



January 2002

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

A.H. McCurry

Sandra Thomas

University of Tennessee-Knoxville, stomas@utk.edu

Follow this and additional works at: https://trace.tennessee.edu/utk_nurspubs



Part of the [Psychiatric and Mental Health Nursing Commons](#)

Recommended Citation

McCurry, A.H., & Thomas, S.P. (2002). A phenomenological study of the experience of the spouse of a heart transplant recipient. *Western Journal of Nursing Research*, 24, 180-194.

This Article is brought to you for free and open access by the Nursing at TRACE: Tennessee Research and Creative Exchange. It has been accepted for inclusion in Faculty Publications and Other Works -- Nursing by an authorized administrator of TRACE: Tennessee Research and Creative Exchange. For more information, please contact trace@utk.edu.

Western Journal of Nursing Research

<http://wjn.sagepub.com/>

Spouses' Experiences in Heart Transplantation

Alice H. McCurry and Sandra P. Thomas
West J Nurs Res 2002 24: 180
DOI: 10.1177/019394590202400207

The online version of this article can be found at:
<http://wjn.sagepub.com/content/24/2/180>

Published by:



<http://www.sagepublications.com>

On behalf of:



[Midwest Nursing Research Society](http://www.mnrsociety.org)

Additional services and information for *Western Journal of Nursing Research* can be found at:

Email Alerts: <http://wjn.sagepub.com/cgi/alerts>

Subscriptions: <http://wjn.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.com/journalsPermissions.nav>

Citations: <http://wjn.sagepub.com/content/24/2/180.refs.html>

Spouses' Experiences in Heart Transplantation

Alice H. McCurry
Sandra P. Thomas

In this phenomenological study, in-depth interviews were used to obtain a description of spouses' experiences in heart transplantation. Thematic analysis of the transcripts revealed four major, interrelated themes: death-life, vigilance, change, and gift. The experience was contextualized by the existential grounds of time and other people. Findings suggested that the changes inherent in the transplant experience have not been fully described in previous studies. The theme of death-life was dominant and pervasive in all interviews. As the threat of their husbands' deaths became less prominent, wives reported difficulty letting go of their vigilance. Although the most outstanding gift was that of the donor organ, spouses also gratefully remembered the donor and donor family. Time was not perceived as a boundary separating periods of the transplant experience; all aspects of time seemed to be woven seamlessly from the past through the present and into the future. Spouses were adamant that health care personnel should recognize them as coparticipants in the critical life event of cardiac transplantation.

Heart transplantation may have had its beginnings in ancient civilizations as body parts were experimentally grafted from person to person (Kesling, 1987). Not until the 20th century, however, did transplantation become an increasingly common treatment for end-stage cardiac disease (Mai, 1993). Currently, 312 transplant centers worldwide now perform heart transplants, with 3,175 performed in 2000. More than 90% of adult recipients required the transplant because of coronary artery disease or myopathy, with an additional 8% of the operations being performed as a result of valvular dysfunction, congenital problems, or retransplantation (*The Registry of the International Society for Heart and Lung Transplantation: Eighteenth Annual Report*, 2001). Candidates for transplantation are each required to name one primary support person who agrees to share both the transplant experience and the responsibilities for ongoing care in the immediate posttransplant period (for 6 weeks to several months). In most instances, the support persons are

Alice H. McCurry, Ph.D., R.N., Associate Professor, Carson-Newman College, Division of Nursing; Sandra P. Thomas, Ph.D., R.N., FAAN, Professor and Director, Ph.D. Program in Nursing, University of Tennessee, College of Nursing.

© 2002 Sage Publications

180

recipients' spouses. As the population of transplant recipient spouses increases, nursing must address the experience and care needs of this group.

