Relationships in Transition: Young Couples Facing Renal Failure and Transplant

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Young people are not the typical population one might imagine when thinking of chronic illness, yet many young people encounter major health issues. The current literature neglects to adequately examine the impact serious health concerns might have on young couples. This study seeks to examine the impact of End Stage Renal Disease (ESRD) and its treatments on relationships between the ill spouse and partner. In an exploratory, phenomenological fashion, six couples shared details of their experiences with ESRD and its impact on their relationships. This research presents a complex picture of the disease experience itself, and indicates that the experience of illness is not always negative for couples. The conclusion contains suggestions for those working with couples facing ESRD.

END STAGE RENAL DISEASE

According to the National Kidney Foundation (NKF, 2001), chronic kidney disease is the ninth leading cause of death in the United States. The two most common treatments for End Stage Renal Disease (ESRD) are dialysis and kidney transplantation. Of the 345,000 Americans being treated for kidney failure, 100,000 of those are currently living with a functioning kidney transplant, while the remaining 245,000 are receiving dialysis treatment.

FROM DIALYSIS TO TRANSPLANT

Unlike individuals waiting for other transplantable organs (e.g., hearts, lungs), patients with ESRD are not as likely to die from their disease because artificial means of filtering bodily waste (i.e., dialysis) are available. However, dialysis is uncomfortable, time-consuming and changes 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, yet were rarely treated. Yeun and Depner (2000) noted that common responses to dialysis include denial, anger and negative attitudes toward renal replacement therapy, and these responses are often most intense in younger patients. Devins et al. (1997a) found that maintenance dialysis provided patients with a limited opportunity for high quality of life compared with patients with renal transplants.

For dialysis patients awaiting transplant, the delay between being placed on a donor list and receiving an organ is often many years; the screening process is strict, and tests can last for months or years. While on dialysis; patients must carry pagers or find other ways to maintain constant contact with the transplant center. Travel must be 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; these time constraints, health concerns and freedom restrictions not only take a toll on the patient, but also significantly impact the patient's relationships and loved ones. Artinian (1990) reports that patients undergoing dialysis complain about being treated like a child; having reduced responsibilities, capabilities or trust; and feeling a lack of support. He also suggests that the "sick" partner has no choice about his or her lifestyle or role while undergoing dialysis treatment, in contrast to the "well" partner.

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, 1991). 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.

However, according to Koch and Muthny (1990), kidney transplant is 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) found that levels of depression were substantially lower for those who actively sought out health information following their transplant. Rudman et al. (1995) found that patients who complied with their medical regimen post-transplant were more likely to rank satisfaction with life and health high. Zumbrunnen et al. (1989)

Study conducted through Colorado State University, Department of Psychology, Fort Collins, CO.

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.

GOALS OF THE CURRENT STUDY

This study seeks 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, as noted, is the effect upon relatively young couples, who statistically and socially would not be expected to deal with such a dramatic, traumatic event so early in their lives and relationships. Given the relative dearth of information within this area, the present study focuses on gathering a full picture of each spouse's experiences and viewpoints on changes within the relationship using a phenomenological interview process. The research focuses on both partners' impressions and experiences, from diagnosis to post-transplant, social and family relationships, sexuality, communication, division of labor and overall relationship well-being.

Social Issues

Much of the research on ESRD, dialysis and transplant focuses on the physical and medical issues faced by renal patients. Unfortunately, this research often neglects 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 (Conley et al., 1981; Revenson, 1994; Smith et al., 1986).

Impact on Spousal Relationships

Helgeson (1993) found that, in most marital relationships composed of two healthy individuals, spouses alternate 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 tend 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 et al., 1990).

