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DISSERTATION

RELATIONSHIPS IN TRANSITION: THE LIVED EXPERIENCE OF YOUNG
COUPLES SHIFTING FROM RENAL FAILURE TO POST-RENAL TRANSPLANT

Submitted by

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In partial fulfillment of the requirements

For the Degree of Doctor of Philosophy

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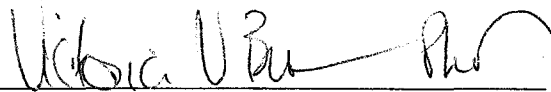
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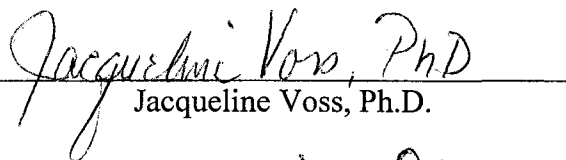
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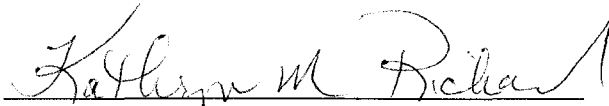
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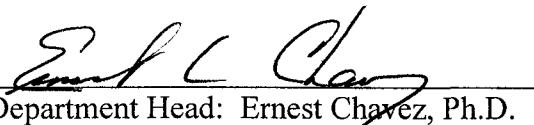
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ABSTRACT OF DISSERTATION

RELATIONSHIPS IN TRANSITION: THE LIVED EXPERIENCE OF YOUNG COUPLES SHIFTING FROM RENAL FAILURE TO POST-RENAL TRANSPLANT

Young people are not the typical image one has when imagining persons facing chronic illness, yet there are many young people who do encounter major health issues. The current literature addresses this issue somewhat, but neglects to examine the impact these serious health concerns might have on young couples, particularly early marriages. This study seeks to examine the impact of one such illness, End Stage Renal Disease (ESRD) and its treatments on the relationship between the ill spouse and his or her well partner. In an exploratory, phenomenological fashion, six couples are asked to share the intimate details of their experiences with ESRD and its impact on their relationships. Their stories and comments are included and analyzed to present a complex picture of the disease experience itself. This research indicates that the experience of a life-threatening, sometimes debilitating illness does not always have a detrimental effect on couples. In fact, positive impacts were noted by all couples. Suggestions for improvements in the research design, as well as suggestions for clinical practice for those working with young people facing ESRD are included in this study.

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End Stage Renal Disease

According to the National Kidney Foundation (NKF, 2001), there are currently 345,000 Americans being treated for Kidney Failure, technically known as End Stage Renal Disease (ESRD). They report that 100,000 of those are currently living with a functioning kidney transplant, while the remaining 245,000 are receiving dialysis treatment. Diabetes is listed by the NKF as the leading cause of kidney failure, accounting for 43 percent of new cases each year. The second leading cause is high blood pressure, followed by specific kidney diseases such as glomerulonephritis and cystic kidney disease. According to the NKF, chronic kidney disease is the 9th leading cause of death in the United States.

The major role of the kidneys is to filter waste products and excess fluid from the blood. In a healthy person, kidneys can filter approximately 200 quarts of fluid per day, excreting 2 quarts into urine while the remainder stays in the body (NKF, 2001). In addition, the kidneys serve a role in regulating blood pressure, controlling growth and controlling the production of red blood cells. When the kidneys cease to work properly, these systems fail to function normally, potentially leading to serious health consequences. Once the kidneys fall to a functioning level of 10-15 percent, kidney failure or ESRD is diagnosed. At this point, the wastes within the blood are not being filtered well enough to maintain normal functioning, leading to such symptoms as vomiting, weakness, confusion, loss of appetite, fatigue and difficulty concentrating.

Timeline of Modern Treatments for ESRD

Until the past 60 years or so, a person whose kidneys failed had few options and death was likely imminent. In fact, without current dialysis procedures, more than half a million patients worldwide would die within a few weeks (Yeun & Depner, 2000). The lifesaving technology that prevents this from happening developed over many years, culminating in the first “extracorporeal dialysis” being performed as a life-saving technique on a human occurring during World War II by Willem Kolff, a Dutch physician. The actual purpose and mechanism of dialysis will be described in a later section. Until the 1960s, dialysis could only be used for acute renal failure on a short-term basis, as the veins used had to be tied off to prevent excess bleeding after each treatment, thereby rendering them useless. In 1960, researchers in Seattle created an artificial means of strengthening veins by inserting plastic tubes (i.e., a “Scribner Shunt”) into the patient’s artery and vein. Since then, a more permanent and natural technique for strengthening veins was developed in Italy. This procedure, known as arteriovenous fistulas, involves connecting the patient’s natural vein to his or her artery. By doing so, the blood flow through this tube increases, and the walls of the fistula become stronger and thicker from increased use in order to withstand multiple needle insertions. The shunt remains a more viable treatment option for those with older or weaker veins and arteries, but both the shunt and the fistula provide patients with the ability to undergo years of life-saving therapy (Yeun & Depner, 2000).

Renal transplants have also improved dramatically over the past century. The first attempted kidney transplantations were recorded in 1906, and were rather unsuccessfully performed using organs from sheep, pigs, goats and primates without the

use of anti-rejection medications (NKF, 2001). After many years of research and surgical experimentation, the first successful kidney transplant was performed between identical twins at a hospital in Boston in 1954. New anti-rejection medications began to appear through the 1970s, and new developments continue to improve the patient's recovery and lessen rejection episodes. In 1995, Dr. Paul Teraski and his fellow researchers at UCLA reported that living-donor transplants from spouses of patients were just as successful as parent to child donations, and far better than cadaveric organs. Due to a shortage of organs available for transplantation, non-related living donor transplants began to be attempted more often, with positive results.

Hemodialysis

The most effective treatment for ESRD, aside from a kidney transplant, is dialysis (Yeun & Depner, 2000). The two forms of dialysis available to today's patients are Peritoneal Dialysis, a cleansing of the body's wastes using a solution transferred through the abdomen, and Hemodialysis, a cleansing of the body's waste by filtering the blood, generally through an artificially enlarged and strengthened vein in the patient's arm as described previously (Yeun & Depner, 2000).

Yeun and Depner (2000) reported that 62% of ESRD patients are on hemodialysis, and only 14% of ESRD patients use peritoneal dialysis. The remaining 24% have undergone kidney transplantation or choose to live without treatment. Given that hemodialysis is the most common form of treatment for ESRD, this paper will focus on psychosocial issues related to this form of dialysis. Dialysis targets uremic syndrome, which is the buildup of toxins in the blood. These toxins would normally be excreted through the kidneys as urine, but instead remain in the patient's body since the kidneys

cannot perform their normal functions. “Dialysis” is the passage of molecules in a solution through a semi-permeable membrane by the process of diffusion. This process includes a solvent that contains dissolved solutes, and the porous membrane through which some or all of the solutes move (Yeun & Depner, 2000). “Hemodialysis” then is just this process applied to blood, namely “dialysis of the blood.” Solute are added to the dialysate (the fluid in the dialysis machine) in order to reintroduce the balance of hormones and nutrients into the patient’s blood that would normally be maintained by his or her kidneys. This process works by inserting a needle into the venous section of the shunt or fistula, and one into the arterial section. The needles are attached to tubes that run through the dialysis machine. The blood moves out of the body through the arterial line, through a blood pump and then through a dialyzer, or artificial kidney. It is in this dialyzer that the diffusion of wastes and solutes takes place and the blood is cleansed. The wastes are removed, and the blood returns to the patient’s body through an air-detector (to ensure that no air bubbles re-enter the body) and the venous line (NKF, 2001).

The primary purpose of dialysis is renal replacement therapy or replacement of the renal excretory functions. However, kidneys also perform the task of producing hormones that act on distant organs within the body. Therefore, the secondary function is to replace hormones normally produced by the kidney (i.e. those regulating the thyroid, blood pressure and bone growth), in order to prevent bone degeneration, uncontrollable blood pressure, anemia and other possible risks of kidney failure (Yeun & Depner, 2000).

Kidney Transplant

The miracles of modern medicine continue to surpass even the most forward thinking individuals. Today, organ transplants occur on a daily basis and have become a somewhat routine surgery. As previously noted, one of the newest advances in renal transplantation is living donation, or a kidney donated by another living person. Kidney donors elect to have one of their healthy kidneys surgically removed and transplanted into their recipient, and must rely on their remaining kidney to provide the needed filtering processes for the remainder of their lives.

Ko and Delmonico (2000) reported that kidney transplant is the optimal therapy for ESRD. Yeun and Depner (2000) concurred, stating that while dialysis can effectively prolong a patient's life, transplants can restore a normal or near normal level of renal function without as high of a level of inconvenience to the patient as is associated with dialysis. However, there were approximately 400,000 people waiting for renal transplants in 1999, and only 7,000 cadaveric kidneys available for transplantation (McKay & Milford, 2000). Given this information, it is sadly unsurprising that 2,295 people died in the United States in 1998 while waiting for a life-saving organ transplant. Given the low availability of organs (demonstrated by the high mortality rate of those awaiting transplantation) and high need, as demonstrated by the extensive waiting list, there is a great need to increase the number of living donors available for renal transplant. McKay and Milford reported that since 1996, more than 160 transplant centers have routinely used kidneys from living, unrelated donors. In fact, more than 10% of transplants in the United States come from living, unrelated donors, the majority of whom are the spouses of the transplant recipient.

Kidney transplants are performed by first removing a kidney from the donor. The left kidney is generally taken, due to the longer renal vein attached to this kidney. The left kidney of the donor is generally placed on the right side, in the front section of the recipient's abdomen. The blood vessels of the new kidney are attached into the recipient's body. The surgery must be very precise, since transection of the veins in this area can lead to impotence or other surgical complications for either the donor or the recipient. Next, the bladder or ureter of the recipient is connected to the new kidney. Surgeons can confirm the successful operation of the newly transplanted kidney by observing the recipient's bladder filling with urine processed through the new organ (Ko & Delmonico, 2000).

Impact of ESRD treatments upon the patient

Unlike individuals waiting for other transplantable organs (e.g., hearts, lungs), patients with ESRD are not as likely to die from their disease since artificial means of filtering bodily waste are available. However, these forms of cleansing, in addition to being uncomfortable and time-consuming, change a patient's life and self-image in many ways. Shulman et al. (1987) reported that nearly 40% of patients receiving dialysis were diagnosable as clinically depressed. Their research suggested that this depression is often seen as normal or understandable, and thus rarely treated. Yeun and Depner (2000) noted that common responses to dialysis include denial, anger and negative attitudes towards the renal replacement therapy, and that these responses are often most intense in younger patients. Devins et al. (1997) found that maintenance dialysis as compared to successful transplantation provided patients with a limited opportunity for high quality of life, and that it was associated with higher levels of difficulty assimilating ESRD into a more

“normal lifestyle.” For example, the illness was more likely to be foremost in a patient’s mind and more time was likely to be spent in treatment for or coping with ESRD for dialysis patients than for patients with renal transplants.

For dialysis patients awaiting transplant, the delay between being placed on a donor list of people who qualify to receive a donated kidney and actually receiving an organ is often many years. While on dialysis, patients carry pagers or find other ways to maintain constant contact with the transplant center. Travel is restricted due to the difficulty of arranging for and finding dialysis in different areas of the country. Dialysis patients often spend up to 20 hours per week in treatment-related activities, including travel time to and from the clinic for at least three, 3-5 hour sessions per week. The time constraints, health concerns and restriction of freedoms all take a toll on the patient, but also significantly impacts the patient’s relationships and loved ones.

Many patients who are on dialysis will never receive a transplanted kidney due to various health factors and/or or personal convictions. Age can be a qualifying factor, as can overall health. Transplants cannot be performed if a patient has had a recent malignancy, is infected with HIV, is an active substance abuser or has an uncontrolled psychiatric disorder, among other reasons (McKay & Milford, 2000). In fact, 94% of transplant centers require some form of psychosocial evaluation in order to assess for successful transplant candidates (Levenson & Olbrisch, 1993). Young, otherwise healthy patients tend to be ideal candidates for transplant. (NKF, 2001). However, for those who do qualify for a transplant, the wait is often quite long. Even with relatives and friends who are willing to attempt living donation, the screening process is strict and tests can last for months or even years.

The long wait has a worthwhile payoff in the end according to Koch and Muthny (1991). They found that kidney transplants are preferable to dialysis in many areas of post-surgical functioning. They noted that patients who received a successful renal transplant reported more positive functioning in the areas of health, work and emotional well-being than those patients who remained on long-term dialysis. Christensen, *et al.* (2000) examined the aftereffects of a transplant upon the patient's mental health and found that for those who actively sought out health information following their transplant (i.e., those who were active in asking questions of their medical staff and researching appropriate diets or exercise plans), transplant recipients' levels of depression were substantially lower. In addition, Rudman, Gonzales and Borgida (1995) noted that patients who complied with their medical regimen post-transplant were more likely to rank life-satisfaction and health-satisfaction high and similar to one another. Zumbrunnen, Abraham and Gunn-Sechehaye (1989) found that although patients experienced fears of their bodies rejecting the new kidney, they also experienced great relief at being free of their reliance on a cumbersome machine for their survival, leading to a dramatic improvement in their overall quality of life.