IMPACT OF HEART TRANSPLANTATION ON THE SPOUSE OF THE RECIPIENT

Thousands of studies of various aspects of heart transplantation have been reported in professional journals during the past 20 years. Initial studies reflected concerns about surgical technique, control of infection and rejection, and improvement of medical and nursing care of the transplant recipient. More recent studies have begun to consider the effect of transplants on spouses and/or family of recipients, examining stressors, coping strategies, and quality-of-life issues, although no study has asked spouses to describe their experiences from a personal perspective (Canning, Dew, & Davidson, 1996; Collins, White-Williams, & Jalowiec, 1996).

Transplantation involves long waiting and recovery periods for potential candidates and their families. The transplant couple is often some distance away from their usual support system, residing in an apartment near the urban medical center during the period leading up to the transplant surgery and immediately thereafter. Beginning with the disease process that evokes the need for a heart transplant, potential transplant recipients and their families face periods of uncertainty and unpredictability that may dominate their lives and challenge their abilities to cope (Buse & Pieper, 1990; Mishel & Murdaugh, 1987). Waiting for a heart transplant has been described by the potential recipients and their spouses as "life on hold" (Williams, 1991). In many ways, this experience does not end with a return to pretransplant "normal" existence after the actual transplantation but continues to affect recipients and family members for an undetermined period of time (Mishel & Murdaugh, 1987).

Although few studies directly address the effect of this significant life experience on spouses, some information can be gleaned from studies of heart transplant recipients in which data were incidentally obtained from spouses. Such data were collected for the purpose of assessing factors that could affect recipients' pretransplant and posttransplant adjustment and compliance with the medical regimen. Results from the various studies are sometimes conflicting.

Mishel and Murdaugh (1987) studied pretransplant and posttransplant adjustment processes of heart transplant recipients and spouses or designated significant others. These authors described the posttransplant

experience for spouses as passage from immersing oneself in sustaining transplant candidates' lives for surgical intervention to negotiation of spouses' regained independence and the couples' future lives together. The authors described the posttransplant period of adjustment as a "dynamic interaction between the patient and the partner" (Mishel & Murdaugh, 1987, p. 336) comprised of interpersonal conflict as their future lives together are negotiated. Level of conflict and degree of family stability and cohesion reflect the success of negotiating the conflict. The authors noted that resolution of the negotiation is a gradual process without identified time limits.

Although this study presents valuable findings, some questions about the methodology remain. Study participants were members of various 12-week support groups conducted during a 2½-year period of data collection. Although meetings were attended by researchers, their level of participation was not described. Data were compiled by recording and transcribing researchers' memories of the meetings. For any needed clarification and/or verification, data were presented to other professional members of the support group rather than to participants. In addition, the time frame for the study is unclear: The support group included transplant candidates, transplant recipients, and spouses of candidates and recipients, but the researchers did not identify the stage of the experience for any of the study participants and did not specify what portion of the participants' experience was included.

Buse and Pieper (1990) studied the effect of cardiac transplantation on the lives, relationships, and perceived stress of recipients' spouses. In their study, 30 participants completed three questionnaires regarding their experiences. No difference was found between the spouses' stress scores for the pretransplant and posttransplant periods, suggesting continued stress throughout the experience. Collins (1994) investigated predictors of quality of life in spouses of heart transplant recipients and found that the spouses' physical health, coping ability and effectiveness, and family resources had strong positive relationships to quality of life. Of the participants, 65% reported high stress levels, and increased stress was found to be negatively related to coping and quality of life. Spouses employed outside the home had increased stress scores, possibly related to their perception of increased socioeconomic responsibility. Increased stress was negatively related to the spouses' life satisfaction and effective coping. In another study of spouse stressors while waiting for the transplant, Collins et al. (1996) found similar results. These two studies lend more support to the premise that this experience has a great impact on the lives and well-being of spouses.

