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Life on Hold: A theory of spouse response to the waiting period prior to heart transplantation

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LIFE ON HOLD: A THEORY OF SPOUSE RESPONSE TO THE WAITING PERIOD PRIOR TO HEART TRANSPLANTATION

by

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STATEMENT BY THE AUTHOR

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ABSTRACT

The purpose of this study was to generate a grounded theory explaining the social and psychological processes used by spouses during the waiting period prior to heart transplantation. Theory discovery was accomplished using the grounded theory methodology.

Life on Hold was identified as the basic social psychological process generated from the data that explains the responses of spouses during the waiting period prior to heart transplantation. Life on Hold is the process of "tabling" life's activities for an indefinite period of time in order to devote one's life to another person(s) or event. Spouses of heart transplant candidates set aside life's activities and focus all thoughts, actions, and energy on maintaining the life of the candidate until a donor heart is obtained. The process consists of two stages: Freeing Self and Making Life the Transplant.

The theory provides a basis for the development of relevant interventions to assist family members to cope with the uncertainty and stress of the transplant experience.

CHAPTER 1

INTRODUCTION

This study has involved theory discovery, specifically discovery of the social and psychological processes used by spouses of heart transplant candidates during the waiting period prior to transplantation. The introductory chapter is organized into three sections. First, the research problem is discussed. The significance of the study to the discipline of nursing, including nursing theory and nursing practice, is then addressed. The chapter concludes with specification of the study's purpose and research questions.

The Research Problem

Once considered experimental, heart transplantation for end-stage heart disease is now an acceptable therapeutic option. Such a reality has resulted from decades of laboratory experimentation dating back to the early part of the 20th Century. The first reported attempts at experimental heart transplantation were in 1905 in the Hull Physiological Laboratory at the University of Chicago where hearts were removed from small dogs and transplanted into the necks of larger dogs (Carrel, 1907; Carrel & Cuthrie 1905). Following the initial transplant attempt, laboratory work continued during the 1930's, 40's and early 50's in a somewhat aimless and random fashion with experimentation focusing on the heterotopic heart model wherein the recipient's heart was left intact and the donor's heart was grafted parallel to it. This heterotopic procedure was designed to allow heart transplantation in patients with excessively

elevated pulmonary vascular resistance acquired from chronic left failure (Barnard & Losman, 1975). During the late 1950's and early 1960's the momentum accelerated as investigators started work on auxiliary heterotopic transplants and direct orthotopic transplants. The orthotopic transplant involved removal of the diseased heart and implantation of the donor heart into the normal anatomical position of the recipient's chest (Lower & Shumway, 1960). The focus during this time changed from development of the surgical technique to the feasibility of heart transplantation as a therapeutic surgical procedure (Baumgartner, Reitz, Oyer, Stinson, & Shumway, 1979; Griepp & Ergin, 1984). Continued experimentation culminated in the first clinical or human heart transplantation on December 3, 1967 by Christian Barnard in Capetown, South Africa. Barnard transplanted the heart of a 25 year old woman into a 55 year old man. The patient lived 18 days before succumbing to a combination of infection and rejection problems (Barnard 1967; Barnard & Pepper, 1969). Barnard's second transplant was performed one month later and the patient lived nearly 18 months. Barnard recalls his first experience with heart transplantation as follows (Barnard & Pepper, 1969, p. 290):

> On the way to the operating theatre, I felt for the first time that the transplant was actually going to happen. Until that moment, there had been so many hurdles to cross, that the reality of the event had been lost in getting ready for it. Only now did it seem possible. And only now, alone in the passage leading to this theatre, was I aware that I was walking forward with the hope that I would never get there, that something would still block my way.
>
> The further I went, the worse it became. With each step, the weight of my doubt grew until it seemed almost unbearable. I wanted to turn back, but there was no turning. Two people--a girl and a man--were now being moved into adjacent theatres. Both of them had living

> hearts that could not continue to beat for much longer. We were approaching the moment when there would be nothing else to do other than cut out both their hearts, and place one of them--the girl's--within an empty chest of this man who would otherwise never leave the operating table alive.
>
> If we succeeded it would be more than the grafting of a heart. It would be the conjoining of many disciplines of medicine and science. It would also be the crowning effort of a team of men and women who would bring to bear upon that moment the training of a lifetime, structured with the inherited technique and skill of a millennium. All of it would be fused into one objective--to replace a dying heart with a new one, to save one life.

Initial enthusiasm over Barnard's success stimulated worldwide interest in heart transplantation. During the first year following Barnard's transplant, approximately one hundred transplantations were performed by 40 teams, in 17 countries and on five continents (Haller & Cerruti, 1969). However, by 1970 a rapid and dramatic decline of activity in the field of heart transplantation occurred which was largely attributable to the low survival rates. Approximately 22% of the patients died within the first two days postoperatively and another 12% of the patients died during the first postoperative week. Only about 21% of the patients survived beyond the first year (Haller & Cerruti, 1969). Debates developed as to whether the procedure of heart transplantation was adequately developed for human use. Many questioned whether a moratorium had already occurred as demonstrated by the decline in the number of heart transplants. Controversy arose as medical professionals and people tried to determine whether a moratorium meant total cessation of the procedure among humans or a temporary slowdown in clinical application (Fox & Swazey, 1974). Professional and lay commentators aired their concerns about the rejection

problems facing those already transplanted. For instance, in January 1968 Dr. Howard Rusk wrote the following in the New York Times:

> This writer has discussed the present status of transplants with more than two score experienced cardiologists and researchers in immunology during the last three days. The consensus has been unanimous. The technological advances and surgical techniques have completely outstripped the basic immunological knowledge needed to prevent rejection (p. 86).

Needless to say, only four centers, Stanford University and Medical College of Virginia in the United States, and LaPitie Hospital in Paris, and Groote Schuur Hospital in South Africa continued transplant programs (Cooper & Lanza, 1984). Eventually results began to improve. Increased survival was attributed to better selection criteria, enhanced postoperative care including rejection management and more effective diagnosis and treatment of infectious complications (Cooper & Lanza, 1984). Additionally the Federal Drug Administration's approval of the immunosuppressant agent, cyclosporine, in 1983 brought about further significant improvement in the results of the procedure. Cyclosporine, a peptide with T-cell specificity and limited effects on B-cell function has significantly reduced the incidence of infections, shortened the length of hospitalization, and lowered the cost of organ transplantation (Griffith, Hardesty, Deeb, Starzl, & Bahnson, 1982; Oyer, et al., 1982). The International Heart Transplant Registry has documented significant improvement in the worldwide survival rate of heart transplant recipients since cyclosporine was added to immunosuppressive protocols (Fragomeni & Kaye, 1988).

Hence, heart transplantation once considered a "bold experiment" now enters a new era of "reality" (Evans,et al., 1984, p. iii). What was once considered experimental is now a therapeutic option for end-stage heart disease. The International Heart Transplant Registry reports a world wide 1-year survival rate of approximately 81% and a 5-year survival rate of 72% in adult recipients (Kriett & Kaye, 1990). Along with improved survival rates are indications that the rehabilitation and quality of life of heart transplant recipients is now acceptable (Evans, 1987; Evans, Manninen, Maier, Garrison, & Hart, 1985; Gaudiani, et al., 1981; Lough, Lindsey, Shinn, & Stotts, 1985). Additionally trends in both the private and public insurance industry further validate the acceptability of heart transplantation in that increasing numbers of agencies are deciding to extend transplant insurance coverage to their beneficiaries. For instance, it is estimated that over 80% of all private insurers pay for heart transplantation (Evans, 1985). Also, Medicare now offers coverage at selected centers. The landmark declaration by the U.S. Department of Health and Human Services that heart transplantation is no longer considered an experimental procedure further confirms the new era of heart transplantation we now enter, with increasing numbers of medical centers initiating heart transplant programs (Fragomeni & Kaye, 1988).

Thus, with improved survival rates and the biotechnological maturity of the transplant procedure a second generation of issues require attention. Until recently, research has almost exclusively focused on the biological survival issues of infection, immunosuppression and rejection (Bieber, et al., 1981; Jamieson,

et al., 1984; Jamieson, Oyer, Bieber, Stinson, & Shumway, 1982). However, current research has begun to expand to psychosocial issues such as quality of life, life satisfaction, psychiatric complications, and psychological adjustment (Evans et al., 1984; Lough, Lindsey, Shinn, & Stotts, 1985; Watts, et al., 1984; Allender, Shisslak, Kaszniak, & Copeland, 1983; McAleer, Copeland, Fuller, & Copeland, 1985). With new areas of inquiry, little attention has been focused on the needs of family members of heart transplant recipients as they proceed from diagnosis through surgery and into the recovery phase.

The families of patients with other cardiovascular conditions have been studied. In fact some have suggested that cardiovascular conditions have a qualitatively different effect on family members than other medical conditions (Blacher & Cleveland, 1979; Rakoczy, 1977). The suggestion is based on the notion that the heart has unique meaning to individuals both as the life sustaining organ and the seat of emotions. For instance, spouses of patients undergoing coronary artery bypass surgery reported a myriad of stresses both during hospitalization and recovery. Stressors include lack of control of hospital events, lack of privacy, and fear of caring for the patient upon discharge. The stressor most commonly identified by families was waiting for the surgery (Gillis, 1984). Mayou, Foster, and Williamson (1978) found that among wives of patients who had suffered a myocardial infarction, substantial psychological symptoms persisted even up to a year following the infarction. The symptoms had continued effect on work, leisure time, social activities and family life of the spouses. Conclusions of the investigators suggest that

cardiovascular conditions and related surgical procedures are tremendous sources of stress to family members and can threaten the very integrity of the family.

Only recently have the psychological aspects of heart transplantation been considered. However, literature reports are primarily descriptive in nature and focus almost exclusively on the patient without considering the influence on the family. For example, Lunde (1969) reported a myriad of psychological complications postoperatively among transplant recipients. The most serious was psychosis. He attributed many of the complications to self-image alteration and the acquisition of another person's heart. Kraft (1971) identified some of the psychodynamic consequences of transplantation by describing the relationship between postoperative psychological complications and preoperative expectations for the donor heart. Molish, Kraft, and Wiggins (1971) demonstrated postoperative deficits in intellectual functioning in five transplant recipients; however, no preoperative data were available for comparison. Abram's (1971) review of the literature suggests that a combination of factors are responsible for psychosis following transplantation: anxiety about death, sensory deprivation, reverse isolation, as well as physiological factors including high doses of steroids, increased catecholamines and decreased cardiac output. Mai, McKenzie, and Kostuk (1986) reported a high prevalence of psychological complications preoperatively, postoperatively and during the convalescent period. The complications ranged from preoperative anxiety and depression to postoperative delirium, and to social and behavioral problems during convalescence. McAleer and associates (1985) identified frequently occurring psychological problems in 595 heart

transplant recipients at eleven centers. A questionnaire was used to evaluate two time periods: initial hospitalization and after the initial hospitalization. During the initial hospitalization patients at all centers reported depression and mood alterations. Other frequently occurring problems were increased family stress and changes in body image. After the initial hospitalization, family stress was the most common problem reported with depression, mood alterations, and non-compliance also occurring frequently. The above studies demonstrate the stressful effect that heart transplantation has on the recipient as evidenced by the high incidence of psychological dysfunction among recipients as they proceed from diagnosis through surgery and into the recovery phase. However, none of the studies except McAleer et al. (1985) addresses the effect of transplantation on the family members. Based on McAleer and associates' (1985) findings family stress is a frequently occurring problem both during the initial hospitalization as well as after the initial hospitalization that requires study.

Three studies have specifically addressed the effect of heart transplantation upon family members. As part of the National Heart Transplantation Study, Evans and associates (1984) collected extensive data to determine the influence of heart transplantation on recipients and their families. Data were obtained through standardized telephone-assisted mail surveys. Six centers in the United States were utilized and a sample of 135 family or household members was generated. To date, only selected results relative to recipients' families have been published and these are descriptive in nature (Manninen & Evans, 1986). For instance 21.4% of the family

members characterized the transplant as "often" interfering with the family routine at home. About 70% of the family or household members believed the transplant had drawn the family closer together, whereas only a few family members thought the transplant had drawn the family apart. Approximately one-third of the spouses indicated that the heart transplant placed strain on their marriage and 83% described themselves as being "extremely worried" about the surgery. Hence, although the reported results are limited, they provide preliminary evidence of the stressful effect of heart transplantation on family members.

Buse and Pieper (1990) using a nonexperimental descriptive design, explored the effects of waiting for the heart transplant and the transplantation on the life, relationships and reported stress of the patient's spouse. Thirty spouses completed three instruments. Findings indicated that the pretransplant period had a greater overall effect on life than the posttransplant period. Spouses perceived the posttransplant period as significantly more positive than the pretransplant period although no significant differences were found between pretransplant and posttransplant stress scores. During the pretransplant phase items perceived to most influence life were feelings of fear over loss of spouse, need to learn more about transplantation, time available for self and life in general. Learning more about transplantation, availability of support from others, relationships with family and friends, and the need to make decisions independently were thought to have the most positive effect on life during the pretransplantation period. During the pretransplantation period areas identified as most important with the relationship of

the spouse to the patient were the need to monitor the patient's physical and emotional condition, sexual activity, and the need to protect the spouse from upsetting information. Feelings of closeness and tenderness, and marriage were reported to be most positive in the patient's and spouse's relationship during the waiting period. During the posttransplant period, life was influenced most by the need to learn more about transplantation, life in general, feelings over loss of spouse and feelings of security. Factors perceived to be most helpful during this time were independent decision making and relationships with children and grandchildren. Most significant in the relationship with the patient during the posttransplant period were feelings of closeness and tenderness, and the need to monitor the spouse's emotional and physical condition. Buse and Pieper's (1990) study suggests that the pretransplant period is perceived by spouses to change life more than the posttransplant period although stress levels remained similar throughout both phases. Although the study was descriptive, areas were identified that seemed to have the most effect and were most influential during both the pretransplant and posttransplant time periods from the spouse's perspective.

Using a grounded theory methodology, Mishel and Murdaugh (1987) explored the processes family members of heart transplant candidates and recipients use to manage the unpredictability evoked by the need and receipt of heart transplantation. Twenty family members were theoretically sampled from three separate support groups each of 12 weeks duration. The basic social psychological process generated to explain family adjustment to heart transplant is the process of

"redesigning the dream". This process describes the cognitive and behavioral changes that occur in the partner from the time the patient enters the transplant program until an unknown period post-transplantation. Mishel and Murdaugh (1987) in describing the process of redesigning the dream suggest that when families are accepted into the program they have the dream that life will return to normal after the transplant. The partner frees self and completely immerses self in maintaining the physical condition of the patient so death can be averted. As partners experience the waiting period, hospitalization, and recuperation after discharged their attitudes, beliefs and behavior undergo an evolution. Clues that life will not return to normal are gradually acknowledged and the initial dream is reshaped to fit the reality of life. The process of redesigning the dream comprises three concomitant inter and intrapersonal concepts. The concepts include immersion, passage, and negotiation. Mishel and Murdaugh's (1987) findings provide insights into the processes family members use during the transplant experience.

All transplant phases may be stressful to the recipient's family. Some of the psychological stresses frequently occurring include the inability of the breadwinner to work with resultant loss of earnings, loss of status and reversal of roles. Additionally, the stress of leaving family and home and relocating where the transplantation can take place often occurs. Also, the possibility of death is ever present as the candidate and family realize that the transplant is the last option, the last hope for life. Individuals in the clinical setting working closely with recipients and families suggest that the waiting period is perhaps the most stressful time of the

entire process (O'Brien, 1985; Suszycki, 1986). Several studies have substantiated these beliefs (Gillis, 1984; Mishel & Murdaugh, 1987). This time period has perhaps best been described as "interminable" (Watts et al., 1984, p. 244). Eisenman (1986) a physician who was the recipient of a transplant describes the waiting period in these words:

> I found my pretransplant life to be almost unendurable. The most frightening aspect of the situation was the loss of my mental capacities. Whether the cause is physical, psychological or both, the loss of one's most valued human property is frightening and depressing, and it is a fear that feeds on itself. Toward the end, I was unable to identify the day or the date correctly (p. 134).

Although the waiting was found to be stressful in previous studies, Mishel and Murdaugh (1987) and others did not focus exclusively on the waiting period. The lack of indepth inquiry focusing solely on the waiting period suggests the need for further investigation.

The intensity of the waiting period and the helplessness experienced by family members have increased even more as centers performing transplant procedures have proliferated resulting in increased competition for the limited donor supply. As of August 1986, 475 heart transplants have been performed in the United States, with 200 patients still waiting for donor hearts. An estimated 15,000 more could benefit from heart transplantation (Miller, 1987). Additionally, it is estimated that up to one-third of the patients die waiting transplantation (Schroeder, 1979; Thomas & Lower, 1978) and that these figures may well be increasing as we see increased numbers of

heart transplantations each year and increased numbers of centers performing transplantations.

In summary, based on the limited research conducted to date, the effects of heart transplantation upon family members warrants further investigation. The waiting period may be the most stressful phase of the transplantation process for the patient and family members. No research has focused exclusively on the waiting period resulting in limited information about family members' responses during this time. Since the waiting period is an important time for interventions designed to maintain family integrity in other phases, processes family members experience during the waiting period need to be identified.

The Significance of the Study for Nursing

As nursing science evolves, the need for theory becomes more evident to allow for description, explanation, prediction, and ultimately intervention for phenomena of interest to the nursing profession (Fawcett, 1975). Nursing theory relative to the family members' experiences during illness is limited. The family constitutes the most important context within which illness occurs and consequently acts as a primary unit in health and medical care (Litman, 1974). Additionally, the dynamic interrelationship between health and the family members, and the dramatic effect each has on the other is increasingly evident (Udelman & Udelman, 1980; Fife, 1985). In clinical practice, nurses have long been involved with family members and formally nurses have recognized them as clients (American Nurses' Association, 1980; World

Health Organization, 1985). However, the scientific activities of the nursing discipline have focused almost exclusively on the ill individual without consideration of the effect on family members. This deficiency led Barnard (1980) to question whether nursing had made the family as client tenet a reality.

> The importance of the family in health care delivery has not been properly recognized; this lack of recognition must be remedied if we are to provide quality health care with limited professional resources. Although nursing espouses family-centered care, the lack of scientific literature in this area leads me to believe that family-centered care is not widespread reality (p. 210).

Others have questioned the atheoretical nature of nursing research relative to the family. For instance, Feetham's (1984) review of nursing research on families indicates that the majority of studies are not based on theoretical or conceptual models.

Additionally nurse theorists who have attempted to articulate the philosophy and goals of nursing in theory have focused primarily on the individual without consideration of other family members (i.e. Abdellah, Beland, Martin & Matheny, 1961; Wiedenbach, 1964). Only recently have nurse theorists began to broaden their frameworks to include other members of the family (King, 1971, 1981; Rogers 1970; Travelbee, 1971). Hence, the nursing profession espouses and recognizes the importance of a family focus in the prevention of illness and promotion of health but exploration of the theoretical base necessary to implement the tenet has just recently begun.

The present study provided for the development of substantive theory relative to the social and psychological processes used by spouses of heart transplant

candidates during the waiting period. Spouses were chosen in that there is evidence to suggest spouse's ability to care for an ill partner not only influences the health and functioning of the family (Olsen, 1970; Runions, 1985), but also the patient's long-term physical and emotional well being (Bedsworth & Molen, 1982; Chatham, 1978). Additionally, empirical evidence exists indicating spouses are particularly negatively affected by the emotional strain of an illness of a partner (Bedsworth, & Molen, 1982; Caplin & Sexton, 1988; Croog & Fitzgerald, 1978; Mayou, Foster, & Williamson, 1978; and Stern & Pascale 1979).

The significance of the research to nursing practice will ultimately be determined by its utility and relevance to clinical situations (Glaser & Strauss, 1967). Nurses in clinical practice may be able to use the results as a guide in assisting persons involved in the substantive area of interest. As previously indicated evidence suggests that the waiting period prior to heart transplantation is the most stressful time for the family and threatens its very integrity. Gaining insight into the social and psychological processes used by spouses during this time enables interventions to be developed and implemented. The development of secondary problems can then be prevented as the spouse and family members proceed through the transplant and convalescence phases.

Additionally, the research will provide for dialogue among nurse scientists, theorists, and clinicians concerning the importance of the findings to this area of human health. For example, nurse clinicians can use the study results as a guide in responding to family members of heart transplant candidates. Therefore, the findings may enhance the nurse's ability to be a significant resource. Likewise, the clinician

can evaluate and validate the knowledge generated by the nurse scientist and nurse theorist for its soundness and transferability to other appropriate clinical situations.

The Purpose of the Study and the Research Questions

The purpose of this research was to identify, describe and provide a theoretical analysis of the psychological and social processes used by spouses of heart transplant candidates during the waiting period. The specific aim was to generate substantive theory systematically and inductively from the data.

The research focused on the following research questions: 1) What are the psychological and social processes used by spouses of heart transplant candidates during the waiting period prior to transplantation? 2) What are the intervening conditions facilitating or constraining the psychological and social processes discovered?

Summary

This first chapter has described the evolution of heart transplantation to its present state of acceptance as a therapeutic intervention for end-stage heart disease. Evidence was provided for the need of inquiry into family members and particularly spouse response to the waiting period prior to heart transplantation. The chapter concluded with specification of the study's purpose and research questions.

CHAPTER 2

THEORETICAL CONTEXT

The theoretical context of the present investigation encompasses only the substantive area of interest. The grounded theory methodology, used in the present research, allows for the theory to unfold during the course of the research process, rather than basing the research on pre-existing logically deduced theory. Inherent in the generation of the theory is the maintenance of theoretical sensitivity or openness throughout the inquiry allowing for theoretical insights (Glaser & Strauss, 1967). Glaser and Strauss (1967), suggest that the initial step to ensure theoretical sensitivity is for the investigator to enter the research setting with as few preconceived ideas or commitment to theories as possible, particularly theories that have been logically deduced. Limiting review of pre-existing ideas and theories assisted the investigator to remain open and questioning as the theory unfolded. The substantive context will be organized into three sections. First, a description of the typical heart transplant recipient is described. The acceptance protocol into a transplant program is then addressed. The chapter concludes with a description of the waiting period from the candidate and candidate's family members' point of view.