Much of the research on ESRD, dialysis and transplant focuses on the physical and medical issues faced by renal patients. Unfortunately, this research has often neglected to address the patient's social environment and relationships. The experience of a chronic or long-term illness such as ESRD takes a toll not only on the well-being of the patient, but also on those people with whom the patient has significant relationships. Spouses, particularly, are impacted tremendously when their partner is diagnosed with a

serious health problem (Revenson, 1994; Smith, Redman, Burns & Sagert, 1985; Conley et al., 1981).

Impact of chronic illness on spousal relationships

Research on chronic illnesses such as rheumatoid arthritis, heart disease, multiple sclerosis and others provide a background for examining how the introduction of an illness into a marriage can impact the dynamics of that relationship.

Helgeson (1993) found that in most marital relationships composed of two healthy individuals, spouses alternated between providing and receiving support, as needed. However, at least in the initial adjustment to illness, the patient is far more likely to be the one receiving support and the spouse is more likely to be providing the support. While this makes sense when one spouse becomes ill, it can result in stress and lack of support for the healthy spouse. In addition, Carter and Carter (1994) noted that spouses of the chronically ill tended to report that the illness created more negative effects on the marriage than did the spouse who was diagnosed with the chronic medical condition. The negative emotional impact and feelings related to the intrusion of the illness into the marital relationship tend to be shared by both partners (Gritz, Wellisch, Siau & Want, 1990).

Since it is widely recognized that when a married person is ill, it is their spouse who serves as his/her main source of support (Revenson, 1994; Smith, Redman, Burns & Sagert, 1985; Conley et al., 1981), it is essential to facilitate a healthy, strong relationship between spouses in order to enhance the well-being of this primary relationship and the patient. Kalayjian (1989) noted that spouses of an ill partner often report their own feelings of depression, loneliness, and helplessness. Davis-Ali, Chesler and Chesney

(1994) noted that both spouses reported participating equally in the treatment process, but there was significantly more social support available to the patient than to the “well” spouse. The well spouse may report feelings of resentment or anger related to the time, energy and attention focused on the patient (Wilber, 1988; Williamson, Shaffer & Schulz, 1998). As it is often considered to be culturally unacceptable to express negative emotions about a loved one who is ill, these feelings of anger and resentment are likely to turn to guilt (Oberst & James, 1985).

Rolland (1994) noted that couples who are faced with long term health issues are often greatly challenged when it comes to developing and maintaining healthy communication skills. Farkas (1980) examined relationships in which one spouse was experiencing a chronic illness and discovered that many wives of men with chronic illnesses may tend to disregard their own physical and emotional needs in order to more fully focus their attention on or care for their husbands. Many of these women recognized rationally that they needed to care for themselves in order to care for their husbands, but were unable or unwilling to change their behaviors. Perhaps following from this tendency, Hafstrom and Schram (1984) noted that having a chronically ill husband negatively impacts a wife’s self-reported marital satisfaction. Similar findings by Wilson (1991) suggest that men may perform similar behaviors when their wives are ill. She noted that husbands often engage in “buffering,” or attempting to filter information to provide a shield from the potential pain and suffering their wives might experience if they knew how difficult or serious the situation really was. Davis-Ali, Chesler and Chesney (1994) found that “well” spouses tend to worry more about the patient’s future than the patient him- or herself. Spouses of the chronically ill may also

wish to minimize the health problems of their partners in order to promote optimism or an image of health to the outside world. Heijmans, DeRidder and Bensing (1999) found that, however unintentionally, this may give their ill spouse the impression of not being taken seriously and damage the relationship.

Rolland (1994) suggested that couples are often so shocked or terrified when they receive the initial diagnosis of a serious illness that they react either by pulling away from each other or clinging together in a fused manner. Parker (1993) presents a more positive light on chronic illness and disability within a marriage, citing that while all couples noted some negative impacts on their lives together, many of those same couples believed that the shared experience actually brought them closer together as a couple and strengthened their relationship. In a similar vein, Rait, Lederberg, Coyle et al. (1989) noted that many couples use the experience of a long-term illness in a positive manner, establishing better communication skills and learning to value every moment with each other as life partners.

Much of the research on the effects of chronic illness within a marital relationship focuses on couples in middle-adulthood and beyond (Devins et al., 1997; Parker, 1993). This makes sense, given the demographic occurrence of chronic illness within the United States (CDC, 1996). As people age, bodies tend to be more susceptible to illness. Chronic illnesses such as heart disease, Alzheimer's and strokes tend to occur in older populations. What about when a chronic illness affects a younger population?

Impact of chronic illness on young relationships

When one considers that the well-being of patients and spouses is benefited so greatly by a healthy sense of mutual support and by the strength of the relationship, what

might one expect to happen in a young relationship? Spouses who promise themselves to one another “in sickness and in health” rarely expect a life-threatening disease to test that promise early in that relationship, when both partners are relatively young and the relationship is in its early stages.

Given that Revenson and Majerovitz’s (1991) research suggests the quality of the marital relationship prior to illness onset is an important resource for couples coping with serious illness, a young couple might be at particular risk if their relationship is fairly new and untested. If a marriage is young and the partners have not yet learned to trust and rely on their spouse, it is likely that the introduction of a serious health threat could cause significant distress for the members of that couple. Similarly, Peteet and Greenberg (1995) identified types of couples who are at greatly increased risk for marital distress and difficulty due to long-term illness. One of those “at risk” groups is made up of couples who are “immature.” These include those in which the ties between partners have not yet been tested and in which partners are either not capable of or unskilled at providing mutual support and nurturance. Therefore, couples in young relationships who are faced with long-term illness in one partner are at particular risk for difficulties within their relationship.

Revenson (1994) noted that spouses of chronically ill partners have a dual role, that of primary provider of support to their partner and that of a family member who needs support in coping with the illness of a loved one. Parker (1993) reported on the guilt many ill spouses feel about the difficulties their conditions placed on their spouses’ lives. Obviously, both spouses are greatly impacted by the introduction of a chronic illness into their marital relationship. However, in these studies of the partners involved

and the personal impacts of the diseases, the methodological approach fails to address the relationship itself. How do interactions change? How does sexuality within the marriage change? How do involvements with the outside world change and impact the marital relationship? How is hope for the future affected, as these couples move through young adulthood coping with a chronic illness that may be foreign to their original expectations?

Rolland (1994) suggested that young couples are impacted greatly because most of their dreams, both individually and as a couple, have yet to be realized. He noted that many couples reported “an acute sense of loss or being robbed” (p. 330). In addition, he reported that these couples are somewhat out of sync with their peers, as most other young couples are not facing chronic health issues. Therefore, the members of this young couple are more likely to become socially isolated and feel disconnected from their peer groups.

Impact of cancer on relationships

Although the experience of receiving a diagnosis of cancer and undergoing the subsequent treatments is qualitatively different than the experience of living with ESRD, dialysis, and transplant, there are many similarities. The time spent in chemotherapy and recovery could be likened to time spent in dialysis, with significant time commitments required from both partners within a marriage. In addition, both illnesses are life-threatening and spouses must live with the ever-present knowledge of their own mortality within the relationship. Henderson (1997) reported that the experience of cancer often includes long term physical effects, fear of recurrence, and a chronic uncertainty of life. Koocher and O'Malley (1981) suggested that survivors of cancer may be happy within their marriages, but will often worry about the fertility of the survivor and other sexual

issues that might arise following surgery and other treatments. The fears and discomfort associated with cancer and ESRD make the two seemingly different illnesses much more similar in actual experience.

Rolland (1994) expressed the fears associated with cancer well as he stated, “Cancers in remission may not necessitate day-to-day pragmatic issues, but the undercurrent of threatened loss can nonetheless invade all aspects of couples’ lives” (p. 328). Skerret’s (1998) examination of couples facing cancer noted that the most resilient couples were those who had made a concerted effort to separate the disease from the relationship. For example, they made times and spaces in their lives in which the disease could not and would not be the primary focus, thereby ensuring that their relationship remained a priority and did not become subsumed by concerns about cancer. These couples also made a concerted effort to rely on one another in order to cope with the disease, without trying to face their fears alone.

Wilber (1988) suggested that the problems of the long-term support person are often not well understood when his or her spouse is undergoing treatment for cancer. He stated that it is often not so difficult for a support person (i.e., the “well spouse”) to deal with the behavioral aspects of caring for his or her spouse. For example, the caregiver can rearrange his or her schedule, perform more household chores and drive his or her spouse to the doctor’s office. However, there are far more difficult issues to be faced. Wilber stated that it is more difficult to cope with the inner turmoil and the emotional and psychological issues that arise when caring for an ill spouse. The caregiver may recognize that his or her problems pale in comparison to what the patient is coping with, and therefore disregard or ignore those problems until they build up to an unbearable

level. The caregiver may feel anger or jealousy towards his or her loved one for the attention she or he requires, and then react with feelings of guilt when that anger comes to the surface.

The issues of communication and interpersonal interactions between members of the couple are significant in helping both partners cope with the illness experience of cancer. Hannum et al. (1991) found that it was actually interpersonal variables, such as the manner in which members of the couple interacted with each other, that were more important in determining the effectiveness of each members' coping, rather than the individual coping styles of each partner. In addition, the "buffering" attempts by spouses to protect the person living with cancer, similar to those mentioned in the discussion of chronic illnesses, are not always negative. Hagedoorn et al. (2000) noted that overprotection and buffering were only seen as negatively impacting marital satisfaction when the patient was experiencing high levels of physical limitations or psychological distress. Therefore, if the patient is functioning without high levels of stress or limitations, perhaps "buffering" can help him or her maintain that relatively stable level of functioning.

Similarly, the patient's health and overall level of distress may be tied to his or her level of satisfaction within the marriage. Weihs, Enright, Howe and Simmens (1999) found that a couple's level of marital satisfaction early in the recovery process was a better predictor of future distress than was their actual level of distress early in the process of recovery. This finding suggests that marital satisfaction is a key variable in an overall sense of well-being. In contrast, Baider, et al. (1998) found that family, including marital, cohesion had very little impact upon the level of distress experienced by the

spouse of the patient. Their research suggested that family cohesion did have a somewhat beneficial or positive effect upon the patient's level of distress, but after a period of two years, the level of initial family cohesion had little to no impact upon either spouses' level of distress. It seems that there is currently no general consensus on the actual effect of spousal cohesion or marital satisfaction upon either spouses' overall distress.

The level of physical intimacy between partners is also an important factor when considering cancer's impact upon couples. Body image is often affected, and King et al. (2001) noted that this is a particular issue for married women following mastectomy. Leiber et al. (1976) found that couples in which one member had received chemotherapy treatment were more likely to report an increased desire for physical closeness following completion of treatment, but a decreased desire for sexual intercourse. The demonstration of affection in a physical, yet non-sexual manner, became critical and healing for these couples.

As noted previously in the discussion of chronic illnesses and relationships, some couples may actually gain strength from surviving or coping with such an intense experience together. Fuller and Swensen (1993) found that those couples facing cancer who were in a "postconformist" stage of development, or who were less interested in what the outside world believed they should do or be, were more likely to actually gain strength as a couple from the illness experience.

Impact of cancer on young relationships

Although there is an extensive body of literature examining couples and the impact of cancer upon marital relationships (see Carlson, Bultz, Speca & St-Pierre, 2000;

Hoskins, Haber & Budin, 2001; Manne, 1994; Schmaling & Sher-Goldman, 2000) for reviews of the literature), very few studies focus specifically on young couples. Skerret (1998) found that couples who were at the most risk for developing relationship problems were those who had not been married as long as the other couples studied. She reported that younger couples reported stronger feelings of shock, fear and loss of control than did older couples. King, et al. (2001) noted that younger women facing breast cancer tended to report lower levels of satisfaction on quality of life measures than older women, and that the negative impact on a woman's body image following mastectomy tended to be greatest among married women in general, but particularly young married women. This heightened concern over the female partner's body image is likely to be an issue within the young couple's life, particularly affecting intimacy and sexual behavior or comfort.

Impact of dialysis and renal transplant on relationships

One might question how such a dramatic change in lifestyle, caused by ESRD, would affect a marital relationship. In contrast to patients with other chronic illnesses, persons who qualify for and are hoping for a transplant and an end to the frustrations and limitations of dialysis are in a much different situation. However, ESRD is a major illness and couples facing this disease face many of the same issues as other couples facing chronic illnesses. Conley et al. (1981) suggested that persons undergoing dialysis who were married or younger and single with strong parental support tended to have higher levels of social functioning than those without such stable means of support. Conley et al.'s research indicated that this might be due to an avoidance of forming new relationships once a patient is undergoing dialysis. Similarly, Hooper's (1994) research found that patients who were not involved in long-term relationships tended to experience

difficulties forming close relationships and tended to cease sexual activity until they received a transplant.

