, nurse educators must model the above skills and espoused values of the discipline. Nursing espouses a holistic approach to clients, the development of nursing care plans with the client, and the protection of client autonomy. The results of this study indicate a need for a type of nursing which demonstrates respect for the individual client and empowers the client to be an informed consumer of health care as well as an active participant in all aspects of client care.

Implications for nursing research. Given the scarcity of research which focuses on the spouse of the heart transplant recipient, many opportunities for continued research exist. Since the spouses in this study were all females, phenomenological interviews of male spouses of heart transplant recipients should be done to determine if their experience is different from that of the female spouse. Phenomenological interviews of heart transplant recipients themselves should provide richer insight into the experience of the recipient and offer a view of the spouse's behavior from the recipient's point of view. Simultaneous interviewing of both

transplant recipients and their spouses might also provide an understanding of the experience that is similar to, or different from, the results of this study. Additionally, phenomenological study of children of transplant recipients would enlighten nursing knowledge of this arena for care.

In addition to studying the experience of the recipient, the spouse, and their children, phenomenological studies of the experience of nurses and physicians who care for transplant recipients would enrich our knowledge of this experience from the point of view of health professionals. Since the spouses in this study indicated some dissatisfaction with the care given by some health care providers, intervention studies could provide needed knowledge for improving the current level of care of transplant recipients and their spouses. In the specialty area of transplantation nursing, opportunity for needed research remains. Since heart transplantation has become a treatment of choice for end stage heart disease, this research is needed to amplify the knowledge needed in order to provide appropriate nursing care to all individuals involved in the transplant situation.

REFERENCES

REFERENCES

- Annells, M. (1996). Hermeneutic phenomenology: Philosophical perspectives and current use in nursing research. Journal of Advanced Nursing, 23, 705-713.
- Artinian, N.T. (1991). Stress experience of spouses of patients having coronary artery bypass during hospitalization and 6 weeks after discharge. Heart & Lung, 20(1), 52-59.
- Artinian, N. T., & Hayes, M. G. (1992). Factors related to spouses' quality of life 1 year after coronary artery bypass graft surgery. Cardiovascular Nursing, 28(5), 33-38.
- Baumann, L. J., Young, C. J., & Egan, J. J. (1992). Living with a heart transplant: Long-term adjustment. Transplant International, 5, 1-8.
- Beach, E. K., Maloney, B. H., Ploccia, A. R., Sherry, S. E., Weaver, M., Luthringer, L., & Utz, S. (1992). The spouse: A factor in recovery after acute myocardial infarction. Heart & Lung, 21, 30-38.
- Bedsworth, J. A., & Molen, M. T. (1982). Psychological stress in spouses of patients with myocardial infarction. Heart & Lung, 11(5), 450-456.
- Bohachick, P., and Anton, B. B. (1990). Psychosocial adjustment of patients and spouses to severe cardiomyopathy. Research in Nursing and Health, 13, 385-392.

Bohachick, P., Anton, B. B., Wooldridge, P. J., Kormos, R. L., Armitage, J. M., Hardesty, R. I., & Griffith, B. P. (1992). Psychosocial outcome six months after heart transplant surgery: A preliminary report. Research in Nursing and Health, 15, 165-173.

Boyd, C. O. (1993). Philosophical foundations of qualitative research. In P. L. Munhall and C.O. Boyd, Nursing Research: A Qualitative Perspective (2nd ed.). New York: National League for Nursing Press.

Buse, S. M., & Pieper, B. (1990). Impact of cardiac transplantation on the spouse's life. Heart & Lung, 19, 641-648.

Canning, R. D., Dew, M. A., & Davidson, S. (1996). Psychological distress among caregivers to heart transplant recipients. Social Science and Medicine, 42(4), 599-608.

Caplin, M. S., & Sexton, D. L. (1988). Stresses experienced by spouses of patients in a coronary care unit with myocardial infarction. Focus on Critical Care, 15(5), 31-40.

Cohen, M. Z. (1987). A historical overview of the phenomenologic movement. Image, 19(1), 31-34.

Collins, E.G. (1994). Quality of life predictors : Heart transplant spouses. Unpublished dissertation. Loyola University, Chicago.

Collins, E.G., White-Williams, C., & Jalowiec, S. (1996). Spouse stressors while awaiting heart transplantation. Heart & Lung, 25, 4-13.

Creswell, J. W. (1994). Research Design. Qualitative and Quantitative Approaches. Thousand Oaks, California: Sage.