Heart Transplant Recipients

The descriptive overview of heart transplant recipients, is provided by data primarily from the Registry of the International Society for Heart Transplantation (ISHT) (Kriett & Kaye, 1990). The registry has compiled data on over 12,600

patients worldwide from 1967 to December 31, 1989. Where needed, the data were supplemented from results of the National Transplant Study (NHTS) (Evans et al., 1984). The NHTS utilizes data from six heart transplant centers which comprised 75% of all transplant procedures ever performed in the United States from 1968-1983.

According to the ISHT (Kriett & Kaye, 1990), cardiomyopathy and coronary artery disease are the two leading indications for heart transplantation accounting for 49% and 41% respectively. Cardiomyopathy is myocardial disease often of unknown etiology which necessitates transplantation due to irreversible left ventricular failure. Cardiac transplantation may be necessary in patients with coronary artery disease who cannot benefit from bypass surgery or other procedures because of extensive vessel involvement and intractable angina, or who have untreatable heart failure because of loss of muscle through repeated infarction. Other indications for heart transplantation include the following: Congenital heart disease, valvular disease, and retransplantation.

The average age for patients undergoing heart transplantation is presently 44 years of age with a range in ages from newborn to 78 years. Most adult and pediatric heart transplant recipients are male, 83% and 62% respectively (Kriett & Kaye, 1990). According to the NHTS the racial distribution of recipients in the United States, clearly indicates that the vast majority of recipients are white (91.4%) with Blacks being the second most frequent race receiving heart transplants (3.9%). The distribution of recipients according to their marital status at the time of evaluation, indicates that the majority are married (71.2%) (Evans et al., 1984).

The data of the NHTS indicate that heart transplant recipients, on the whole, are well educated. To summarize, 11.2% have received advanced college degrees, 21.7% have received a college or university degree, 56.6% have received a high school diploma. Only 10.5% of the recipients have never graduated from high school (Evans et al., 1984). In conclusion, the majority of heart transplant recipients are white, well-educated married men approximately 44 years of age.

Selection of Recipients for Heart Transplantation

Selection of recipients for heart transplantation has received much ongoing attention since the first heart transplant over 20 years ago. The attention is warranted in that selection may be the most important determinant of long term survival (Copeland et al., 1987). However, such decisions remain difficult and controversial.

During the 1960's and early 1970's a patient was considered for heart transplantation only if death was imminent within a matter of weeks. Then in the mid 1970's a generally accepted set of criteria evolved which emulated the Stanford selection protocol as they were recognized leaders in pioneering heart transplant surgery and patient management (Evans et al., 1984). The Stanford protocol specified age, functional class, emotional stability, family support as well as the absence of severe pulmonary hypertension and other specified systemic diseases (Evans et al., 1984) (see Appendix A for specific criteria). Now, with the maturing of the procedure, selection criteria have broadened with institutional variation relative to age, functional status, and excluding systemic illnesses (Copeland et al., 1987).

The typical procedure for acceptance into a transplant program is as follows. Patients can be referred to a transplant program in one of several ways, and their evaluation may vary in extent. For instance, initial screening of a potential transplant candidate is usually done by the referring physician who either calls the transplant program and describes the details of the patient's case; or the physician may transfer the patient's medical and psychosocial history to the cardiovascular surgeon at the transplant center for review. The objective of the preliminary review is to identify patients who warrant further evaluation. After reviewing the materials from the referring physician the transplant team then decides whether or not the patient is a candidate for a complete evaluation. If a complete evaluation is deemed appropriate, then the potential candidate travels to the transplant center for an extensive medical, psychosocial and financial evaluation. The evaluation process is designed to assess the patient's chances for surviving heart replacement and achieving a quality rehabilitation. Additionally, the evaluation period enables the transplant team to share adequate information to allow the patient and family members to make an informed decision about whether to proceed with the surgery. Inherent, in the informed decision is that the patient must be provided with an understanding of the risks, limitations and benefits of the transplant as well as the ongoing medical regimen required during and after the transplant process (Christopherson, 1987). Following the evaluation a decision is made to accept or reject the patient as an transplant candidate. Patients who are accepted as candidates must then wait for the identification of a suitable heart donor. In a few rare cases during the waiting period,

the candidate's heart status and health may improve to such an extent that he/she is no longer considered a candidate. Another more common possibility is that the candidate may die before a suitable donor is identified.

The Waiting Period

The waiting period is perhaps the most stressful time for the recipient and family member of the entire transplant process. The stress of this time has been accentuated recently as the waiting times have increased dramatically for a number of reasons. Improvements in immunosuppressive treatment and proliferation of transplant centers have led to a more rapid increase in the number of transplant candidates compared to the number of available donors. In the United States, the number of transplant centers has increased from 79 in 1986 to 148 in 1989 and the centers outside the United States have increased from 36 to 88 during the same time period (Fragomeni & Kaye, 1988; Kriett & Kaye, 1990).

The typical scenario of a recipient and family members during the waiting period can be described in the following manner. Acceptance as a transplant candidate brings to a vivid reality the notion that no other medical options are available except heart transplantation. The possibility of death is brought clearly into focus as the patient experiences increased frequency and severity of symptoms and wonders if a donor heart will be found before death occurs. Since the family can do nothing to influence organ availability, the only alternative is to maintain the patient's condition so that death can be avoided. Mishel and Murdaugh (1987) describe

families as "immersing" and "freeing themselves" (p. 334) during this time so that all efforts can be directed toward keeping the patient alive. They describe "life as being on hold, with no roots, commitment or involvement with anything other than the patient" (p. 334). Family systems are often disrupted which means alteration of priorities and reassignment of roles and responsibilities. For instance, families may move, terminate jobs, and relocate to a temporary home near the hospital. Spouses and families often find themselves taking on the roles and responsibilities performed by the patient prior to the illness. Other responsibilities such as child care may be shifted to grandparents or aunts and uncles (Mishel & Murdaugh, 1987). Patients and families must deal concomitantly with both the possibility of the patient's death and the patient's survival (Christopherson, 1976).

Summary

In Chapter Two, three theoretical context headings related to heart transplantation were discussed. First, the transplant recipient was described. The acceptance protocol for heart transplantation was next addressed. The chapter concluded with a description of the waiting period from the recipient and family perspective.

CHAPTER 3

METHODOLOGY

The methodology is described in three sections. The first section introduces the grounded theory methodology and includes discussion of its background, nature, and its appropriateness to the research questions posed in Chapter One. The second section specifies the procedures of the grounded theory methodology used in the study and is organized under the following headings: sampling procedures, data collection methods and respondent characteristics, and data analysis procedures. The third section addresses issues related to the grounded theory methodology including maintenance of theoretical sensitivity and the establishment of trustworthiness including credibility, transferability, dependability, and confirmability.

Introduction to the Grounded Theory Methodology

Background of the Grounded Theory Methodology

Although the grounded theory methodology was first described by two sociologists, Glaser and Strauss, the historical roots are in nursing. With the establishment of the Doctor of Nursing Science Program at the University of California at San Francisco, a cadre of sociologists were employed to help facilitate and guide nurses in their research. Among those chosen were Barney G. Glaser from Columbia University and Anselm Strauss from the University of Chicago. Shortly after their arrival, they obtained a Public Health Service Research Grant from the Division of Nursing to study patients who were dying in hospitals. As Glaser and

Strauss conducted the study, they realized that their method of research involved a new approach to scientific investigation. The method brought together the two worlds of quantitative and qualitative research to provide a clearer picture of reality than either method could do singularly (Glaser & Strauss, 1967; Stern, Allen, & Moxley, 1984). The method, called grounded theory, has been explicated in three classical texts which have become the authoritative sources. The three texts The Discovery of Grounded Theory: Strategies for Qualitative Research (Glaser & Strauss, 1967); Theoretical Sensitivity (Glaser, 1978); and Basics of Qualitative Research: Grounded Theory Procedures and Techniques (Strauss & Corbin, 1990) provide the basis for the outlined methodology of the study. Also, recently, nurse scholars have outlined the use and processes of grounded theory for the discipline of nursing (Chenitz & Swanson, 1986; Morse, 1989; Stern, 1980; Stern, Allen & Moxley, 1984). These published manuscripts were also utilized.

Nature of the Grounded Theory Methodology

Grounded theory methodology is a systematic research approach for the collection and analysis of qualitative data designed to discover basic patterns of social life. The purpose of the methodology is to generate explanatory theory that is inductively derived from the data, i.e. grounded in the data. The ultimate goal of the theory is to provide understanding of social and psychological phenomena.

In grounded theory generation, multiple aspects of a phenomenon are integrated into a logical and understandable whole. The major units of analysis of

grounded theory are categories and their properties. The theory evolves as categories are linked together. The central or core category, usually a process, appears late in the analysis and accounts for most of the variation in the pattern of behavior. This central or core category forms the main theme around which the other categories and their properties revolve. The core category has the prime function of "integrating the theory and rendering the theory dense and saturated as the relationships increase" (Glaser, 1978 p. 93).

Appropriateness of the Grounded Theory Methodology For the Research Questions

Two aspects are important to consider in determining the appropriateness of the grounded theory method for the research questions: (1) the phenomenon and (2) the fit and contribution of the methodology for nursing. Two areas were considered in evaluating the appropriateness of the methodology relative to the phenomenon: (1) the "state of the art" of the phenomenon and (2) the nature of the phenomenon.

With regards to the "state of the art" theory development describing the effect of heart transplantation on family members particularly during the waiting period is in its initial stages of development. The limited research that is available identifies and describes the waiting period as stressful for both the candidate and family members. However, none of the studies except the work of Mishel and Murdaugh (1987) attempt to describe the processes used by candidates and family members during the waiting period. The lack of a theoretical description of family member's experience

during the waiting period makes an exploratory design seem most appropriate to answer the research questions (Hinshaw, 1979).

Several types of exploratory designs are appropriate when little information is available. However, none except the grounded theory methodology enables one to generate theory. In addition, grounded theory methodology aligns itself to the research questions and nature of the phenomenon of study. The investigator desired to discover, identify and describe the psychological and social processes used by spouses of heart transplant candidates during the waiting period as well as the intervening conditions associated with the processes. Based on the purpose, the grounded theory methodology, which is specifically designed to discover social and psychological processes, was well suited to answer the research questions. Several key features of the grounded theory methodology further illuminate the method's unique suitability. For instance, considering the complexity of the experience during the waiting period, the grounded theory methodology allowed for the discovery of the process over time. Additionally, the methodology provided for various perspectives of spouses as they experienced the waiting period.

In selecting a methodology to answer the research questions one needs not only a fit between the research question(s) and methodology but also the selection of a methodology that will maximally contribute to the discipline of nursing. Of the various exploratory designs that could be used to study the research questions the grounded theory methodology was most likely to provide significant contribution.

Grounded theory allows for theory discovery which is grounded in the data and derived from the practice area.

The inherent importance of theory generation to the development of the discipline of nursing is well established (Benoliel, 1977; Carper, 1978; Donaldson & Crowley, 1978; Feldman, 1981; Hurley, 1979). In fact some scholars suggest the development of theory is the most important task currently facing the profession (Chinn & Jacobs, 1978). Nursing must generate theory that is unique to nursing and theory that is linked closely to the practice of nursing (Dickoff, James & Wiedenbach, 1968; Jacobs & Huether, 1978; Jacox, 1974; Wald & Leonard, 1964; Wooldridge, Schmitt, Skipper, & Leonard, 1983). Such a belief prompted Dickoff, James, and Wiedenbach (1968) to suggest the mutually interrelatedness and interdependency of nursing theory, nursing practice and nursing research by stating that "theory is born in practice, is refined in research, and must and can be returned to practice." (p. 41). Jacobs and Huether (1978) further caution that theory constructed without earnest consideration of practice will pose a questionable relationship to practice and practice without theory will be practice carried out intuitively. A methodology that allows for generation of theory closely linked to practice is important to the enhancement of the nursing discipline. Glaser and Strauss (1967) suggest that theory discovered from the grounded theory method is most likely to be relevant to the substantive area of interest in that it will "fit the situation being researched" and "work when put to use" (p. 3). Their idea is based on the notion that the theory is generated and grounded systematically from research data derived from the natural (practice) setting.

In summary, a grounded theory methodology was selected to answer the proposed research questions. The method enables discovery of process and the generation of theory that is "practice" oriented in nature. In particular, the methodology guided the discovery of the processes used by spouses of heart transplant candidates during the waiting period.

Specification of Procedures

The grounded theory methodology combines several processes which occur concurrently rather than following a series of linear steps. The methodological section will be organized to depict the design used in the study: Sampling, data collection procedures, and data analysis plans.

Sampling Procedures

Theoretical sampling guided the sampling procedures of the research. Simultaneous collection, coding and analysis of the data were used to determine future sampling direction. Sampling decisions were not made a priori, but rather were guided throughout the inquiry by the presenting theory (Glaser & Strauss, 1967).

Initial sampling of data began with interviews of spouses of candidates waiting for heart transplants. Two sampling criteria were used to select respondents. First a respondent had to be a spouse of a heart transplant candidate/recipient who was either waiting for the partner to undergo heart transplantation or who had already experienced the waiting period. Second, respondents had to speak English. At first broad general questions were asked in an attempt to identify processes that were used

during the waiting period (see Appendix B). As categories, properties, and hypotheses about the nature of the relationship between categories and properties began to develop questions became more focused to "densify" the categories (Chenitz & Swanson, 1986) and verify emanating hypotheses. In addition non-respondent sources of data were sampled. The non-respondent data included both scientific and lay literature, newspaper articles, and media presentations. Non-respondent data sources were also sampled purposefully and theoretically.

As the study proceeded several methodological challenges effecting theoretical sampling evolved. Two challenges of special significance were the lack of available data sources, and the multiplicity of variables that were theoretically relevant. Sample limitations are generally inherent in most inquiries. However in this study, respondents who met the sampling criteria were not always available. Difficulties were encountered in obtaining adequate numbers of respondents who represented the various intervening conditions such as relocating versus not relocating, heavy child care responsibilities versus no child care responsibilities, and perceived significant social support versus minimal or inadequate social support.

At the end of each interview, several hypotheses and intervening conditions were identified that appeared most relevant to sample. For example, after interviewing the first spouse who was in her 60's, the investigator hypothesized that the intensity of the response was less with this respondent than with younger spouses. The spouse's partner was physically stable at the time of the interview. The investigator was unsure if the lessened intensity was due to the older age of the

spouse or the stability of the candidate. Following the interview with the sixty year old spouse it was determined future data sampling should include respondents of varying ages with different levels of physical stability to determine the role of stability and age in relation to response. Hypotheses that needed to be explored were: (1) As stability of the candidate decreases the intensity of the response increases, and (2) The older the spouse the less intense the response. Early in the study, there was some flexibility in obtaining respondents from which data could be sampled. That is, due to myriad of codes and intervening conditions that seemed to have relevance to the unfolding theory, the limited sample pool could be re-interviewed to further develop the evolving theory. As the study proceeded and the focus became more limited, obtaining appropriate respondents from which to sample relevant data became more problematic. Often the investigator had to wait a period of time to properly theoretically sample. Thus, theoretical sampling did not always proceed in a linear fashion; rather the investigator attempted to match groups of data sampling needs from the presenting theory with the limited respondent pool.

Data Collection Procedures and Respondent Characteristics

Data for the present research were collected from both respondent and non-respondent sources. Sources of data included interviews, observations, newspaper and media presentations, and relevant literature. The various "slices" of data gave the investigator different views or vantage points from which to understand the categories, related properties, and relevant relationships (Glaser, 1978; Glaser & Strauss, 1967). The procedures for data collection for both respondent and non-

respondent sources will be described. First, respondent characteristics and data collection procedures for respondents will be presented. The discussion will be followed by procedures for non-respondent data collection.

Nineteen interactive interviews were completed on sixteen spouses of heart transplant candidates/recipients who were waiting or had just recently received a transplant (see Tables 1 and 2). The respondents included fifteen female spouses and one male spouse. The mean age of the spouses was 50 years old, with ages ranging from 34-64 years of age. All spouses were white and most had at least a high school education. Most spouses had children with the ages ranging from four to forty-six years of age. Occupations of spouses included housewife, telephone operator, secretary, play ground supervisor, teacher's aide, waitress, dog groomer, broker, and pipeline constructionist. The economic status of the families ranged from annual income categories of 3,000-4999 dollars to above 50,000 dollars yearly.
yearly. Ten (62%) of the sixteen spouses had relocated with the candidates. One spouse chose to remain at home although the candidate relocated. The spouse visited every few weeks. All except one spouse saw the relocation as temporary. Spouses and families relocated from nine different states. The majority had relocated from the western United States although a few were from the mid-west and one relocated from as far east as New York state. At the time of the interview the number of days waited for the transplant ranged from five to 332 days ($\bar{x}$=56.375; S.D.= 82.60). Two of the interviews were done within days after the candidate was transplanted and

Table 1. Demographic Characteristics of Respondents

Respondent	Sex	Age	Race	Years of Education Completed	Occupation	Family annual income
1	F	50	white	13	Housewife	30,000 - 49,999
2	F	48	white	12	Telephone operator	30,000 - 49,999
3	F	49	white	14	Secretary	30,000 - 49,999
4	F	41	white	12	Playground supervisor	30,000 - 49,999
5	F	47	white	16	Teacher's Aide	20,000 - 29,000
6	F	43	white	18	Housewife	50,000 - more
7	F	50	white	11	Housewife	5,000 - 9,999
8	F	64	white	12	Housewife	30,000 - 49,999
9	F	57	white	12	Banking receptionist	20,000 - 29,000
10	F	34	white	11	Waitress	20,000 - 29,000
11	F	58	white	18	Broker	30,000 - 49,000
12	F	60	white	12	Housewife	10,000 - 14,999
13	F	50	white	13	Housewife	3,000 - 4,999
14	M	50	white	12	Pipe constructionist	20,000 - 29,000
15	F	45	white	12	Dog groomer	15,000 - 19,000
16	F	57	white	12	Housewife	10,000 - 14,999

Table 2. Relevant Respondent Characteristics

Respondent	Children and Ages	Relocated	Days waited at time of interview
1*	27, 26, 24, 10, 9	Spouse did not but candidate did	First interview 28 days; second interview 63 days
2	26, 23, 18, 13	yes	25 days
3	29, 26, 24	no	Interviewed 1 day after transplant - waited total 14 days
4*	None: Two children from candidates previous marriage	yes	First interview 77 days; second interview 31 days after transplant
5	28, 26, 9	no	125 days
6	20, 16, 15, 13, 10	yes	7 days
7	32, 31, 29, 27, 25, 23, 21	yes	11 days
8	46, 39, 35	yes	9 days
9	40, 38, 36, 28	yes	23 days
10	16, 14, 4	no	14 days
11	none	yes	5 days
12*	37, 33	yes	First interview 10 days; second interview 4 days after transplant
13	30, 29, 20, 19	yes	35 days
14	25, 23	no	Interviewed 2 days after transplant; waited a total of 95 days
15	24, 20, 13, 10	yes	Interviewed 3 days after transplant; waited a total of 92 days
16	38, 36, 35, 33, 27, 24	no	332 days

*Two interviews done

two of the repeat interviews were done several days after transplantation. The remainder of the interviews were conducted during the waiting period.

Potential respondents were obtained by contacting the transplant coordinators from two hospitals. Respondents were selected based on their theoretical relevance to the developing theory. Initial contact with the respondents was usually made by telephone. The study was explained and interview arrangements were made. The interviews were conducted in an area selected by the respondent. All respondents chose to be interviewed in a private office at one of two hospitals. Prior to beginning the interview, informed consent was obtained (see Appendix C). The purpose of the interview was to obtain a description of the respondent's experiences and to elicit "rich, detailed materials," (Lofland & Lofland, 1984, p. 12). Throughout the study, the interview questions moved from general to specific. A list of the initial interview questions for the study are presented in Appendix B. At the onset of the study, the questions served only as a guide for the interviews. The use of the questions in this manner helped to maintain theoretical sensitivity and prevent forcing patterns on the data. As patterns were discovered in the data the questions became more focused in order to densify the categories, properties and to verify emerging hypotheses. At the end of each interview, selected demographic information was obtained from the respondent. The demographic information assisted in identifying relevant intervening conditions which could influence the unfolding theory.

The entire interview was audiotaped after permission was received from the respondent. Within several days of the interview, each tape was reviewed by the

investigator. Listening to the tapes allowed for memoing significant impressions of non-verbal behavior displayed during the interview. Additionally missing data such as words that were not audible due to mechanical difficulty in taping were recalled and inserted before they were forgotten.

After the investigator had listened to the tapes, the tapes were transcribed by a transcriptionist skilled in processing audiotaped data. In the process of transcription, all names were changed to initials to maintain confidentiality. Additionally the tapes were identified by number. When the tapes had been transcribed, the tape was again reviewed simultaneously while reading the transcript to detect errors. Corrections were made and the audiotapes were erased. The transcripts were then formatted for analysis of the data. The formatting involved large margins with each line being numbered using the Ethnograph computer software program. Two copies of each transcription were made, one for data analysis and the other was saved in a permanent file.

Adherence to the above outlined procedures was strictly maintained to ensure protection of human subjects and to assure the quality of the data collected. The research project was reviewed and approved as exempt from the University review by the College of Nursing Ethical Review Subcommittee of the University of Arizona Human Subjects Committee (see Appendix D). Additionally the project was reviewed and approved by both Institutional Review Boards at the two institutions from which respondents were obtained.