Glass, Fielding, Evans and Ashcroft (1987) found that there were significant differences between the sexual functioning of dialysis and transplant patients. They found that dialysis patients reported a lower frequency of sexual intercourse, and men undergoing dialysis reported more difficulties gaining and maintaining erections than men who received kidney transplants. In addition, they reported that more marital difficulties in general were reported by participants who were undergoing dialysis than those who had received transplants.

Hope and optimism, particularly, are factors that may be impacted uniquely by couples facing ESRD, as the prospect of transplant is often far on the horizon. While a kidney transplant is not a cure for ESRD, but instead a treatment that must be continually monitored and cared for, it is still far less intrusive into one's life than is dialysis.

Frazier, Davis-Ali and Dahl (1996) reported that while ESRD patients experienced higher overall levels of stress, spouses were equally or more stressed than the patients on some issues. In addition, they found that patients reported more depression than spouses, and that spouses who reported less personal stress were more helpful to their recovering spouse.

Impact of dialysis and renal transplant on young relationships

Peven and Shulman (1999) state that early in a marriage, an erotic attraction is necessary to facilitate a healthy relationship. This presents an obvious difficulty for young couples in which one member is too ill to fulfill the physical demands of that attraction. The exhaustion of dialysis, coupled with the inevitable, unpredictable health

issues that will arise with ESRD may affect the physical and emotional energy of both members of the couple, thus challenging them in the very basic elements of their relationship. It could easily be surmised from these patterns that the introduction of a life-threatening illness into a marriage at this stage would cause a significant disturbance and change the manner in which the two spouses interact with one another. As previously noted, research on the effects of chronic illness on the marital relationship found that this major change is likely to create a deep impact upon the relationship and the roles within that relationship played by each partner.

Very little research has examined how life-altering experiences such as ESRD, dialysis and renal transplant impact relationships in young couples. However, Artinian (1990) examined the issue of ESRD in younger couples and found that the roles anticipated in early marriage cannot be taken for granted in a couple facing dialysis. As stated by Artinian, “when young couples marry, they expect that each will assume personal responsibility for self-care. When one of the young adults is a dialysis patient, this cannot be assumed” (p. 51-52). This research focused on courtship and marriage between young people when one member of the couple was undergoing dialysis, and found that dialysis interferes greatly with these processes, as might be expected given the time and energy the “sick” partner must devote to dialyzing.

Artinian (1990) found that many young couples did not handle the dependency issues or the uncertainty well. She noted that many of the marital difficulties stemmed from resentment over extra work on the part of the well spouse or worry about the survival of the spouse undergoing dialysis treatment. Artinian explored the question of ESRD on young couples and found that many couples consider divorce or actually

divorce in the face of such uncertainty and stress. Common complaints noted by Artinian on the part of the spouse undergoing dialysis included being treated like a child, such as perceiving oneself as having reduced responsibilities, capabilities or trust, and feeling a lack of support for the crises she or he is facing due to ESRD. Artinian's research suggests that the "sick" partner has no choice about his or her lifestyle or role while undergoing dialysis treatment, while the "well" partner can choose to lead a life outside of the realm of ESRD, even the choice of leaving the relationship and health issues behind.

Following a renal transplant, the fear of organ rejection eliminates a feeling of complete health and well-being, and the anti-rejection medications come with their own unappealing side effects (Kong & Molassiotis, 1999; Viswanathan, 1992). In fact, Kong and Molassiotis found that life after a renal transplant is often marked by a fear of rejection, difficulties complying with medication regimens, fear of infection, financial concerns and uncertainty about the future.

As previously noted, young patients tend to qualify for renal transplantation, and can be placed on transplant lists waiting for cadaveric donors or find friends or relatives willing to attempt living donation. Much like chronic illness, major surgery is not often expected or anticipated in young people. Therefore, similar to dialysis, it is likely to fall outside of the realm of expected experiences in a marriage between relatively young individuals. How does the surgery, or even the prospect of this surgery, affect the relationship between young spouses? The surgery and related events are not inexpensive, and patients and their spouses are often faced with financial burdens related to treatment. This could be especially troublesome for young couples, given that Horwitz, McLaughlin

and White (1997) found that financial need is associated with more problematic and less supportive partner relationships in young couples. In the face of all of these potentially stressful circumstances, young couples may be particularly at risk. It seems that in order to provide the needed support to this often ignored segment of our society, the young chronically ill, researchers should examine the impact of such significant medical difficulties upon the young people who are actually surviving the daily experiences of serious illness.

Examining the shift from dialysis to transplant

The transition between dialysis and post-transplant life is a major shift in lifestyle for most couples. What impact does it have to go from a debilitating and time-consuming treatment to a life post-transplant, when one's illness no longer functions as the major focus of one's day? Again, in young couples who have faced dialysis and major surgery, partners must adjust to this new phase in their lives together and face yet another major change within the young relationship.

Role changes within the marital relationships first induced by the introduction of dialysis are then changed again as partners try to adjust to yet another significant life event. Helgeson (1993) found that after the initial impact of a chronic illness on a marital relationship was over, most spouses subjectively reported that their boundaries and roles were back to pre-illness levels. In contrast, Helgeson's objective measures to compare actual role shifts and division of labor found that the well spouse continued to provide more support and received less support and help than prior to the illness. Schover, Novic, Steinmuller, and Goormastic (1990) noted somewhat similar findings in that levels of sexual desire increased significantly post-transplant, but sexual activity and overall

sexual satisfaction remained relatively unchanged three years following the transplant. In contrast, Abram, Hester, Sheridan, and Epstein (1975) reported that 40% of the men they studied who received a kidney transplant noted an increase in sexual potency after the transplant. These findings all serve to provide the researcher with information about the overall impact of dialysis and renal transplant upon individuals and the relationship between the spouses, while omitting actual examination of the interpersonal aspects of marriage themselves.

Therefore, this study sought to examine the effect upon a relationship when one member of the couple received a kidney transplant after experiencing the diagnosis of ESRD and its treatments. Of particular interest is the effect upon relatively young couples, who statistically and socially would not be expected to deal with such a dramatic and even traumatic event so early in their lives and relationships. Given the relative dearth of information within this area, the present study focused on gathering a full picture of each spouse's experiences and viewpoints on changes within the relationship using a phenomenological interview process. The research focused on both partners' impressions and experiences with the following major areas of life and relationships, and particularly upon how they were impacted by the transition from diagnosis to post-transplant: sexuality, communication, social and family relationships, division of labor and overall relationship well-being.

Methodology

The Phenomenological Method

Creswell (1998) describes the phenomenological method as one that enables the researcher to focus on the lived experiences of the individuals being studied. This is a qualitative technique that forces the researcher to step back from his or her own constructions of reality and allows the participants to tell their story and share their own experiences fully (Jones, 1985). Given the exploratory nature of the present study, the phenomenological method was selected in order to allow the researcher to delve into the actual experiences, emotions and perceptions of persons who had experienced the transition from dialysis to post-transplant (Miles & Huberman, 1994). Participants in this study were asked open-ended, non-leading questions that examined their experience. They were allowed to use their own words and asked to describe their experiences beyond the scope of what might be tapped by a short survey or quantitative questionnaire.

Researcher's Perspective

Conducting an effective qualitative analysis requires that the researcher be aware of any potential biases and preconceptions he or she might hold prior to beginning the research. While it is difficult for an individual to hold a completely neutral stance without the interference of prior experience or beliefs, the researcher must at least address and maintain awareness of those potential biases.

My personal experience with ESRD and dialysis has been an unexpected roller-coaster over the past few years. Shortly after becoming interested in the general field of

health psychology, I was surprised by a health crisis in my own life when my husband, a very healthy and active young man, was diagnosed with ESRD. We fought the inevitable transition from simply monitoring his kidney failure to beginning dialysis. He had several friends and family members volunteer to be living donors, but none of them could pass the stringent qualification requirements before his kidneys were deteriorated to the point when he could no longer survive off of dialysis. Given his size (picture an offensive line coach and former player), he was unable to consider the less intrusive peritoneal dialysis. Instead, he would have to attend a hemodialysis clinic in a nearby town, three days per week for five hours per session. We had an amazing physician who worked with us through the process, and incredibly kind and understanding nurses and technicians at the dialysis clinic where we eventually began spending upwards of fifteen hours per week to keep my husband alive.

My husband received his new kidney from a family friend fifteen months after beginning dialysis. The anticipation and the uncertainty involved in waiting for a transplant were excruciating, yet the payoff was enormous. The surgery was terrifying for me, for my husband, and for our donor, but the dramatic change in lifestyle from living as a “sick couple” to a life of relative “normality” has been far more than worth the fear. Thus, my interests stem from my own experiences, but have grown beyond my individual situation. In conducting this research, I hoped to encounter and learn from other young couples who have coped with this process of transition between dialysis and transplant. My goals are to increase and improve the literature available on this topic, as well as to inform and teach those in clinical settings about the many issues this often “hidden population” faces.

In order to avoid the possible biasing of my interpretations of the qualitative data collected, I underwent a “bracketing interview” prior to commencing data collection for this study. In this interview, a master’s-level student in social work first interviewed me using the same questions and techniques as I was to later use in actual data collection. From the information gathered in this setting, I was able to gain insight about my own possible biases and expectations and was therefore more able to look more objectively at the data collected later from participants. My experiences were quite similar to some of the participants, but there was more diversity in the reports than I initially anticipated. I could relate to many of the concerns about mortality and other fears, but often struggled to maintain my “researcher’s distance” when analyzing data that was less in synch with my own experiences. Using the input from my colleagues who assisted with data coding was instrumental in allowing me to maintain the necessary distance in these cases.

Creswell (1998) defines the phenomenological term “epoche” as the process by which researchers contain their own perceptions and experiences with the subject of interest in order to avoid biasing both the responses of participants and the later analysis of those responses. Given that the basic tenets of the methodology in this type of research require communication and dialogue between the interviewer and the participant, each entering the interaction with their own life experiences, it is essential to do one’s utmost to separate the interviewer’s own perceptions, experiences and biases from the interview and analytical process. In order to do this, questions were phrased in an open-ended, non-judgmental fashion to eliminate the expectation of a particular response bias. For example, a question such as “How did you cope with the increased responsibility you held when your spouse was on dialysis?” would instead be asked as

“Please describe your experiences with marital roles and responsibilities when your spouse was on dialysis.” The second question allows the respondent to answer in any way that honestly describes his or her experiences, while the former question implies that the “correct” answer would be one involving definite role changes, negative emotion and coping strategies. Questions examined the partners’ experiences from pre-diagnosis of ESRD, through diagnosis, dialysis and other treatments to the relationship post-renal transplant. Responses to oral interviews were summarized and reflected back to the participants to allow for clarification and ensure that the interviewer understood the responses correctly.

Participants

Participants included 6 couples (comprised of 12 individuals) who had recently (within the last 10 years) experienced one partner shifting from diagnosis of ESRD to post-renal-transplant. Both members of the couples were under the age of 40 at the time of transplant (to maintain a population from an age range in which chronic illness is less common), and were married for at least 6 months but no more than 10 years prior to transplant. There were no other major chronic illnesses present in either partner.

Sampling

The methods of recruiting participants changed dramatically throughout the course of the study. Participants were originally to be selected based upon their response to an inquiry placed by the social worker at a large regional transplant center. The social worker contacted persons who meet inclusion criteria and informed them of the study, while ensuring their awareness of the voluntary nature of participation. Those potential participants who agreed to be interviewed were provided contact information. Potential

participants called the investigator to arrange for an interview time. This format of interview was the initially proposed and selected mean by which data was to be collected. However, the researcher experienced significant difficulty obtaining an adequate sample by this method. After 13 months of recruitment, only one couple was interviewed by the above means. Therefore, a broader sampling appeared to be necessary. The researcher gained review-board approval to use telephone interviews rather than in-person interviews, and was able to recruit another couple by this means. However, the interview never occurred, given scheduling difficulties and the couple's apparent lack of interest in participating after their initial commitment. At that point, review-board approval was gained in order to allow recruitment through a well-known transplant website and to permit a written version of the interview questions (see Appendix C), rather than a verbal interview format.

Given the difficulty of obtaining an adequate local sample with the aforementioned procedure, participants were recruited through a message posted on the National Kidney Foundation's Transplant Recipient Message Board on the NKF webpage (see Appendix D). Potential participants were provided with the researcher's electronic mail address and asked to express their desire to participate by writing to the researcher. Potential participants were offered the choice of a written interview format or a telephone interview, at the researcher's expense. No participants selected a telephone interview. They were encouraged to complete this written version as thoroughly as possible and in as much detail as they are able to do. In addition, they were encouraged to complete the questionnaire in private, without input from their spouse. These measures were requested in order to provide the researcher with a clear and understandable picture of the

experiences they encountered individually and as a couple through the process of ESRD and its treatments.