Because it is widely recognized that when a married person is ill, it is their spouse who serves as his/her main source of support (Conley et al., 1981; Revenson, 1994; Smith et al., 1986), it is essential to facilitate a healthy, strong relationship between spouses 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 et al. (1993) noted that 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 et al., 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 were unable or unwilling to change their behaviors. Wilson (1991) suggests that men may perform similar behaviors when their wives are ill, and 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 et al. (1993) found that "well" spouses tend to worry more about the patient's future than the patient. 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 et al. (1999) found that, however unintentionally, this may give their ill spouse the impression of not being taken seriously and damage the relationship.

Impact on Sexuality

Glass et al. (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.

Coping With Stress

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 dialysis. Frazier et al. (1995) 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.

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 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.

However, 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., 1997b; Parker, 1993). This makes sense, given the demographic occurrence of chronic illness within the United States (Centers for Disease Control and Prevention, 1996), chronic illnesses tend to occur in older populations. What happens when a chronic illness affects a younger population?

IMPACT OF CHRONIC ILLNESS ON YOUNG MARRIAGES

What might one expect to happen when long-term illness strikes a young relationship, when a healthy sense of mutual support may not have had a chance to fully develop? Relatively young spouses who promise themselves to one another "in sickness and in health" rarely expect a life-threatening disease to test that promise. "Immature" couples, who are either not capable of or are unskilled at providing mutual support and nurturance, were noted by Peteet and Greenberg (1995) to be at greatly increased risk for marital distress and difficulty due to long-term illness.

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 with young couples and found that many couples consider divorce or do divorce in the face of such uncertainty and stress.

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 also needs support in coping with the illness of a loved one. Obviously, both spouses are greatly impacted by the introduction of a chronic illness into their marital relationship. However, in these studies, the methodological approach fails to address the relationship itself. How do their 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?

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 this most basic element of any relationship. Hooper's (1994) research found that younger patients without spouses often tended to cease sexual activity until they received a transplant.

Young Lives on Hold

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 and thus are more likely to become socially isolated and feel disconnected from their peer groups.

Examining the Shift From Dialysis to Transplant

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 non-living donors or find friends or relatives willing to attempt living donation. How does the surgery, or even the prospect of this surgery, affect the relationship between young spouses? The surgery and related events are expensive, and patients and their spouses are often faced with unbearable financial burdens. This could be especially troublesome for young couples. Horowitz et al. (1998) found that financial need is associated with more problematic and less supportive partner relationships in young couples.

In addition, 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? Young couples who have faced dialysis and major surgery must face yet another major change within the young relationship.

Helgeson (1993) found, that after the initial impact of a chronic illness on a marital relationship was over, most spouses reported that their boundaries and roles were back to pre-illness levels. But Helgeson found that the well spouse continued to provide more support and received less support and help than prior to the illness. Schover et al. (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 3 years following the transplant. In contrast, Abram et al. (1975) reported that 40% of the men they studied who received a kidney transplant noted an increase in sexual potency after the transplant. But these findings omit actual examination of the interpersonal aspects of marriages themselves.

FOCUS OF THIS STUDY

As noted, the relatively limited research addressing young couples facing ESRD and transplant makes this an area much in need of research. The present study attempts to address some of the gaps in research by using a phenomenological, qualitative approach to examining the experiences of several young couples who have faced ESRD together.

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. To avoid biasing both the responses of participants and the later analysis of those responses, questions were phrased in an open-ended, non-judgmental fashion to eliminate the expectation of a particular response bias. 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 and written questionnaires were summarized and reflected back to the participants to find if there was any confusion and to allow for clarification and ensure that the interviewer understood the responses correctly.

Participants and Sampling

Participants included 6 otherwise healthy 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, and were married for at least 6 months, but no more than 10 years, prior to transplant.

Participants were given the option of in-person or written versions of data collection. One couple selected an in-person interview, the other five selected a written version. Participants were recruited from both contacts with a regional renal social worker and through posting on a NKF transplant recipient message board on the NKF Web page. There were no significant demographic differences between the interviewed and the surveyed couples.