Data collected from sources other than respondents, was also selected based on the developing theory. Non-respondent data were collected as necessary to saturate categories, identify properties, and to elaborate, integrate, and densify the theory. Initially, non-technical literature supplemented the interviews. For instance, the investigator found it helpful to study the historical evolution of heart transplantation through use of books, newspaper writings, and other materials. Books such as Barnard and Pepper's (1969) One Life, and Fox and Swazey's (1974) The Courage to Fail were most helpful in understanding the historical development and sociological perspective of heart transplantation. Also, Hawthorne's The Transplanted Heart (1968) provided valuable insights into heart transplantation from a physician's perspective. The book describes what it was like becoming a cardiovascular surgeon, training to perform heart transplants, and then performing transplants on a routine basis. The book also has description of individual patients and their families who were experiencing heart transplantation. Local media and newspaper clippings were also reviewed to more clearly understand the local context in which heart transplants were being done. As the processes used by spouses during the waiting period began to be identified non-respondent data sampling became more focused. Attempts were made to find written reports by individuals who were experiencing the process. There was basicaliy a dearth of materials in this area. The investigator began to focus on writings by family members who experienced what might be considered similar life threatening experiences such as cancer and other cardiac conditions.

Books such as Stichman and Schoenberg's (1974) How to Survive Your Husband's Heart Attack were helpful in identifying if the experiences were similar.

As the categories, properties, and hypotheses were generated, the technical literature was reviewed. Scientific literature was selected in areas that were significant to the presenting theory. Conceptual perspectives in the literature that were relevant included stress, families experiencing illness and crisis, uncertainty, and life threatening response behavior. Review of the literature in these conceptual areas densified the categories and properties and assisted in maintaining theoretical sensitivity.

Data Analysis Plan

In grounded theory, data analysis is a complex process of reducing raw data into concepts that are designed to represent categories which are then integrated into a theory. Data analysis is interactive with data collection. The primary method of data analysis is called the constant comparative analysis method. In the discovery of grounded theory, the constant comparative analysis method is used conjointly with theoretical sampling. The following discussion describes how constant comparative analysis was used to allow for the generation of the theory. For organizational purposes, the discussion will be divided into three procedural sections: Coding, memoing, and theoretical sorting.

Coding

According to Glaser (1978) open coding allows the investigator to transcend the empirical level of the data by breaking down the data, then conceptually grouping it into categories that become the theory. Coding began by fracturing the data (Phillips & Rempusheski, 1986). The interview or other data source was read line by line and partitioned into relevant phrases, sentences or passages of interest. In the margin of the data source, next to the partitioned data, substantive codes were identified which reflected the basic ideas of what people said or did. Over 450 pages of data sources were analyzed resulting in approximately 275 different substantive codes. Data bits were then incorporated into memos which allowed for theorizing about the coded data and for comparing it to other similar and dissimilar coded data bits. Additionally the memoing directed further sampling.

Initially open coding was used, where data was coded in every possible way. Open coding proliferated the codes rapidly and guided further theoretical sampling (Glaser, 1978). Categories were formed as codes were compared and similar codes clustered. Ongoing data collection and analysis produced more categories, recoding of categories and in some cases the combination of two or more categories. As theoretical properties were discovered by ongoing comparative analysis the investigator identified various aspects of the category including its dimensions, the conditions under which it was accentuated or minimized, its major consequences and its relation to other categories (Glaser & Strauss, 1967).

Eventually the investigator analyzed the data for patterns of relationships between two or more categories and their properties. These patterns of relationship allowed for the development of initial hypotheses which were then tested by incoming data. Substantive codes were then compared to a family of theoretical codes which best represented the nature of the relationship (Glaser, 1978). The theoretical family codes of process, consequence and dimension appeared most relevant in describing the relationships between categories in this study. These theoretical codes provided order to the relationships between categories facilitating the discovery of the theory. Relationships between categories continued to evolve until a pattern among the relationships was conceptualized. Hypotheses about the categories were generated from the patterns and tested with the data.

When the investigator had compared the data sufficiently to delimit the theory to one core category (i.e. Life on Hold), open coding ceased and selective coding began (Glaser, 1978). Coding was then limited only to those categories that related to the core category in a significant way. Data collection continued until no new conceptualizations were added to the core category or related categories.

Memoing

According to Glaser (1978) the "core" in the process of generating theory using the grounded theory methodology is writing theoretical memos. Memos are the written recordings of theoretical ideas about codes and their relationships as they

strike the investigator during the inquiry process (Glaser, 1978). They allow for abstraction and conceptualization the empirical data.

Memo writing was initiated at the beginning of the inquiry and continued throughout the entire study. Each memo was entered into a computer program and identified by number, date, related source (i.e. tape number) and topic which was usually a code, category, property, intervening condition or relationship. Also, a summarized statement of the scenario that triggered the memo was included. As the memo procedure evolved, the investigator began to incorporate the data bits into the memo. This procedure allowed for ease of comparison of other incoming data bits as well as modification of the findings as new insights occurred. The format of the memos provided for efficient sorting (Glaser, 1978). During the study, theoretical insights frequently occurred and the investigator did not always have a computer available for recording the insight. The investigator always kept paper and a pencil available to record the new finding. Later when a computer was available, the memo was recorded in its entirety. As the study proceeded, memoing slowed the investigator's pace and facilitated integration and verification of categories and provided for assuring fit and relevance (Glaser, 1978). Memoing also helped clarify unclear and confusing theoretical thinking. Additionally, memoing, frequently produced enlightenment in areas about which the investigator was not currently memoing. Even though memoing was often tedious, the investigator looked forward to the process because of the tremendous insights gained.

Theoretical sorting

Theoretical sorting of memos is the impetus to formulate the theory in a way that others may understand the phenomena. Sorting is the process of putting the fractured data back together at a conceptual level. The sorting of theoretical memos is essential to the development of a dense, complex and well integrated theory that is multi-relational and multivariate. The desired outcome of theoretical sorting of memos is to organize the memos in a theoretical outline in preparation for the writing stage.

Theoretical sorting began when the interviews were near completion and the categories were almost saturated (Glaser, 1978). Theoretical sorting was guided by how the memos related to the core category of "Life on Hold." Sorting took place at two levels, first by stage and then within the stage. Sorting by stage was done by placing memos into one of the two distinct theoretical stages, "Freeing Self" or "Making Life the Transplant". Sorting proceeded within the two stages by segregating memos into categories, properties, and connections between categories and properties.

After this initial theoretical sorting, the investigator formulated an outline. The investigator constantly moved back and forth between the memos and the outline so that as much as possible there was a fit of categories, subcategories and properties. Movement between the outline and memos provided a powerful corrective function. As the process continued, theoretical decisions about the preferable location of a particular memo was based on grounding the idea in the data. The process of sorting

stimulated fruitful new insights which were memoed. Sorting ceased when the investigator could explain the greatest scope parsimoniously, and with as much variation as possible (Glaser, 1978).

Issues Related to the Grounded Theory Methodology

The Maintenance of Theoretical Sensitivity

The investigator who uses the grounded theory methodology must maintain theoretical sensitivity or openness to the data throughout the inquiry to allow for theoretical insights (Glaser & Strauss, 1967). This sensitivity or awareness must be retained while the investigator continues to cope with conditions of life such as fatigue, cycling of motivation, life interests and other commitments and responsibilities. Glaser and Strauss (1967) have emphasized the focal position of theoretical sensitivity by indicating that "the root sources of all significant theorizing is the sensitive insights of the observer himself" (p. 251). Without attention to procedures for the maintenance of theoretical sensitivity, questions may arise as to how biases of the investigator were kept from skewing perceptions of the data. Four approaches were used to assist in maintaining theoretical sensitivity throughout the inquiry process. They include: (1) Limiting predetermined ideas and dealing with biases, (2) incorporating the investigator's skills into the research process, (3) ongoing literature review and (4) theoretical pacing.

Limiting Predetermined Ideas and Dealing With Biases

One strategy to assist in the maintenance of theoretical sensitivity is to enter the research setting with as few preconceived ideas as possible. Preconceived bias was a concern because the investigator had previous exposure to the phenomena of study. For example, the investigator worked with Dr. Carolyn Murdaugh and Dr. Merle Mishel as a Research Associate in their study of family response to the uncertainty of the heart transplant experience (Mishel & Murdaugh, 1987). The nature of this role was to assist in the establishment of trustworthiness (Lincoln & Guba, 1985) of their findings. Their transcripts were reviewed for data bits which supported their identified categories. Although the role was limited, the investigator had some preconceived ideas as to what might be found. For instance, the investigator believed that during the waiting period prior to transplantation all other options for life had been exhausted, and the magnitude of the focus on keeping the candidate alive would be intense. Mishel and Murdaugh (1987) termed this process "immersion". The investigator suspected that perhaps family members would be willing to do anything to provide the candidate the opportunity to receive the transplant and to maintain the candidate's life until the transplant became available. A second exposure to Mishel and Murdaugh's data (1987) came in preparation for the present study. A secondary data analysis on a portion of their data was conducted to practice some of the procedures involved in the grounded theory methodology (Glaser, 1978; Glaser & Strauss, 1967). The experience led the investigator to suspect that perhaps a central theme which explained other categories was "Life on

Hold". However, the finding was viewed cautiously because concurrent data sampling and analysis was not performed. It was difficult to verify hypotheses unless Mishel and Murdaugh had verified a similar hypothesis in the transcripts. It was impossible to theoretically sample because only available data were analyzed. Hence the investigator entered the research setting with preconceived ideas about what might be found.

Several steps were taken to handle biases of the preconceived ideas. As the investigator began the interviews with spouses, extreme caution was taken to allow the interviews to flow without probing in relationship to the preconceived ideas. However, amazingly early in the interview process similar themes found in Mishel and Murdaugh's (1987) data began to unfold. When the themes were heard great effort was exerted to review the data for grounding of the findings. Also, similar themes were reverified in future interviews. Notes of the verification were recorded in the form of trustworthiness notes. Additionally, an audit trail was established and an audit was conducted by an individual experienced in grounded theory methodology to help validate the identified categories and linkages based on the data.

Limiting the initial literature review to only the substantive area of interest prevented the development of logically deduced preconceived ideas. Initially, limiting the literature assisted the investigator to remain sensitive to the developing theory without filtering it through pre-existing hypotheses (Glaser, 1978; Glaser & Strauss, 1967).

Using the Investigator's Skills in the Research Process

The second approach in maintaining theoretical sensitivity was utilization of the investigator's skills. Glaser and Strauss (1967) suggest that theoretical sensitivity is "forever in continual development" (p. 46) and is cultivated in investigators as they think in theoretical terms about what they know. The background of the investigator, including educational and professional experiences helped to sensitize her in addressing broad questions and phenomena theoretically (Glaser, 1978). For instance, prior to beginning graduate education, the investigator was involved in nursing education for approximately eight years. A vital part of educating nursing students is helping them learn concepts from a variety of disciplines which are then used to plan and implement patient care. Also, in educating nurses great emphasis is placed on learning to set priorities, critically think, and effectively problem solve. Inherent in developing these skills is assisting students to think conceptually and relationally. Providing students with an environment to facilitate learning, facilitated the investigator's ability to think theoretically. Such experiences increased and expanded the investigator's own skills. This ability was further enhanced as the investigator studied intensely and indepth, concepts from nursing, sociology, psychology, and anthropology during her doctoral studies. These previously developed skills helped the investigator to think theoretically and remain sensitive to the evolving concepts during the theory generation process.

The Ongoing Literature Review

The third approach to ensure theoretical sensitivity was an ongoing literature review throughout the inquiry. Glaser (1978) suggests that sensitivity is increased by being "steeped in the literature that deals with both the kinds of variables and their associated general ideas" (p. 3). A unique feature of the grounded theory methodology is that the literature is searched throughout the study. However, to limit the development of predetermined ideas, initially the search encompassed only the substantive area of interest. As the study proceeded, readings were directed by the data and conceptualizations that evolved. Purposeful literature selection enabled the literature to become integrated into the theory. As the theory began to densify and categories saturate, the investigator found the need to intensify the literature search to maintain theoretical sensitivity.

Theoretical Pacing

The last approach used to facilitate theoretical sensitivity was theoretical pacing (Glaser, 1978). Glaser (1978) has suggested that the discovery of grounded theory takes time and is a "delayed action phenomenon" (p. 18). Theoretical sensitivity is maintained by pacing oneself to allow time to "grow with the data and its analysis... and to provide for the out-of awareness processing" (Glaser, 1978 p. 18). At the beginning of the study the investigator attempted to process the discovery of the theory in short segments of time such as two to three hour blocks because of the myriad of responsibilities and time commitments competing for her time. As time

progressed, the investigator became aware that such short periods of time were inadequate to establish theoretical sensitivity. The investigator reorganized her time commitments to remedy the problem so that she had six to eight hour time blocks once or twice a week. During intense analysis, time blocks were increased to six to twelve hours a day for a week. The investigator found that these lengthened times frames greatly enhanced her theoretical insights.

Establishing Trustworthiness

The last section addresses the specification of procedures used to establish the scientific merit or scientific adequacy or rigor of the study. Scientific adequacy and rigor in research is usually based on the degree to which reliability, validity, and objectivity are achieved. These concepts, however, are not applied easily to methodologies in the naturalistic framework such as grounded theory. However, comparable attempts to establish the scientific merit of studies using the naturalist framework have been suggested by Guba (1981), Guba and Lincoln (1981), and Lincoln and Guba (1985), and are based on the ability of the investigator to establish the trustworthiness of the data. They suggest four criteria to assess the rigor of qualitative investigations: credibility, transferability, dependability, and confirmability. The procedures used to meet these criteria are specified in the following discussion.

Credibility

Credibility refers to having confidence in the "truth" of the findings (Guba, 1981; Guba & Lincoln, 1985; Lincoln & Guba, 1985). Guba (1981) suggests nine methods to establish credibility. Four of the methods were appropriate for this study: Prolonged engagement, triangulation, peer debriefing, and member checks.

Prolonged engagement at the site was made possible by the long data-collection period. Data collection and analysis occurred over a nineteen month period.

Triangulation was accomplished by sampling different data sources which served to cross-check the data and interpretations (Denzin, 1978). Inherent features in the grounded theory methodology, facilitated the utilization of a variety of data sources. For instance, the constant comparative method provided for collection of data from respondent and non-respondent sources. This strategy was designed to minimize distortions from a single data source or a biased investigator and is a form of triangulation (Duffy, 1985). Data sources from scientific literature, lay books and articles, and mass media presentations were compared to the unfolding perspectives gained from respondent interviews to provide verification and support.

Peer debriefings involves exposing the investigator's thinking to a jury of peers and dealing with their responses (Guba, 1981). This process was put into effect by scheduled discussions and evaluations of the findings with the two transplant coordinators and two social workers at the two institutions from which respondents were obtained. These individuals worked closely with transplant candidates and

recipients and family members. They were most helpful in providing insights particularly in the area of intervening conditions that may have affected the observed differences in the process. At the completion of the study the investigator met with them again to review the generated theory and intervening conditions. They concurred with the findings. The generalized response was, "this is what happens, yes, yes".

Member checks are perhaps the most valued and crucial test in establishing credibility. This process was ongoing throughout the study, both informally and formally. As the conceptualizations were generated from the data, they were verified and appropriate modifications made based on input from the spouses. For instance, as categories, properties, relationships, and hypotheses were generated, ongoing informal verification was gathered until clarification on a particular item was obtained. The process of informal verification became more extensive and elaborate as the theory was generated. On a formal level, as the investigator began the final writing stages, two spouses were presented the model and asked for their comments. Again there was generalized consensus on the process and variation according to intervening conditions as expected. As one spouse whose partner had just been transplanted put it, "Exactly" (15).

Transferability

Transferability refers to the generalizability of the findings to other contexts. Guba (1981) suggests that transferability is dependent upon the degree of similarity or

fittingness between the two contexts for which generalization is to be made. Attempts are not made to generalize to all circumstances, but rather to formulate working hypotheses that may be transferred depending upon the degree of "fit" between contexts. Lincoln and Guba (1985) indicate that it is not the investigator's task to establish transferability, but rather it is their responsibility to provide the data base that makes transferability judgments possible for those wishing to apply the findings.

Several approaches were used to provide adequately "thick descriptions" so transferability could be judged. For instance, the process of theoretical sampling, maximized the range of information uncovered and helped provide a sufficient assessment base for determining relevance to other related contexts. Other strategies used to provide a "thick" descriptive data base were journal writings, transcribed interviews and memos which included a description of intervening conditions impinging on the process (Guba, 1981).

Dependability

Dependability refers to the stability of the results over time and trackability, of the results (Guba, 1981). Guba (1981) suggests the use of overlapping methods or the use of two research teams to establish dependability. However, neither of these approaches are appropriate for the grounded theory methodology. Instead, a third method, an audit was used to establish dependability.

Halpern's audit process as outlined by Lincoln and Guba (1985), was followed. Initially the auditor was chosen based on the desired characteristics

outlined by Lincoln and Guba (1985). The auditor was experienced in the grounded theory methodology. She had conducted several studies using the methodology and had guided students on thesis and dissertation studies that employed the methodology. She had some insights into the substantive area of study as she had conducted research in the area of caregiver burden. The investigator had confidence in the auditor's judgement based on her past research experience and personal attributes. The auditor had no vested interest in the study thus providing for objectivity. Additionally, the auditor was at a similar career position as the investigator which established an equal peer and power status. The auditor was provided a written copy of the proposed study followed by verbal explanation.

Both the investigator and auditor determined that the goals of the audit that were to establish dependability and confirmability. Mutual agreement was made on the materials necessary for the audit. Halpern's audit trail categories as described by Lincoln and Guba (1985) were used to establish appropriate records to facilitate the audit. Five of the six categories were used for the audit. They included raw data, data reduction and analysis products, data reconstruction and synthesis products, process notes, and materials relating to intentions and dispositions. The methods chosen to demonstrate the categories included (1) transcribed interviews; (2) a journal including daily occurrences, reflexive notes, and methodological decisions; (3) memo's reflecting conceptualizations and theoretical sampling; (4) audit notes reflecting the process of the audit; (5) trustworthiness notes specifying the methods and processes used to establish trustworthiness of the findings; and (6) files of non-

respondent data sources including related articles, newspaper clippings, and media presentations. After the above outlined process was completed, the investigator and auditor again met following several interviews to determine if the identified methods were sufficiently detailed and provided an audit trail. The materials were then not shared with the auditor until the study was completed to minimize the possibility of the auditor becoming coopted (Lincoln and Guba, 1985). The audit was then conducted.

Dependability was established with the audit trail materials by addressing the following questions: (1) Are the inquiry decisions and methodological shifts identified, explicated, and supported? (2) Considering the investigators biases has the investigator resisted early closure, explored all reasonable areas, resisted influence by client interest or deadlines, and sought negative as well as positive cases? (3) Are the sampling decisions and triangulation processes appropriate? (4) Is there evidence of premature judgments or being coopted? (5) Is the overall design appropriate? Are instabilities noted? (6) Has the study be influenced by Pygmalion or Hawthorne effects? (7) Is the level of investigator's sophistication adequate? See the letter in Appendix E attesting to the dependability of the study.

Confirmability

Confirmability refers to the objectivity of the data and whether the data can be substantiated (Lincoln & Guba, 1985). The major technique for establishing confirmability is an audit (Lincoln & Guba, 1985). The process of the audit has been

discussed under establishing dependability. Questions used by the auditor to determine confirmability were: (1) Are the findings grounded in the data? (2) Are the inferences based on the data and logical? (3) Does the category structure have utility based on its clarity, explanatory power, and fit to the data? (4) What was the degree and incidence of investigator bias? (5) Did the investigator use accommodating strategies to ensure confirmability such as triangulation? See Appendix E attesting to the presence of confirmability.

Two other techniques suggested by Guba (1981), triangulation and practicing reflexivity, were also used to establish confirmability. Triangulation has previously been addressed. Reflexivity was accomplished through the use of memos previously discussed and a journal where regular entries were made. The journal enabled the investigator to assess the extent to which her biases influenced the outcomes (Lincoln & Guba, 1985).

Summary

The methodology used in the proposed research has been described. A thorough explication of the procedures followed which included: sampling, data collection and data analysis procedures. In addition, maintenance of theoretical sensitivity and establishing trustworthiness were discussed in terms of credibility, transferability, dependability, and confirmability.

CHAPTER 4

THE GROUNDED THEORY

Chapter Four provides a description of the grounded theory generated by the research. The chapter begins with a description of the basic social psychological process (BSPP) discovered from the data. The description is followed by identification of the stages (Glaser, 1978) of the BSPP along with the subcategories, their properties and relationships. The chapter ends with a discussion of the intervening conditions which act to facilitate or constrain the phenomena (Strauss & Corbin, 1990). Data bits will be used to substantiate the description of the theory.

Life on Hold

The basic social psychological process and core category that explains spouses' responses during the waiting period prior to heart transplantation is "Life on Hold." The waiting period includes the time from acceptance into a transplant program until the candidate is transplanted. The process refers to the cognitive and behavioral responses that occur in the spouse during the waiting period. Life on Hold is the process of "tabling" life's activities for an indefinite period of time in order to devote one's life to another person or event. Spouses of heart transplant candidates, set aside life's activities and focus all thoughts, actions, and energy on maintaining the life of the candidate until a donor heart is obtained. Corbin and Strauss (1984) also found that couples attempting to manage chronic illness often dramatically changed their "biographical scheme" or life course. Prior to the illness each partner had some

biographical scheme for achieving their dreams, both individual and mutual, which is set aside or altered as needed (Corbin & Strauss, 1984). When candidates are accepted into a transplant program, generally all other options have been exhausted. Receiving a heart transplant is the last hope for life. The candidate and spouse are constantly faced with the uncertainties of whether the heart will become available before the candidate's condition deteriorates and death ensues. During the waiting period the candidate and spouse can do nothing to effect organ availability. Hence, all efforts are directed towards the candidate to maintain life until the donor heart arrives.