Data Collection

When potential participants contacted the primary investigator, each was provided with a description of the study, the tasks involved in participation, and the voluntary nature of participation within this research. A 90-minute appointment was arranged for those selecting an in-person interview to take place (90-minutes per individual) as soon as possible following the initial contact. Upon arriving at the location of the interview, participants were reminded that participation was voluntary and that they had the right to terminate the interview at any time and to refuse to answer any questions that made them feel uncomfortable. Participants were asked to sign the informed consent form prior to the interview (see Appendix E), and then the tape recorder was turned on and the interview began.

Each partner participated in a confidential, audio-taped interview with a research assistant, who was a Master's level student well-trained in clinical skills. Each interview began with a request for information regarding the patient's initial diagnosis, dates of dialysis and transplant, length of marriage and current health status. Following the preliminary information, the interviewer asked broad, open-ended questions designed to gather information about the participants' relationships and any changes, strengths or weaknesses throughout the process of dialysis and transplant.

The interviews were guided by the major questions being asked by this study, regarding sexuality, communication, social and family relationships, division of labor and overall relationship well-being. The interviewer took care to complete questioning in an

open-ended manner in order to avoid guiding or biasing the interview. She employed reflection, probes, and requests for clarification in order to gain a comprehensive understanding of the participant's experience and story. In order to ensure that she had information in all areas of the study, the interviewer employed a visual representation of areas to question, for her own use and clarification (Appendix B).

If participants chose to complete a written version of the interview instead of an oral interview, they were sent a copy of the questions by email, fax or mail as per their preference. They communicated with the researcher via email regarding any questions they had about the study and the questionnaire, and returned their informed consent paperwork by mail or fax at their discretion. Three of the couples emailed their responses to the questionnaire to the researcher, despite warnings that email is not a confidential medium of communication. All participants were offered or provided with return postage and requested to complete the written interview in private, without feedback from their spouse in order to provide the most accurate and unbiased results possible. The researcher gained permission to contact participants with questions later if she was unclear about a particular statement or description. Two participants were contacted later to clarify small issues. All interviews were transcribed or retyped to ensure accurate and adequate data analysis, although names of participants or others who might later be identifiable as well as names of locations were removed from the transcribed text in order to guarantee confidentiality.

Data Analysis

Data was analyzed in several stages, according to the recommendations of Creswell (1998), Moustakas (1994) and Patton (1990).

- 1) The researcher reviewed all transcribed interviews. Information not relevant to the experience of ESRD and its treatment was eliminated from further analysis.
- 2) The researcher identified significant statements from each participant (i.e. “horizontalization”) and treated all statements with equal value.
- 3) The significant statements were formulated into meaning clusters.
- 4) The meaning clusters were combined into themes.
- 5) The researcher then integrated the themes into a narrative description of the lived experience of ESRD and the treatments for it, namely the transition from diagnosis to post-transplant and its impact upon marital relationships. The narrative description incorporates both “textural” and “structural” descriptions, (i.e., what was experienced and how it was experienced). At this level, the text presents a summary of the underlying, universal (within the context of the participants studied) experience of the transition from dialysis to post-transplant as described by the interviewees.

The themes that emerged from the analysis of these interviews were then summarized within the context of the five original research areas (communication, sexuality, social and family relationships, division of labor and overall relationship well-being).

Reliability and Validity

In order to promote reliable and valid results, the researcher used reflexivity, described by Patton (1990) as a process to examine one’s own influence upon data collection, analysis and presentation, in order to assess her impact and behavioral homogeneity

throughout the interviews. In addition, the investigator herself as well as two doctoral-level assistants re-coded the data from the interviews multiple times in order to examine the replicability of the data analysis. Written and oral interviews were compared to ensure that no major differences in themes or content occurred, and all data coders agreed that the basic content was similar between the two formats. However, the depth of material gained from the verbal interviews was significantly greater, given the availability of probes and clarification in this format rather than the more impersonal nature of the written interview format.

Introduction to the Participants

Participating Couples

Ann and Brian have been married for ten years. Ann was unexpectedly diagnosed with ESRD less than two years prior to the study, and she started dialysis approximately one year later. She and Brian worked together to establish a life around her dialysis treatments, and Ann received a kidney from a family member five months later. They participated in the study just 3 months after Ann's transplant. Both spouses were currently healthy at the time of the study, and they completed a written version of the interview. Brian was 36 years old and Ann was 34 years old as they completed the questionnaire.

Carol and David have been married for 3.5 years. Carol was diagnosed with ESRD just two years after they were married, and although dialysis was not required, she did receive a kidney from a cadaveric donor just one year after her diagnosis. Carol received her kidney transplant approximately 7 months prior to participation in the study. Both spouses were healthy at the time of the study, although Carol had recently suffered a broken limb. At the time of their participation in the study, Carol was 30 years old and Brian was 34 years old. Carol and David also completed the written version of the interview.

Erica and Frank have been married for four years. Frank was diagnosed with ESRD just six months after their wedding, and they coped with dialysis as a couple for approximately 16 months, starting five months after his diagnosis. At the end of that

time, Frank received a donated kidney from a family friend. Both spouses were healthy at the time of the study. At the time of their participation in the written version of the interview, Erica was 30 years old and Frank was 33 years old.

Gail and Heath have been married for 14 years. Five years ago, Heath was diagnosed with ESRD and underwent dialysis treatments for just one month before receiving a kidney from his wife Gail. Both spouses were healthy at the time of the study, although Heath was suffering from some mild heart problems. At the time of their participation in the written version of the interview questions, Gail was 38 years old and Heath was 40 years old.

Iris and John have been married for 8 years. Iris was diagnosed with ESRD following a long history of diabetes two years prior to their interview. She received dialysis treatments for seven weeks before obtaining a kidney transplant from a friend of the family. Both she and John were quite healthy at the time of their participation. Iris and John were interviewed in person, and were 32 and 33 respectively at the time of their interviews.

Kathy and Louis have been married for 4 years. Louis was diagnosed with ESRD two years after they were married, and he received in-home dialysis for two years before receiving a kidney transplant from Kathy six months prior to their participation in the written version of the interview. Both Kathy, age 34, and Louis, age 37, were healthy at the time of their participation.

For a clearer demonstration or summary of the demographics and other information related to the couples who participated, see Table 1.

Table 1

Name	Age	Time married before tx	Time since transplant	Where recruited from?	Interview Format	Patient or spouse?
Ann	34	9 years	3 months	NKF	Written	Patient
Brian	36	9 years	3 months	NKF	Written	Spouse
Carol	30	2.5 years	7 months	NKF	Written	Patient
David	34	2.5 years	7 months	NKF	Written	Spouse
Erica	30	2 years	2 years	NKF	Written	Spouse
Frank	33	2 years	2 years	NKF	Written	Patient
Gail	38	9 years	5 years	NKF	Written	Spouse
Heath	40	9 years	5 years	NKF	Written	Patient
Iris	32	6 years	2 years	Hospital	Verbal	Patient
John	33	6 years	2 years	Hospital	Verbal	Spouse
Kathy	34	2.5 years	2 years	NKF	Written	Spouse
Louis	37	2.5 years	2 years	NKF	Written	Patient

Findings

Universally Emerging Perspective

Throughout the written and verbal interviews, in spite of their shared experiences and similar states in life, the couples all described diverse experiences and different outcomes. However, they seemed to agree completely in one arena. Every member of every couple at some point in their interview expressed a sense of having gained something positive from the experience of ESRD. There was an overarching sense of optimism and growth among participants, who all expressed that there was some sort of gratitude for what they had learned or gained from their own or their partners' struggle with ESRD and renal transplant.

Analysis of Themes

As the researcher examined the commentaries and qualitative data provided by the 6 couples (12 individuals) interviewed, several overarching themes and fundamental issues emerged. Partners discussed the specific topics addressed in the interview questions, regarding communication, sexuality, social interactions, division of labor, and overall satisfaction within marriage. However, their responses touched on so many other aspects of life, it was somewhat difficult to filter that data into a small number of themes. Some of the discussion topics that emerged were fears, financial concerns, and worries about the impact of the disease on the couples' children. Sexuality in the face of medical intervention was discussed candidly, and many couples noted improvements after the transplant in this arena. Although the only factor universally noted by couples was a

sense of optimism and gain from the experience, not all aspects of couples' struggles with ESRD were a positive experience. Many couples noted negative consequences from experiencing ESRD which impacted far more than their health, and which reached into areas of their lives that they might not have expected to have impact them at such young ages.

Several couples noted surprise that this severe of an illness experience could happen to them, a newly married, young couple. As Brian stated, "when we got married, it never occurred to either of us that something like this could happen...when it happened, it was very hard to deal with." Others indicated that they could not be sure what sort of impact the transplant had really had on their relationship, because they had never been in a "young marriage" without this experience. Their experience of "normal" was tainted by the introduction of ESRD and renal transplant so early in their marriage. His expressed this well, saying, "not every relationship has to go through something like this. I have no idea what our lives would have been like if we didn't have this in our life, because I don't know, but it was just a stepping stone in our relationship, we went through it, we don't really have any major complaints, we just kind of accepted it. Sure, it's brought us closer together, because of the more time we spent, I don't know. It's hard to say how it affected us, because we're only on one side of the fence. We don't know what would have happened otherwise."

After analyzing the data, the research seemed to suggest several prominent themes. The themes were considered dominant if they emerged in six of twelve interviews. The themes noted included: improved connections with and reliance on outside support systems, negative impacts on life, improved communication between

spouses, coping with fears, sexual concerns and an increased sense of bond or connection between spouses.

Improved Connections With and Reliance on Outside Support Systems

The experience of ESRD, both the physical aspects of the disease and the practical aspects of its treatments, is exhausting. Many couples discussed their reliance on one another for support, stating that they could not have survived the experience without the support of their spouse. However, there was also a strong emphasis on the support provided to the couple from outside sources. Most couples noted that they actually increased their social connections as a result of ESRD. Iris noted that when she and her husband were having difficulties sharing their fears with one another, they counted on friends to help them through the emotional difficulties. In her words:

my two girlfriends became my confidantes, listened to me, you know, during the whole crying and being scared, and John turned towards the guys in the group, and he shared more with them about what he was feeling, his fears, etc.

Sometimes a neutral party felt safer to share with than did a spouse. She continued to describe the support of those friends, indicating that they seemed to have a sense of what the couple needed. "They all tended to be 'okay, if you need your space, you need your space, if you need our support, we're here' and they definitely helped us through a lot of tough times." By not intruding or forcing themselves on Iris and John, the friends created a support network the couple knew they could lean on in times of stress.

Others noted a reliance on friends and family for more practical matters. John noted:

We had some friends in the neighborhood that would drop by, bring us a meal, without us asking for it. They'd ask if they could help and we'd tell them 'no', but they'd keep bringing us food and stuff.

In spite of his protests of self-sufficiency, the support was remembered and appreciated months later as John discussed his difficulties. Erica described similar friends and support from family, stating:

Close friends were amazing about bringing meals and caring for our pets when my husband would be in and out of the hospital, and it meant the world to us to have that support.

We counted on Frank's family for help with transportation during dialysis days.

My family helped us out financially and by coming to visit and help out during the transplant, and friends did fundraisers and called just to offer groceries if they were out shopping or other support when they could.

Ann described the help a friend provided as they struggled with the logistics of treating ESRD.

We are very fortunate to have a good friend who has been an angel to us. She has helped with watching our son when I had to go to the doctor's or if I was in the hospital. She organized people to bring dinners over on certain nights, etc.

David reported that even household chores were not beyond the scope of support.

Her family has helped us around the house when my wife wasn't feeling well, and her sister often came over during the day and just sat with her when she wasn't feeling well.

Kathy noted that her father also "helped with certain things around the house."

In addition to concrete support, connections between the couples facing ESRD and their friends and family were improved as well. Ann noted:

I started going to church more when I got sick, and met some truly wonderful people. I think I have become a much more open person since I got sick.

Brian indicated a similar pattern for his wife, and stated:

My wife has finally found some good friends. Ann is enjoying life to the fullest now.

Frank reported a stronger connection with friends, stating:

I think we both really appreciate close friends and family more than we did before. I don't think we knew how much support we had until it was tested by this experience...I thank God we had it or I don't know how we could have made it!

Carol indicated, "I think I'm more social now than I ever was before," and her husband David concurred, "I think my wife's illness has actually helped us grow closer to our family and some of our friends."

Kathy and Louis indicated that their social lives diminished somewhat post transplant, but did not stay changed. Louis reported that "there really has been no real difference other than the feeling of complete acceptance of my wife by my family," a change that followed her risking her life to donate a kidney to their son. Kathy indicated:

The only time we intentionally took breaks from being social was during our recovery after the transplant. We got back into the swing of things relatively quickly and began socializing again after a few weeks.

Negative Impacts on Life

Many couples noted that the ill spouse sometimes felt useless or even guilty for their lack of energy or productiveness. Some even mentioned the well spouse feeling resentful or frustrated, however briefly, at the workload that inevitably fell on their shoulders instead. Others noted that the well spouse worked to ensure that their partner felt needed or useful in some realm. The impact of the illness took a toll in many areas of life, from finances to housework, employment to independence. Financial losses were prevalent, as Ann noted:

When I got real sick, I had to quit my job of 15 years. My husband took a couple of months off of work in order to help out with everything.