Croog, S. H., & Fitzgerald, E. F. (1978). Subjective stress and serious illness of a spouse: Wives of heart patients. Journal of Health and Social Behavior, 19(6), 166-178.

Dew, M. A., Roth, L. H., Schulberg, H. C., Simmons, R. G., Kormos, R. L., Trzepacz, P. T., & Griffith, B. P. (1996). Prevalence and predictors of depression and anxiety-related disorders during the year after heart transplantation. General Hospital Psychiatry, 18, 48S-61S.

Dew, M. A., Roth, L. H., Thompson, M. E., Kormos, R. L., & Griffith, B. P. (1996). Medical compliance and its predictors in the first year after heart transplantation. The Journal of Heart and Lung Transplantation, 15, 631-645.

Dew, M. A., Simmons, R. G., Roth, L. H., Schulberg, H. C., Thompson, M. E., Armitage, J. M., & Griffith, B. P. (1994). Psychosocial predictors of vulnerability to distress in the year following heart transplantation. Psychological Medicine, 24, 929-945.

Duitsman, D. M. (1991). The relationship of psychosocial factors to recuperation and quality of life in heart transplant recipients. Unpublished dissertation, Indiana University.

Duitsman, D. M., & Cychoz, C. M. (1993). Quality of life in heart transplants: Indications for education. Health Values, 17(6), 55-61.

Gilliss, C. L. (1984). Reducing family stress during and after coronary artery bypass surgery. Nursing Clinics of North America, 19(1), 103-112.

Gilliss, C. L., Neuhaus, J. M., & Hauck, W. W. (1990). Improving family functioning after cardiac surgery: A randomized trial. Heart & Lung, 19, 648-654.

Hentinen, M. (1983). Need for instruction and support of the wives of patients with myocardial infarction. Journal of Advanced Nursing, 8, 519-524.

Hirth, A. M., & Stewart, M. J. (1994). Hope and social support as coping resources for adults waiting for cardiac transplantation. Canadian Journal of Nursing Research, 26(3), 31-47.

Hwang, H. (1996). Patient and family adjustment to heart transplantation. Progress in Cardiovascular Nursing, 11(2), 16-18,39.

International Society of Heart and Lung Transplantation (1997). Fourteenth annual data report: March 1997. Retrieved November 4, 1997 from the World Wide Web: <http://www.richmond.infi.net/~ishlt/registry.html>.

Jones, B. M., Taylor, F., Downs, K., & Spratt, P. (1992). Longitudinal study of quality of life and psychological adjustment after heart transplantation. Medical Journal of Australia, 157, 24-26.

Keenan, M. (1992). Adjustment issues and quality of life among heart transplant recipients. Unpublished doctoral dissertation, Temple University, Philadelphia.

Kesling, G. L. (1987). The historical development of cardiac transplantation. Unpublished dissertation, Texas Woman's University.

Kuhn, W. F., Davis, M. H., & Lippman, S. B. (1988). Emotional adjustment to cardiac transplantation. General Hospital Psychiatry, 10, 108-113.

Kvale, S. (1996). Inter-Views. An introduction to qualitative research interviewing. Newbury Park, CA: Sage Publications.

Lincoln, Y. S., & Guba, E.G. (1985). Naturalistic inquiry. Newbury Park: Sage.

- Lough, M. E. (1986). Quality of life issues following heart transplantation. Progress in Cardiovascular Nursing, 1(4), 17-23.
- Lough, M. E., Lindsey, A. M., Shinn, J. A., & Stotts, N. A. (1985). Life satisfaction following heart transplantation. The Journal of Heart Transplantation, 4, 446-449.
- Mai, F. M. (1993). Psychiatric aspects of heart transplantation. British Journal of Psychiatry, 163, 285-292.
- Mai, F. M., McKenzie, F. N., & Kostuk, W. J. (1990). Psychosocial adjustment and quality of life following heart transplantation. Canadian Journal of Psychiatry, 35, 223-227.
- Mayou, R., Foster, A., & Williamson, B. (1978). The psychological and social effects of myocardial infarction on wives. British Medical Journal, 1, 699-701.
- McAlear, M. J., Copeland, J., Fuller, J., & Copeland, J. G. (1985). Psychological aspects of heart transplantation. Heart Transplantation, 4, 232-233.
- McSweeney, J.C., Richards, R., Innerarity S.A., Clark, A.P., & Mitchell, M.B. (1995). What about me? Spouses' quality of life after heart transplantation. Journal of Transplant Coordination, 5(2), 59-64.