Data Collection and Analysis

Within the oral interview couple, each partner participated in a confidential, audiotaped interview with a research assistant who asked broad questions about

each research area. If participants chose to complete a written version of the interview instead of an oral interview, the questionnaires were collected, transcribed or retyped from their original format to ensure accurate and adequate data analysis and assure confidentiality. The questions for each method were identical. The participants were asked to respond to questions in the format of the following: "What changes, if any, did you notice in your life and relationship regarding the area of [sexual intimacy]?" Each area of inquiry was denoted in a separate question, similarly phrased. Data was analyzed in several stages, according to the recommendations of Creswell (1998), Moustakas (1994) and Patton (1990). The researcher identified and integrated major 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 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.

INTRODUCTION TO THE PARTICIPANTS

Participating Couples

Ann and Brian have been married for 10 years. Ann was unexpectedly diagnosed with ESRD less than 2 years prior to the study, and she started dialysis approximately 1 year later. She and Brian worked together to establish a life around her dialysis treatments, and Ann received a kidney from a family member 5 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 2 years after they were married, and although dialysis was not required, she did receive a kidney from a non-living donor just 1 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 completed the written version of the interview.

Erica and Frank have been married for 4 years. Frank was diagnosed with ESRD just 6 months after their wedding, and they coped with dialysis as a couple for approximately 16 months, starting 5 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 1 month before receiving a kidney from 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 2 years prior to their interview following a long history of diabetes. She received dialysis treatments for 7 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 years old respectively, at the time of their interviews.

Kathy and Louis have been married for 4 years. Louis was diagnosed with ESRD 2 years after they were married, and he received in-home dialysis for 2 years before receiving a kidney transplant from Kathy 6 months prior to their participation in the written version of the interview. Both Kathy, 34, and Louis, 37, were healthy at the time of their participation.

FINDINGS

Analysis of Themes

As the researcher examined the commentaries and qualitative data provided by the 6 couples interviewed, several fundamental themes and issues emerged. Partners discussed the specific topics addressed in the interview questions: communication, sexuality, social interactions, division of labor and overall satisfaction within marriage. Other topics that emerged were fears for the future, financial concerns and worries about the impact of the disease on their children. Sexuality in the face of medical intervention was discussed candidly, and many couples noted improvements after the transplant in this arena. It is worth noting that the only factor universally noted by couples was a sense of optimism and gain from the experience.

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, and reliance on friends and family during times of need was essential to surviving the experience. The couples described receiving meals, child care, transportation, 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:

> My two girlfriends became my confidantes, listened to me ... 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. (Iris)

Sometimes a neutral party felt safer to share with than did a spouse; friends created a support network the couples knew they could lean on.

> We had some friends in the neighborhood that would drop by, (would) 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. (John)
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> 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. My family helped us out financially and by coming to visit and help(ed) out during the transplant, and friends did fundraisers and called just to offer groceries if they were out shopping or (offered) other support when they could. (Erica)
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> 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. (Ann)

In addition to practical support, emotional connections between the couples 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." 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."

Erica and Frank learned to spend quality time with people whom they trusted and 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 … 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)

Improved Communication Between Spouses

In 8 of 12 interviews, the partners mentioned an improvement in communication as a result of their mutual experiences with ESRD and renal transplant, and felt that they had not only been tested by the experience, but had passed a test. They felt it had strengthened them, were proud of how they handled it, and were glad they had been given the opportunity to prove their commitment to one another in this manner.

Ann noted several small changes:

> 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: "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 Brian concurred:

> 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.

> [W]e 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. (Frank)
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> 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 … 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 … [Th]is whole procedure has made us better about just saying what we mean and not beating around the bush. (Erica)

Kathy reported that Louis was not particularly communicative at first. 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. 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.

John reported poor communication with Iris at first, but after they were able to acknowledge the need to speak more openly, he noted:

> We certainly relaxed some … [and] 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 … got better after that discussion.
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> [After the dialysis, we have] 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. (Iris)

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 experience with ESRD.