Fortunately, Ann and Brian were able to withstand this financial drain. Many couples would not be able to have a partner leave work. Carol indicated that the financial and emotional strains took a toll on her:

I felt very guilty about him having so much to do and still work every day at his job. My disability and social security definitely helped financially, but the feeling of not really contributing otherwise was quite stressful. I wanted so desperately to be helping out in some way.

Frank put it more succinctly, "I wished I could do more, but I just couldn't." He stated:

I know there were times when I was sick that I did pretty much nothing, and my wife took care of a lot around the house, more than her share for sure. I never heard her complain about it, even when she was repeatedly scrubbing out bedside buckets from me being sick. It meant a lot to me that she was so willing to take over and take care of me and our world.

Erica described such times, when Frank was unable to help out.

There were days when he could hardly get out of bed without being sick, and it seemed silly to get upset over him not doing his dishes or not wiping counters. During dialysis, we just didn't have time for anything else.

Our house was perpetually messy, and we learned to deal with it.

There were some losses the couples were willing to accept, such as not having a spotless house. As Erica noted, priorities just seemed to shift. Iris also noted a change in her ability to work around the house.

It was hard, because I was always on top of it, and when I was on dialysis, there were days when I just couldn't do anything. . .of course, there were days on your in-between days [between two dialysis treatment days] when I would actually feel better than I'd felt in a long time, because that dialysis just cleaned so many toxins out of my system. . .so there were some days when I felt good enough to do things so I did them. I got tired, but I took advantage of those times and would do a load of laundry or pull out the checkbook and pay bills or whatever...when I did feel good, I felt

like I took advantage of it, and when I didn't, I just had to accept the fact that I couldn't do anything.

Her husband, John, indicated that he felt a need to help her help herself, so that she would not be frustrated and feel useless.

I certainly tried to do more for her, to allow her to rest more. I was certainly understanding of that, and certain things she wanted, if I had taken over every responsibility she would have felt totally useless. I think she would have felt worse, so there were things that she still did. She still balanced the checkbook, because she would have felt useless, see she doesn't trust me to do the checkbook. I did it once, and I do it this way and she does it that way, she doesn't see how my way works and I don't see how hers works, so she went ahead and did it and I said that's fine, you were in the finance business, go right ahead.

This description seems to emphasize the effort to which the couples went to maintain some level of normality, and to keep them both somewhat equal partners in the relationship. David also emphasized the efforts they went to in order to avoid feeling "different,"

Sometimes, her illness just made it take us longer to get things done. On days when she felt good, we could go shopping, clean the house, and walk the dogs together. On days when she felt poorly, I would do those things on my own and she would help out however she could, she pitched in whenever possible...The work around the house involved a lot of tasks that my wife simply could not perform, but she did what she could and I always made sure to let her know I appreciated her help.

The support of spouses seemed to alleviate some of the difficulties encountered when independence and mobility were impaired, but the impairment itself continued to have an impact.

Improved Communication Between Spouses

In eight of twelve interviews, the partners mentioned an improvement in communication as a result of their mutual experiences with ESRD. Ann noted several small changes, including:

I think my husband and I have become much closer. We learned how to communicate without talking. I have learned how to ask for and accept help. My husband has been helping me to express my feelings.

Frank also noted an improvement in communication without needing to talk or explain one's self overtly, indicating:

I am more able to share my feelings with her, and we are really good at understanding each other without a lot of explanation.

Ann's husband concurred with her evaluation of their communication, indicating:

We learned to understand what the other was feeling and to be able to listen to each other. We talk much more than we did before. We also talk about more realistic things.

Frank and Erica also indicated a positive impact on their communication from the experience, but with a different focus.

I don't know if much changed in this area that wouldn't have changed anyway as we moved from being a "new couple" to being an "old married couple" but we have gotten easier with one another and less likely to be embarrassed about sensitive topics. We have had to discuss stuff that probably isn't normal for young couples to discuss, like all the physical aspects of what kidney failure and dialysis did to my body. It was probably good for us in some ways... it helped us to learn to be comfortable discussing pretty much anything. (Frank)

We certainly learned to talk about issues that other married couples might get away with ignoring. . .bodily functions and feelings being number one there. We had to learn to listen to his doctors and still make our own decisions based on what WE wanted. . .that made us have to really be open and honest with each other through this whole process. (Erica)

After the transplant, we had to talk pretty openly about body functions still, but it was with a different perspective. It was more hopeful and less related to nausea and pain. We are really open with each other, I think, and I think this whole procedure has made us better about just saying what we mean and not beating around the bush. (Erica)

Gail suggested that having to talk more openly throughout the process of coping with ESRD drew her closer in her relationship with Heath.

I would say that there have only been good changes. We talk about all sorts of things more now. It drew us closer to each other, knowing how much we each care for one another.

Kathy reported that Louis was not particularly disclosing at first. He was more of a private person, and they were not communicating at the level to which she wanted them to communicate. She described his reticence to have her come with him to dialysis, and his lack of sharing information.

Finally, he allowed my mom to join him for one of the visits and afterwards she gave me a [long] replay of the visit. During that conversation, Louis mentioned that he finally understood what I was interested in hearing, that he had no idea I wanted that much information. Once I was designated as the donor, he seemed to be even more open to communicating. As we met with doctors together, we grew to understand each other better. Fast forward to after the transplant, and now he is able to open up more.

Experiencing the transplant together and really listening to the needs of their partners helped them to establish a more communicative, open relationship overall.

John reported that he and Iris also were not communicating openly at first, mainly due to concerns about sharing their fears with one another. After they confronted those fears and spoke openly, he noted:

We certainly relaxed some, simply we realized we were both feeling the same thing, so the stress of us trying to help each other kind of changed gears a little bit. We realized what the other person needed after we talked about it that one particular night, then we shifted more to getting through to the next step, we would set benchmarks for ourselves, when we get to this point we'll be this much closer. The relationship, I know our relationship got better after that discussion.

Being able to work through their fears and being forced to communicate about their innermost thoughts and feelings helped them to improve their relationship overall. Iris

concurred with John's positive outlook on their communication in marriage, but noted a different improvement as well:

I can't say that our communication has gotten better or changed, but our attitudes certainly have improved, because it's not always, "Well, I wonder what is the surgery going to be?" "How are we prepared for it?" "What are we going to have to do?" "Which doctor's appointments do we have to go to this week?" Then I spent the seven weeks on dialysis, and he was with me through all of that too, and now it's just like, everything is great, you know, we're, our whole experience through it was really positive. We have both just been very thankful and very happy, very lighthearted, and that of course can improve a relationship.

Our attitudes are better, our worries are less, I think we joke around more now. We did that, earlier in our marriage, but as the surgery got closer that kind of got put on the back burner for a while. So now we're back to more joking around, more laughing, more let's go out and do something, kind of more spur of the moment type things.

As Iris noted, there were "bumps" in the road to communication, when their world revolved around medical appointments and crises, but through all of that they have emerged to a place where they can communicate openly and interact in a more positive manner.

Coping With Fears

Many of the partners mentioned a tendency to hide their fears from their spouses, both to protect themselves from discussing difficult topics and to avoid frightening or upsetting the other member of the couple. Carol reported that she wanted to keep David from knowing how bad the outcome could be if her kidneys did eventually fail. During that time, she indicated that their communication suffered somewhat.

I think I withdrew a little bit, especially early on when there was no diagnosis. I think I went through a bit of a depression for the first six months after my creatinine started to rise, and I didn't know how scared to be, and I think I tried to shelter my husband from that a little bit. In a way, I just wanted to protect him. [after she was put on the transplant list] I felt

like I once again had hope. At that point, I think I became fully open in my communication again.

David was aware of her lack of communication. During his interview, he indicated:

I know there were times when my wife didn't tell me about health problems she was experiencing right away because she didn't want to frighten or worry me, but for the most part she did a great job of telling me what was going on. I also made sure she always knew she could depend on me to help her. I never wanted her to feel like her illness was a burden on me.

His way of coping with her withdrawal was to open himself up more, and to encourage his wife to share with him when she felt able to do so. John, however, had more difficulty expressing his fears about his wife's illness and his desire to support her. Iris described her experience of this phenomenon:

The last six months before the surgery, I was very worried and very scared. I was wanting to talk to anyone about it who I could communicate with who would listen to me talk or listen to me cry, and who could take in all of my worries and be very understanding. I think the closer the surgery got, although John and I could talk about anything else, he seemed a little more closed up, and I could tell he was just worried but didn't want to let me know he was worried.

Iris perceived that John was scared and was trying to protect her by hiding his fears, but instead he was removing from her one of the major sources of support from which she might have drawn strength. John also noticed the strain from this pattern, and described it as follows:

I think maybe we were both trying to hide from the other person how scared we were. I was trying to be strong for her, and she was trying to be strong for me. We finally came to a point where we were just stressed to the max, so to speak. We kind of had an argument and over the course of the argument started talking about what was really bothering us, and were able to open up about the fact that we were both scared snotless.

[after that argument] certainly we were less stressed, realizing that we didn't need to be stoic for each other. That was causing stress in that we each thought perhaps the other person was taking it too lightheartedly, and

we realized, no, we're taking it pretty serious, and we have a strong faith, as far as church and stuff, and we spent a lot of time in prayer, trying to let go of it, and realized that there are some things that are beyond our control.

By openly discussing their fears and ceasing their pretenses of strength and stoicism, John and Iris were able to let go of the tension that was building between them and improve their communication and relationship.

Frank and Erica also noted a tendency to try to protect one another as they dealt with the difficulties posed by life with ESRD. Frank's method for avoiding the discussion of his fears, or preventing what he anticipated as a potential problem of focusing only on fear, was to use optimism.

I think I annoyed her sometimes by always looking at the positives and trying to avoid getting scared, but I had to so I wouldn't focus on fear. I think I need a "light at the end of the tunnel" to focus on, whereas she was more open to talking about what she was scared of. (Frank)

I think there were times that he didn't want to tell me when he was feeling bad and there were times I was terrified about his health that I didn't want to scare him so I kept it to myself. (Erica)

As we got closer to a transplant, we did talk more about what we were afraid of, but he was always trying so hard to be optimistic and hopeful so I still kept some of my fears to myself and talked to my family or friends instead. (Erica)

Different ways of coping with fear can lead to frustration or avoidance, but allowing for those differences within a relationship and recognizing that they exist, and can even be healthy, may be beneficial in helping communication to grow and relationships to succeed.

Sexual Concerns

Ann and Brian noted that their sexual relationship all but disappeared when she was ill. Brian indicated that this was not always well-received, but given the

circumstances of her medication status and health, one might understand why it happened.

When I got sick, our sex life pretty much came to a screeching halt. I didn't have the energy, nor did I feel well enough to enjoy it. In addition, I was on medications that decreased sexual desire. (Ann)

Sex life, what sex life? When she got sick, she didn't know the meaning of sex. Every once in a while we would try to make love, but she was just so sick that it rarely occurred. It put a strain on our relationship because I felt like she didn't care about me. Since the transplant, it has improved. (Brian)

On a different note, Iris indicated that the mechanics of the treatment modalities for ESRD negatively impacted her feelings of attractiveness. She described her feelings of being unattractive due to the catheter (placed for dialysis) which was hanging from her chest.

I can recall that on dialysis, it was just a couple of days after I got out of the hospital, and my body was totally fine, but I had my catheter in and it was a little uncomfortable. But I told myself "you gotta prove to yourself that you're fine" and I remember wanting to make love to him one night. For the first couple of times I kept a shirt on because I thought it was very unattractive to have this thing coming out of me, because it was right here, right above my right breast. And of course men have this whole thing with breasts, and I was thinking, "man, this is so ugly." For a while I was keeping my shirt on and I think he kind of noticed that, and he kind of encouraged me to the fact that, you know, it's just one of these hurdles and it's not forever, and it's not that noticeable. I'm sure he was exaggerating but he was very supportive in that, he never ever said anything about me being less attractive because I had this catheter.

I've got this scar that's on my left side, from the tip of my finger up to here, it's a pretty good scar, but it fades a little as the months go on. I think he's just more, "it's okay, everything's going to be okay, your scars will fade in time and it's not that big of deal." I think it's more just me being a woman. I'm just more self conscious, with having it here I've got a harder time holding in my stomach. So different female things go through my mind, is he grossed out because of my scar...I've asked him, and he's just always "it's no big deal, don't worry about it, you're you and I love you and it's not going to make that big of a difference"

In addition to discomfort with physical appearance, Iris noted that she experienced something similar to what Ann described previously while undergoing dialysis treatments.

I can't recall that my sex drive actually slowed down any. Of course there were days during dialysis that I didn't have the energy to do anything, and he definitely knew that and he never pushed me.

Iris noted the exhaustion as well, but was lacking the diminished desire that Ann noted in response to her medications.

John reported that sometimes he had a diminished desire to be sexually active, but not for the reasons that Iris indicated she feared.