Life's activities, responsibilities and future plans are put on hold until the transplant. One spouse said, "Like I said, we've canceled Christmas because I just can't get my mind to go on Christmas. To me M.'s heart transplant is it right now" (7). Another spouse whose husband had just been transplanted within days said, "Our life was on hold, now it is on go" (12A). During the waiting period the spouse's life is in limbo resulting in the inability to do any futuristic planning. The spouse is unable to make long term plans until they know the physical outcome of the candidate. That is, will the candidate receive the heart and live or will the candidate's physical condition deteriorate resulting in death. The focus becomes the moment and living from day to day. As one spouse said, "I'm planned through about Thursday afternoon at this point. Twenty-four hours and that's all I plan ahead... My next step in my life isn't until he gets the transplant, then I'll jump to the next aspect" (6). Another spouse said, "You don't think about what's going to happen two or

three months down the road you just get through today" (4). In describing the inability to reorganize life and make future plans one spouse said, "I just wish something would happen one way or the other so we could get on with our lives" (16).

The process of "Life on Hold," is comprised of two stages (see Figure 1). The first stage is Freeing Self and the second stage is Making Life the Transplant. Each stage will be discussed, identifying the subcategories, properties and significant relationships.

Freeing Self

Freeing self is the first stage in the process of "Life on Hold." Mishel and Murdaugh (1987) also identified the term of "freeing self" as part of the "immersion" process which occurs during the waiting period. Freeing Self is terminating or tabling all possible activities and commitments so the spouse is available to invest all energies and efforts in maintaining the candidate's life until a donor heart becomes available. Spouses are willing to relocate, give up homes, familiar surroundings, close proximity to family and friends, financial security - everything in order to provide the candidate the opportunity to receive a heart transplant. The willingness to give up everything rests on the knowledge there are no other options for life. They believe the giving up is only temporary, and life will eventually return to normal and perhaps be even better. The perspective of the situation being temporary corresponds

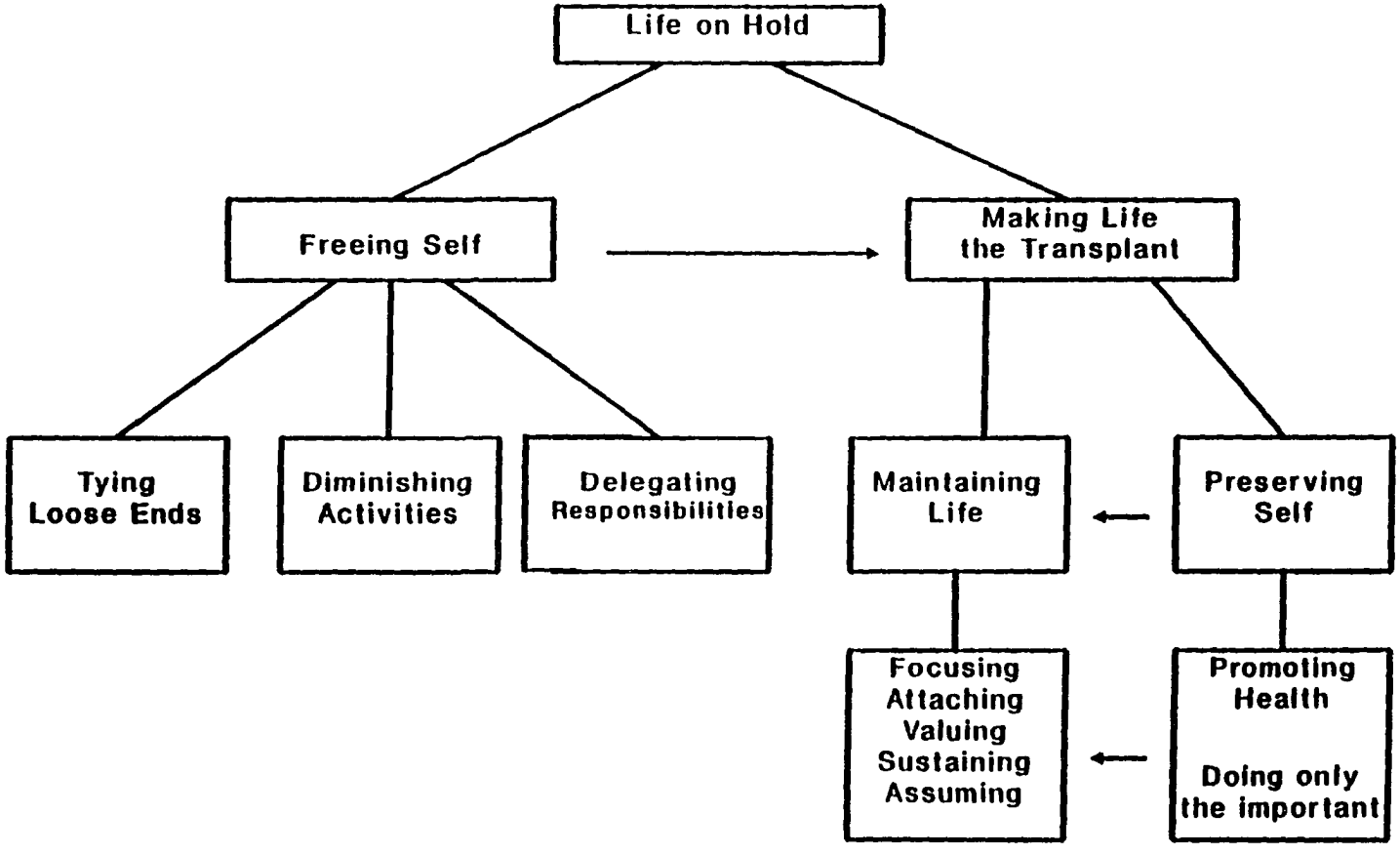

Figure 1. The Grounded Theory of Life on Hold

with Mishel and Murdaugh's (1987) findings. Often the situation is intensified when the candidate is young or middle aged. One spouse summarized this stage.

> You really don't have a life anymore. You just have to give up everything you did before, everything you intended to do, and you just have to put it on hold. You just have to go into a whole different situation. When that's over you can go back to your former life. At least that's what you keep thinking. Your life totally changes; it's upside down and inside out and it's all different (4A).

One spouse indicated how much she missed her children and grandchildren and could not talk to them as frequently as she would like. She said, "But, I wouldn't have it any different. This was his last chance for life, you know. I mean, that 1300 miles didn't, hey, if we had to go 2300 miles we would have" (12A). Another spouse described the value of viewing the situation as being temporary.

> That's what keeps you going. Because if you think I'm giving up my life, I'll never have a life again, you can get really depressed and bitter but if you think it's just temporary and I'll get back to what I'm doing later then you'll get through it (4A).

Koocher and O'Malley (1981) describe the Damocles Syndrome in relationship to cancer victims. Like Damocles, heart transplant candidates and family members often feel the candidate's life is as fragile as a "naked sword suspended above their head by a single horsehair" (pg xvii). The vulnerability of the candidate's life provides the

motivation for spouses to give up everything, to give up their present life, freeing themselves so they can completely focus on the candidate if only for a short time.

Freeing Self generally begins immediately after the candidate is accepted into the transplant program. The stage usually ends when spouses relocate or consider themselves sufficiently free of commitments and responsibilities. However, certain aspects (i.e. delegating responsibility) may continue on to the next stage although not at the same magnitude. Intervening conditions which may intensify the first stage are relocating and child care responsibilities. Relocating increases the number of arrangements necessary to free self of responsibilities and commitments. Lack of social support and social networks may make it more difficult to free self since individuals are not available to assist with responsibilities in the new location. Freeing Self includes three subcategories: Tying loose ends, diminishing activities, and delegating responsibility. Each will be described.

Tying Loose Ends

Tying loose ends involves performing activities or projects prior to the transplant that can not be postponed. Getting financial and business affairs in order are examples of such activities. One spouse told of getting her financial affairs in order to minimize present expenses.

> One thing that we did do, we had just bought a new car, which we of course financed. We can get loans against our profit sharing. Because that was the first thing that came off the top of my head, get money off of my profit

> sharing when you're not suppose to do that for this kind of thing. But our doctor was good enough to write a medical thing that we would have added expenses that we did need the money. So, we paid off the car, so we don't have to worry about that. That was a big payment that we had (9).

Another spouse described making arrangements so that they would have financial sources from which to draw.

> We had a lot of things like for instance, I like to be prepared, that money-wise that we'd have some cash, money in the checking accounts, if we had to write checks. I wanted to make sure the Visa Card would be in order (11).

Diminishing Activities

Diminishing activities means terminating unnecessary commitments and refraining from beginning new responsibilities. Quitting jobs, closing businesses, resigning from organizations, cancelling appointments, and not starting new projects are examples of activities. One spouse said, "I have taken a leave of absence from work. At this point a leave of absence where I work is two months" (9). Another spouse said, "First of all I had to quit my job, that was one of the things I had to do"(9). One spouse told of her hesitancy to seek employment even though she wanted to for financial security.

> A friend of mine even said I should start applying at the school and things like that. I don't think I should because I would not be a good employee at this time because I would want to be leaving when C. needs me and I want to

> come up at least once a month while he's waiting. So, I don't think it would be fair to anyone; not to the employer, not fair to me. If I go to work I want to do my best. I don't like being just half a person. If I'm doing something I want to do it well... I don't want to think about it at this point. I have the Scarlet O'Hara Syndrome. I'll think about it when I need to, which is too soon (1).

Delegating responsibilities

Delegating responsibilities involves assigning others to take care of necessary duties and commitments. Getting someone to care for one's home if relocating, assigning relatives to care for children or animals, making arrangements for mail, hiring someone to take charge of business and financial affairs are examples of responsibilities delegated. One spouse described tasks her parents assumed.

> They have been very supportive, to have someone back on the home front watching my house and taking care of the mail, my bills. My folks go through my mail and are pulling out the bills, things that look important, sticking them in an envelope and mailing them to me. Because all that stuff has to be met (6).

Another spouse said, "I have an office and my one brother who is a broker, he usually is in F. now, he's staying there trying to take care of the office for me" (11). This same spouse said, "I've called the bank and said watch our account because I don't ever want to get over drawn... If I do I've given permission to put it right into

the checking" (11). Another spouse described what she had delegated to her twenty year old son.

> That poor twenty year old kid was in charge of the ten year old, the thirteen year old, getting them to school, taking care of their dental appointments and all of that, plus he has a job of his own and my house and I've got three animals, one being a monkey that he has to take care of. He was like ahhhh (15).

In describing how helpful it was to have the children move them out of their apartment one spouse said, "The kids got everything out, packed up the things that we needed out here and stored everything else... They stored it in different places" (7).

Making Life the Transplant

Following stage one, the spouse is generally free from daily activities and responsibilities except those that are absolutely necessary. During Stage Two, the spouse's life becomes immersed in the waiting period. As one spouse said, "You don't have a life, it all belongs to the transplant" (4A). The spouse now focuses on those activities that are central to the transplant. Tasks considered of little relevance to the transplant are given minimal attention. As one spouse said, "That's all your thoughts are. I mean you live with it everyday. You just eat it, drink it, and you sleep it. You think of it all the time" (16). The Stage usually begins within days after the candidate is accepted into a transplant program. However, it may not begin for weeks or months after acceptance. It follows Stage One and commences after the

spouse is freed of life's activities and responsibilities. The stage ends when the candidate receives a heart transplant. Two subcategories comprise this stage; Maintaining Life and Preserving Self. Each subcategory and related properties will be discussed.

Maintaining life

Maintaining life describes the intense concentration on the candidate to preserve life until the donor heart is obtained. The subcategory has five properties; focusing, attaching, valuing, sustaining, and assuming.

Focusing. Focusing is the cognitive process of concentrating on activities specifically related to the candidate's receiving the donor heart. Spouses attempt to block unrelated tasks and responsibilities from their mind. Generally the focus is directed towards the candidate's physical condition but may include attention to other activities connected with the transplant such as fund raising. The nature of the focus is intense and all-consuming. One spouse described the inability to concentrate on anything else.

> You just wake up in the morning and you go through your daily routine and it is always with you. You try to sit down and read a book or something. It would always be there, read the same paragraph a couple of times or read and didn't know you read anything. With watching T.V., a show would go off and what the hell was the show about? What happened back there, you watched the whole show but you missed half of it (14).

Another spouse demonstrated the blocking of unrelated responsibilities when she described her feelings of being told her business was folding.

> I can't be bothered with it. I don't really care about the business. I've got this man I've got to nurture and watch and make sure he makes it through every night... It's just a business. This is our life right here. This is his life and my life. We'll deal with the other things later (15).

This same spouse had left her 10 and 13 year old children with her older son in another state. In talking about her concerns in relationship to the children, she said, "If I had any great concerns, I'd just have to block it. That was my defense" (15).

Another spouse expressed irritation at those inquiring about her husband's condition. She was angry because they were distracting from her focus on the candidate. One spouse told of needing to raise $115,000 for the transplant. She indicated that her thoughts were consumed in trying to think of ways to raise the money.

> Like I said you just keep thinking. We just keep thinking about what we can do, what we can sell. Like I said right now we're trying to get this garage and bake sale, we did one two weeks ago and really had a good response from it. Gosh we had neighbors bringing things and making cookies for us and different things. So we're trying again and there's been a lot that have donated things for the garage sale. We have done good but it's just a drop in the bucket (16).

The intense focusing on activities related to obtaining the donor heart and the blocking of unrelated tasks is not without conflict. Particularly spouses with significant child care responsibilities describe the conflict as feeling torn between responsibilities. One spouse said, "He wants me here, I am pulled in half... You know they (children) need me too" (6). She told what it felt like to be focusing on him and yet trying to meet the needs of the children.

> I feel like some days I'm a circus act. Have you ever seen the act where the guy twirls the plates on these little things? I feel just as I get these going, these are falling down, so I run over and I get these spinning and these are fine and that's how I feel like I'm keeping all these plates and they're spinning on the edge of the stick (6).

Another spouse told about her twelve year old daughter who was staying with her older sister at their home town several hundred miles away. The spouse was staying with a sister in the city of the medical center where her husband was hospitalized. She had talked on the telephone to the twelve year old daughter who thought she had started her menstrual period. She said "It just seems like you don't want to leave them, (candidate)... but oh, I should be there, you know, I should be with this little girl" (2). Wilson and Morse (1990) similarly found that husbands of women undergoing chemotherapy focused predominantly on their wife's needs with minimal attention given to the emotional needs of the children.

Attaching. Attaching occurs during the waiting period and is the desire to stay physically close to the candidate. Attaching is motivated by the fragility of the candidate's physical condition and the desire to assist in preserving the candidate's life. Spouses express the hesitancy to leave the candidate for fear something will happen and they will not be there to intervene. Spouses of hospitalized candidates often sit at the bedside or in the waiting room. One spouse whose husband had been hospitalized since relocating, spent most of the day by his bedside. Since she was not use to sitting so much she would take walks. "Then as time went on, I'm ready to get back and see what's going on and how he's doing" (12). Another spouse expressed the need to stay nights at the hospital.

> I've been sleeping on the couches in the waiting room which was really a valuable place. I know, it just seems like you just don't want to leave, you don't know if your going to be told he's dead or dying (2).

Even when spouses leave the hospital they establish methods to be in contact with the candidate. "I'm in constant touch with a telephone, an answering machine. I live for were there any messages? Are there any messages on the machine? In other words, I'm waiting for the hospital to call" (6).

Spouses whose partners are not hospitalized likewise expressed the need to be in close proximity.

> The whole time I was fishing I couldn't concentrate on what I was doing. I should be home, I should be with her, but mainly I was just happy being close

> to her, that way I knew if anything happened I'd be with her to help her get to the hospital (14).

Another spouse said, "I don't let him get too much out of my sight. I've kind of really become a mother hen worrying when he was out of my sight" (4A). One spouse who did not relocate with the candidate told of the need to be in touch by telephone. "You just kind of track day to day, you know. I call C. at least once a day and he calls me at least once a day and we still have this little connection" (1A).

The intensity of the need to be in close proximity to the candidate is related to the physical condition of the candidate. When spouses view the candidate's condition as stable at the moment, they feel more comfortable in leaving the candidate if only for a short time. One spouse stated as the candidate's condition improved she would go to work for a few hours.

> As he got better I got so I'd come up in the morning. I felt like I needed to see him. To see how he was and then the doctors would be here and then I got so I'd go to work for a few hours. Then I'd try to get back in the afternoons (3).

In contrast, when the candidate's condition is unstable the spouse is hesitant to leave the candidate.

Occasionally attaching takes the form of an enmeshing with the candidate where the spouse takes on the feelings of the candidate. "You're up when he's up, you're down when he's down... if they're having a good day, you're having a good day along with them" (12A). One spouse even mentioned she experienced some of

the same symptoms as the candidate. The enmeshing with the candidate is similar to the "loss of self" found in transplant partners described by Mishel and Murdaugh (1987).

Valuing. An increased appreciation of the candidate and the spouse's relationship with the candidate often takes place during the waiting period. The appreciation is frequently expressed in the desire to be with the candidate and do more with the candidate. The instability of the candidate's condition and the concern the spouse faces daily as to whether the donor heart will be found before the candidate dies seems to motivate the valuing. Often spouses express that materialistic pleasures are less important and that what is "really important" is their relationship with the candidate. One spouse said, "You find out what's important, our life style has changed quite a bit. I just try to do more with him" (3). Another spouse said, "I'm wondering if he's not going to be in the hospital here before too much longer. I'm hoping not though, because all those hours at home are very, very precious to us" (7). This same spouse also said,

> I sew a lot, I make crafts and things and that was kind of a second income for us. Well, now I've put that down and M. and I are together more. Even if we're just sitting there watching T.V. We're together (7).

One spouse described the need to express appreciation to the candidate because she knew their time together might be limited.

> We were close, but I think it's brought us even closer. I think we said things to one another that really, it isn't that we haven't wanted to have said, but we want the person to know because we know that time might be short (12).

Another spouse identified the motivation behind her valuing the relationship with the candidate.

> I think you focus on the one thing like I said is in the back of your mind. If he doesn't make it though then let's at least do the best we can and be as happy as we can...Little things that you take for granted you don't take for granted. Like just living, you know people just think I'm going to live forever but you don't think about dying but you start thinking about that so you think well it's not important to have this or that. We might be broke or whatever but we're together and we're happy and that's kind of how you think of it. You don't think about material things like you used to (4).

Another spouse indicated that there had been marital problems in the past but the situation had acted to clarify where she wanted to be.

> We've had some marital problems and we've been separated several times over the last ten years and this has drawn us closer together. It makes us realize what we have as a unit. As a family unit. At least it does for me. I can't speak for him. I'm the one who has been wanting out of the marriage and he has been pulling me back. This has just kind of cemented where I need to be. And this is where I need to be.

> I have no desire to want to leave the group or take my children and run like I have sometimes in the past (15).

Sustaining. Sustaining during the waiting period describes the behavioral attention given to the candidate's physical condition so that life is preserved until the donor heart arrives. Since the spouse can do nothing to influence obtaining the heart, they see their role as sustaining life until the transplant. They vigilantly carry out functions thought to maintain the physical stability of the candidate. The functions have a common goal of "doing whatever to get the candidate through this time"(12), although the expression of the functions vary with each spouse. One spouse said it this way.

> Anything he wants. Anything he wants was my attitude; within my power I would do for him. Rub my back, ok rub your back...I was completely focused on him and anything that is any whim, well I want rice for dinner, well I don't rice for dinner, want rice I'll fix rice. Anything I could do in my power to make him not happy but comfortable (15).

Sustaining functions fall into the areas of protecting, supporting and monitoring. Each function will be discussed.

The protective functions involve preventing candidates from participating in activities that may be harmful to their physical condition. Protective functions include withholding information that may be upsetting. Harmful activities involve such things

as lifting heavy items, carrying out the garbage, caring for the lawn, removing snow, driving the car, having too many visitors, and seeing family members who are upset. At times spouses will take on responsibilities previously done by the spouse to prevent physical harm. One spouse described taking over household tasks to prevent the candidate from becoming fatigued.

> I did assume more responsibility as her condition got worse. I'd help with the washing and some of the cleaning of the house and then the dishes and a lot of the time I'd cook supper. Yeah, just things like that to try and keep it so she wouldn't get too tired.

Preventing spouses from hearing upsetting information includes such things as "not telling him I'm worried" (12), or "I don't want her to hear all the horror stories of other transplants" (15), or "I try not to let him know how much money is in the foundation" (16). At times spouses hesitate to let candidates know about a situation or problem at home. For instance, one spouse described plumbing that needed to be done. She felt if the candidate knew he would be upset. She went ahead and had the plumbing completed without his knowing although she felt deceptive. Protecting candidates from harmful or upsetting information corresponds with the "filtering of information" function identified by Mishel and Murdaugh (1987). Bowers (1987) also identified protective functions among adult caregivers in relation to their aging parents. Protective caregiving involves protecting the parents from consequences that may threaten the parent's self-image. Protecting the parent from awareness of

incompetent acts or the need to be taken care of are examples of protective caregiving (Bowers, 1987).

The supportive functions involve activities used to provide comfort and assistance to the candidate. The activities take varied forms such as getting the food he desires, fixing her pills, being his booster, lifting her spirits, helping her feel good, looking good so he knows he is going to be ok, and bringing Christmas to his room. As one spouse put it, "My role is probably just to be there when B. needs me. Just to be there and be his companion" (9). Another spouse said, "I felt like it was so important to keep his spirits up and keep his desire that he wanted this" (3). One spouse stated how she tried to look good in an attempt to reassure the candidate that he would live.

> I tried hard to pick myself up and to put my makeup on every morning and clean up so I didn't look like death warmed over because I wanted him to feel like, 'She looks cheerful and happy and I'm going to be ok and we're gonna make it' (2).