McSweeney, Richards, Innerarity, Clark, and Mitchell (1995) used both a quality-of-life instrument and in-depth interviews to examine the quality of life of 10 heart transplant recipients and their spouses 1 to 5 years posttransplant. Study results showed perceived quality of life was lower for spouses than for recipients. Spouses discussed such issues as financial concerns, future plans and personal desires, stress, and secrets not previously shared with any of their health care personnel or members of the support group from which they were recruited for the study. Relationship concerns included recipients' posttransplant functional status, sexuality issues, other marital relationship concerns, burden of others needing assistance, and reaction of others to the transplant couple. This study presented little positive data regarding the posttransplant experience. The transplant situation had resulted in continued personal stress as well as feelings of resentment and guilt. Without knowledge of the specific interview questions, it is unclear whether the participants' responses were freely elicited or somehow inadvertently guided toward a focus on negative aspects of their experience.

In a study of adjustment and quality of life in transplant recipients, Keenan (1992) reported a significant relationship between psychological and marital adjustment of recipient and spouse. If the recipient reported increased distress, the spouse reported similar distress. According to Keenan (1992, p. 121-122),

The recipient and their [*sic*] partner should be considered "co-patients," as they are both coping with the lifelong impact of a serious condition. . . . Given the importance of family support to the patient's adjustment and quality of life, it is crucial that adequate attention be given to "caring for the caregiver."

The extended posttransplant period has received little attention from researchers. Although some authors (Hwang, 1996; Lough, 1986) asserted that family relationships return to "normal" over time, several studies (McSweeney et al., 1995; Mishel & Murdaugh, 1987) depict prolonged anxiety, changes in role function, and complicated relationship negotiations after the transplant.

To summarize extant literature, a few researchers have examined the impact on spouses of the transplantation experience, measuring variables such as stress and quality of life. There are conflicting findings regarding family dynamics during the posttransplant period. A nondirective interview methodology, permitting spouses to more fully describe the significant aspects of their lived experience, could clarify areas of ambiguity and provide a better understanding of their process of adaptation.

PURPOSE OF THE STUDY

The purpose of this study was to explore the experience of spouses of heart transplant recipients using a qualitative design. The method selected was existential phenomenology, as elucidated by Pollio, Henley, and Thompson (1997) and Thomas and Pollio (2002). The tenets of this approach are drawn largely from the philosophy of Maurice Merleau-Ponty (1962). Within existential phenomenology, what is sought is “a rigorous description of human life as it is lived and reflected upon in all its first-person concreteness, urgency, and ambiguity” (Pollio et al., 1997, p. 5). According to Merleau-Ponty (1962), perception is primary in describing the experience of human life. Phenomenologists use the figure-ground metaphor to depict their understanding of human experience as a dynamic process in which certain things stand out in one’s perception, whereas others recede into the background. The concept of figure-ground is often illustrated in textbooks by the combined figures of faces and vase or beautiful woman and witch. Both figure and ground are constantly present, although only one is prominent at a time against the background of the other.

What stands out as figural in a person’s experience are those things that are most meaningful to the person. For example, someone could enter a room and notice only the furniture, whereas another person notices the children, the food, or the artwork (Thomas & Pollio, 2002). A description of human experience would be incomplete, however, if there was no consideration of the context: the temporal and spatial elements of the lifeworld in which the experience takes place and the interpersonal connections that are important in the narratives of study participants. The description of the phenomenon, therefore, must include both focal (figural) aspects of lived experience and the contextual background against which it is perceived.

METHOD

Sample

Purposeful sampling was used to acquire a sample of spouses of transplant recipients whose transplants were done at least 3 months prior to the study. Spouses were English speaking and had no known cognitive impairment. The 7 participants were women whose ages at the time of their husbands’ transplants ranged from 43 to 65 years. The time since transplant ranged from 2.4 to 8.9 years, with an average of 4.3 years. Variability in

length of time since transplant was viewed as desirable rather than as a limitation of the study; in phenomenology, variation in experience “enhances the opportunity for the thematic structure of the phenomenon to reveal itself” (Hawthorne, 1988, p. 11). The couples had been married from less than 1 year to 47 years. Participant education ranged from 11 to 16 years. Male spouses were not intentionally excluded from the study, but none were accessible to the researcher during the specified data collection period. Each participant gave informed consent by reading the consent statement aloud at the beginning of the audiotaping. Prior to initiating the study, approval was received from the Institutional Review Board of the University of Tennessee.