Miller, Sr. P. J., & Wikoff, R. (1989). Spouses' psychosocial problems, resources, and marital functioning postmyocardial infarction. Progress in Cardiovascular Nursing, 4(2), 71-76.

Mishel, M. H., & Murdaugh, C. L. (1987). Family adjustment to heart transplantation: Redesigning the dream. Nursing Research, 36(6), 332-338.

Monahan, D. J., Kohman, L., & Coleman, M. (1996). Open heart surgery: Consequences for caregivers. Journal of Gerontological Social Work, 25(3/4), 53-70.

Munhall, P. L. (1994). Revisioning Phenomenology: Nursing and Health Science Research. New York: National League for Nursing Press.

Nolan, M.T., Cupples, S.A., Brown, M., Pierce, L., Lepley, D., & Ohler, L. (1992). Perceived stress and coping strategies among families of cardiac transplant candidates during the organ waiting period. Heart Lung, 21, 540-547.

Nyamathi, A., Jacoby, A., Constancia, P., & Ruvevich, S. (1992). Coping and adjustment of spouses of critically ill patients with cardiac disease. Heart & Lung, 21, 160-166.

Pascoe, E. (1996). The value to nursing research of Gadamer's hermeneutic philosophy. Journal of Advanced Nursing, 24, 1309-1314.

Polkinghorne, D.E. (1989). Phenomenological research methods. In R. Valle & S. Halling (Eds.), Existential-phenomenological perspectives in psychology (pp. 41-60). NY: Plenum Press.

Pollio, H. R., Henley, T., & Thompson, C.B. (1997). The phenomenology of everyday life. Cambridge, United Kingdom: Cambridge University Press.

Porter, R. R., Bailey, C., Bennett, G. M., Catalfamo, A. T., Daniels, K. J., Ehle, J. E., Gibbs, S., Krout, L. S., & Luers, E. S. (1991). Stress during the waiting period: A review of pretransplantation fears. Critical Care Nursing Quarterly, 13(4), 25-31.

Radley, A., & Green, R. (1986). Bearing illness: Study of couples where the husband awaits coronary graft surgery. Social Science and Medicine, 23(6), 577-585.

Saad, E. B. (1997). Cardiology: Heart transplantation. Medstudents Homepage, pp. 1-10. Retrieved November 10, 1997, from the World Wide Web: <http://www.medstudents.com.br/cardio/cardio4.htm>.

Sandelowski, M. (1997). "To be of use": Enhancing the utility of qualitative research. Nursing Outlook, 45, 125-132.

Spiegelberg, H. (1971). The phenomenological movement. A historical introduction (2nd ed., vol. 1). TheHague: Martinus Nijhoff.

Swanson-Kauffman, K., & Schonwald, E. (1988). The personal path to nursing knowledge. In B. Sarter (Ed.), Paths to knowledge. Innovative research methods for nursing (97-105). New York: National League for Nursing.

Valle, R., King, M., & Halling, S. (1989). An introduction to existential-phenomnenological thought in psychology. In R. Valle & S. Halling (Eds.),

Existential-phenomenological perspectives in psychology (pp. 3-16). NY: Plenum Press.

Williams, M. (1991). Life on hold: A theory of spouse response to the waiting period prior to heart transplantation. Unpublished dissertation, University of Arizona.

APPENDICES

APPENDIX A: IRB Approval

THE UNIVERSITY OF TENNESSEE
KNOXVILLE



02/24/99

IRB # : 5680 B

Title : Living as the Spouse of a Heart Transplant Recipient

Office of Research
404 Andy Holt Tower
Knoxville, Tennessee 37996-0140
PHONE: (423) 974-3466
FAX: (423) 974-2805
URL: <http://www.ra.utk.edu/ora>

McCurry, Alice
Nursing
7905 Pedigo Rd.
Knoxville, TN 37938

Thomas, Sandra, Co-PI
Nursing
1200 Volunteer Blvd.
Campus

Your project listed above was reviewed. It qualified for expedited review and has been approved.

This approval is for a period ending one year from the date of this letter. Please make timely submission of renewal or prompt notification of project termination (see item #3 below).

Responsibilities of the investigator during the conduct of this project include the following:

1. To obtain prior approval from the Committee before instituting any changes in the project.
2. To retain signed consent forms from subjects for at least three years following completion of the project.
3. To submit a Form D to report changes in the project or to report termination at 12-month or less intervals.

The Committee wishes you every success in your research endeavor. This office will send you a renewal notice (Form R) on the anniversary of your approval date.

Sincerely,

A handwritten signature in cursive script that reads "Brenda Lawson".