Monitoring involves assessing the physical condition of the candidate. The spouse uses information from health care providers, physical appearance, and responses of candidates to determine physical status at any given time. Color, breathing, appetite, pain, sleeping patterns, expressions, moods, and interactions with nurses, are constantly observed by the spouse. Mishel and Murdaugh (1987) also found similar monitoring behaviors. One spouse said, "I can tell by his expression. I can tell by the way he breathes. I can just tell when I walk in the room by what his

first words are whether he's having a good day or not" (12). Another spouse said, "You watch him, you watch the way he breaths, you watch his hands, you watch his color, you watch just everything" (16). One spouse said, "When he had the swan in I always checked the cardiac output. Numbers that mean something to me I would always check every day" (6). Monitoring is often patterned in nature in that it is done a certain way, a particular time, and similar behaviors are observed. One spouse said,

> First thing when I come from the housing in the morning I'm always wondering how I'm going to find him. Did he have a good night? Is he feeling good? Has he had any bad news? Has he had any good news (12)?

Another spouse said,

> In the morning before I go to work and she'd usually be in bed, I'd wake her up and ask her how she was feeling. Sometimes I could tell she was sleeping good and I could tell she was feeling good, so I would slip out the door and let her rest. And then there were times when you could just tell she didn't sleep good. And I could tell when she was watching television. I got my chair kind of in a corner. We've got a bookcase between my chair and her chair and I can tell when she was breathing funny and I'd say are you alright? And she'd say yeah or if she wasn't she'd say she didn't feel good or something (14).

Monitoring is interactive with the supportive and protective functions. That is spouses intervene with the supportive and protective functions based on assessments made. When one spouse was asked what she would do if she determined the

candidate's physical condition was not as stable as previously responded, "I would stay close to him and see if I could lift his spirits or if I could do anything for him. Rub his back, get him an apple, get him a drink, a newspaper, or something to read" (12). In another situation, a spouse told about the candidate's appetite diminishing and her concern about this. She contacted the dietician for permission to obtain fried chicken for her husband. The dietician gave approval as long as the breading was removed from the chicken. The spouse purchased the fried chicken and the candidate ate it. Spouses also learn to determine when they can intervene to help maintain the candidate's physical condition, and when they need to solicit the help of others such as members of the health care team. In other words they determine when they can intervene and when their observations require medical assistance.

> If I couldn't make him feel better by getting his mind off of things or something and if I saw he was having a really difficult problem, sure I would get hold of whoever I thought he needed or whatever he needed (12A).

Assuming. Assuming involves taking on the responsibilities previously held by the candidate. As the candidate's physical condition deteriorates, out of necessity, the spouse assumes more and more of the tasks usually done by the candidate. Mishel and Murdaugh (1987) describe the process of assuming more responsibility as "trading places". Taking over household duties, business affairs, car maintenance, and yard work are examples of such responsibilities. One spouse said, "This year when he got so bad I took over the complete lawn care, the garbage, house and yard

work and snow removal" (12). Another spouse told of having to take on additional responsibilities including learning to drive a car at the age of fifty.

> Yeah like carry the groceries, carry heavy things. He doesn't do any of those any more. Driving. I never drove before and now I have my driver's license...All the kids were all for me, oh mom, you can do it you know (7).

Depending on the candidate's physical condition, assuming responsibilities may occur gradually over months and years or suddenly. However, during the waiting period the candidate's physical condition generally deteriorates more rapidly resulting in the spouse doing more and more tasks.

Preserving Self

The other subcategory of "Making Life the Transplant", is Preserving Self. Preserving Self describes the behaviors spouses engage in to maintain their own health and energy so they can completely focus and sustain the candidate's life. Wilson and Morse (1991) identify similar behaviors among husbands whose wives are undergoing chemotherapy. The preserving self behaviors enable the spouse to sustain their own health and well being so all energy resources can be invested to maintain the life of the candidate until a donor heart is obtained. "Promoting Health" and "Doing only the Important" are the properties of Preserving Self. Each property will be described.

Promoting Health. Promoting Health involves participating in behaviors to sustain the spouse's well-being and prevent illness. The behaviors include eating

nutritious foods, getting adequate exercise, decreasing smoking, and obtaining sleep. One spouse described her concern about becoming ill.

> I kept thinking, I can't get sick. M. needs me really bad now. At first I couldn't eat at all. This wasn't going to do me any good at all because it's now when he needs me the most so I am trying to eat, sleep, and everything to take care of myself (7).

Another spouse indicated,

> I have been a smoker and I am trying to cut down. I do think you want to do what's right and keep your own strength up. We've been in a position where we've had to eat out over a week now and we're trying to choose good foods such as salads (11).

One spouse who relocated with her five children described how she placed limitations on the time she could spend at the hospital and the time she could spend with the children. She then said, "This is what I needed to do to keep myself sane" (6). Another spouse said,

> It's just like you're running on adrenalin. But I just have to tell myself that I've got to take care of myself, I've got to eat...I've got to be able to help, so, I just really have to watch what I do. I run up and down the flights of stairs (3).

Doing Only The Important. Doing Only the Important is a method of conserving energy and managing limited energy resources. It involves identifying

only what absolutely needs to be done. Spouses often decrease house hold duties and do only the necessities.

> I don't do much housework any more. I use to be a fanatic. Even after C. left certain things on certain days, I do less and less. I just said it's not worth it...I'm not worried about scheduling any more. It just doesn't seem important and I think that's o.k. I figure out the important stuff (1A).

Another spouse who had relocated with five children said,

> I try to think to myself what's important. I just do that thing and let other things slide. If my bed isn't made who cares you know, if the kids don't make their beds, I could care less. Who cares, you know...It's all that priority routine, that's important. You hear it over and over and my priorities have shifted down to the things that are not important. As long as I'm basically o.k....that we have got food in our tummy and we're physically o.k. I'm just going day to day (6).

Intervening Conditions

Six intervening conditions (Strauss & Corbin, 1990) which act to facilitate or constrain "Life on Hold", include relocating, social support and social networks, age, child caring responsibilities, physical stability of the candidate, and length of the candidate's illness. Several of the factors interact. Each factor and its interrelationships will be discussed.

Relocating

Relocating can create complexities and difficulties with the processes of "Life on Hold" and yet also facilitate the processes. For example, the logistics of "Freeing Self", can be complicated as relocating, involves more extensive and numerous arrangements. Relocating necessitates finding someone to care for the home, business, finances, animals, and sometimes children. Finding living accommodations in the new location can be stressful along with the added expense of maintaining two residencies. Family and friends may not be available to delegate ongoing responsibilities such as child care. Additionally, when spouses need the support of family and friends as they vigilantly attempt to keep the candidate alive they are often alone and in an unfamiliar environment. In contrast, relocating may free spouses of previous commitments such as child care and employment responsibilities resulting in increased time and energy to focus on the candidate as they progress to the second stage of "Making Life the Transplant".

Social Support and Social Networks

Social support and social networks, the number of individuals and the amount of support they can provide, mitigate the stress and facilitate of the entire process. The ability to free self and intensively focus on the candidate in part rests on the availability of family and friends who will assume responsibility for ongoing life's activities. Support and networks are particularly important when small children are involved who require close attention. Lack of access to social support and social

networks results in conflict because the spouse feels the need to focus energy resources on the candidate. Yet the energy is limited because other family members are competing for time and energy. The effect of perceived social support and social networks is not surprising as researchers over the past two decades have demonstrated support acts to buffer individuals from the harmful effects of stress (Cassel, 1974; Cobb 1976; and Dean & Lin, 1977).

Age

Age often effects the intensity of the process. The thought of losing candidates because they "still have so much life to live", often magnifies the concentration of younger spouses on keeping the candidate alive. Older spouses are more able to reconcile the potential loss of the candidate as indicated by the statement, "we want him to make it but if he doesn't he's had a good life". Often more responsibilities and commitments need to be placed on hold or delegated with younger spouses, particularly if small children are involved. Older spouses generally have less difficulty freeing themselves and maintaining their focus on the candidate and activities related to the transplant.

Child Care Responsibilities

Child care responsibilities create obstacles in both stages of Life on Hold. During Freeing Self there are more arrangements to be made when children are involved. If the spouse relocates without the children then long term arrangements must be made which may necessitate taking the children out of school and sending

them to relatives. If the children relocate with the spouse, moving and finding appropriate living accommodations become more complex. After relocating ongoing arrangements must be made for child care. Sustaining the focus towards the candidate during the waiting period is continuously problematic because of the myriad of responsibilities competing for the energy and time of the spouse. Social support and networks become instrumental in enabling and facilitating Freeing Self and Making Life the Transplant when children are involved. Lack of support and networks inhibit the processes.

Physical Stability of the Candidate

The physical stability of the candidate motivates the actions of the spouse during the waiting period. Fluctuation in the intensity of "Freeing Self and "Making Life the Transplant" are directly related to the stability of the candidate. If the candidate's condition is unstable, the illness is more intrusive, the spouse more rapidly frees self and begins focusing attention on the candidate and activities central to the transplant. In contrast, when the candidate's condition is stable the spouse may free self at a slower pace and give more time to activities such as children or work. The spouse often feels more comfortable in leaving the candidate when stability is present.

Length of the Illness

The length of time the candidate has been ill affects the ability of the spouse to engage in the processes of "Freeing Self" and "Making Life the Transplant". If the

candidate has been chronically ill for an extended time (i.e. years), the spouse is often depleted of emotional resources which inhibits the spouse's ability to mount the energy needed to free self and intensely focus on the candidate. Spouses may have done anticipatory grieving and are prepared for the spouse to die. The transplant means generating energy when emotional and physical resources are already exhausted. Spouses express anger and resentment at having to change their lives because of the transplant. The responses of spouses during an extended illness are supported in the literature. Lazarus and Folkman (1984) indicate that when coping resources are depleted or insufficient to reduce the appraised threat, emotions such as anxiety, depression and burnout occur (Maslach & Jackson, 1981). Lazarus suggests once these emotions are aroused, they can negatively affect the way persons appraise the demand and their ability to cope with the requirements of the demand (Lazarus & Folkman, 1984).

Summary

This chapter has described the substantive theory of Life on Hold. The core category, the basic social psychological process, Life on Hold, was discussed in terms of its stages, subcategories and properties. Evidence for the findings was supported by illustrative data bits from the research. The chapter concluded with identification of intervening conditions which facilitate or constrain the process.

CHAPTER 5

CONCLUSIONS

The final chapter presents the conclusions of the study. The basic social psychological process discovered was Life on Hold which describes spouse' response during the waiting period prior to heart transplantation. Chapter Five begins with discussion about substantiation of previous research. Consideration of the grounded theory's potential for linkage with existing theoretical perspectives follows. Implications of the study for nursing theory, research, practice, and future research are discussed. In the final section study limitations are described.

Substantiation of Earlier Research

This study provides support for replicating and expanding theory generated using a similar grounded theory methodology. The findings of the present study substantiated the results of Mishel and Murdaugh's (1987) study who used a grounded theory methodology to study families of heart transplant candidates and recipients. The findings of the present study will be compared and contrasted to Mishel and Murdaugh's (1987) findings. Mishel and Murdaugh (1987) used the term of "Immersion" to describe the overall process that occurs in family members during the waiting period. They described the process as a "series of behaviors in which one family member usually pledges self to the welfare of the patient" (p. 333). Immersion is similar to "Making Life the Transplant" identified as Stage Two of the present study. During Making Life the Transplant the spouse focuses on those

activities that are central to the transplant and attempts to block peripheral activities. Activities identified in the Immersion and Making Life the Transplant, focused on the welfare of the candidate and preservation of their life until a donor heart becomes available.

The three categories of Immersion which occur concurrently are "Freeing Self", "Symbiosis", and "Trading Places" (Mishel & Murdaugh, 1987). The present study identified "Freeing Self" as the overall process describing Stage One. The nature of the activities in the present study are similar to those found by Mishel and Murdaugh (1987). Freeing self of home tasks, child care responsibilities, work and social commitments are examples of such activities. In the present study, Freeing Self was accomplished by the processes of "Tying Loose Ends", "Diminishing Activities", and "Delegating Responsibility".

Mishel and Murdaugh (1987) define Symbiosis as a parasitism or antagonistic association with the patient which is destructive to the partner. Patients benefit from the close relationship because they are taken care of where as partners lose their sense of self. The partner's identity becomes bonded with the candidate's identify. In the present study the investigator did not find the relationship of the spouse and candidate symbiotic in nature. Rather, it was found that the spouses felt the need to be in close proximity to the candidate and expressed an increased appreciation for the candidate. Generally the spouses identity did not become enmeshed with the candidate.

Mishel and Murdaugh (1987) identified "Filtering Information" and "Monitoring" as two properties of Symbiosis which serve as protective functions. In

the present investigation both the processes were identified as part of "Maintaining Life" which is a subcategory of "Making Life the Transplant". Filtering upsetting information and monitoring were seen as methods to sustain the life of the candidate. Additionally, in the present study, the investigator found that spouses also tried to maintain life by protecting candidates from doing activities which were perceived as physically harmful. Also spouses used supportive functions to help maintain the candidate's physical stability. In the present study, monitoring was found to be interactive with the supportive and protective functions. The spouse would intervene with a supportive or protective function based on observations about the candidate's physical condition.

Trading Places the third category of Immersion identified by Mishel and Murdaugh (1987) describes the taking on of the roles and behaviors patients performed prior to the illness. The present investigation also found that as the candidate's condition deteriorated, out of necessity and also to protect the candidate the spouse assumed more and more of the responsibilities previously done by the candidate.

In the present study the investigator discovered the process of "Preserving Self". Preserving Self enables the spouse to maintain their health and energy so they can focus intensely on the candidate. Preserving Self was not found in Mishel and Murdaugh's (1987) work. As previously mentioned Mishel and Murdaugh (1987) did not specifically focus on the waiting period. However, in the present study Preserving Self was critical to enable spouses to maintain the lifes of the candidate.

Conclusions of the Study

Human beings have the ability to successfully adjust to life threatening events, such as the illness of a loved one, on their own. They use their individual resources and social supports to develop strategies, also known as coping behaviors, in an effort to gain mastery over the event and maintain their self-esteem (Taylor, 1983). The grounded theory, Life on Hold, describes the process used by spouses to manage the waiting period. Spouses free themselves from other responsibilities and become immersed in the patient's illness to keep the candidate alive.

Life on Hold, a substantive theory, can be substantiated with the theories of cognitive adaptation (Taylor, 1983), uncertainty (Mishel, 1984), and stress (Lazarus, 1966). Each of these theories will be discussed in the context of the substantive theory.

Cognitive Adaptation

When an individual experiences a personally threatening event, the readjustment process focuses on an attempt to gain mastery over the event and one's life and to feel good about one's self again. The adjustment process requires the ability to form and maintain a set of illusions, or as Taylor (1983) states, to look at facts in a different light. Spouses believe that life is on hold for a temporary period and then things will get back to normal. They believe the future will be better, so they are willing to place their life on a shelf and immerse themselves into the period prior to the transplant to keep the patient alive. Thus the Life on Hold process leads

to improved emotional functioning, as they enhance efforts of control, where control is possible. Both processes, Freeing Self and Making Life the Transplant, enable spouses to cope with the waiting period.

Uncertainty

According to the Uncertainty in Illness theory, uncertainty reduces the sense of mastery over a threatening event (Mishel, Padilla, Grant, & Sorenson, 1991). Uncertainty during the waiting period became evident as spouses expressed concern about whether a donor heart would be available before the candidate's physical condition deteriorated and death ensued. The physical instability of the candidate's condition often resulted in rapid changes from day to day. Spouses would say, "I feel like I am constantly on a rollercoaster or it's like a yo yo." One spouse in describing the waiting period said, "It's like hell, because you don't know what to expect" (12).

Mishel (1988) has conceptualized uncertainty in illness as the inability to determine the meaning of illness-related events. Due to lack of insufficient cues, the individual is unable to adequately structure or categorize an event. In the illness experience uncertainty has four forms: (a) ambiguity concerning the state of the illness, (b) complexity regarding treatment and system of care, (c) lack of information about the diagnosis and seriousness of the illness, and (d) unpredictability of the course of the disease and prognosis (Mishel, 1988). The findings of the present study, suggest that all forms of uncertainty are present during the waiting period except perhaps lack of information about the diagnosis and seriousness of the illness.

Mishel and Sorenson (1991) found that uncertainty reduces gynecological cancer victims' sense of personal resources to manage the situation resulting in the potential of harmful outcomes. Uncertainty which may potentially result in harmful outcomes suggests that spouses of heart transplant candidates are at risk for negative consequences.

Ambiguity is closely related to the concept of uncertainty. Family boundary ambiguity is a concept used in family research to describe and predict the effects of family membership loss and change over time. Boss introduced and operationalized the term family boundary ambiguity as a state in which family members are uncertain in their perception about who is in or out of the family and who is performing what roles and tasks within the family system (Boss & Greenberg, 1984). The result of the boundary ambiguity is that "if a family cannot clarify who is in and who is out of the family system, it cannot reorganize; the process of morphogenic restructuring in the system is blocked and the system is held in limbo" (Boss & Greenberg, 1984, p. 535). Sources of boundary ambiguity are from either outside the family where the family cannot get the facts surrounding the event of loss or from inside the family where for some reason they deny or ignore these facts. Boss and Greenberg (1984) suggest that the predictability of time influences the ability to reorganize the system. For instance, when there is a known date of the return of an absent family member or when a family member has been permanently lost such as in death or final separation, the family may be able to clarify its boundary ambiguity since there is more information about who remains in or out of the family. However, if there is no time

frame to determine its present or future structural boundary the family is exceedingly stressed and the integrity of the group may be threatened (Boss & Greenberg, 1984).

The conceptualization of family boundary ambiguity, closely links with the discovered theory, Life on Hold. The unpredictability of knowing whether the candidate will live or die creates uncertainty about whether the family member will be in or out of the family boundary. The uncertainty is intensified in that no definite time frame to determine the candidate's status can be made since it rests on the candidate remaining alive until a suitable donor is found. Availability of a donor heart may take from days up to weeks and months. The boundary ambiguity is intensified because of the disruption of roles and tasks. Due to the physical deterioration of the candidate the spouse and family members often take on tasks normally performed by the candidate. Other family members may assume responsibilities once done by the spouse to free the spouse to focus on the candidate. Life on Hold connotates a system in limbo. Spouses indicate their inability to plan for the future because they do not know if the candidate will live or die. Futuristic planning rests on getting the donor heart. One spouse said, "I just wish something would happen one way or the other so we can get on with our lives" (16).

Stress

Spouses experience tremendous stress as they wait for their partner to receive a transplant. The stress is reflected in descriptions of the waiting period. Words and phrases such as, "it's just trying, just trying; it's stressful... anxious; extremely

anxious; depressing, you have a lot of anxiety; it was hell; and I just want it over with," were terms used to describe the waiting process.

Theoretical orientations describing stress can be categorized into three perspectives: (a) stress as a stimulus; (b) stress as a response; and (c) stress as a transaction (Lyon & Werner, 1987). Stress defined as a stimulus is conceptualized as causing a disrupted response. Historically the stimulus orientation had its roots in the works of Holmes and Masuada (1966) and Holmes and Rahe (1967) who measured stress according to life changes or life events. The theoretical relationship proposed by the stimulus model is that too many life changes increase susceptibility to illness.

Stress defined as a response, represents disruption caused by a noxious stimulus or stressor. In the response model, stress becomes the dependent variable rather than the independent variable as it is in the stimulus model. For instance, Selye (1956, 1976), defines stress as a general adaptation syndrome which is characterized as a nonspecific response of the body to demands placed on it, that is the response is the same regardless of the cause or context. Like the stimulus model of stress, the response model does not allow for individualized response pattern.

For the present study, the investigator was particularly interested in the effect of stress on cognitive processing. During the waiting period, there is an intense focusing on the candidate and those activities considered central to maintaining life until the transplant. Activities viewed as peripheral to this goal are blocked and given minimal attention. Mandler (1982) suggests that perceived dangerous situations tend to increase the level of arousal resulting in a narrowed focus and increased attention

to aspects of the situation considered most important. Aspects seen as less relevant are not attended. Mandler's (1982) theoretical orientation would support the findings of the present research.

Stress defined as a transaction emphasizes the relationship between the person and the environment taking into account individual characteristics and the nature of the environmental event (Lazarus & Folkman, 1984). Lazarus's (1966) model of psychological stress is an example of stress as a transaction and has theoretical linkage to the present study. Lazarus and Folkman (1984) define psychological stress as a relationship between the individual and the environment appraised as taxing resources and endangering well being. They suggest when faced with stress the individual cognitively appraises the situation before reacting. Three kinds of cognitive appraisal have been identified: Primary, secondary, and reappraisal (Lazarus & Folkman, 1984). Primary appraisal consists of the evaluation that an encounter is irrelevant, benign-positive, or stressful. Stressful appraisals can take three forms: Harm/loss, threat, and challenge. Harm/loss involves damage already sustained, threat refers to anticipated harms or losses, and challenge refers to events that hold the potential for mastery or gain. Secondary appraisal concerns judgment relative to what might and can be done. During secondary appraisal a complex evaluative process takes into account which coping options are available, the likelihood that a given coping option will accomplish what it is intended to, and the probability that one can apply a particular strategy or set of strategies effectively.

Reappraisal refers to a changed appraisal based on new information from the environment and or the individual.

The generated theory of Life on Hold indicates that spouses use primary appraisal by recognizing the threat to the candidate's life if heart transplant surgery is not performed. Secondary appraisal occurs as spouses evaluate possible options to decrease the threat by making certain the candidate has the opportunity to receive a transplant and then maintaining life until the donor heart becomes available. The stages of "Freeing Self" and "Making Life the Transplant" are considered coping processes, based on secondary appraisal. Additionally, evidence of reappraisal is demonstrated by the interactive monitoring process which occurs as the spouse attempts to sustain the candidate's life. For example, monitoring information enables the spouse to implement a supportive or protective function.