Stress reduces that drive. I think there were a few times where she came to me feeling like I was turning away from her, and it wasn't so much that I didn't love her anymore. It was just that, I was pretty shaken up about it. I'm a [helping professional], and I usually am rendering aid to other people and not needing it in return. It was real hard for me to deal with, this whole macho ego thing, 'I don't need any help', so to have it hit me so closely. I try not to be egotistical about it, but I'm sure that was some of it, that male, socialization that I need to be 'the man.'

When asked what helped him work through this tendency to avoid Iris when he was feeling pulled in too many directions emotionally, he responded:

Crying like a baby usually helps, [laughing] it does. I mentioned earlier that we had one night that we argued, just because we were so stressed. We argued usually about something stupid, but then we started talking more and more and realized what the real issue was that we were both so scared, so after that we, a lot of communication and were able to work through the other problems.

Again, by opening the lines of communication, they were able to work through the issues that arose in a sexual arena as well. John's admission of his own fears impacting their sexual relationship may have alleviated some of Iris's concerns about her body's new scars and changes being the root of their problems.

Frank and Erica noted that they too had some miscommunication and hurt feelings arise in the area of their sexual relationship.

When he first got sick, it was hard for me because he didn't desire sex as often and I was insecure and felt that he didn't desire me. We got that talked through pretty quickly, and even though I sometimes still had my feelings hurt if I offered and he declined, I knew it wasn't a personal rejection and that helped. (Erica)

I think there were times when I was sick that I hurt my wife's feelings because I just didn't want to have sex. I was too tired or I felt bad, and I just couldn't be sexual. We talked about it a lot, and she understood in her head why this was the case, but she had a hard time not feeling rejected. I think in the long run it all turned out okay, though. I just spent time telling her how much I love her and find her attractive, and blamed the rest on my old, tired, sick body. We laughed a lot about it. After the transplant, things got better. (Frank)

However, Erica was not completely unable to empathize with Frank's exhaustion and lack of desire. She indicated that the lifestyle required for dialysis helped her to understand a bit more, and that the two of them were more in sync with their sexual needs and desires during this time period.

Dialysis drained him a lot, both from the physical experience of it and the time we had to commit to the treatments, so we were sexual much less often during that year. I think we were both exhausted though, physically and mentally, so it wasn't horrible.

Several couples indicated concerns about returning to an active sex life after the transplant.

During dialysis, I'm sure the number of interactions was probably decreased, which I'm sure is normal, I would think, and of course immediately following the surgery, that was one of the questions she asked the doctors, was 'how long should we wait' so we don't damage anything. You're concerned about damaging this freshly attached organ, so there was some trepidation when we first started back into our relationship, to make sure that there was no pain or discomfort. (John)

After his transplant, we were both a little scared about the process of being intimate again, but once we tried and realized he wouldn't 'break' we were okay. (Erica)

The stent terrified me at first. I was afraid my body would not work the right way since they had operated on regions that were pretty close to sexual areas, but everything works great. (Frank)

Another couple indicated that sexual desire has not yet returned post-transplant.

Kathy indicated that during treatment:

It was a little weird for us to make love when he was hooked up to the dialysis machine during the night. We tried to avoid it.

However, even now that Louis is no longer undergoing dialysis treatments at home in the night, their sexual relationship has not returned to normal.

After the transplant, now that he is taking so much medication, we don't have sex as frequently. However, we cuddle and are affectionate, and I feel very close to him. (Kathy)

Due to the heavy medication, there has been a lower level of sexual desire on my part. (Louis)

This couple has found ways to compensate for the changes in their level of desire or ability to interact sexually, in order to avoid allowing these changes to cause a rift in the relationship somehow.

Improved Bond or Connection Between Spouses

Many of the couples indicated that the experience of ESRD was actually somewhat beneficial to their relationship itself. This was the theme that emerged most often, occurring in eleven of the twelve interviews conducted. Brian expressed this sentiment as follows:

I learned just how much she means to me and just what a special person she is. In a way, I am glad we went through this. We have a stronger marriage because of this.

His wife Ann concurred, stating:

I think we are much stronger as a couple. Having to go through something like this puts a huge strain on a marriage. Brian and I learned just how much we really do love each other. It was very hard at times, and we easily could have given up, but we didn't. Our love survived and got a heck of a lot stronger.

Heath stated a similar perspective, when he indicated, "I think the transplant brought us closer together."

Frank and Erica expressed a sense of renewed faith in their relationship and a belief that they had been tested and grown closer through this experience.

My wife and I are closer now than we have ever been, and we can talk to each other about anything. I think that we are compatible in every way and have learned to deal with each other's quirks and insecurities on a whole new level. I know she will stand by me through anything, and I trust her completely. . .I do not know how I could have made it through all of this without her. We laugh that if we can make it through our first five years of marriage, we know we're in it for good. I think we're in it for life! (Frank)

I think that overall, our marriage has been improved by this experience. I would not wish it on ANYONE, it was not fun to go through, but we have learned to talk really openly to each other and we have learned to trust each other to be there no matter what. I have no doubt that we can make it through anything together, after what we have been through already...I think the whole experience has taught us how much we value each other and our relationship and our love. In a sad, backwards sort of way, I am glad we went through it all. (Erica)

During their interviews, they described a sense of hopelessness at some points in the process, but stated that they felt they emerged a stronger couple because of the experience. Carol and David indicated a similar sense of strength and growth, stating:

I know we're both stronger individually and as a couple because of the past couple of years. (Carol)

My wife's renal failure and transplant have definitely brought us closer together and made our marriage stronger. (David)

Iris and John reported an increased bond within their marriage as well. Iris indicated that some of this was due to her own fears of mortality and disability, and John's commitment to remain at her side through the whole experience.

It was good for me to realize that if I am going to go through a hard time, he's going to be there for me...I think now I'm more confident than ever that he and I are soul mates, and we're the best of friends, and I know that I can rely on him and he knows he can rely on me. (Iris)

She indicated more specific ways their relationship has improved, and suggested that much of it has to do with the cloud of illness being lifted from their everyday interactions.

I think we joke around more, we laugh more, I'll pick on him more, and he's a big guy but I feel like I can hold my own and I feel stronger. It's been a real positive thing for us, not necessarily to go through, because it wasn't fun, especially all the worry and the planning and the 'what ifs', but once you get past the healing and knowing that everything is on the right track, it's a wonderful feeling and you can't help but want to enjoy life again. (Iris)

John responded in a similar manner when queried about their relationship, stating:

The growth that we've experienced because of what we were put through has certainly made our relationship stronger and more meaningful. We certainly understand each other on a deeper level than we did before.

Iris described their relationship prior to her medical condition worsening, and indicated specifically how this experience has helped them grow.

In the first couple of years of our marriage, it was always kind of, not real rocky, but fighting about little things. Because you're trying to learn stuff about each other, and every once in a while we'd go to the doctor and he'd tell us things weren't going too well, and it kind of puts life into perspective. I think in a way it was good for us, made us realize that we needed to grow up and make some priorities and figure out different goals and what we needed to do.

By improving communication, facing difficult decisions and supporting one another through incredible stress, their relationship was forced to progress from an early, perhaps more self-focused or idealistic phase into a more realistic, substance focused phase.

Kathy and Louis described the improvements in their relationship in a different manner, indicating that the experiences they went through not only tightened the bond between them, but also separated them somehow from external influence. Louis stated it this way:

There has been a closer relationship between us as if we were connected at a different level. We are definitely more sympathetic to each other's needs...There is a connection made between the two of us that separates us from the rest of the world. The feeling is of a true bond above and beyond what we had prior to the transplant.

Kathy reported a similar feeling:

Overall satisfaction within our marriage is high. We have gone through so much. During dialysis, I was frustrated by the situation and Louis's lack of communication. I learned a lot of patience and after the transplant, I believe that Louis and I can get through anything. We have an impenetrable bond.

The difficulties they faced together, and the lessons they learned in facing those challenges, seem to have served as an impetus for relationship growth and restoration.

Discussion of Negative Cases

Although the above themes seemed to be the consensus among participants, there were several examples of negative cases, or responses that disagreed somehow with the themes identified in the majority of cases. The themes described above were representative of ideas or sentiments that appeared in at least half of the interviews. However, not all participants expressed similar views. As noted before, all of the couples were very unique in their own ways, and it therefore seems natural that there were

variations in responses and experiences noted. By examining these differences, the researcher is given insight into a more diverse and varied exploration of the actual experiences of participants.

Negative case #1: Many couples noted improvements in their sexual relationships

While many couples described difficulties within their sexual relationship during preliminary diagnosis phase, dialysis and even post transplant and recovery, other couples indicated that for various reasons they felt that their sexual relationships had improved from this experience. Some of the same couples who noted difficulties with sexual interactions during early phases of coping with ESRD did in fact indicate improvement in this area later in the process. Some, however, did not note sexual difficulties as prevalent at all throughout their experience. David, for example, indicated that while Carol was tired at times, they worked to maintain a high level of sexual intimacy even during difficult dialysis days.

Somehow, even when she was in the worst stages of her renal failure, she would have a few hours or a day when she felt good and we would capitalize on it.

Because we were able to maintain a healthy sex life throughout her illness, I think it helped us maintain a high level of emotional intimacy, which, in turn, helped us deal with the health issues we faced.

Frank and Erica described sexual difficulties during pre-dialysis and dialysis days, including her fears of not being desired and his physical exhaustion and depletion from his health conditions. However, once they communicated about these concerns and his health improved, they both indicated that their sexual relationship is better now than ever before.

We are back on track to a very healthy sexual relationship. (Frank)

We talk more now [while being intimate], too, and laugh, which we didn't used to do. I think we're both more comfortable with each other and less worried about being embarrassed. (Frank)

Sex in general was changed from all of this though, because ...we had to learn to talk about EVERYTHING in detail without being embarrassed, so I think this actually helped in our sex life! (Erica)

Thus, even those couples with temporary sexual difficulties might find that the impact overall on their sexual relationship may not be permanent or negative.

Negative case #2: Not all communication changes were positive

By the end of her interview, Iris indicated that she and John had learned to improve their communication. However, it was a struggle for them to work through, and his communication actually seemed to be less open and less helpful to their relationship for a significant portion of their experiences of ESRD.

He's the type that is very, he likes to communicate and he's very good at communicating, but if you've got something that he's afraid of he doesn't like to admit it. So I was very puzzled for the last six months or so before the surgery. Because he didn't talk about it as much, when he did talk about it he was very passive, like everything's going to be fine, don't worry about it, you know I've been praying a lot about it, given it a lot of thought, and that's it.

John described some of the factors that were keeping him from feeling open about communicating.

That was part of the issue, was that 'I don't want you to go to the hospital and not come back.' She didn't realize how much stress that was causing me. But I was extremely confident that she was going to be just fine, I just, it's a conscious/ unconscious battle. I know that she's going to be fine, but unconsciously those fears are building up. Until you bring them out into the light of day, force them out and deal with them, that certainly caused, that was what led us down the path of having the really explosive argument.

I usually am rendering aid to other people and not needing it in return, and so it was real hard for me to deal with, this whole macho ego thing, 'I

don't need any help', so to have it hit me so closely. I try not to be egotistical about it, but I'm sure that was some of it, that male, socialization that I need to be 'the man'...

He was not avoiding communication to avoid connecting with his wife, but instead out of fear for harming her or making her feel bad for causing him stress. He also reported some role-conflict, with who he felt he "should be" and what he was actually feeling. After the transplant was over and he could figuratively "let go" of the tension he was trying not to show, Iris later found out how John reacted:

As soon as they knew I was okay, John pretty much had this total release of all of his emotions he had had bottled up inside. He was crying on everyone's shoulders and just became very protective, very excited, I could tell that he was excited that everything had gone well, and I think he had a tremendous relief.

By not communicating openly with his wife, he had bottled up an enormous level of stress and fear that was released only by knowing that she was going to survive the surgery and be okay. His lack of communication, whether out of fear of seeming less strong and masculine or whether out of concern for adding stress to the already high burden his wife was shouldering, was able to be released and he could share with others what he had been feeling.

Negative case #3: Social connections were not always increased

The bonds between the couples experiencing ESRD and their family and friends were reportedly improved and increased in many of the couples interviewed. However, others noted that the stress of being "different" or of having so much chaos occurring in their lives served as a barrier between themselves and the outside world.

Going way before, knowing that the transplant was coming, you have this group of people who are very open, joking around, laughing a lot, and you put this burden in the relationship and it kind of affected all of us. (Iris)

Our social life dropped down to almost nothing during dialysis, but that was okay, it was actually a benefit because we were able to spend that time together, and really try to work through it with each other. (John)

Erica and Frank noted that their social network was decreased as well, but also indicated a sense that this may have been a positive result, rather than a negative consequence of their experiences. Instead of being surrounded by acquaintances, they learned to be more selective and spend quality time with people whom they trusted, loved and with whom they felt a true bond.