> 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. (Iris)

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 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 of 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 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, whether out of fear of seeming less strong and masculine, or that he could add stress to the already high burden his wife was shouldering, John had bottled up an enormous level of stress and fear that was released only when he was sure that she was going to survive.

Improved Bond or Connection Between Spouses

Many of the couples indicated that the experience of ESRD was actually beneficial to their relationships. This was the theme that emerged most often, occurring in 11 of the 12 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 similarly: "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 [this], 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 ... 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)

Carol and David indicated a similar sense of strength and growth. Carol said, "I know we're both stronger individually and as a couple because of the past couple of years." David said, "My wife's renal failure and transplant have definitely brought us closer together and made our marriage stronger."

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 valued his commitment:

> 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)

After the cloud of illness had been 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)

> 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. (John)

Iris described their early relationship and specifically how this experience has helped them grow from a more self-focused or idealistic phase into a more realistic, substance-focused phase:

> In the first couple of years of our marriage, it was always kind of, not real rocky, but fighting about little things. [Illness] 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.

Kathy and Louis describe how the experiences they went through not only tightened the bond between them, but also insulated them from external influence:

> 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. (Louis)

> 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. (Kathy)

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

Sexual Intimacy

While many couples described difficulties within their sexual relationship during the preliminary diagnosis phase, dialysis, post-transplant and recovery, other couples indicated that their sexual relationships had improved.

> 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. (David)
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> 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)
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> 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)

Decrease in Social Connections

The stress of being "different" or of having so much chaos occurring in the lives of these couples served as a barrier between themselves and the outside world.

> 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)

Negative Impacts on Life

Not all aspects of these couples' struggles with ESRD were so positive; although some of these negatives turned out to be positives. As we will see, the impact of the illness took a toll in many areas of life, from finances to housework, to sexuality and communication, and to employment and independence.

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 agreed that they could not be sure what sort of impact the transplant really had on their relationship, because as young couples, they had not yet experienced marriage without it. They had not yet experienced "normal."

Dealing With Guilt, Anger and Resentment

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, and indicated that 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)

Iris also noted that as the patient, before her transplant she was not always as caring or giving as an equal partner might be expected to be:

> 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.

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."

> 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 (had) helped financially … I wanted so desperately to be helping out in some way. (Carol)

Others also noted a change in ability to share the workload 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. (Iris)
>
> 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. (Frank)
>
> 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. (Erica)

Treading the Fine Line: Balancing Fears with the Need to Protect

Several couples indicated a tendency to withdraw, or even to hide their fears from their spouses at times, out of fatigue or in an attempt to not only protect their spouse but to convince themselves that this was not "really happening."

> 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 6 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. (Carol)
>
> 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. (David)

Some had more difficulty expressing fears about their partner's illness:

> 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)
>
> 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 … [O]ver the course of [an] argument [we] started talking about what was really bothering us, and were able to open up about the fact that we were both scared notless … [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. (John)

Frank and Erica also noted a tendency to try to protect one another as they dealt with ESRD difficulties. His method for avoiding the issue 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 … 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, can even be healthy, and may be beneficial in helping communication grow and relationships succeed.

Sexual Concerns

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 the illness and treatment.

Ann and Brian noted that their sexual relationship all but disappeared when she was ill:

> 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 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." [B]ut...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 … 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"

Iris' husband reported that sometimes he had diminished sexual desire, but not for the reasons that Iris feared:

> Stress reduces [sex] 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. (John)

John's frank admission of his own fears may have helped alleviate some of Iris's concerns about her body's new scars and changes being the root of their problems; 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 … (but) we started talking more and more and realized what the real issue was: that we were both so scared.

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 thought 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 able to empathize with Frank's exhaustion and lack of desire: "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."

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 … 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)

Sometimes sexual desire doesn't return post-transplant. However, after the treatments ended, they found ways to compensate. Kathy said,

> (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 … 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.