Implications for Nursing Theory

This study has expanded the knowledge of spousal response to the waiting period prior to heart transplantation. Existing cognitive adaptation, uncertainty, and stress theories as they relate to individuals and family members have been supported in relation to a particular phenomenon of study. The discovered process of "Life on Hold", is congruent with themes of interest to nursing including the patterning of human behavior in interaction with the environment in life threatening situations (Donaldson & Crowley, 1978).

Life on Hold provides empirically based support for nurse theorists to continue to develop and test theories which emphasize the effects of an individual's illness on the family members and the family as a whole. Additionally the results of the study suggest the importance of ongoing study of concepts such as coping adaptation, stress, uncertainty and ambiguity as they relate to various phenomena of interest to nursing. The grounded theory of Life on Hold provides a basis for continued examination of the effect of the heart transplant process on family members. The conceptualization of the waiting period as a process may challenge nurse theorists to continue to devise more effective ways of describing the complexities of family response to a life threatening illness.

Implications for Nursing Research

This study provides support for replicating and expanding theory that was generated using a similar grounded theory methodology. In logical positivism terms this is called convergent validity (Kerlinger, 1986). The findings substantiate the results of Mishel and Murdaugh's (1987) study, who used a grounded theory methodology to study families of heart transplant candidates and recipients. Mishel and Murdaugh's (1987) study was conducted in a different geographical location. They used a group method to obtain respondent data in contrast to using individual interviews to obtain respondent data. In addition they did not focus exclusively on the waiting period. Similar findings provide support for studying phenomena using different investigators, sources and methods of data collection.

Recommendations for future research include the continued exploration of the effects of placing life on hold for other family members and on the integrity of the entire family. As spouses intensely focused on the candidate they felt an overwhelming feeling of being torn between the desire to be with the candidate and yet the responsibility of caring for other family members. The feeling of being torn was particularly evident when small children were involved. Several data sources provided evidence that the children may feel deprived and traumatized as the spouse focuses on the candidate.

Various coping strategies used during the waiting period also need to be evaluated for their effectiveness during both the waiting and then the post-transplant period. For example, Preserving Self an enabling behavior used to maintain spouses' health and energy during the waiting period needs to be observed in the future transplant phases to see if it continues and acts to maintain emotional and physical health. Such a finding would be important since existing literature suggests prolonged and cumulative consequences of exposure to stresses of caregiving can result in psychological and physical morbidity effects (Neundorfer, 1991; Schulz, Visintainer, & Williamson, 1990).

Responses of family members of similar substantive groups need investigation to determine if the processes are similar. For example family members of liver, pancreatic, and kidney transplnts would be appropriate to study. Also studying dissimilar comparison groups such as those experiencing life threatening illnesses (i.e.

AIDS, transplantation, and cancer) with and without social support has potential to elaborate the findings of the present study.

Implications for Nursing Practice

The conceptualization of the processes experienced by spouses during the waiting period prior to heart transplantation has potential for generalizability to other life threatening illnesses which are acute in nature and considered temporary. Examples of other life threatening illnesses include family members of trauma victums and other cardiac conditions.

The identification of the processes spouses experience during the waiting period prior to heart transplantation forms a base for developing and implementing interventions to facilitate the maintenance of individual well being and the family integrity. Taxed financial, physical, and emotional resources place individual family members and the entire family at risk. Both stress and uncertainty theory provide evidence that, without proper intervention, transplant families are vulnerable to harmful outcomes (Boss & Greenberg, 1984; Lazarus & Folkman, 1984; Mishel, 1988). Caplan (1966) has suggested that stress can result in crisis when there is an imbalance between the difficulty of the problem and the resources immediately available to cope with the problem. Additionally appropriate intervention during disequilibrium promote healthy outcomes. Likewise, Hill's ABCX Family Crisis Model (1949, 1958) suggests that a significant factor in preventing a crisis is the family's crisis meeting resources. The Double ABCX Model (McGubbin, Boss,

Wilson, & Lester, 1980) which expands upon Hill's ABCX Family Crisis Model explains pre-crisis variables that account for differences in family capability to cope with the crisis. Post-crisis variables which effect the family's ability to achieve adaptation have also been added. Both models suggest the potential of interventions to prevent crisis and facilitate positive outcomes when crisis occurs.

Coping outcomes have two functions: (1) To regulate emotional responses, and (2) to regulate problem-solving activities (Johnson & Lauver, 1989). The ability of spouses to regulate problem-solving activities is reflected in the degree to which they successfully free themselves from usual life activities and begin making life the transplant. Therefore, interventions can be developed which assist spouses achieve the goal of successfully placing life on hold. Interventions may include strategies to monitor the patient or techniques to preserve the spouse's emotional and physical health. Both short term and long term interventions need to be developed due to the prolonged length of the waiting period.

In summary, the findings of the study suggest that family members of heart transplant candidates are at risk for crisis and unfavorable outcomes. Nurses are in a significant position to intervene to potentiate family resources in facilitating positive coping outcomes.

Study Limitations

The findings of this study revealed that among respondents from which data were sampled all were willing to place their life on hold in order for the candidate to have the opportunity to receive a donor heart. Although there was variation in the

degree both to which activities were tabled and the type of attitudes expressed in doing so, all spouses placed their life on hold to some degree. No data were collected from negative cases. In future investigations purposiveful sampling of data from spouses who did not place their life on hold during the waiting period would be important.

Potential limitations of the study due to limited respondent pool were previously noted in the theoretical sampling procedures. These limitations do not necessarily detract from the worth of the study, but serve as relevant considerations for future research. Although the research process continued until saturation of categories significantly related to the core category, theoretical sampling of additional respondent and respondents in comparison groups who were experiencing family members with similar life threatening illness may have provided greater substantiation and clarification of data categorizations.

Respondent statements were taken at truth value. Assumptions underlying qualitative methodologies include the acceptance of subjective experiences as truth (Haase & Myers, 1988). However, Miles and Huberman (1984) suggest validating data by looking for deception and ulterior motives in respondent statements. The potential for deception was present in this study if spouses perceived the information might have effected the candidate's opportunity to receive a donor heart. The likelihood of such deception is minimal. However, future interviews need to obtain additional information or repeat the interviews to reduce respondent distortion of data.

Summary

The experiences of spouses waiting for the candidate to receive a heart transplant result in stress and uncertainty and compromise the well being of the individual family member and the integrity of the family. Since nursing is concerned with health outcomes in relationship to stress and crisis of both individuals and families, the responses in life threatening illnesses is important.

The qualitative methodology of grounded theory expanded existing theories of coping adaptation, stress and uncertainty both from an individual and family perspective. The grounded theory of Life on Hold has provided an understanding and theoretical basis for the development of relevant interventions to assist individuals and families in obtaining positive outcomes when experiencing life threatening illnesses of a family member.

APPENDIX A

STANFORD'S PATIENT SELECTION CRITERIA

Inclusion criteria:

less than 55 years old
functional Class IV (NYHA)
poor prognosis for six-month survival
would benefit health-wise from transplant
emotionally stable
strong desire to live
long term commitment from family or companion
strong supportive family

Exclusion criteria:

severe pulmonary hypertension, as reflected by calculated pulmonary vascular resistance above the range of 4-6 Wood units if unresponsive to an intravenous infusion of a vasodilator such as nitroprusside

severe,irreversible hepatic or renal dysfunction, the etiology of which is considered separate from cardiac failure

any active systemic infection

any separate systemic illness considered likely to limit or preclude survival and rehabilitation after cardiac transplantation

recent and unresolved pulmonary infarction

diabetes mellitus requiring insulin for control

severe peripheral or cerebrovascular disease

systemic disease (i.e., severe peripheral vascular disease, insulin-requiring diabetes, malignancy)

moderate to severe prerenal azotemia and/or hepatic abnormalities (may be accepted if mild to moderate in severity and secondary to right heart failure)

active peptic ulcer disease

history of a behavior pattern (such as drug or alcohol abuse), or psychiatric illness considered sufficiently severe to interfere with compliance of lifelong medical regimen

APPENDIX B

EXAMPLES OF INITIAL INTERVIEW QUESTIONS

1. Tell me what brought your (husband or wife) to the point of having a transplant?

2. How do you feel about your (husband or wife) having a transplant?

3. What is it like waiting for the transplant?

4. How has waiting for the transplant affected your family life? What changes have been made in your life?

5. What is most difficult for you as a family to cope with during this waiting time?

6. What has been most helpful for your family in coping from day to day?

7. What strategies have your family used in dealing with the stresses of this time? How well do they work?

APPENDIX C

INFORMED CONSENT

CONSENT FOR PARTICIPATION IN AN INVESTIGATIONAL STUDY

Family Perception of the Waiting Period
Prior to Heart Transplantation

INFORMATION:

The purpose of this research study is to explore what family members experience while waiting for a family member to have a heart transplantation.

The expected duration of participation in this study will include the time from which your family member is accepted as a candidate for heart transplantation until the heart transplantation takes place. This time period varies from individual to individual depending on many factors. It is expected that approximately 20-25 family members of heart transplant candidates will participate in the study.

Participation in this study will entail a private audiotaped interview, averaging an hour, that will be transcribed for later data analysis. At the time of the interview transcription, all names used in the recording will be changed. The audiotape will then be erased. It is expected that one interview will be sufficient. However, as circumstances seem appropriate, other interviews may be requested during the waiting period prior to heart transplantation. The interview will be carried out at a place of your convenience and choosing.

There are no risks or discomforts to you as a result of participating in the study; nor are there any known benefits to you as an individual. However, the information gained may be helpful in assisting other family members as they deal with the stresses of the waiting period prior to heart transplantation.

Please feel free to ask any questions you may have regarding the research and/or my intentions as a researcher. For questions concerning the research and your rights as a subject, contact Mary Williams at 262-3645. If you have other concerns that are not answered by Mary Williams you may contact the Institutional Review Board at the University of Utah Medical Center (581-3655).

CONSENT:

I understand that participation in this study is voluntary and that may refusal to participate will involve no penalty or loss of benefits to which I would otherwise be entitled and that I may discontinue participation at any time without penalty or loss of benefits to which I would otherwise be entitled.

The information gathered in this research project will be held in confidence by the investigator, the sponsor of the research and the Institutional Review Board. they may be inspected by the Food and Drug Administration. Any release of information derived from these records to scientific organizations, medical journals, etc. will be done only without identification of the subjects.

I have read the foregoing and my questions have been answered. I have been provided a copy of the informed consent. I desire to participate in this study and accept the benefits and risks. I give permission for information gathered in this study to the released to Mary Williams.

_____ _____

Date Signature of Subject

_____ _____

Date Witness

APPENDIX D

THE UNIVERSITY OF ARIZONA
TUCSON, ARIZONA 85721

COLLEGE OF NURSING
[redacted]

MEMORANDUM

TO: Mary Williams

FROM: Suzanne Van Ort, Ph.D., R.N.
Associate Dean for Academic Affairs

DATE: September 5, 1989

RE: Human Subjects Review: "Family Perception of the Waiting Period Prior to Heart Transplantation"

Your project has been reviewed and approved as exempt from University review by the College of Nursing Ethical Review Subcommittee of the Research Committee and the Director of Research. A consent form with subject signature is not required for projects exempt from full University review. Please use only a disclaimer format for subjects to read before giving their oral consent to the research. The Human Subjects Project Approval Form is filed in the office of the Director of Research if you need access to it.

We wish you a valuable and stimulating experience with your research.

SVO/ms

APPENDIX E

ATTESTATION TO DEPENDABILITY AND CONFIRMABILITY

November 12, 1991

Mary Williams
5420 Kenwood Dr.
Murray, UT 84107

Dear Mary:

I have completed the audit for your study on spouses of heart transplant recipients. My charge was to determine both dependability and confirmability of the findings. As you know, a variety of procedures were used, based on the audit format suggested in Lincoln and Guba (1985). I will briefly list those procedures I used to determine dependability and confirmability, and will provide a written, detailed description of the steps I took within one week.

Confirmability

1. Assessed whether findings were grounded in data. A sample of findings were traced back through summaries, field notes, theoretical notes and memos to the raw data contained in interview transcripts. In all cases, the linkages between raw data and synthesized data were clear and well-explicated.

2. Assessed whether inferences were logical. This assessment was made by identifying the analytic strategies used, and seeing if the strategies were applied appropriately. Descriptions were obtained from the methodological notes and journal entries, and the strategy was traced back through the theoretical notes to the raw data. The inferences stood up well to this examination, and the examples given in the notes demonstrated that the logic was evident in the data.

3. Assessed utility of category structure, including clarity and explanatory power, and fit between categories and examples. Again, the structure identified in the descriptions of the grounded theory was traced back through working hypotheses found in the theoretical notes and journal entries, as well as in the memos from each interview. Examples were analyzed and traced back to the raw interview data.

4. Assessed inquirer bias through examination of inquirer's use of own language, versus use of respondent's language. The handling of the uncertainty data is a good example of how the inquirer was careful not to impose her own language onto the respondents meanings. In all cases, those meanings were ascertained by checking with respondents. Tacit processes used by the inquirer were explicated in memos and notes.

5. Assessed accomodation strategies. There were sufficient efforts to ensure confirmability, as evidenced by the methodological, theoretical, and personal notes and memos. In particular, negative evidence and cases were analyzed and accounted for in the theoretical statements.

Dependability

1. Assessed appropriateness of inquiry decisions through analysis of theoretical notes and memos. There was clear evidence of theoretical sampling, as well as support for theoretical decisions. The process for changing or adding lines of questioning to the interviews was documented, and was based on persistent responses by paticipants regarding previously unidentified issues. There was no evidence of early closure on either sampling or data analysis. There was a sufficient search for negative cases. Termination of data collection was determined by saturation of categories, versus deadlines or agency pressure.

Overall, there were no unexplored areas in the data or field notes. There were several categories that were eliminated from the grounded theory, primarily because of insufficient data. An example of such an area is the responses of transplant recipient's children to stress. Though the data do not appear specifically in the theory, they are addressed elsewhere in the paper, mainly as areas needing further exploration. There is no evidence of unexplored leads in the data.

2 Assessed the overall design and implementation of efforts, and integration of outcomes for dependability. Major design decisions were identified through the trustworthiness notes. Evidence was found for peer debriefing, member checks and interactions, and prolonged engagement in the setting. The evidence suggests that sufficient attempts were made to ensure dependability.

I attest that the study herein audited is credible. The findings are both dependable and confirmable, based on the evidence provided to me in the audit trail.

Sharon L. Sims

Sharon L. Sims, RN, PhD
Assistant Professor,
Indiana University School of Nursing

APPENDIX F

OVERVIEW OF DATA

Life On Hold

We can't look too far down the road. We're just on hold for a minute, you know. We've gotta take time and find out what we can do. (2:836)

You know, you just have to put your life on hold for a while and be right there with him. And that's what I've really tried to do. (3:351)

So you tried during this time,to put your whole focus on him and tried to minimize other things. (Investigator)

I just put everything on hold. (Spouse) (3:870)

Uh-huh, I really think that's helped. I feel bad for people that have to go through that on their own. There's no one more important than their companion. You know your kids are important but they come and go and they have their own lives an that's what I've tried to stress with our kids. I know it's hard on you, I know it's hard for you to study but you have your life; I can put my life on hold. Your dad is what's important. If you can come, come. Like our daughter is in E. trying to get home. She is in the cheerleading squad and her dad said you have got to go. It's part of your job, so trying to keep them on their path and it's been hard to. (3:473)

Well, like I said the first thing is keeping your life in perspective. If you look at it like my whole life is disrupted and I don't like this and I want to go home then you've got the wrong attitude. If you look at it like well we're going to have to put our life on hold for a while so that we can go home and live a normal life then you're looking at it in the right way. You have to, no matter what little things come up and you might get frustrated, you have to say well, we have to do this so things can be better on up the road. (4:236)

Well, I imagine it's just what I've been going over before. It's having a good attitude about it, thinking everything's going to be alright and you can go on with you're life. Putting things in perspective; I think that's the most important thing. Because you can't dwell on it, you have to just tell yourself it's just temporary; we have to go through it so in the end it'll be better. (4:412)

And just going from day to day and not looking into the future anymore than you have to. (4:429)

Yeah, you do, your whole life is just turned upside down. You just have to stop one phase of it and go into another phase and hope you can go back to the first phase later. You have to because, otherwise, you're going to be real upset about it because things are not the same. (4A:394)

You really don't have a life anymore. You just have to give up everything you did before, everything you intended to do, and you just have to put it on hold. You just have to go into a whole different situation. When that's over you can go back to your former life. At least that's what you keep thinking. Your life totally changes; it's upside down and inside out and it's all different. (4A:214)

I'm planned through about Thursday afternoon at this point; 24 hours and that's all I plan ahead. (6:913)

Right now my focus, my life frame is from now until he gets his heart. That's all I'm focusing on... (6:932)

That's the only thing right now. Like I said we've cancelled Christmas because I just can't get my mind to go on Christmas. To me M.'s heart transplant is it right now. (7:225)

I don't try to look forward I just try to look for that heart to come in and then take it from there. That's what I'm trying to do, I'm not trying to focus ahead so the rug gets pulled from under me again because I don't want that. That was hard. (12:693)

You're just waiting to see what happens for you to go on. I mean are you going to go on to the fact that he's going to have a little more time or are you going to the fact that it's only minimal. So you really don't want to plan ahead until you know the outcome of this. (12:995)

Life has been on hold and now that the transplant is done, it is on go. (12A:892)

Really. I wish that, I mean we all certainly wish that he would get it but I wish that something would happen so that we could get on with our lives. (16:376)

Oh, I don't know. I have some health problems. I have a lower back problem and what not in my knees. I went to the doctor the other day and he says you'd better go have an MRI and see. I said I just can't do anything until I have him taken care of because even though we've got very good insurance, it's always these few hundred dollars still have to come out of your pocket. (16:574)

Oh, if we could just get the money, get the transplant and get on with our lives. (16:632)

I often think, oh I wish I had time to do this or that but I know I can't. After things either go one way or the other, you know then you can get back to life again, really. (16:403)

We've got to handle it one day at a time. That's all we could do up until that transplant, we lived one day at a time. (2:701)

Right. Don't think about what's going to happen two or three months down the road you just, let's just get through today. That's all we're thinking about. (4:117)

Then, like I said if you just live from day to day. If you think, oh my God, we're going to be here for 8 or 9 months or whatever, you can get really depressed. But, if you think, well, we really don't know, let's just get through today, it makes it a lot easier. (4:273)

That's all you think about. Just getting through today and letting tomorrow take care of itself. (4:401)

One day at a time. We've borrowed it from AA but by God, we live by it. (15:1175)

Freeing Self

I just walked away from a job, you know, in which I made eight hundred dollars a month just part-time but I just had to walk away and he needed me here and so I will have that job when I go back, I hope if I can go back, if it's still there, you know. (2:559)

When he got to be number one, all of a sudden you're closing up your houses and your businesses and you're finding someone to take care of the animals and you just leave everything behind. You just put your life on hold and of course a move to anything unfamiliar that's stressful. (4:53)

It's stressful leaving your friends and your house and everything that you're familiar with. That can be stressful but you just have to handle it that's all there is to it. You have to. You know, you think well this is just temporary and so we can go on with our lives and that's how you have to look at it. And then like I said you just have to get through each day, you don't worry about tomorrow or the next day or the next month you just get through each day. (4:161)

So it's kind of hard on the wives because they have to quit their jobs, you have to stop everything. (4:496)

It was kind of hard for me because I worked for the school and I worked with about 300 kids a day. I worked a couple hours a day. It was hard for me to tell my kids good-bye because I had become so attached to them. It was hard for them to tell me good-bye but there again you think when I go back I think I can get my old job back, you know. (4:485)

Leaving my friends, leaving the animals. That's hard on both of us because we've had a dog and a cat for seven years; we're very attached to them. But every place up here you want to rent in your means won't take animals and so we had to do something with them. That was hard on us. It wasn't so bad about the kids because they lived out of town anyway so we didn't have that problem to cope with. It was probably a little easier with us than it is for a lot of people I'm sure. (4:505)

Yeah, that's what keeps you going. Because if you want to think I'm giving up my life, I'll never have a life again, you can get really depressed and bitter but if you think it's just temporary and I'll get back to what I'm doing later then you'll get through it. (4A:259)

You really don't have a life any more. You just have to give up everything you did before, everything you intended to do, and you just have to put it on hold. You just have to go into a whole different situation. When that's over you can go back to your former life. At least that's what you keep thinking. Your life totally changes; it's upside down and inside out and it's all different. (4A:214)

The kids, they were real hesitant about coming out here and starting school, and the friends and the routine, and they talked about how scared they were and all this getting into a new situation and stuff and I said well, if it makes you feel any better, those feelings are feelings that I have too, that will never go away, even when you're a grown person, you feel afraid to meet new people, you feel afraid to get into new situations and I said, how much better I would have been if I could have learned how to deal with when I was 10, 12, 14, 15 instead of waiting till I was in my 40's to figure out my feelings about myself. I said just think of it as temporary kids. (6:987)

But, hey I wouldn't have it any different. This was his last chance for life, you know. I mean, that 1300 miles didn't, hey, if we had to go 2300 we would have went. (12A:792)

It's true I gave up a job that I like to come to a place I didn't want to come to. Dark, old apartment that doesn't have a park or a little green area. (13:368)

I guess it's all my activities that I was doing in A. When you're real busy like that, it's stressful and so when I got here and I was less busy and all I had to do was concentrate on him. (15:897)

Tying Loose Ends

Then we had to go back home because we thought we're coming out for consultation and they put him in the hospital for a day and a half to run a bunch of tests. And then he had to go back home he hadn't tied things up yet. (1:246)

I decided that I'd better go get my hair cut because I'm going to be kind of busy. (3:376)

One thing that we did do, we had just bought a new car, which we of course financed. We can get loans against our profit sharing. Because that was the first thing that came off the top of my head, get money off of my profit sharing when you're not suppose to do that for this kind of thing. But our doctor was good enough to write a medical thing that we would have added expenses that we did need the money. So, we paid off the car so we don't have to worry about that. That was a big payment that we had. As far as, no we've been able to manage quite well. One thing that helps us is that the house payment that we have is very small, in O. (9:139)

We had appointments that we had to cancel, for myself. (9:421)

He's an attorney, but he had cut down considerable on that. He has had accounts h's had to handle but he's had to handle. Before leaving, we just kind of called and canceled them. (11:293)

We had a lot of things like for instance, I like to be prepared, that money-wise that we'd have some cash, money in the checking accounts, if we had to write checks. I wanted to make sure the Visa Card would be in order. (11:229)

Oh yeah. We had to cancel appointments before coming here. (11:285)

Like I said it happened within a week and three days we were out here and so you more less trying to get your papers in order, trying to get your house in order, trying to get a few things. (12:572)

You know, I had to shut up the house. I had to figure out all the finances, I had to get money from different places and get them in accounts and do it real fast, and make sure there is enough food in the house for the kids and I got on life flight and came down. (6:309)

And we literally closed up our business and then we moved up just the basic things that we would need. Just a few of things as possible and we just left. That's basically what we did. We just left. (4:72)

Diminishing Activities

A friend of mine even said I should start applying at the school and things like that I don't think I should because I would not be a good employee at the time because I would want to be leaving when C. needs me and I want to come up at least one a month while he's waiting. So, I don't think it would be fair to anyone; not to the employer, not fair to me. If I go to work I want to do my best. I don't want to be just be half there. I don't like just being a half a person. If I'm doing something I want to do it well. So, I haven't, I don't want to think about that at this point. (1:1500)

I had quit my club for six weeks while we were up in C. and I don't think I have time for it now. (1:998)

First of all I had to quit my job, that was one of the things I had to do. (9:419)

I was working part time, I'm on a leave of absence now. (6:399)

I have taken a leave of absence from work. At this point a leave of absence where I work is 2 months. In January when the time comes, I think I will probably be doing and it will probably be more my decision, it will be our decision I guess. I will probably ask for an early retirement without taking my benefits, or something like that. I have a profit sharing plan that I would probably put into a program where we could get income off of it. (9:25)

Since he was in the hospital the last time I haven't worked. (10:252)

Delegating Responsibilities

I guess I should start writing things down. I have said to C. that I'm writing you a list of what needs to be done with the kids and anything I put in there that might hurt your feelings don't take it that way because I'm writing it down as they come up.