Procedure

Prior to the beginning of data collection, the first author (McCurry) was interviewed by another member of the interdisciplinary phenomenology research group at the University of Tennessee. This “bracketing interview,” conducted for the purpose of sensitizing the researcher to her presuppositions concerning the nature and meaning of the phenomenon, was audiotaped, then transcribed and reviewed within the research group. The interview evoked and clarified thoughts and feelings not previously enunciated by the researcher, who is the spouse of a heart transplant recipient. Bracketing was a continuing process throughout the data analysis.

In-depth audiotaped interviews with participants began by asking, “Now that you have been the spouse of a heart transplant recipient for some time, what in that experience stands out for you?” Following this initial question, further questions were used only to facilitate further description. Interviews were concluded when participants indicated they had given complete descriptions of their experiences. Although a second interview is not precluded in the procedure outlined by Pollio et al. (1997), none of the participants felt it necessary. Transcripts were analyzed according to the steps prescribed in Pollio et al. (1997), which include independent examination of the text by the researchers, line-by-line and subsequent thematic analysis within the research group, and presentation of the findings to both the research group and at least one of the study participants for review. Validity of a phenomenological study is evaluated according to both methodological and experiential criteria (Pollio et al., 1997), the first criterion pertaining to rigorous adherence to the analytic procedure and the second criterion pertaining to the plausibility of the interpretation. In the following section, findings are reported with inclusion of sufficient verbatim quotes to indicate the

decision trail of the researchers and lend credence to the development of specific figural themes or patterns within the lived experience of participants.

FINDINGS

Overview of Thematic Structure

The central core of the experience is a profound awareness of death and of how close the transplant recipient was to death. This central theme is designated *death-life*. Three other themes under the aegis of this awareness of death and life are vigilance (watching and letting go), change (in recipient, self, faith, roles, and relationships), and gift (giving and receiving). Each theme is inextricably related to each of the other themes as these occur within a contextual ground defined by time and other people. With a variation in any theme, other themes also vary. For example, if there is movement toward death, vigilance is likely to increase with simultaneous variation in the spouses' awareness of change in transplant recipients, in roles and relationships, and in spouses' faith systems. When death becomes less figural, vigilance and change also recede in the participants' awareness. When the gift of the donor heart is received, awareness of impending death diminishes, renewed life becomes more figural, and awareness of change is noted in the recipient, the marital relationship, and the participants' faith systems. This reciprocal effect is true of all thematic configurations.

Contextual Grounds for the Experience

Time. All human life can be described as being experienced within the existential ground of time. Time assumes more significance, however, when it is seen as the line of demarcation of finite human existence and important relationships. Time is the context for the life of the marital dyad and for the trajectory of the heart disease of the husband. As stories unfolded, specific dates and measures of time (hours, days, weeks, years) were used to move the narrative along or to chronicle significant events. For example, one wife described a temporal sequence of 14 years of medical management, subsequent surgery for a cardiac valve replacement, diagnosis of heart failure 4 years later, and finally, the heart transplant the following year.

For the spouses of heart transplant recipients, time is a limited commodity that eventually can be extended only through successful cardiac

transplantation. As one wife related, "He had got really low. It was beginning to look like that, you know, it was the day's, a day's game, not week by week." Although the transplant granted extended time, the life of the recipient remained precarious, again perceived to be in jeopardy during threats of rejection. When becoming aware of the deaths of other transplant recipients, the spouse was concerned anew with time for her mate. As one spouse remarked, "So now it seems like there's a *new* time bomb starting up."