Louis said,

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

DISCUSSION

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. As we have seen, the participants in the present research have 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 followed, 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 certainly experienced this with Frank. Additionally, Frank's withdrawal from sexual interaction may have been due not only to physical limitations, but due to feeling impaired sexually and not knowing how to adapt to the 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), since her impaired sense of self-worth and value as a sexual being was impacting her ability to trust that John still loved her, and still found her attractive.

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, because 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. 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.

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 firsthand. However, they 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. … [O]ne 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 becomes a lonely struggle.

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 immersed in the outside world following the transplant. This pattern 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 although they sometimes found it difficult to reconnect into a broader social network, they felt better when they were able to interact with people (p. 190).

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. These feelings are echoed in the research of Smith and Soliday (2001). They reported participants saying, "our family is intact but (we are) 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 facing illness together may find that placing the emphasis on their needs as a couple and on supporting one another actually strengthens their relationships and is supported by other recent research. In a comprehensive review of the literature on couples facing chronic illness, Kowal et al. (2003) noted that "the onset and course of chronic illness does not necessarily have a detrimental influence on couples" (p. 301). 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, and in today's fast-paced society, meeting with couples from across the country in person was not practical or feasible for most participants. Thus, some richness of data is lacking. A second limitation of this research was the self-selection of participants. Five out of 6 of the participant couples were from a somewhat skewed population who chose to respond to a solicitation on the NKF Web site. 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. The heterosexual bias of the sample used for this study also presents a limitation. Additional couples, whether heterosexual or homosexual, might not be legally married but are involved in committed, long-term relationships, which could present a more diversified picture. The inclusion of couples who have divorced or separated after their ESRD experiences might provide insight as to the more detrimental aspects of new relationships being tested in such a manner.

Recommendations for Future Research

Researchers could devise a method for approaching all couples within a particular setting and offering them the opportunity to participate in a research study. 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 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. 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 experiences they might be able to offer would richen the data immeasurably, and one way of obtaining data from these couples would be by implementing the *in vivo*, longitudinal method as described earlier. 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 to avoid the elimination of possible participants who are no longer members of a couple. Actual, in-person interviews would provide much richer data than the present study. In addition, future researchers might consider adding a quantitative portion to the interview

process 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, 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). Therapists, physicians and other professionals who can help couples recognize the power within their relationship, as well as encourage them to see one another as more than a collection of symptoms or responsibilities, are crucial to maintaining healthy relationships throughout the illness experience. Rolland (1994) also argues that by working from a collaborative or "we" stance, 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.

Many of the couples noted that they felt overwhelmed, frightened and unable to keep up with the daily tasks of living during the course of treatment. 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 in counseling. 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, 2001). 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. A more realistic approach might be asking couples just to listen to one another more. Their weekly "assignment" might simply provide a change of focus: trying to understand and communicate as openly with their partner as they are able.

Research suggests that by knowing what others have encountered as they traveled along similar paths, some of the sense of isolation and difference might be alleviated and anxieties lessened as their lives begin 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)

Local social 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 search within their community to find the resources available to them: financial aid, assistance with meals, child care or other practical aspects of life. Physicians and nurses can help patients and their partners anticipate reality by preparing them for the physical impacts of the disease and its treatments, from the effects of medications to dialysis to transplant. Psychologists, counselors and social workers can help couples find support groups, where they can meet others in similar situations. They can also help to prepare clients for the possibility of sexual difficulties or impediments. These methods could help mitigate the sense of being isolated from the community, and might help strengthen the web of trust and flow of information between patients, spouses and the treatment community.

FINAL COMMENT

The couples who participated in this study provide a detailed glimpse of the experience of living through ESRD and kidney transplant and a clearer picture of how this disease impacts young couples, which, in turn, can help those working in medical and mental health fields who might wish to help other couples in their practices who are coping 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.

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