I think we lost a lot of acquaintances through the process, but learned a lot about what really matters in relationships and friendships. (Erica)

I spent less time with people from work and more time with just my husband and close friends. . . I think we both really liked the shift from less “superficial bonds” trimmed down to real connections. (Erica)

I might have gotten less social during this experience because I got tired of everything that was going on in our lives and didn’t have any more energy left to give away to others. I sort of “cocooned” into our families and our really close friends, and I don’t think I ever branched back out. . . (Erica)

Others did not note an increase or improvement in their social connections, but also did not notice a decrease. Gail and Heath indicated that nothing really changed socially throughout this process.

Everything has stayed pretty much the same. When going out, we just don’t drink a lot anymore. (Gail)

We have a lot of friends and things are pretty much like they were before the transplant. (Heath)

Negative case #4: Not all interactions within the relationships were positive

From reading about the improved connections between spouses and the level of commitment and bond that was increased and developed through this process, one might get the impression that the experiences were purely positive and the spousal interactions

were always selfless and giving. However, the couples interviewed were subject to normal human emotional reactions, and indicated that there were times when it was difficult to be the primary caregiver for someone who was supposed to be their equal partner.

There were times when my wife was sick that I got a little mad about having to mow the lawn or clean the house when she was lying in bed. I never really said anything about it though, because I knew it was killing her not being able to help out. I knew how much she hated being weak and nauseous all the time. I just reminded myself that she certainly would have helped out if she could. (David)

It was hard for me to know what to do for my wife. She didn't want any help, even though she really needed it. I would get mad at her for not doing something, and then she would tell me that she just couldn't do it. (Brian)

His also noted that as the patient, she recognized she was not always as caring or giving as an equal partner might be expected to be. She reported that this has improved since the transplant occurred and her health is more on a par with John's, but was willing to disclose that John's burden had been great.

I probably sound like I thought I was going to die or something, and I guess of course the thought did go through my mind a couple times. But I think I did have my mind so much on "I'm going to have to go through this surgery" that I kind of forgot maybe some of the main parts about life. As far as just being, maybe being the person that he needed me to be. I'm sure that I had several selfish times when maybe I didn't give to him as much as I should have, because I was just so wrapped up in the worry of it all. Now, it's all behind us, and I can mentally be there for him for anything now, where before it was probably the other way around, like he felt like he needed to be there for me, supportive for me, now we're more meeting each other in the middle. It's been a good thing.

Both spouses were faced with very difficult emotions and experiences throughout their battles with ESRD, dialysis and transplant. The fact that they were not always perfectly behaved towards one another or completely selfless in their internal responses to their

partners' needs seems to be understandable, given the level of stress they were experiencing.

Discussion

Summary

The impact of ESRD on the relationships of the couples interviewed within this study varied across several factors. Many couples noted a negative impact on their financial status and their abilities to care for their daily needs, such as cleaning or caring for children or pets in times of crisis. Many of those interviewed suggested that their reliance on friends and family during times of need was essential in surviving the experience. They indicated receiving meals, childcare, dog-sitting, and some even noted friends or family who helped clean the house or sat with the ill spouse for support when she or he was unable to socialize in his or her normal fashion. Another area of life where participants noted a negative impact was in their sexual relationships. While some couples noted an overall improvement in their sexual lives after the transplant experience was over and they were in full or nearly-full recovery, most couples indicated some decrease in sexual desire or satisfaction throughout this illness experience.

Learning to communicate in a more effective manner was essential to the success of the relationships between the individuals in the couples interviewed. While many of these young couples indicated that they were strong communicators to begin with, they also suggested that experiencing the stress and turmoil of the impacts of ESRD on their lives impacted their communication greatly. Several couples indicated a tendency to hide their fears from their spouses at times, in an attempt to protect their spouse from the fears or in an attempt to convince themselves that this was not “really happening.” By doing

so, many individuals noted that there were difficulties with trust and openness within the relationship until this barrier to communication was removed and they could speak truthfully and openly to one another about the issues, fears and concerns at hand. Communicating openly about bodily functions, overpowering fears of mortality or concerns about a partner's lack of desire was not always an easy process for the couples interviewed. However, these couples indicated that this was instrumental in maintaining and improving their relationship as a couple, rather than dissolving into two separate individuals when coping with this illness.

All of the couples interviewed mentioned some level of improved closeness or bond within their relationship from having experienced ESRD and renal transplant. They mentioned feeling that they had been tested by the experience and had succeeded in passing that test. Others noted that while many couples will be thankful to never face this type of stress within their lives, it was not perceived as a completely negative life event to have gone through together. They felt it was a strengthening experience and rather than regretting having lived through it, they were instead proud of how they handled it and glad they had been given the opportunity to prove their commitment to one another in this manner.

Comparison to Literature Review

The patterns of negative impacts from ESRD which became apparent in the present sample of participants were quite similar to those noted by Smith and Soliday (2001) in their review of related literature. They noted a similar pattern of changes in division of labor as one spouse became increasingly more ill. They quoted patients indicating feeling "useless" or feeling as though they were not taking adequate care of

their responsibilities. This theme was echoed in the present research, through the aforementioned statements of Iris, Frank and Carol. In addition, Smith and Soliday noted that some of the most notable results of chronic kidney disease are financial problems and a feeling of exhaustion or low energy. This pattern was prevalent throughout the stories of the participants in the present research, as they described the manner in which the loss of jobs, energy and desire impacted them throughout this experience.

As for the loss of sexual desire and the communication issues that seemed to follow this concern in the case of several participants, Boss and Couden (2002) indicated that this pattern is not atypical within the chronic illness community. They suggested that “a husband with diabetes may shun his wife because the illness had impaired his sexuality, and she is confused by his emotional withdrawal and because he no longer touches her” (pp. 1353-1354). Erica’s fears about Frank no longer feeling attracted to her may indeed be related to such confusion, an incomprehension about what might be causing such a drastic change in this most intimate of areas of their relationship. Additionally, Frank’s withdrawal from sexual interactions may have been only partly due to physical impediments, and instead partly due to feeling impaired sexually and being unsure of how to express this facet of himself in the face of such an impairment. By communicating about their confusion and concerns, the potential for serious misunderstanding or permanent damage to their relationship was averted.

The fears that Iris expressed as she described the changes to her own body might also be reflected in the research of Boss and Couden (2002), in that her impaired sense of her own worth and value as a sexual being was impacting her ability to trust that John could still not only love her, but find her attractive as well. Again, by communicating her

fears and really listening to her partners' reassurance about his desire and love, they were able to avert permanent negative consequences to their intimacy or sexual relationship.

Communication was thus key to many of the couples in surviving this difficult experience. As Treif, et al. (2003) noted, "a high potential for conflict exists, as partners may cross the line from reminding to nagging, or struggle with how to respect their spouse's need for independence while dealing with their own fears about the consequences of poor disease management" (p. 65). Spouses of ill partners might want to help in any way they can, but they cannot make the final choice of how to cope with the illness itself, since that illness resides within the patient. Some of the participants in the current study reported protective behaviors toward their partners as well, often narrowly avoiding being over-controlling or "nagging." Some patients indicated feeling taken care of in this regard, whereas others felt less than grateful for the interference.

In the process of caring for their ill spouses in the best way they knew how, several of the participants in this study noted that they were not always positive about their tasks. In the negative cases of Brian and David, both expressed frustration at their wives for not being able to complete tasks or function normally, but also expressed some sense of regret for having felt that way. As Skerrett (2003) noted, "blame, both self and other, is usually a central feature of troubled couples and tends to be more toxic in couples with illness because there is a greater tendency for the blame to go underground. As one couple put it, 'How in the world could I ever admit that at times I blame her for getting sick in the first place and also blame her for not taking care of herself?'" It seems disloyal to be angry at someone who is struggling with a medical impairment, so the well spouse might be tempted to send that blame "underground". However, once buried, it

can lead to resentment and further breakdown of the relationship and the communication therein.

Negative emotions such as anger or guilt are not the only topics that might be tempting for well-spouses or patients to avoid. Rolland (1994) noted that healthy partners might refrain from expressing their concerns and fears out of a desire to avoid frightening or upsetting their spouse as she or he copes with the illness first-hand. Both the patients and the well spouses in the present research acknowledged a tendency to hide their fears from one another for various reasons, but mainly to avoid hurting or frightening their partners. However, all indicated that when they opened up the lines of communication and shared openly with one another, they felt closer and more connected with their spouses.

Opening the lines of communication was not always easy for the participants in this study, and Iris and John described a “blowup” fight in which they finally realized they could not communicate in the stoic, closed-off fashion they had been using. As Skerrett (2003) reported, “it is a formidable challenge to support couple strengths amid unbearable pain, uncertainty, fear and loss. When one partner in a marriage or committed partnership lives with illness, particularly of a chronic nature, one of the compounding dilemmas is the isolation that often develops between them” (p. 69). That isolation can lead to losing the sense of themselves as a couple, and instead focusing on individual fears and needs. When this happens, the illness experience becomes more difficult and support is no longer assumed present in the existence of one’s partner.

Other sources of support were found to be very helpful for the participants in the present study. Many of the couples noted that they were more socially involved and

interested than ever after they recovered from the transplant. This pattern of becoming more immersed in the outside world following an illness is supported by other recent literature, such as Henderson (1997) who found that after recovering from cancer, patients “thought about other people more, they preferred socializing with others more, and they felt better when they were able to interact with people” (p. 190). However, they also noted that recovered cancer patients sometimes found it difficult to branch back out from the intensive, individual support of their closest family or spouse into a broader social network. This seeming contradiction in patterns, one becoming more sociable, one clinging to close family out of comfort and habit, may fit best with the negative case described by Erica. She indicated that she and Frank had lost contact with many of their “superficial” friendships and contacts, but had strengthened the bonds with those who mattered the most in their lives. The pattern of expanding social networks and seeking out more social contact seems to fit with the overarching theme described by more participants, such as Iris, Ann, Brian and Carol.

The feelings indicated in the negative case of Iris, who described the burden placed on her friendship network when the ESRD was introduced, are echoed in the research of Smith and Soliday (2001). They reported responses in a similar vein, with participants stating that “our family is intact but much ‘older’ than our years” (p.175), as well as a woman who indicated that she felt “family and friends tend to stay away out of fear and pity” (p. 175). Couples who are young and newly married might not find a social network of other young, newly married couples who can truly comprehend what they are going through. However, the majority of the couples interviewed in the present

study did not indicate similar results, instead focusing on the broadening and strengthening of the social support they received.

The couples interviewed in the present study all seemed to note an overall positive effect on their relationships from having gone through the ESRD and transplant experience. This may, of course, be impacted by the self-selection biases described later in this discussion, but the result was universal within the couples who participated. Surprisingly, perhaps, this result is supported by other recent research. In a comprehensive review of the literature on couples facing chronic illness, Kowal, Johnson and Lee (2003) noted that “the onset and course of chronic illness does not necessarily have a detrimental influence on couples” (p. 301). Couples facing illness together may find that the emphasis on their needs as a couple and on supporting one another actually strengthens their relationships. As Rolland (1994) argued, by working from a collaborative or “we” stance, rather than a “you” and an “I”, partners can remember that they are not defined by illness and that their relationship has more substance than the physical conditions impacting it at the present time. This focus on togetherness and teamwork may be what “normal couples,” or those not faced by illness, develop through years of shared life experiences. Perhaps the couples interviewed in the present study obtained a “crash course” in working as a team and caring for one another as a couple, rather than focusing on the “I” or “individual” needs first and foremost.

Limitations of This Study

Given the limited participant pool from which this study drew, it was difficult to find an adequate sampling of participants. Ideally, all participants would have been met with individually and in-person by the interviewers, and all interviews would have been

oral and extended. However, in today's fast-paced society, finding 90-minute interview times and meeting with couples from across the country in person was not practical or feasible for most participants. While the researcher was able to contact participants with questions about the written interviews they completed, this did not provide the richness of data that a collection of in-person interviews might have been able to provide. While the initial intention of the researcher was to obtain this deeper level of information from a local sample, there was perhaps some advantage to instead obtaining a more nationwide sample of participants, however more abbreviated their responses might be.

A second limitation of this research was the self-selection of participants. Although those participants on a local level who were eligible for the study were contacted by their renal social worker (response rate: one of one couple approached agreed to participate), the remainder of the participants were from a somewhat skewed population. They consisted of ESRD patients and spouses who not only were aware of and exposed to the National Kidney Foundation website, but also who chose to respond to a solicitation contained therein. The response rate is thus impossible to calculate, as there is no way to determine how many potential participants were reached who chose not to participate.

Another limitation of this study was the retrospective nature of the data collection. Participants were asked to recollect their experiences from their current viewpoint, rather than being interviewed as they progressed through the ESRD experience. Their perspective is necessarily different and therefore not as wholly accurate when asked to recount experiences in this manner, thus some valuable information is lost through the process.

The heterosexual bias of the sample used for this study also presents a limitation. Additional couples, whether they be heterosexual or homosexual in nature, who might not be legally married but are involved in committed, long-term relationships could provide information and data on a more diverse collection of relationships and the impact of ESRD and its treatments on such relationships. In addition, the inclusion of couples who were not happily married or continuing in long-term relationships after their experiences with ESRD would offer a more in-depth examination of the impact this disease might have on relationships. Those couples who have divorced or separated, perhaps in part due to stressors related to the illness experience, might provide insight as to the more detrimental aspects of new relationships being tested in such a manner.