Brenda Lawson
Compliances

cc: Joan Creasia

APPENDIX B: Informed Consent

A RESEARCH STUDY OF THE EXPERIENCE OF SPOUSES OF HEART TRANSPLANT RECIPIENTS CONSENT FORM

You are invited to participate in a research project. The purpose of this study is to explore the experience of spouses of heart transplant recipients. Understanding what this experience is like for the spouse may assist nurses and other health care providers to more adequately assist spouses of heart transplant recipients in the future. An interview will be conducted by the principal investigator.

You are asked to participate in an audiotaped interview that will last approximately one hour (maximum of 2 hours) in a place of your choice. You will be asked to share your lived experience of being the spouse of someone who has had a heart transplant. Subsequent questions will be based on your comments and responses. This interview will be audiotaped so that the investigator can use your exact words to understand your experience. These interviews will be transcribed into written form for analysis. Your name will not appear on the tape or the transcript and will be known only to the principal investigator. Tapes and transcripts will be kept in a locked file in a locked data storage room at the College of Nursing at the University of Tennessee, Knoxville, which is accessible only to the principal investigator and the co-principal investigator. You may contact the investigator following the interview and during the analysis to clarify the interpretation of your experience. Your verbal consent will be included on the audiotape made of the interview. Tapes will be retained for three years after completion of the study and then destroyed by removing the tape from its plastic case and cutting the tape into small pieces. Other data without your name will be kept for future analysis. No incentives are offered to you for your time and effort in participating; however, you may personally benefit by talking about your experience.

The nature and direction of the interview will be determined by you and the investigator and will unfold as the interview progresses. You may experience some stress as a result of the interview related to the potential sensitivity of disclosure of your feelings or the emotions the interview may evoke. You are free to choose not to participate in this study or you can withdraw from this study at any time by notifying Ms. McCurry. Your audiotape and/or transcripts would be destroyed upon your request.

Any and all information you provide will be kept in confidence. Neither your name nor any identifying information will be used in any reports although your words may be used to support the interpretation and analysis. At no time will your words be linked or traceable to you.

Alice H. McCurry, Principal Investigator

Sandra Thomas, Co-Principal Investigator

SUBJECT'S STATEMENT

This study has been explained to me, and I voluntarily consent to participate in this study. I have had an opportunity to ask questions and understand that I may ask further questions at any time in the future by contacting the investigator named above. I can withdraw from the study at any time without penalty. I have received a copy of this consent form. I understand that I may receive a copy of the results of the study.

Principal Investigator: Alice H. McCurry, RN, MSN
Doctoral Student, College of Nursing
University of Tennessee, Knoxville
(423) 974-7581

APPENDIX C: Confidentiality Agreement for Research Group

Confidentiality Agreement

As a member of the Qualitative Research Group in the Department of Psychology under the direction of Dr. Howard Pollio or in the College of Nursing under the direction of Drs. Sandra Thomas, Patricia Droppleman, Johnie Mazingo, and Mitzi Davis at the University of Tennessee, Knoxville, Tennessee, I agree to guarantee confidentiality to subjects who participated in the study entitled "Living as the Spouse of a Heart Transplant Recipient." I will not publicly divulge information that I learned.

Signature

Date

APPENDIX D: Demographic Data Form

Demographic Data Form
Spouse of Heart Transplant Recipient

ID# _____

Date of Transplant _____

Work/Retirement Status _____

Your age at the time of the transplant _____

Your husband's age at the time of the transplant _____

Number of years married at time of transplant _____

Total numbers of years married _____

Family income:

- _____ Less than \$10,000 per year
- _____ \$10,000-\$24,999 per year
- _____ \$25,000-\$49,999 per year
- _____ \$50,000-\$100,000 per year
- _____ greater than \$100,000 per year

Education: highest level of education completed _____

VITA

Alice Hill McCurry was born in Anderson County, Tennessee. She attended schools in the Anderson County School System and graduated from Clinton High School in May, 1967. In the fall of 1967, she entered Berea College, Berea, Kentucky, graduating in May, 1971, with a baccalaureate degree in nursing. In December, 1983, she received a master's degree in nursing from the University of Tennessee, Knoxville.

Alice's nursing career has included nursing within a hospital setting, expanded practice as a family nurse practitioner, and nursing education at both vocational and baccalaureate levels. She was employed by Carson-Newman College in 1987 and is currently a tenured educator in the Division of Nursing.

In August, 1991, she enrolled in the nursing doctoral program as a part-time student at the University of Tennessee, Knoxville, and received the Doctor of Philosophy degree in December, 1999.