Other people. The spouse's experience also emerges from the context of the existential ground of others. Beginning with her relationship to her significant other, the marital partner, the spouse's experience expands to include family, friends, medical and nursing personnel, transplant donor and donor family, and a variety of other people who are involved in the life situation of the heart transplant recipient and the spouse. "Family" was often broadened to mean the other patients and wives at the apartment house where they lived awaiting donor hearts.

The ground of others was described in terms of contrasts such as caring-uncaring, supportive-nonsupportive, and helpful-unhelpful. Spouses expressed dissatisfaction with care given by some health care providers. They spoke about, or alluded to, their lack of knowledge about heart transplantation and their need to be given more detailed information by physicians and nurses. For example, one spouse reported, "And I always told them [the health care team], 'You give me the information, you give me the numbers that are pertinent, and I'll be a happy camper. Because if you don't, then I'm going to be upset.'"

Participants' stories were often presented in "we" language, beginning with such phrases as "when we first found out" and continuing through the experience's timetable to "when we got the transplant" and "we can live with it." One participant suggested how health care personnel should recognize this conjoined experience:

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

The donor and the donor's family are a concern, although they are unknown to the recipient and the spouse. One participant related her thoughts about the donor family as follows:

And you remember that family, I guess, as long as you live for what they have, what they have done. . . . And it comes at a time, uh, I mean they have to make that decision, and you know how broken hearted they are, and you wonder how they can even do it. It takes a very special person to . . . and I'm not sure that I would have been able to have done the same thing.

Another spouse described similar feelings as follows:

For the young person that had to give his life, we think about the family. And, uh, it's hard sometimes for (my husband) 'cause you can see him tear up when he thinks about the young person. We think it's a young man. That family, what they did was very unselfish, and uh, we have benefited from it.

Other people who did not effectively support the spouse were described as uncaring or worse. Of the health care staff who did not notify one spouse of critical changes in her husband's pretransplant health status, the spouse said, "They never had the decency to call me." In this same situation, the spouse confronted others who seemed to her to be endangering the bit of life left for her husband: "I finally went to the top officials. I told them, 'Listen, I didn't bring him up here for y'all to kill. I brought him to see if he needed a heart transplant.'"

Figural Themes of the Experience

In the following sections, we explicate the four figural themes—those aspects of the spouses' experiences that stood out most prominently against the existential grounds of time and other people.

Death and life. The spouses' experiences are centrally focused on an acute awareness of the nearness and reality of death. This awareness of the possibility of death crystallizes as ongoing pretransplant medical evaluation and follow-up inexorably move the transplant recipient ever closer to the inevitability of heart transplantation. The wives watch as their husbands' physical conditions deteriorate over time, with observable signs of approaching death becoming apparent.

One participant directly addressed this theme when asked the opening question about what stood out in her experience, as follows:

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

At a later point in the interview, she said, "You see your spouse laying there dying inches by inches." Another participant spoke of the fragility of her husband's life prior to the transplant, describing him as "one heartbeat away from death."

One participant had discussed the possibility of the recipient's death with family members who were initially opposed to the transplant. When family members expressed their fear that the recipient would die during or after the transplant, the participant reported, "I had to come right out and say, 'Well, he is going to die if he don't [*sic*] have it. And this is giving him a chance.'"

In this declaration to family members, the participant clearly verbalized the certainty of death without the transplant as well as the uncertainty of its success in continuing the recipient's life.

Repeated experiences of the ultimate reality of death were described. Posttransplant clinic visits were times of renewed fear: "And every time you go, you're just terrified, you know, that something's going to go wrong." While attending the funeral of a friend who had had an organ transplant and seemed well just days before her demise, one woman was "struck with the reality that you can be here one minute and gone the next minute." This pivotal awareness of the nearness of death results in vigilance, change, and an appreciation of the ongoing process of giving and receiving that occurs in this life situation.