I call C. and say, "Go check on this and take care of this. I've got friends I can call and say, "run down to the house and make sure the doors are locked." (2:991)

My brother just took over Christmas. He took over the girls and picked up the Christmas. I had layaways strung from here to S. (2:1009)

And so it's been real hard and it's like I said I live with my sister so up here she's taking care of things as far as checking on things and food and stuff like that. I haven't had to worry. (2:991)

We're from a small town. Everyone out there, my mother, I just put her on the phone list. I just told people to call her because I just couldn't handle being here with him and then having people come and wondering how he was doing. (3:426)

And it's been helpful to have my mother and it's been good for her. She's talked to more people than she's talked to in years. It's helped to have her as kind of the spokesman. I can keep her updated and slip out and just make one call and then she can just relay it on to the others. I even told my bishop that people can call my mother. (3:859)

They really help when I got home. My youngest son and his girl friend will load the dishwasher and feed the dog and they've taken over with people; you know with calls and people coming. That's been very helpful. They kind alternate, one being home at night. Which that doesn't bother me to be home at night. Very comforting to have one of them there to help. That is no problem. (3:994)

When he got to be number one all of a sudden you're closing up your houses and your businesses and you're finding someone to take care of the animals and you just leave everything behind. You just put your life on hold and of course a move for anything unfamiliar that's stressful. (4:53)

Our older daughter, she's our only daughter, she has taken time off work too, when necessary, to help with CCC and I think that they have helped him too because he's felt good about going there, it's not that I'm just leaving him any place under the sun. I've had someplace where he's felt comfortable, you know, I could leave him. I never felt like I was being a burden to them or anything, they've just been so good. (5:958)

I had to find someone who'd take a pet because I had my little maltese with me. I couldn't find anyone to take care of my little doggie, so she's been in the kennels for most of the month. I have to find some place to take her. But again, I found that... (6:359)

It helped tremendously, my parents living next door. We each have 3 acres out in the woods and they have taken over the total responsibility at the house because our home was broken into about 2 weeks ago and we had a bunch of stuff stolen. I think that we think that it was teenagers that knew we were gone, at the high school, and took advantage of it. (6:760)

They have been very supportive to have someone back on the home front watching my house and taking care of my mail, my bills. My folks go through my mail and are pulling out the bills, things that look important, stick them in an envelope and mail them to me. Because all that stuff has to be met, all those bills, all, and so that's been tremendously supportive and I had family in the area, if I didn't it would have been more complicated. (6:774)

Our children are all grown. The youngest is 21 and the oldest is 32. They're all married and have families of their own. They have all gotten together. We have an apartment in CB. and they've all gotten together. One son-in-law and one son brought stuff out to us last weekend that we would need in our car and this weekend they packed up all our stuff in our apartment and stored it. (7:141)

Kids got everything out, packed up the things we needed out here and stored everything else. They all have houses. They stored it in different places. (7:173)

They've done everything back there. Changed the address, the whole bit. It's a big long list of things that have to be done. They've all gotten together and done it. Which makes, it's a big help to us. (7:180)

We have a friend who is single, who's been a friend of B.'s for a long time, he's divorce, we asked him to live in our house. We have a condominium. He's living in our house. (9:76)

That was another big thing. We just decided no, we're not going to do that we'll just leave our addresses exactly the way they are and then this gentleman sends us our mail on a weekly basis and then we handle everything from here. (9:431)

And then R.'s sisters and my mom and R.'s mom, everyone just does all the running. (10:218)

I have a brother back there that is watching the mail so when that comes in it gets paid so we don't get cut off from using it or something. Same thing with phones. I have a brother that goes to the house every weekend anyway, he's a bachelor, he just comes out every weekend, he's continuing to do that. He'll run our cars and make sure that the dogs, my sister, our dog is with her family, her dog is with another family. We get a lot of support. (11:236)

Same thing with work. I have an office and my one brother who is a broker, he usually is in F. now, he's staying there to try and take care of the office for me. I have a lot of friends who have offered to go in and work and keep it open. And it's our busy time actually starts now. (11:256)

Oh yes, and I've called the bank and said watch our account because I don't ever want to get over drawn and I know that if I do I've given permission to put it right into the checking and things like that. (11:332)

The children come, they go once a week. They'll be sending the mail out here for us. Hopefully, we're hoping the son will drive the car out for us when we need it so we'll have a car to get around here. (12:234)

My daughter and her husband are living with us to help out with the house work and stuff. (14:108)

That poor 20 year old kid was in charge of the 10 year old, the 13 year old, getting them to school, taking care of their dental appointments and all of that, plus my business, plus he has a job of his own and my house and I've got three animals, one being a monkey that he has to take care of. He was like ahhhhhh. (15:181)

I have a horse, we have a big golden retriever, I have little maltese doggie, we have a parrot, we have a bird, I have 4 kids, you know, I had to find somebody; my parents live next door and so they took care of the house, they said they'd take care of the house, they took care of the kids while I flew out on life flight. That was not a good deal, my parents are in their early seventies and they just can't cope with four teenagers, i.e. a sixteen year old daughter that just got her drivers license so that was a bad scenario. I had to find someone to board the horse. I just had to get a hold of my cousin, came over got a friend, they took it to their pasture and so my horse is boarded. Another friend took our golden retriever, our dog, he's taken care of down there, down the road about a half a mile at their place. (6:287)

And, actually it was a day and a half we were told like on Tuesday afternoon that we would have to leave Thursday morning. I had a small business I was running that was a very young business, it had only been in operation for about a year. It was still getting on it's feet. I have two school age children and two adult children. One of whom was in A. and staying with us at the house. So, when we were told it was time to go, like I said, a day and a half, I just turned around to my 20 year old son and said handle it kid. We went to the bank and I wrote up a little sales agreement for my business, signed it over to him so I shouldn't have to worry about it. I figured I was going to have enough to worry about down here so I just have him power of attorney for everything and we just walked out. Consequently, 20 years old with no experience in the type of business that I was running.... (15:29)

Well, in L. we have two houses and a business. One of the houses is rented out and the one that we were living in we had a friend of ours come in and stay in the house to take care of it and take care of the animals because we couldn't bring them with us. (4:66)

Making Life the Transplant

Totally. You don't have a life, it all belongs to the transplant. You give up everything you ever did or ever wanted to do and that is your life. I could see where someone might get bitter over a situation like that but you can't be selfish in the least, if you're going to make it, you just can't. You have to say well this is just for a while, he'd do it for me under the same circumstances and you can't think about going to get your hair done or buying a new dress or anything like that. You have to think about well we need this, this medicine. So, you can't be a bit selfish if you're going to support somebody. (Spouse) (4A:226)

If felt like I was on a bike and I was pedaling as fast as I could and my kickstand was down; I was getting no where. All these, the children, I tried to explain to them about, they have all these needs and wants and demands and they're finally kicking into gear here how serious we are about how big of a mess we're in here but it took them a long time to really kick into gear and to unfocus from their world of wants and desires and to open up and see I've got to sacrifice these things for my family to be o.k. I've got to not ask mom that I want a new pair of shoes, or ask mom can I go to my friends house, and they were still doing that to me while I was trying to take care of this man that kept collapsing on me and it was just really hard. (6:478)

That's the only thing right now. Like I said we've cancelled Christmas because I just can't get my mind to go on Christmas. To me M's heart transplant is it right now. (7:225)

I miss them very much. We're a very close family and I do miss them a lot. But M. is my main concern right now, and he's theirs too. That's what they wanted me to do. Because I said well, I can always come back and do all these things and they said, no mom, we'll do them, you stay there with dad and we'll do them. But it is hard. I'm sure it will get harder because I haven't been away that long. (7:201)

That's my life. (8:463)

That was a rough time here for Easter because we're always together for Easter and we have four grandchildren and we just love them dearly and this is the first time we've ever been away from them. When we did call, it was kind of hard. It was. But, then we know this is his chance for life. (12:57)

Exactly. You know, you live from day to day. Anything else, when I would get the calls from home during the waiting period, well this isn't quite going right. Well, I'm sorry I've got this man right here that I am concentrating on, you have to do

what you can. When we first started talking about the business starting to fall, let's close it, I can't be bothered with it, you know. It's just a business. This is our life right here. This is his life and my life. We'll deal with the other things later. (15:88)

Yes, I signed the business over to you so legally it is your business but I don't really care about the business. I've got this man I've got to nurture and watch and make sure he makes it through every night. (15:354)

Maintaining Life

I always kind of, I don't really think about myself. I'm more less concerned about him, he's the sick one, I don't feel I'm sick. He's the one that needs me right now; whatever I can do to help him. Whatever I can do to get him through this time. (12:1421)

Any thing he wants. Anything he wants was my attitude; within my power I would do for him. Rub my back, o.k. rub your back. We have a real playful relationship. We'll, lot's of joking and laughing and so if he did say rub my back I'd say well, you didn't rub mine. Wait a minute, you know, I'm a me first kind of girl. But yeah, I was completely focused on him and anything that any whim, well I want rice for dinner, want rice I'll fix rice. Any thing I could do in my power to make him not happy but comfortable and keep his attitude as up as possible. That was my main focus, to keep the attitude, to keep the lightness in the air rather tan focusing on the severity of the whole situation. I wanted to keep things light and breezy and happy. (15:624)

Focusing

Now my youngest one is kind of an airhead and she hasn't done real well in school. And so we didn't want to bring her up here because that's going to divide my attention to her and T. and so we decided to leave her down there in school for now and see what happens. (2:613)

My oldest daughter called and I got to talk to my younger daughter, I warned her that her period is gonna come. One of these--I warned her probably a year, year and a half ago that this could happen, not to be frightened, you know. I've done this with each girl and she called me up and she gets whispering on the phone, "Mom, I think I started my period." And I think, "Oh, I should be there, you know, I should be with this little girl." "Have you talked to Cathy?" "No, I can't tell her." And so then I said, "I'll tell her. Let me talk to her" and so I'd even warned her. (2:910)

"Mom," she says, "I'm still having a hard time. I don't know whether I'm starting or not. It doesn't get on my little pad." She said, "Have you told dad?" And I said, "Yes, I told your dad." "Well, don't tell anybody else." "Where's C.? Why are you at the house?" Well, C. as at work. She works at the phone company too and so I'm just going, oh, I need to be down there and I need to be up here and I'm concerned about my house, you know, fire more than anything or leaving the doors open. (2:937)

I cannot let these children go unattended while M. wants me here, he wants me here by his bedside talking to him, don't leave now, don't leave now, while the kids need me. That's a grave concern, I guess there must be transplants with children but they all seem to be in their 60's and their kids are grown, that's a big worry for me, what am I going to do with these children while I'm at the hospital all day. (6:1221)

He wants me here, I am pulled in half, he wants me here, he's getting lonely, he's depressed. (6:1247)

That's the only thing right now. Like I said we've cancelled Christmas because I just can't get my mind to go on Christmas. To me, M's heart transplant is it right now. (7:225)

Our whole focus right now it trying to get the money raised so we can get the transplant. (10:296)
And it's been this whole year, it sounds like, or even longer than that when there's been repeated deaths. Now the whole focus is on G. (11:399)

Generally I spend as much time with my husband as I can. That's about it. Like I said, I stay at the house and then I get up in the morning and I'll come over here and I'll see if he had a good night, if he's feeling right, what the doctors had to say, how is he doing. Then I'll spend some time with him and then I'll leave him for a little bit so he can rest and maybe I'll take a walk around and see the vicinity around here and then I'll come back and then I'll talk with him again a little bit and go down to S.'s and maybe pick him up a donut or something and some apples; he enjoys fruit. Really, you know, right now my focus is on him. I just, it's beautiful country and everything. But, right now he's my main objective, right here. (12:909)

It was always there. It's always there. I mean it was just like when I would leave here at night I would go home and go to sleep. The first thing in the morning, boy I can't wait to get over here to see what's going on with him. (12A:485)

Well, she has, basically felt that whenever she's had a problem, it's last on the list, that his health is first. That's basically the way it is. She's just left home. I don't

even know where she's at. She doesn't have a job that I know of. She has no money that I know of. I think she's staying with some pretty listy people. (13:33)

Probably the thing that hurts me the most is my daughter. I'm trying to get settled here and if I don't hear from her and even against G wishes I'm going to D. and looking for her. (Spouse)

Do you ever feel like you're having to choose between him and her? (Investigator)

Always. (Spouse) (13:517)

You know, there are a lot of things like going fishing and stuff like that, I went a few times this spring but my heart wasn't in it. I just thought I'd be home with my wife just in case. Everyone knew where I was and could come get me in a few minutes but it's just that point of I should be there. I never could relax or anything. And I'd get to work and I'd try to work a little harder and concentrate a little more on what I was doing instead of thinking about what could be going on at home. (14:206)

Going fishing didn't help because like I said the whole time I couldn't concentrate on what I was doing. I should be home. I should be with her. But mainly I was just happy being close to her then that way I knew if anything happened I'd be with her to help her get to the hospital. (14:498)

You just wake up in the morning and you go through your daily routine and it's always with you. It ain't like you try to set down and read a book or something. It would always be there, read the same paragraph a couple of times or read, didn't know you read anything. Watching T.V., sit down and watch T.V. and a show would go off and what the hell was that show about? What happened back here, you watched the whole show but you missed half. That's the way I am I guess. You can't think about tomorrow. (14:965)

So, that was a big worry at home. But I had no choice at that particular time but to say do what you guys can. See ya. (15:67)

Yes I signed the business over to you so legally it is your business but I don't really care about the business. I've got this man I've got to nurture and watch and make sure he makes it through every night. (15:354)

But yeah, I was completely focused on him and anything that any whim, well I want rice for dinner, want rice I'll fix rice. Any thing I could do in my power to make him not happy but comfortable and keep his attitude as up as possible. That was my main focus, to keep the attitude, to keep the lightness in the air rather tan focusing on

the severity of the whole situation. I wanted to keep things light and breezy and happy. (15:624)

I tend to block. I do a lot of blocking. They're o.k. They're going to be o.k. because I can't do anything about it because I'm here and if I got real concerned I'd call. But I knew I couldn't hop on an plane and go home and check on them. Mother's automatically have an instinct. A little thing in their ear, they can hear if something's really wrong; the children's voices. Just in talking to them helped me a lot to know that it's o.k. But if I had any great concerns I'd just have to block it. That was my defense. (15:1184)
I had tunnel vision. And that's the only way I could deal with it. If I had to spread my emotions out to everything around me I would have been a mess. (5:1200)

Yes, that's all your thoughts are. I mean, you live with it every day. You just eat it, you drink it, you sleep it. You think of it all the time. (16:397)

So, I know they're like me, it's on your mind all the time. I mean, it's just there, it's just there and it's all the time. (16:447)

Like I said you just keep thinking. We just keep thinking about what we can do, what we can sell. Like I said right now we're trying to get this garage and bake sale, we did one two weeks ago and really had a good response from it. Gosh we had neighbors bringing things and make cookies for us and different things. So we're trying again and there's been a lot that have donated things for the garage sale. Which we have done good but it's just a drop in the bucket.

You just wake up in the morning and you go through your daily routine and it's always with you. (14:965)

Attaching

You just kind of track day to day, you know. I call C. at least once a day and he calls me at least once a day still and we still have, we have to have this tiny little connection; just seeing how he is and stuff. (1A:472)

I had been sleeping on the couches in the waiting room which was really a valuable place. I know, it just seems like you just don't want to leave, you don't know if you're going to be told he's dead or dying. You just want to be there. (2:282)

And then after they told him that he needed the transplant they just let me stay in CCU and the nurse told me the next day that he hadn't had a break in the night so I

stayed after that until about 3 nights before the transplant and I was just getting too tired. (2:290)

It's so hard for the companion because you worry you can't, he's a very independent person, you can't smother them, but you worry. He said I'm going to go to J. today and I said well I can't go today, I'm having staff meeting, can you wait and go next Friday. No I'm going to go. He's just so determined and it's such a panicky feeling that you don't want to take that away from him but you just worry so. I just kept thinking, what will I do. (3:186)

My husband has been gone a lot because he worked long hours on his ranch and so having him home and having to leave him and wonder how he s going to get things done because I said several months ago you really need to learn to do some things that aren't so physical. You really ought to set up a puzzle or let's do this and to leave him so despondent saying you know I'm not going to make it because yeah, I've probably only got 6 months to live. (3:318)

I felt that if nothing else gets done, if I don't get my clothes changed for a week, I need to be here. As he got better days, I could go to work a little bit. I'd go to work 2 to 3 hours. So, I just kind of worked it out. I think that's been real important. (3:894)

Then as he got better I got so I'd come up in the morning. I felt like I needed to see him. To see how he was, and then the doctors would be here and then I got so I'd go to work for a few hours. Then I'd try to get back in the afternoons. So I haven't left him very much yet. But, I can see that that's paid off because his spirits, he was so down. Of course he wasn't feeling good. But I just feel like his spirits were lifted. (3:959)

It's been hard to go home at night. You feel like you have this feeling all the time that you need to be here and yet you know you have to take care of other things especially when he hasn't felt good. In a way when he hasn't been able to think about anything else. You need to be there. But it's gotten better as he's gotten better. It's probably better for him to be alone a little bit too. To have me away. So you just have to keep talking to yourself. (3:1252)

The only thing I was thinking about is not probably that it would help anybody, and I don't know how many people it will affect but something that's kind of strange is I don't know if any of the other wives are like this but I take on sympathy pains for people; always have. Like the year before my mother died, she was sick for a year and I took care of her, for a year, she had a horrible case of rheumatoid arthritis, and during that period every joint in my body, every muscle, everything hurt, I couldn't even sleep at nights because of the pain. The day after she died, it all quit,

everything that had been hurting I noticed, I'm taking on all his physical ailments and I hurt an awful lot of the time, physically. (4A:408)

Well, of course this has been going on before the waiting period but not letting him do anything physical, even if he wanted to. And not letting him get too much out of my sight. Kind of really became like a mother hen worrying when he was out of my sight for a few minutes; I was quite the worrier. You do, you find yourself acting as if it's a child of yours and that it's your job to protect and watch him. I guess that's just kind of natural, especially with the women. (4A:560)

For instance if you saw the numbers didn't look good, his condition didn't look as good, would it make you want to stay here longer? (Investigator)

Longer? Yes. Because I've done that, when he was really, really sick in the beginning. (Spouse)

Whereas, if things were looking better. (Investigator)

I could go home, absolutely. And if he expresses a desire for me to stay longer I will stay an extra 30 minutes from what I planned to stay but then I go home. (Spouse) (6:1760)

I'm always in constant touch with a telephone, an answering machine. I live for were there any messages. Are there any messages on the machine? Other words, I'm waiting for the hospital to call. (6:916)

Like I said, the first week, you've pretty well stayed close to where you want to see if any doctor's been in and what they've had to say, nurse, anything anyone had to say were right there, you were anxious for the report or whatever. (12:1174)

When he's feeling good you're feeling good. When he's not feeling good you're not feeling good. You go up and down according to him. That's what I would say. (12:1321)

I want to stay close to him and see if I can lift the spirits or if I can do anything for him. Rub his back, get him an apple, get him a drink, wants a newspaper, wants something to read. I feel that the party that is sick should have their loved ones close to them if they are family oriented people. I feel that helps the sick party and I feel that helps the other party. It puts me more at ease when I'm here and I can see how he is than if I'm sitting outside wondering. Naturally, I know if he's very ill and the nurses are very busy with him then I have no business being in there but now, and they're very good about it, they let me stay there all day long with him. And they're very good. I don't bother them. If they need any help I'll be glad to pitch in and

help. I'm not use to sitting around either. I'd like to be going and doing. I feel more at ease when I can. (12:1459)