Recommendations for Future Research

Given the difficulty of random selection within a health-psychology setting, the recommendation that participants be selected in this manner might seem absurd. However, the self-selection bias that so obviously impacted the present research would be alleviated if researchers could devise a method for approaching all couples within a particular setting and offering them the opportunity to participate in a research study. Certainly, participants would already be those diagnosed with ESRD, but they would then also include those who do not respond to advertisements or solicitations. In order to obtain an adequate sample size, this approach might need to be instituted across several settings, perhaps at large transplant facilities in several regions to alleviate location-related biases as well.

Interviewing couples as one partner is initially diagnosed with ESRD, and then following them through their illness, treatment and recovery would provide a more

accurate representation of the lived experience of this process. This would entail a much greater time commitment from participants, which might limit participation, and would also require a more longitudinal design that could have impacts on research budgets and researcher availability. However, the advantages and rewards this shift in methodology could offer would likely far outweigh the difficulties inherent in its implementation.

A sample population that was missed in this research includes those couples whose marriage does not survive and thrive through the experience of ESRD diagnosis, treatment and recovery. Throughout my research I was told of several couples who “stayed together” through the spouse’s transplant, then divorced soon thereafter. The design used in the present study neglected to address these couples, but the input and experiences they might be able to offer would richen the data immeasurably. One way of obtaining data from these couples would be by implementing the in vivo, longitudinal method as described above. Another suggestion might be to simply ask for experiences from all persons who have experienced this process of illness and recovery, individually or as a member of a couple, in order to avoid the elimination of possible participants who are no longer members of a couple.

Actual interviews, in person and including time for the researcher to ask questions and clarify the participants’ responses, would provide much richer data than the present study. Again, given the limited population from which this type of research draws participants, the researcher’s budget might need to be increased to include travel to and from the locations where she or he might find willing participants. A written, open-ended and qualitative questionnaire provided a basis for exploratory research, but a more in-depth interview could offer much more. In addition, future researchers might consider

adding a quantitative portion to the interview process in order to provide for another method by which to verify results and avoid researcher bias. Future researchers might consider an established scale for marital satisfaction or for current levels of stress within the relationship, perhaps to be completed at several points throughout the illness and recovery process by both partners.

Recommendations for Clinical Practice

As Skerrett (2003) noted, “the essence of the therapeutic work lies in shifting a couple’s focus away from ‘you’ and ‘I’ to the ‘we’” (p. 71). Helping clients to recognize the power within their relationship as a couple, as well as encouraging them to see one another as more than a collection of symptoms or responsibilities, is crucial to maintaining healthy relationships throughout the illness experience. Rolland (1994) also argues that by working from a collaborative or “we” stance, rather than a “you” and an “I”, partners can remember that they are not defined by illness and that their relationship has more substance than the physical conditions impacting it at the present time. If therapists, physicians and other professionals interacting with patients and their partners throughout the illness process can advocate for such a shift in perspective and communication, the spouses together are more likely to emerge from the illness experience with a strong and healthy relationship.

Many of the couples noted that they felt overwhelmed, frightened, and unable to even keep up with the daily tasks of living during the course of treatment. This seems to be a crucial element to be aware of for professionals working with such a population, and might impact treatment in an important way. Primarily, a couple who is feeling overwhelmed by simply surviving in the face of illness and the related chaos is unlikely

to be a couple who can commit to spending many hours per week doing “homework,” such as therapeutic assignments suggested by the counselor. Leading researchers and clinicians often suggest that couples engage in activities or assignments together outside of the session itself (Dattilio, 2002; Donovan, 1999; Weeks & Treat, 2002). This is not to suggest the homework is irrelevant or not of value, as such tasks are generally assigned with the intention of improving the relationship or the couple’s overall well-being. As Skerrett (2003) noted, “in the chaos triggered by illness, regular time together, i.e. setting aside a weekly date night for fun, was typically the first thing to go, if it was ever pursued in the first place” (p. 76). Couples who are coping with the demanding schedule of doctors’ appointments, dialysis treatments, hospital visits and daily experiences with physical exhaustion and decline may not be able to complete a rigorous clinical exercise, or even a simple therapeutic exercise, realistically within their lives. Instead, rather than a full evening commitment of a “date night” or an assignment to work together on relaxation exercises or other typical suggestions, couples might be asked to simply listen to one another more. Their weekly assignment might not encompass hours of time, but instead a simple change of focus to trying to understand and communicate as openly with their partner as they are able.

Perhaps an awareness of what might be anticipated as the illness and its treatments progress would be helpful for these couples. Several participants indicated that what they went through felt “different” than what “normal couples” of their cohort experienced, or noted that they were quite surprised to be coping with such issues this early in their marriage. By sharing with couples early in the illness experience what others have encountered as they traveled along similar paths, some of the sense of

isolation and difference might be alleviated. Researchers suggest that this knowledge of those events or experiences that might be anticipated can lessen some of the anxiety as life begins to change. For example, Boss and Couden (2002) note that “the most stressful losses are those that are ambiguous. When people are unable to obtain clarity about the status of a family member, they are often immobilized; decisions are put on hold; roles remain unclear; relationship boundaries are confusing. . .” (p. 1352). If health status is clearly and honestly evaluated, and relationship or role changes are anticipated and prepared for, some of the sense of ambiguous loss can be avoided.

Support, for both the patient and the well spouse, could be offered in many ways. For example, social workers are specially trained to help clients work within their community to find the resources available to them to alleviate some of the negative impacts of their illness. Couples could benefit from finding financial resources or assistance with meals, child care or other practical aspects of life that can become overwhelming. Physicians and nurses can help patients and their partners be more aware of possible physical impacts of the disease and its treatments, from medications to dialysis to transplant. Being mentally prepared for the nausea, the water-retention, the medical limitations and many other potentially negative side-effects can help patients and their spouses anticipate reality and arrange their lives accordingly. Psychologists and counselors can help couples find support groups (as can social workers), in order to provide a forum in which they can meet others who are experiencing similar life paths, and where they might find a place to vent any anger or frustration at their current situations. They can help to normalize and prepare clients for the experience of sexual difficulties or impediments, in order to alleviate the surprise and personalization that

might occur. These methods could help mitigate the sense of being in this “on our own” or in isolation from the community, and might help strengthen the trust between patients, spouses and the treatment community.

Final Comment

While there were obviously flaws and limitations within the design and implementation of this particular study, the couples who participated provided a very detailed glimpse into the experience of living through the disease of ESRD and kidney transplant. Their stories provide us with a clearer picture of how this disease impacts young couples, and can help those working in medical and mental health fields who might wish to help other couples in their practices as those couples cope with this illness. As a researcher, I greatly appreciated their courage and candor in discussing difficult topics, and believe the risks they took in sharing will have a positive impact on the lives of those following in their footsteps and facing ESRD and renal transplant in future years.

Appendix A

Questions for Interviews

I can imagine that you have been through a lot over the past few years with regard to your (your spouse's) kidney disease. During this interview, I would like to ask you to describe what this experience has been like for you. I am going to ask you five basic questions. I would like for you to start from before you ever knew about this disease, through dialysis and transplant until now, there have been a lot of changes in your life. I would like it if you could try to give me a picture of what your experience has been and how your relationship has changed or not changed through the process. I will let you describe the process as much as you would like, and then I may go back and ask you questions if I am not clear about a particular area. While you may certainly address the questions I have asked in any order, it might be easiest for you to consider them in chronological order, or starting from the beginning of the experience and considering all of the aspects, then moving forward in time across your experiences. Please let me know if there was anything that helped or hindered your adjustment in these areas. Do you have any questions?

1. In describing your relationship and how you and your (husband/wife) have been affected by your experiences, I would like for you to tell me what changes, good or bad, might have occurred in the area of communication between you and your spouse.
2. In describing your relationship and how you and your (husband/wife) have been affected by your experiences, I would like for you to tell me what changes, good

or bad, might have occurred in the area of your sexual relationship with your spouse.

3. In describing your relationship and how you and your (husband/wife) have been affected by your experiences, I would like for you to tell me what changes, good or bad, might have occurred in the area of social interactions, or how you and your spouse interacted with people outside your marriage (family, friends, coworkers, etc.)
4. In describing your relationship and how you and your (husband/wife) have been affected by your experiences, I would like for you to tell me what changes, good or bad, might have occurred in the area of overall satisfaction within your marriage.
5. In describing your relationship and how you and your (husband/wife) have been affected by your experiences, I would like for you to tell me what changes, good or bad, might have occurred in the area of division of labor, or who did how much work or what work within the house, outside the house, etc.

Appendix B

What was your relationship like. . .

Before diagnosis of kidney failure During dialysis During transplant (3-6mo) Now, after the transplant

Current relationship Social relationships Current relationship with family Sexual life Current relationship				

Appendix C

Written Version of Interview Questions

Age of Husband _____(now) _____ (at time of transplant)

Age of Wife _____(now) _____(at time of transplant)

Which partner was diagnosed with ESRD? _____

Who donated the transplanted kidney?	Cadaveric Donor	Spouse
	Other _____	
	Friend	Family Member

Are both spouses currently healthy? If no, please explain. _____

How long were you married prior to the diagnosis of ESRD? _____

How long were you married prior to the kidney transplant? _____

How long have you been married currently? _____

When did the diagnosis of ESRD occur? _____

When did you (your spouse) begin dialysis, and how long did you (they) receive dialysis treatment? _____

When did the transplant occur? _____

I can imagine that you have been through a lot over the past few years with regard to your (your spouse's) kidney disease. During this interview, I would like to ask you to describe what this experience has been like for you. I am going to ask you five basic questions. I would like for you to start from before you ever knew about this disease, through dialysis and transplant until now, there have been a lot of changes in your life. I would like it if you could try to give me a picture of what your experience has been and how your relationship has changed or not changed through the process. I will let you describe the process as much as you would like, and then I may go back and ask you questions if I am

not clear about a particular area. While you may certainly address the questions I have asked in any order, it might be easiest for you to consider them in chronological order, or starting from the beginning of the experience and considering all of the aspects, then moving forward in time across your experiences. Please let me know if there was anything that helped or hindered your adjustment in these areas. Do you have any questions?

(Please call or email me if you have questions, I would be happy to help you out in any way possible.)

- 1) In describing your relationship and how you and your (husband/wife) have been affected by your experiences, I would like for you to tell me what changes, good or bad, might have occurred in the area of communication between you and your spouse.
- 2) In describing your relationship and how you and your (husband/wife) have been affected by your experiences, I would like for you to tell me what changes, good or bad, might have occurred in the area of your in the area of division of labor, or who did how much work or what work within the house, outside the house, etc.
- 3) In describing your relationship and how you and your (husband/wife) have been affected by your experiences, I would like for you to tell me what changes, good or bad, might have occurred in the area of social interactions, or how you and your spouse interacted with people outside your marriage (family, friends, coworkers, etc.)
- 4) In describing your relationship and how you and your (husband/wife) have been affected by your experiences, I would like for you to tell me what changes, good or bad, might have occurred in the area of your sexual relationship with your spouse.
- 5) In describing your relationship and how you and your (husband/wife) have been affected by your experiences, I would like for you to tell me what changes, good or bad, might have occurred in your level of overall satisfaction within your marriage.

Appendix D

To the readers of this board:

I am a doctoral student in Counseling Psychology at Colorado State University. I am also the wife of a man who received the amazing gift of a kidney from his best friend nearly 18 months ago. As my husband's battle with kidney failure progressed to a life with 15 hours per week in a dialysis chair and finally to his transplant, my personal and professional lives collided and my research turned to helping others in our situation. In researching my husband's illness and looking for support from others who might have survived the same process, I noticed a "hole" in the research literature that I am now attempting to fill. Kidney disease is unique among many chronic illnesses in that it does not necessarily strike those in later life...My husband was only in his mid-20s when he was diagnosed with IGA Nephropathy, and 29 years old for his transplant. The impact of chronic illness on young couples is generally unmentioned in research literature, as most young marriages are not forced to shoulder this burden and strain. However, I know we are not alone in the trials and challenges we faced. For this reason, I have chosen the area of "Young couples facing kidney failure, dialysis and transplant" as the focus area for my doctoral dissertation, and am currently working on a research project in this area. I am looking for 5-15 young couples who have gone through this process, in order to conduct in-depth interviews about their experiences. I need couples who meet the following criteria: Experienced one partner who went through kidney failure, dialysis and transplant within the past ten years. Both partners will have been under the age of 40 at the time of transplant. The couple will have been married for at least 6 months but no more than ten years prior to transplant. There are no other major chronic illnesses present in either partner. If you or someone you know seems to fit this profile and might be able to help me with this research, please let me know. I would be happy to email you a copy of my proposal, or of the informed consent information, if that would be helpful to you in making your decision.

My email address is stacis@lamar.colostate.edu, or if you prefer, you may leave a confidential voice mail for me at (574) 631-4357.

Thank you so much for your help!

Staci Simmelink-Johnson, M.S

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