Vigilance. The spouse's experience is one of vigilance. Vigilance includes paying attention to the transplant candidate's physical condition and often involves a protective stance. "Watching" increases as the potential of death comes near, as depicted in this participant's words:

And you listen to him breathe . . . making sure he's all right, and . . . it seemed like a 24-hour thing. . . . With his breathing, he would just not breathe for a while, and I'd have to punch him and get him to breathe."

Another participant spoke of her guilt if she slept longer than 15 or 20 minutes at a time during the pretransplant period: "I was constantly watching. And this was night and day."

Vigilance does not end with the transplant. One wife spoke of her difficulty in relaxing the vigilant stance: "I have had to learn a lot about relaxing how I feel . . . I guess it's the mother in you? You're just so anxious to make sure everything's right." Another wife expressed similar concerns, as follows: "I think the hardest thing [is] just learning to turn loose . . . and I'm not sure you ever get to where you just totally relax." A third participant admitted,

“But to this day, I do still watch him. And I guess I’ll go on watching him until . . . I can’t watch him no more . . . It is a way of life.”

Change. For the wives of heart transplant recipients, the experience is one of change. Differences in their husbands, their roles and relationships, and their faith experience were described. Changes in their husbands’ moods and behaviors could be distressing, although ascribed to the medications in many instances, as follows: “We had a few little temper tantrums with the prednisone. This man that was so laid back, so relaxed, never raised his voice, and suddenly, you know, I had this animal.”

Prednisone I have found can be a very mean, vicious drug, and it can also be very hard on marriages . . . because you have a lot of ups and downs as far as moods are concerned. . . . When you open your mouth, then your head is snapped off, and it’s all because you said, “Hi, honey, how are you?” You have to tell your heart it’s the medicine. It’s hard for your *heart* to accept that your loving husband is now snapping at you.

Spouses also described having to undertake functions, such as paying bills and running a farm, that were previously shared with their husbands. One woman reported having to “take over everything,” which caused her husband to have “tears running down his face to see me having to . . . do all the stuff usually that he would do.” To cope with the disruptive effects of change, spouses described behaviors such as solitary physical exercise. One spouse humorously suggested the need for a specific type of home, as follows: “So, I’ve told people that one way of getting through a transplant is to have a bi-level house. Have an upstairs and a downstairs. I don’t know how on earth people make it when they live on one level” [Laughing].

The transplant experience was also a time of a less tangible change—an increased awareness of and/or reliance on faith. One spouse told of an initial struggle to determine whether organ transplantation actually fit within her belief system and of her answered prayer that allowed her to go forward in the experience. Some participants described an unusual level of support from church members and times of desperate prayer as well as prayers of thanksgiving. Reliance on God was explicitly described, as follows: “You reach a point where you just turn everything over to God”; “I just pray about it. And I know he’s in good hands with the Lord”; “We know that everything is supposed to work the way God meant for it to be.”

Gift. In their experience of increased awareness of death and life surrounding their husbands’ heart transplantation, the spouses in this study also expressed awareness of giving and receiving. The most outstanding gift is

that of the donor organ. The spouses gratefully remember the donor and the donor family for the matchless gift that has been given. Having recognized the gift, spouses then verbalize the responsibility to use the gift to optimize the life that has been extended. Some spouses participated in research, based on a desire to help future transplant recipients and spouses. One spouse strongly expressed her desire to educate the community at large about the needs surrounding organ transplantation: "I have no doubt that through education, that's why he was given a longer life to live. . . . And of course that affects me, and I will be getting the word out."

This participant noted the absence of a support group for transplant recipients and their families at the time when her husband received his transplant. In helping to develop and maintain an active transplant support group, both the participant and her husband found "that's one way that we feel we can give back."