The time when he says go for a walk, I'll go for a walk and I'll feel relief. Then as time goes on I'm ready to get back and see what's going on and how he's doing. (12:1486)

Then of course, you're sitting there, you're trying to raise his spirits and he wants you there with him and you don't want to leave. (12A:457)

If they're having a good day you're going to have a good day along with them. (12A:662)

Well, I have stayed home a lot more. I don't go an awful lot and I do tend a couple of grand kids part of the day. So I'm home a lot anyway. When we go anywhere if I need to go to the grocery store and that I usually see that someone is there, you know, with him. Are they around, or they'll check in. I never leave him. It seems like that's the time that everything always happens. (16:232)

You know, you just have to put your life on hold for a while and be right there with him. And that's what I've really tried to do. (3:351)

Going fishing didn't help because like I said the whole time I couldn't concentrate on what I was doing. I should be home. I should be with her. But mainly I was just happy being close to her then that way I knew if anything happened I'd be with her to help her get to the hospital. (14:498)

Valuing

Yeah, you find out what's really important, our life style has changed quite a bit, I just try to do more with him. That's what I was doing up here. (3:940)

We've always been close and I think it would be a whole lot harder on him if I weren't here. So, I think it's probably brought us closer together because ultimately we know in the end things could go wrong. So, you kind of want to say well let's be happy and let's be together in case something does. You've always got that in the back of you're mind, what if? (4:308)

Well, I think you focus on the one thing like I said is in the back of your mind. If he doesn't make it through this let's at least do the best we can and be as happy as we can; of course you don't always think that way...(4:325)

I'm wondering if he's not going to be in the hospital here before too much longer. I'm hoping not though, because all those hours at home are very, very precious to us. (4:380)

I sew a lot, I make crafts and things and that was kind of a second income for us. Well, now I've put that down and M and I are together more. Even if we're just sitting there watching T.V. We're together. (7:446)

We made it through Thanksgiving, which really wasn't traumatic because I guess as long as we're together, I shouldn't say that we don't care because we do care, but it's not as traumatic as if he was here and I was there because this is what he suggested before we came out here. To begin with, before we ever came out here, he said why don't I go out there and wait and you stay back here. There's just no way that something like that is going to work. Absolutely no way. (9:94)

We were always close but all of a sudden there's more realization of your problems, the house up there has been like a vacation house, because it's a beach resort. And we're always kind of a close family but I think we have more of an appreciation of what one person does for another. (11:389)

It's brought us, we were close, but I think it's brought us even closer. I think we said things to one another that really, it isn't that we haven't wanted to have said but we want the person to know because we know that time might be short. (12:786)

Because of the trauma, we've had some marital problems and we've been separated several times over the last 10 years and this has drawn us closer together. It makes us realize what we have as a unit. As a family unit. At least it's done that for me. I can't speak for him. I'm the one who has been wanting out of the marriage and he has been pulling me back. This has just kind of cemented where I need to be. And this is where I need to be. I have no desire to want to leave the group or take my children and run like I have some times in the past. (15:331)

Sustaining (Monitoring)

Did you find yourself watching his breathing at night? Did you find yourself monitoring things to see, did you have a set criteria you'd look at and say well he's doing better today? Did you find yourself doing that? (Investigator)

Oh yeah. At night, just counting his breaths. I'd find myself just counting as he'd hold his breath. I'm going to have to go in there and see if he's awake. (Spouse) (3:612)

I think I've always kept a close watch on him because I would notice a lot of things that he wouldn't. (4A:533)

When he had the swan in I always checked the cardiac output. Numbers that mean something to me I would always check every day. That would help me know how he was doing. I would ask what the cardiac output was. I would ask where his blood pressure was at. Does he have fluid in the lungs? The cardiac output. What number of the drips is he on, are they upping the Dolbutamine, they were at 2, right now we're hinging on the antibody level. Is it dropping? And I'm waiting for the next result. We wait for numbers here. We wait for numbers. (6:1734)

I watch for his shortness of breath. He doesn't have pain. Just the things that he does. I use to be a nurse aide. I was a nurse aide for ten years and so I kind of know what kind of things to look for. I just watch. I never say anything and he doesn't either. We know, both of us. (7:357)

I watch if he just sits, if he's staring off into space, then I think oh gee, I know he's not having chest pains like he use to have chest pains but he can't breath. Like when we're in bed at night, there are certain times when he will breath and I think this is very calm. He'll breath and then it's like he's not breathing at all. And this disturbs me. (9:249)

It's funny to sleep by him because he always snored and the more drugs he got on the more he's, it's not even like sleeping with the same person. I'll sit and listen to him and he'll like breath real hard and deep one time and then nothing, you know. (10:616)

Yeah, I do that. I can tell by his expression. I can tell by the way he breathes. I can just tell when I walk in the room by what his first words are whether he's having a good day or not. (12:1404)

First thing when I come from the housing in the morning I'm always wondering how I'm going to find him. Did he have a good night? Is he feeling good? Has he had any bad news? Has he had good news? (12:1415)

I went out and bought him some fried chicken. We talked to the dietician, she said as long as he took off all the breading and everything. Because his taste buds, I had told you before were gone, his eating wasn't that great and it started Saturday, he didn't want to eat anything again and Sunday was going to be a bad day again. But I went out and bought this fried chicken for him and he did eat a few pieces. (12A:189)

You know, if I saw that he was really down, maybe you could crack a joke or think of somewhere where we went on vacation and get his mind going in the other

direction. You do, you work harder. You, yourself work harder to try to get him and his thoughts going in a different direction. I think maybe that puts a little stress on you that maybe you don't realize because your mind is trying to go and trying to relieve him. If you love someone, that's what you do. If you try to make them more at ease and more comfortable. (12A:528)

If I couldn't make him feel better by getting his mind off of things or if I saw he needed, because I could tell to what point how he was doing, not good but not really bad. But if I saw he was having a really difficult problem, sure I would get a hold of whoever I thought he needed there, or whatever he needed. (12A:603)

You do. You notice whether they look good or whether they're not looking good. (13:277)

Yeah, the mornings before I went to work she'd usually be in bed and I'd wake her up and ask her how she was feeling. Sometimes I could tell she was sleeping good and I could tell she was feeling good and so I would slip out the door and let her rest. And then there was times when she'd, you could just tell she didn't sleep good. I'm a pretty sound sleeper, when she's not in bed I know it. I could tell she had a rough night. And I could tell when she was watching television and I got my chair kind of in a corner and then we've got a bookcase between my chair and her chair and I can tell when she was breathing funny and I'd say are you all right? She'd say yeah. Or if she wasn't she'd say she didn't feel good or something. (14:591)

Like I said you watch him, you watch the way he breaths, you watch his hands, you watch his color, you watch just everything to see if you see anything. I know before he came down, I guess it was in May, he just got so he kept breathing so heavy. I have two daughters that work at the hospital.. We just said you've got to have some oxygen and he'd say no, I'm all right, I'm all right. No, you're going to get some. So, we called them to bring some up one night and before we came down here he was on it almost every night. (16:161)

And you wonder, everyday, is he going to be all right. I mean when you live with someone, you watch them enough that you can see tale-tale signs of him going down or something not being right. And I don't know, it's just there. (16:476)

Sustaining (Protecting)

I said you need to have someone checking on you every day. Who checks on you because if I would call and nobody answers I would think you're exercising, then I would try again and think maybe you went out and did some running around. (1:1106)

Like I need some plumbing done in the house and a fellow that C. works with has offered to come over and do it and I said should I just call B. and ask him to come. He said no, call a plumber. Then you look in the checkbook and I said C. it's going to be a couple hundred dollars, if he does all these piddly little things around the house, there's about four or five different things. He said, well, still call the plumber. He doesn't want anyone else to do it either but he knows he can't do it. So, I know eventually I'll just go ahead and call that man and won't tell C. about it, then he won't get upset. (1A:824)

Now he didn't realize how bad he was and we didn't want to tell him. (2:194)

I'm a very strong person but you have your weak moments and of course you can't let them see it and I've tried to make light of it. (3:159)

The kids, they'd come and I'd say just don't let your dad see you down. If it happens, head out of here. You know you see a 29 year old boy with tears running down his cheeks it's pretty hard. (3:280)

I didn't want them there. The cardiologist said it was just too hard on him. They all mean well but they make it very hard. They make it very hard and you just become exhausted. And yet it's great to have their love and concern; it really is. So I finally got so I'd say to people, just send him a card. (3:432)

I felt like I had to protect him because we were trying to save his energy. We were trying to save his output and I just felt like talking, you don't think it takes any energy to talk but I could see that is did. He told me it really bothered him, it really stressed him out. He's a real people person and so I just got so you know, well maybe I'm not being fair to him. But then he finally just said, I'd rather not see people, I really can't handle it. And so then I did feel a real protection, I wanted his kids to see him, I knew how important that was but I just said to them, do the talking for him and then don't stay that long. Just see him and then goodbye. (3:471)

One man showed up on the door with flowers, which as you know are not allowed, and he said I didn't know who it was and I said what is that delivery guy doing up there. Well it was a fellow he worked with and W said Hi J. So I just said say hello, goodbye. Go shake his hand and I got up and walked out with him. (3:471)

One day I went in and he had a bandage on his hand and he said I think my thumbs getting a little numb and I said well, did you tell them and he said, oh no, they'll be in a little while. Let's do it now. He's just very passive. He's an easy person to be around. But anyway it's been hard. It just has been hard on me and I'm probably a stronger person than most people. I mean I've had my moments. I just try to have

those at home and you know you've got to tell yourself you've got to go on I can't go up there looking like a rag. I've really got to help this situation out. (3:572)

I was just real protective of people because they'd always want to come and see him. I'd just discourage it because you know when you don't feel good and they would come and try to entertain him as if there's nothing wrong with you and they'd leave and he'd just whoo. And so I became real protective with people. (3:650)

It's really amazing in my mind that he's all right and it will probably go on that way. Because you become their total caretaker, nurse 24 hours a day and your their main worrier and you get a little bit over-protective. keep them out of stressful situations and take the brunt of something yourself and that's real natural. (4A:581)

Yeah, if there's a problem, I have for the last couple of months. Like if a bill comes and that needs to be paid, M doesn't know it, I just go ahead and things like that and anything that's negative I try not to upset him. That's where my kids come in handy back home. We talked to them over there but out here I don't feel like I know anybody that well, well enough to talk to them. But I do protect him a lot. I just don't figure he needs that right now and if I can handle, if I couldn't handle it I would go to him but otherwise I do protect him. (7:789)

I don't want him to hear a lot of the bad experiences that they're going through but after what he went through there could be nothing worse than what he went though. But I haven't let him do hardly any driving. (8:614)

Sustaining (Supporting)

We really tried hard to--we brought in a Christmas tree and he started crying. And we decorated it with some things. He had bought a train to go around our Christmas tree--a childhood memory that he had had and then so we brought a little train in and we decorated it and then one of the nurses was real cheerful all the time. She'd come in singing and she'd hang all his cards on the wall and he'd keep saying, "Well, take all that stuff down. Take all that stuff down." No you're going to have Christmas in here. And so I brought a couple of presents in and he'd open them and he'd cry. One teddy bear that somebody had given him just for fun you pushed and it sang Jingle Bell's and he'd cry. And so finally after Christmas, "Now you can take it out" and "Ok, I'll bring something else. We just did everything we could. And his sister brought buckets of fruit. He has such a hard time eating cause his system...and so the cards he got two or three hundred cards and the sentiments in them...we love you. We'd like you back and he just kept saying, "How could anyone ever love a principal like me." Some of his students would come that have grown up. In their 20's and

some of them went to see him. He just said, "I didn't think that many people cared. So all these things were very valuable to him. (2:1148)

I tried so hard to pick myself up and to put my makeup on every morning and clean up so he didn't look like I was death warmed over cause I wanted him to feel like, "She looks cheerful and happy and I'm going to be ok and we're gonna make it" so you really try to put on a--and I'm sure there was days I walked out of that room just looking like death warmed over. (2:1131)

I almost got to the point where I just hated nights because I thought what kind of a night is he going to have. In fact I even went out and bought him a recliner. I said if you're not going to sleep with me I've got to get you a companion, you know this poor guy is trying to sleep propped up on a couch or something. Then I thought oh, that's really going to help, but it didn't. He'd sleep a couple of hours but he just couldn't breath and that was it. It was just to that point. You try everything. But nights definitely were the worst. (3:630)

Yeah, and that's what the kids have said too, he just looks for you mom. It's different with your kids there but to have your companion. You know, you know them better. It's just different. I just felt that was my part. No one else could do that. I think that's going to help a lot. I really do. (3:905)

Although I was coming in like 7:30 in the morning and I'd stay till 10 o'clock at night. Then I'd go out. I mean I was in the corner and I'd take an hour nap and just kind of, I felt like it was so important to keep his spirits up and keep his desire up that he wanted this. (3:886)

Well, his health. He got real concerned about food one day and they kept trying to feed him something with terradon sauce or something, he got real panicky. He had a very big appetite for a small man, a very big appetite. And so I said I'll go home and fix you something; I know what you need. You're just restricted on salt. I can fix you something. And I just thought I can't do all this; I can't be here all the time and trying to work a couple of hours a day. But, I did take him food up and put it in the fridge. If they feed him something he didn't like, the doctor looked at the dressing, it's o.k. you can have it and then after that I'd go talk to the dietician. He's one that just takes things as they are and would say oh well, it will get better. I said well let's talk to the dietician, I'm sure you can have quite a few things. (3:498)

Well, I feel like I can help with him. Keep him buoyed up. I felt like that was my most important job, just to keep his spirits up. (3:1307)

Like when you get up in the morning, I usually get up a couple hours before he does and you sit there and you think this just isn't possible. I sit and think of seeing him

not being able to do the things that he's done all his life for all of us. M has been a very good supporter as far as that goes. Now, I'm doing all that. (7:264)

That he'll make it through it and be with us and everything. I try to be strong for him but he can't do those things anymore so I will. (7:542)

I just always try to be strong for him. And if he doesn't want me to go to work then I don't go to work. If he wants me home then I stay. But that makes him feel good to be like that then. I'll do whatever. (10:529)

I just want to make him comfortable. (12:957)

So when I see him during the day I try to make him comfortable. (12:965)

I'll fix your pills for you. I try to let him do most of his medications. I know so many of spouses line it all out for them. I did, you know, I'd put them all in alphabetical order and I made a chart for him and for the first couple of weeks I would prepare them for him. Then it got to the point where I'd say did you take your lunch pills and he goes in and follows the chart and fixes his own. Which I think he should do. That's the way I feel. Now, I will probably do it for him now that he's down. (15:701)

Assuming

Are you finding you're having to assume more and more responsibility? (Investigator)

Oh yes. One of my friends said to me, you know, you've been running this household anyway, and that's true. I resented it at times because I didn't really want to run the household. (Spouse) (1:469)

Assuming more responsibility that was hard for him. Like things around the house, like feeding the dog. They seemed like quite minimal, just doing things like that he's always done. Take the garbage out. I've always done the bills and that but you had to be everything. Is the car working o.k. We'll have somebody pick it up and fix it. Things that I hadn't done before and I had done part of it because he worked a lot, was away a lot. But yes, you have to do it all. It's just overwhelming. I hope I make it through the day. So days become, I don't know, I find that as I get older, the kids are gone, you have to do everything. It's like when your kids are home, this one will clean this bathroom, this one will do that and you're doing it all and working, plus this, plus all these extra things. This became even more. It was hard for him to accept it. He tried and like to clean up the dishes and things like that and

he just said you have to do everything, I can't do it. And yet I tried to do it and not make a big thing, oh a bill, I'll run that out. If he tried anything, I'd see him just going up stairs, shortness of breath. You just treat him like a child; just sit down and let me do it. But you can't do that. I just let him do the things I thought he could do. But, it's overwhelming. (3:771)

Yeah, like carry the groceries, carry heavy things. He doesn't do any of those any more. Driving. I never drove before and now I have my driver's license. (7:285)

What is changed, what I do. I take out the trash and like I said, I took over the cars, garage, and house, and yard work and snow removal. (12:1245)

But naturally this year when he got so bad I took over the complete lawn and car care and garage and whatever and yes, it got a little hard on me. (12:1222)

Yeah. I'd help her with the washing and my daughter too. You know having three kids of her own and then being pregnant, she had problems with her pregnancy too. She was down in bed for what was it a month, of her pregnancy. Anyway, between me and my son-in-law we kind of kept things going as much as we could. Of course, guys don't always have the same knack as women do. (14:150)

He doesn't fight me and say I'm going to carry this and that kind of stuff, hey I can carry it. That kind of thing. (1:421)

Preserving Self (Promoting Health)

I knew that when I went home that I had to do as little as I could and get in bed. (3:957)

Tell me a little bit about what you're feelings have been inside as all these stresses kept building and he got sicker with time? What are the thoughts and feelings going on in your mind? (Investigator)

Well the first thought was to try and keep myself healthy so I could handle some of these things. I've had headaches all my life and I just kept thinking I can't be sick, I've got to be strong. That's probably one of the things that was uttermost in my mind that I could be healthy and take care of him. (3:1007)

Yeah, my headaches. It's just like you're running on adrenalin. But I just have to tell myself that I've got to take care of myself, I've got to eat. Just like my husband was telling himself I've got to be able to help, I've got to help so, I just really have to watch what I've done. I ran up and down the flights of stairs. (3:1228)

You can't just go on and on without any sleep and you're running and taking care of someone for 24 hours a day without sleep and so you come to the point where you say unless it's an emergency don't even think about bothering me for a couple of hours but then you feel guilty about it afterwards but, yeah, you have to, you can't keep going on like that. (4A:626)

Exactly, and that's what you have to do. If I didn't have my kids here, if we were, like I said a lot of these transplants are in their 50's and 60's it would be a different deal. I've got to take care of these kids besides him and I've got to try and keep things realistic here. What I need to do to keep myself sane. I can only sit here from about 1 to 5. (6:1293)

I can't get sick, M needs me really bad now, and I eat well, trying to keep my energy up, trying not to, at first, I couldn't eat at all. This wasn't going to do me any good at all, no way, because it's now when he needs me the most. So, I have found that eating, sleeping, everything taking good care of myself. Trying to. (7:679)

I have been a smoker and I am trying to cut down. The hospital is smoke free which I think is great and I have gone out to that little outside room not too long from here. I do think you want to do what's right and keep your own strength up. We've been in a position where we've had to eat out for over a week now and we're choosing a lot of good, salads...(11:623)

Preserving Self (Doing Only the Important)

I don't do much housework any more, M. I use to be a fanatic. Even after C. left certain things on certain days, I do less and less. I just said it's not worth it. Then I think what happens if I get this call and have to leave and his teacher has to come over and I haven't changed my sheets in umpteen days. I vacuumed the house. She doesn't like doing housework either. Then I do it that day. I'm not worried about scheduling any more. It just doesn't seem important and I think that's o.k. I figure out the important stuff. (1A:965)

I don't have the energy because I thought about volunteering. Going out and volunteering just to get out and be around some people. And I have not had the energy to go ahead and just do it. Even make the call and say I could do this for two hours a week. I don't know when I would do it. Something I have in the back of my mind. I have days where I just want to lay around and not do very much. I drag myself to do the things that have to be done so I don't get tired of the house and I just lay down on the couch and take a cat nap or something. Usually one day a week I feel like that. (1A:1000)

O.k. I tell you one thing I realized, and I think my branch president alighted it to me, he said I'm a caretaker, a person that likes to fix everybody's problems. I realized that my sister called and said should I come and my mother said should I do this and so I found myself trying to make decisions for all these people, what would be best for helping us and I determined if you want to come fine, if you don't want to come fine, I can't make those decisions for you, all I know is that I've got to make decisions that are the best of me and my emotional well being and my family and I can not take responsibility for all these people around me that want me to tell them what to do. If they want to bring food, let them bring food. If they didn't want to bring food, don't bring food. But, I couldn't say yes, I am too busy tonight, I need a casserole and I need this and this and this, then on Wednesday night sister so and so, you can do this; I just couldn't do that. That wasn't my responsibility. If they want to bring food, fine. If they don't I could care less, we're not going to starve to death, I could lose 40 pounds, it's no big deal. So, I just found the thing that I need to focus on myself and my sanity, my kids, make sure they're o.k. and support him and all these other people that were like moths on a light bulb all around me trying to help and do all these things, they could do anything they wanted to do but it wasn't my responsibility to make sure they were o.k. That wasn't my job. Does that make sense? (6:540)

It's all that priority routine, that's important. You hear it over and over and my priorities have shifted down to things are not important. As long as I'm basically, we've got food in our tummy and we're physically o.k., I'm just going day to day. (6:1346)

It is, it's a one woman show, for the healthy spouse, it's a one person thing, trying to balance it. I feel like some days, I'm a circus act. Have you ever seen the act where the guy twirls the plates and all these little things, I feel just as I get these going these are falling down, so I run over and I get these spinning and these are fine and that's how I feel like I'm keeping all these plates and they're spinning on the edge of a stick. And I try to think to myself what's important. I just do the things that, some times, I just let things slide. If my bed isn't made, if the kids don't make their beds, I could care less. Who cares, you know. Like the break-in in our house. So, they took 2 VCR's and Nintendo and bunch of tapes. They took my tape, maybe we had too many VCR's, I don't care. I guess that would be, for some people, real stressful; I could care less. I collected the insurance and fixed the window it just doesn't matter at this point. (6:1313)

Let me just ask you this, sometimes during this waiting period time when there's a real focus on the candidate and everything, other wives that I've talked to, talk about they either try to do priority setting in their life because they only have so much energy and they have to conserve this. Is that something you've found in your life that you've done? (Investigator)

I think so. (Spouse)

Have you? (Investigator)

There's a lot of things I've had to let go. (Spouse) (16:546)

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