DISCUSSION

This study explored the complex human experience of spouses of heart transplant recipients. The meaning of the transplant experience for spouses was situated in time and others; from these existential grounds, themes of death and life, vigilance, change, and gift were figural. In previous studies of the spouses' experiences, the transplant experience is usually divided into three temporal periods that delineate boundaries of the specific part of the experience of interest to the researcher. These periods are usually designated as pretransplant, transplant, and posttransplant. For participants in this study, however, time is presented not as a boundary that separates parts of the experience but as an organizing context that becomes more figural when it appears to be more limited and scarce. As participants described their experiences, all aspects of time seemed to be woven seamlessly from the past through the present. Participants seemed unable to look at the present without also seeing both past and future simultaneously.

Other people are usually globally grouped together by quantitative researchers in the variable of "social support." The presence of a good support system has been positively correlated with recipient compliance, decreased anxiety and depression, and facilitation of recipients' coping during the transplant process (Dew et al., 1996; Hirth & Stewart, 1994; Keenan, 1992). The conceptualization of others as an aggregate variable of social support, however, seems more mechanistic and impersonal than the descriptions of others by spouses in this study. The key aspect of others' behavior that

mattered most to these spouses was personal concern shown for the welfare of the transplant recipient and the spouse. Consistent with Keenan's (1992) assertion, spouses in this study were adamant that health care personnel should recognize them as coparticipants in the transplant experience. They wanted the health care team to demonstrate warmth and caring in addition to giving them clinical information.

The theme of death and life was dominant both by its presence and its pervasiveness in all of the interviews. Although few in number, prior studies of the pretransplant period note that the primary stressor for the spouse is the possibility that the transplant candidate might die before a suitable donor heart becomes available (Collins et al., 1996; Mishel & Murdaugh, 1987; Williams, 1991). The theme of life and death is notably more prominent in this study than in previous studies in which bits of data were grouped and labeled as *stress*. Quantification of this basic existential theme seems to minimize its magnitude and importance in spouses' experiences of heart transplantation. The stasis and fear of the waiting period, characterized by Williams (1991) as "life on hold," might be expected to abate when the transplant is completed. Although posttransplant expressions of gratitude for longer life expectancy are abundant in this set of transcripts, spouses acknowledged a continued fear of complications that could lead to death.

Vigilance was closely tied to a fear of death. Watching became a way of life for spouses, who continually monitored recipients for signs of altered health. Spouses, already accustomed to constant observation prior to the transplant, were instructed to monitor their husbands closely after surgery for numerous signs of rejection and infection as part of their role as the designated posttransplant support persons. As the threat of death became less figural, spouses reported difficulty letting go of this hypervigilance to allow the recipients to resume a more normal life.

The changes inherent in the transplant experience have not been fully described in previous studies. These changes have been included in factors such as coping and quality of life in quantitative investigations. Descriptions provided by this set of participants much more richly depict changes in the marital relationship and roles. Whereas some previous research identified conflict as a significant factor in the posttransplant period, participants in this study always related the conflict to the increased dosage level of prednisone and other medications. Like the other themes, the theme of change is more apparent when there is a drawing near to death and a movement away from life. Change has the potential for being perceived as either a positive or a negative aspect of the transplant experience. This study revealed the

importance of spouses' faith systems in helping them to endure a critical life situation.

The fourth major theme in participant narratives was gift. Spouses spoke of the wonderful gift of extended life, of the donors and the donor families who made this possible by giving to someone else in an almost inconceivable situation of grief and personal loss. Some participants also expressed gratitude to God, and some expressed the compelling need to give in return for what they had received from others.

Given the scarcity of research focusing on the spouse of the heart transplant recipient, many opportunities for further study exist. How can spouses learn to relax their vigilance once their husbands have recuperated from surgery and survived the critical period for organ rejection? What kind of anticipatory guidance could better enable them to grapple with changes over time? What differences, if any, might be evident if phenomenological interviews were conducted with male spouses of heart transplant recipients? What aspects of their spouses' experience might be illuminated by interviewing the heart transplant recipients themselves?

Concurrent interviewing of both partners might provide an understanding of the transplant experience that is similar to or different from the results of this study. Phenomenological study of the children of transplant recipients would also enlighten nursing knowledge of this arena for care. Because the spouses in this study indicated some dissatisfaction with the care given by some health care personnel, it would be useful to conduct phenomenological studies of nurses and physicians who care for transplant recipients and their families. Studies of interventions, such as the provision of detailed anticipatory guidance and/or marital counseling prior to transplants, could provide knowledge needed to improve care for transplant recipients and their spouses.

REFERENCES

- Buse, S. M., & Pieper, B. (1990). Impact of cardiac transplantation on the spouse's life. *Heart and Lung, 19*, 641-648.
- Canning, R. D., Dew, M. A., & Davidson, S. (1996). Psychological distress among caregivers to heart transplant recipients. *Social Science and Medicine, 42*, 599-608.
- Collins, E. G. (1994). *Quality of life predictors: Heart transplant spouses*. Unpublished doctoral dissertation, Loyola University, Chicago.
- Collins, E. G., White-Williams, C., & Jalowiec, A. (1996). Spouse stressors while awaiting heart transplantation. *Heart and Lung, 25*, 4-13.
- Dew, M. A., Roth, L. H., Schulberg, H. C., Simmons, R. G., Kormos, R. L., Trzepacz, P. T., et al. (1996). Prevalence and predictors of depression and anxiety-related disorders during the year after heart transplantation. *General Hospital Psychiatry, 18*, 48S-61S.

- Hawthorne, M. C. (1988). *The human experience of reparation: A phenomenological investigation*. Unpublished doctoral dissertation, University of Tennessee, Knoxville.
- Hirth, A. M., & Stewart, M. J. (1994). Hope and social support as coping resources for adults waiting for cardiac transplantation. *Canadian Journal of Nursing Research*, 26(3), 31-47.
- Hwang, H. (1996). Patient and family adjustment to heart transplantation. *Progress in Cardiovascular Nursing*, 11(2), 16-18, 39.
- Keenan, M. (1992). *Adjustment issues and quality of life among heart transplant recipients*. Unpublished doctoral dissertation, Temple University, Philadelphia.
- Kesling, G. L. (1987). *The historical development of cardiac transplantation*. Unpublished doctoral dissertation, Texas Woman's University.
- Lough, M. E. (1986). Quality of life issues following heart transplantation. *Progress in Cardiovascular Nursing*, 1(4), 17-23.
- Mai, F. M. (1993). Psychiatric aspects of heart transplantation. *British Journal of Psychiatry*, 163, 285-292.
- McSweeney, J. C., Richards, R., Innerarity, S. A., Clark, A. P., & Mitchell, M. B. (1995). What about me? Spouses' quality of life after heart transplantation. *Journal of Transplant Coordination*, 5(2), 59-64.
- Merleau-Ponty, M. (1962). *The phenomenology of perception* (C. Smith, Trans.). Boston: Routledge Kegan Paul. (Original work published 1945)
- Mishel, M. H., & Murdaugh, C. L. (1987). Family adjustment to heart transplantation: Redesigning the dream. *Nursing Research*, 36(6), 332-338.
- Pollio, H. R., Henley, T., & Thompson, C. B. (1997). *The phenomenology of everyday life*. New York: Cambridge University Press.
- The Registry of the International Society for Heart and Lung Transplantation: Eighteenth annual report*. (2001). Retrieved October 15, 2001, from <http://www.ishlt.org>
- Thomas, S. P., & Pollio, H. R. (2002). *Listening to patients: A phenomenological approach to nursing research and practice*. New York: Springer.
- Williams, M. (1991). *Life on hold: A theory of spouse response to the waiting period prior to heart transplantation*. Unpublished doctoral dissertation, University of Arizona.